# A comparative study of the construction and implementation of patient choice policies in the UK

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# Glossary of terms/abbreviations

DH Department of Health

DHSSPS Northern Ireland Department of Health, Social Services and

**Public Safety** 

GP General Practitioner

GPSI General Practitioner with a Special Interest

HHI Herfindahl-Hirschmann competition indices

IT Information technology

LHB Local Health Board (Wales)

LHG Local Health group (Wales)

PCA Patient care advisor

PCT Primary Care Trust

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## **Executive summary**

### Background

Health policy on patient choice differs between England, Northern Ireland, Scotland and Wales. In England, there has been a concerted effort to increase patient choice, so that users of NHS services can participate directly in decisions about the place, time and way treatment is offered and provided to them. Following initial pilots in 2002, limited patient choice of provider was introduced in England in 2004 and from 2008, free choice of provider was introduced - initially for orthopaedic elective surgery and then for any non-urgent treatment. This formed part of a policy drive to support a market-type environment (together with initiatives such as Payment by Results and Practice Based Commissioning) as an impetus for raising standards in healthcare provision. Elements of patient choice existed already within the English NHS through NHS Direct and Walk-in Centres and policies aimed at increasing the range and type of providers (such as private and voluntary hospitals, GP specialists) and offering patients additional choices of access (eg self referral to physiotherapists). Such policies have created a more diverse health system within which choices are made and which is projected to be more diverse in the future.

Governments in Northern Ireland, Wales and Scotland have placed greater emphasis on engaging and involving patients and the public in health care decision making at a community level, as alternative to individual choice. All four countries have highlighted the need to make services more responsive to patients and signal a wider shift towards greater consumerism in public services.

#### Aims

The main aim of the study was to examine the content and practice of the different policies in respect of patient choice in the four home countries and to assess their impact on health system performance, including responsiveness to patients. Key research questions of this project were

- to determine the political and ideological origins of the policies on choice and their relationship with other health policies in England, Wales, Scotland and Northern Ireland,
- to illuminate the range of ways in which patient choice is implemented and managed by organisations in the four countries, including delivery of choices at the point of referral,

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- to identify differences and similarities in how patients understand experience, exercise and value choice in the four countries
- to reflect on any emerging findings on the effect of different choice policies on health systems in terms of access to care, responsiveness to patients' wishes and efficiency of resource use. .

#### Methods

Drawing on narrative methods of policy analysis we adopted a multiple case study design. This included analysis of the four nations at the macro-level, selected NHS organisations and GP practices at the meso-level and patients being referred for hospital treatment for orthopaedics or ENT surgery at the micro-level. This research design allowed both a context-contingent understanding of how policy on this issue was constructed and put into practice in ways that reflect the varying politics and policy goals of each nation, and an insight into how such policies impact on patients. In each country within the UK we interviewed national policy makers, politicians and policy advisers to explore the development policies related to patient choice. At the meso level we identified two case study areas in each country where we conducted semi-structured interviews with managers and clinicians from NHS hospitals, private hospitals, primary care trusts, local health boards and general practices. We used standardised interview guides and developed a common framework for analysis for the data collected. From the 10 (or 9) practices in the case study areas we interviewed patients who has been referred for elective orthopaedic or ENT procedures. In total we conducted 42 national policy maker interviews in the four countries and conducted 225 interviews across eight case study areas with general practice, provider and commissioner/health authority staff and patients. We also examined policy documents relating to choice from each country.

## Key findings

#### How national policies on patient choice were formed (macro level)

Although there are distinct policy differences between the four countries, the concept of choice was not completely alien in any system. Choice was linked to initiatives to improve service quality and performance in health and to wider changes in the welfare state to make services more responsive to users and more personalised. There was no clear UK-wide policy coalition across the four countries and, even in England, there was no evidence of a strong policy network advocating increased patient choice. Our findings suggest that patient choice of provider policy emanated from the Department of Health and from the Prime Minister's Office, with key policy

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advisers being important in framing the policy. Patient choice as an explicit policy is most clearly articulated in England, with links between choice and the further development of market approaches to health. A significant finding was the contrast between England dominated by policy on individual choice of provider, and the emphasis in Wales and Scotland, and to a certain extent Northern Ireland, on public and patient engagement and the importance of patient voice.

In terms of the policy context for choice, two consistent themes emerged from our data. The first was the central importance of tackling waiting lists. Choice in England, Wales and Northern Ireland was very closely linked to initiatives for reducing waiting times for patients. The second aspect was in relation to quality. In England choice was part of a set of policy drivers that was also initially seen as a way to drive up provider quality. Broader objectives relating to choices beyond provider choice were less well articulated in all four countries but increasingly recognised as important. Policy objectives also differ in relation to the objectives relating to mechanisms for individual choice (eg the choices website in England, *Choose and Book*) and objectives in Wales for example, relating to public and patient involvement.

#### How organisations implement and manage choice (meso level)

Despite the differing policy stances concerning choice, the referral systems which deliver choices to patients shared a number of similarities. All systems aspired to offer as many choices as possible to patients, including offering a choice of provider where possible. In addition, all countries identified a standard subset of referral choices apart from choice of provider such as choice of treatment, choice of appointment date and time, choice of location of appointment and choice of consultant. But the offering of choices to patients as they were being referred was not always an operational priority due to more pressing needs to meet waiting time targets and limited resources.

In terms of referral options which were available, England had many more potential choices of providers than Scotland, Northern Ireland and Wales, where choice of provider was mainly limited to automatic referral to the nearest provider. Interviewees in Scotland, Wales and England cited the tendency of patients and GPs to 'support your local' as typical referral behaviour. Whilst Scotland, Northern Ireland and Wales distanced themselves from the delivery of choice of provider it was not strictly true that choice of provider did not exist in these countries, and it was noted that a preference would be honoured if it was brought up. The difference therefore was in the way this choice was delivered to patients, with England systems being more proactive with a structured menu system via `Choose

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and Book'. This contrasted with a more reactive approach from the other countries, where choice was offered in response to patient demand with more limited options. However, despite such differences for patients, the actual experience of choice varied little between countries.

In all countries, the choices available to patients often depended on the referrers' understandings of choice availability, and in some case the GPs interviewed expressed confusion about the referral options that were open to them and their patients. In Scotland, Wales and England referrers said they were uncertain about referral options which were available, most commonly whether referral pathways were mandatory or optional. This confusion was partly explained by GPs not knowing their way round the system effectively, and not being aware of the options for appointments which were available. The fact that some referral choices were potentially available to patients only through interface services between primary and secondary care, such as referral management centres or intermediate triage services, also added to the complexity of the process.

Booking systems functioned to offer choices to patients, but also were important in defining the limits of choice and what could reasonably be expected to be offered to patients. In general the priority for those involved in allocating appointments to patients appeared to be the achievement of waiting time targets and controlling resources. A common feature of the systems which offered choices to patients was that they functioned as mechanisms to define and thereby limit choices in order to allow queues to be effectively managed, whether this was by limiting the options open to patients on the *Choose and Book* menu, or by restarting patients' outpatient waiting times when patients had rejected a 'reasonable' offer. This study also noted the differences between choices offered to patients when the 'Choose and Book' system was accessed via telephone or online – the latter providing more choice.

In general terms patient choice was felt to be an important factor in the shaping of health services. Interviewees from Wales and Scotland felt strongly that this was achieved through the involvement of patients and the public more collectively in the planning and redesign of services. Interviewees in England tended to see patient choice as having a strong cultural impact on their organisations, which had embedded the need to attend to the wishes of patients throughout the business of the organisation. The following table summarises our findings relating to the operation of patient choice in the UK.

#### How patients experience choice

Our limited patient research suggests that, perhaps surprisingly, choice policies had not resulted in any obvious systematic differences in patient

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experience across the four countries. We saw as much diversity of patient experience within as we did between nations, and patients raised similar issues in each of the four countries.

For forms of access to specialist care that were mediated by GPs, patients needed to secure the agreement of GPs for referrals. Some patients in all four countries reported difficulties 'getting past' GPs to forms of specialist care that they wanted which may have been a result of GPs' attempts to follow standardised care pathways and referral management protocols that have been introduced with the intention of improving the effectiveness and efficiency of healthcare. Patients' 'success' in overcoming them to access the forms of care they wanted seemed to depend in part on their persistence and skills in negotiating with (or shopping around between) GPs.

Our findings provide some important observations for the development of choice policies from a patient perspective:

- Patients did not want options to choose between providers just for the sake of having options to choose between. Similarly being responsive to patients' wishes does not necessarily require the provision of menus of healthcare provision with multiple options in terms of place, date and time of care
- Patients value being able to access good and individually appropriate health care, with as many options (or as much flexibility within a broadly standardised system) as will allow them to avoid providers they have reason to think are seriously sub-standard in some respect (for example because they currently have very long waiting times or high infection rates).
- Patients wish to be treated at places and times that are reasonably convenient for them personally
- Patients value being involved in referral decisions at least in the sense that they are listened to, given information about the rationale for their referral, and kept informed about how their referral should be progressed and is progressing.
- Rather, responsiveness to patients is promoted by attentive and caring health professionals who engage in careful discussions about individual needs, explain the system and support people to navigate it.

#### How choice policies may have impacted on systems

One of the explicit drivers for patient choice in England was to enhance competition between providers. From our data there was little evidence that

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patient flows had changed as a result of choice at referral policy and provider organisations did not report experiencing significant financial or operational impact. However, recently published Herfindahl-Hirschmann indices of the market position of the organisations provided suggest that in fact all the NHS trusts within our English case studies have been subject to more competition over the period 2003/04 to 2007/08. Therefore whilst organisations did not report experiencing a significant financial or operational impact as a result of choice of provider policy, it may be that they were not sensitised to changes that were taking place.

An interesting finding of this study was the role of service providers in shaping the options available to patients in terms of consultant choice, location choice and time and date. Providers often used the structures of offering choice to manage capacity and utilisation through restricting time slots available and retaining control over allocation between individual consultants and clinic locations within an organisation. Our study did not suggest that providers were changing behaviour in response to patient choice. On the whole, these options tended to be structured to maximise utilisation of resources controlled by the provider rather than maximise patient choices. In our study, there was no evidence of providers actively expanding their capacity or aggressively competing for new patients in response to patient choice. Indeed, providers in our study seemed unaware of increasing competition and the risk of losing market share.

Another observation arising from this study is the focus on the GP consultation in policy. At a local level too, providers have focused promotional activity on GPs rather than patients, for instance by establishing GP liaison posts. In fact, our empirical work suggests that choice decisions about different options are made at a number of points in the referral pathway and do not always happen at the start of the referral process in the GP consultation. A key development during the study period was the growth in intermediate services, such as referral management centres, designed to manage patient referral pathways. These removed decisions about referral choices of provider away from the practice and patients and further diluted the impact of initiatives directed at the GP consultation. A similar effect was seen in the regulation of the referral process by ICATS (Integrated Clinical Assessment and Treatment Services) in Northern Ireland.

#### Conclusions

This study of patient choice policy sought to gain an understanding of the ideological underpinnings of choice and how policy was understood, implemented and experienced in practice. We found that choice was not always defined clearly in policy. This may be deliberate as it allows flexibility

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but, with regard to policy development lack of clarity and different ways of understanding and interpreting choice has led to questions being raised about the extent and purpose of choice. In particular choice, as articulated by patients in our study, had less to do with those aspects of policy relating to time and location and more to do with treatment choices and discussions about referral itself. While choice was seen as important in all the four health systems how choice was to be achieved differed between individual and collective approaches to involving people or patients in decisions. There was a clear distinction between England where most emphasis was placed on individual choices at point of referral and the other countries where 'voice' was seen as key to ensuring appropriate service choices existed for patients. However, elements of both individual choice (of provider, time and date of appointment) and voice (collective public and patient involvement in health service planning/commissioning) existed in all systems. Overall, it is interesting that despite substantive ideological and policy differences, the actual experience of choice and choices available varied little between countries. To some extent, choice for patients remains a limited concept in all four countries.

Providers implementing choice policy in all systems tended to sub-ordinate choice to other key priorities such as ensuring best use of their resources and meeting waiting time targets. It was also clear that in all health systems providers used the mechanisms put in place to provide choice to structure and offer choices that allowed them to control the choices offered in such a way as to ensure that they maximised the best use of their resources while achieving these key targets. There was little evidence in England that choice was key to stimulating provider competition. The introduction of referral management centres and intermediate services has had an important impact on how options within the referral system are offered and when they are offered. Given these changes, a focus on choice at the point of referral in the GP consultation does not encompass the range of choices that need to be made within patient referral pathways. Reliance on the GP is also a problem in terms of GP knowledge of referral systems and options but patients place a high value on discussions about referrals in the GP consultation.

For patients, choice was a more complex issue than simply choosing options offered in relation to time and location of appointments. They saw discussions of their options for referral as complex and relied on GPs to help guide them through this. Menu driven systems do not appear to fully meet patient views about how they want to engage in decision making about referrals. However, patients like the opportunity for choosing the time and date of their appointment. However, their experiences of choice are varied and this did not seem to be related to any particular health system of

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location suggesting that despite national policy frameworks, patient experiences vary.

#### Recommendations

Based on the findings from our study we make the following recommendations:

#### **Practice**

- 1. Professionals should not simply present a menu of choices, but discuss if/how different options might be preferable to their patients in their circumstances; i.e. where appropriate, help to interpret quality information (and its limitations).
- 2. Providers and commissioners need to be clearer about the range of choices being offered and make these clear to patients and local GPs so that there is a clear understanding of what can be chosen.
- 3. Providers and commissioners need a clearer understanding of the patient referral pathways so that choice points are better understood.
- 4. GPs need clear knowledge of referral options and systems if they are to help guide patients through the referral process.

#### **Policy**

- 1. Provide resources (to cover time) and training for professionals (GPs, referral centre staff) to discuss options (where appropriate) with patients.
- 2. Develop and maintain a database for comparative analysis of referral policies across nations for purpose of policy learning.
- 3. The type and method of providing information is crucial and simply making information available is not sufficient for supporting patient choices. Attention needs to be placed not just on the type of information but also the context within which patients are provided with such information and which they discuss it. Our study clearly demonstrates that patients value discussing options relating to their referral with their GP rather than just making choices from set menus.

#### Research

- 1. Investigate relationships between patients' options, decision-making supports and choices and changes in quality of care.
- 2. Further research with patients about their actual experience of the choice process.

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- 3. Further studies are needed about the choices or decision points in patient referral pathways given the increasing use of referral management centres, integrated triage systems or triaging by GPs with specialist interests.
- 4. Political devolution has introduced a new dimension to UK health policy studies. Further studies are needed that explore:
  - The inter-relationship between health policies in each country to inform cross country learning between systems and also to help explore different solutions to common problems.
  - How political devolution is shaping specific country health policies.
- 5. Further research is needed on the role of 'voice' as a mechanism of choice. The complexity of choices and the way that choices are structured by providers suggests that individual mechanisms of exit are not sufficient alone to provide responsive patient services.
- 6. The research also has shown that policy studies need to examine both policy rhetoric as defined by policy makers and in policy documents but also collect data from those involved in implementing and experiencing policies. This study clearly shows that policy is shaped by the context within which it is implemented. The inter-relationship between policies (in this case between choice and waiting time policies) and the demands of ensuring best use of hospital resources) shaped the way choices were offered and experienced by patients in ways that differed from what may have been envisaged at the macro policy level.
- 7. Further application and exploration of narrative analysis is needed to develop better understanding of how policy develops. This examination of patient choice policy reflects a developing policy approach where ideas about choice and the purpose of policy are not always clearly articulated. In this sense policy here could be described as 'unfolding' rather than following a particular pre-determined path.

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# 1 Introduction and background to study

#### 1.1 Introduction

Choice has become a central concept in UK welfare and public policy. It has been a key feature of the consumerist project of New Labour, and since the election of the Labour Government in 1997, choice for service users has been a key plank of central government policy across a wide range of sectors including education, social care and health. Choice has been promoted as a good thing in its own right, but also as a means to meet individual needs with more responsive public services, challenge the power of professionals, drive quality improvements and improve equity. 1,2,3,4,5,6,7

In 2004 the SDO Programme commissioned a literature review on patient choice that concluded that although much work has been done to understand the notion of choice, there was little empirical evidence about the effect of the kind of patient choice being introduced into the NHS.<sup>5</sup> Key areas where insufficient evidence was identified included:

- the effect of patients making choices about where they should receive their care
- access to care for particular groups of people
- impact on inequalities of access
- inequalities in the interest and ability to make choices
- impact of choice in different health service regimes in the UK

This research project was commissioned to address the last of these areas. Since 1997 there has been an increasing policy of devolution in respect of health service matters in Wales and Scotland and Northern Ireland. One of the issues where national policies had been seen to have diverged was in relation to patient choice.<sup>8,9</sup> The research brief highlighted the "natural experiment provided by four different health service regimes in the United Kingdom" and called for proposals for "a comparative study focussing specifically on the policies, processes and effects of the different policies in respect of patient choice in the four home countries."

'Choice' has multiple meanings, and this is a source of ambiguity in policy documents and broader discussion.<sup>10</sup> The aim of the research study described in this report was not to explore all the meanings of choice but rather to focus on the understanding of choice policy in the different countries within the UK. We are here, particularly concerned with the nature of choice policy and how this was understood at national and local levels

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and how policy was interpreted and applied in practice. The nature of choice and its meanings, as well as its application in health policy, have been discussed elsewhere. <sup>5,10</sup> It is useful, however, to distinguish between three different uses of the word choice:

- choice as a decision to be faced: choice as a process of deciding
- choice as a menu from which a selection is to be made: set of options
- choice as a particular selection: that which has been chosen

In addition it is also relevant to note that different types of choice can be provided to patients and it is important to distinguish the different sets of options that are made available and presented to individuals. Choices may include choice of what patients receive (choice of treatment), where they are treated (choice of hospital), who they are treated by (choice of practitioner), when they are seen (choice of appointment time).

Greener et al (2006) suggest that individual choice is often presented as a recent innovation in the NHS but that there is evidence that it has been included in health policy since the NHS was created. For example, patients' right to choose their GP has been protected since the beginning of the NHS.<sup>10</sup> By 2000 choice was being used in numerous ways in policy documents and in 2003, building on a pledge in the NHS Plan, the Department of Health for England (DH) introduced a specific policy to increase "patient choice" in the NHS.<sup>2,10,11</sup> The focus of debate about patient choice is the English policy and the government has argued that a number of distinct benefits should flow from offering patients increased choice of provider:

- Greater choice: a key aim of the NHS Plan was to increase choice for patients. This is choice conceived as a worthwhile in itself, rather than a means to an end, and reflects the view that choice is intrinsically desirable and valued (and increasingly expected) by patients. Government policy in this area is driven by the judgement that there is too little choice in public services.
- 2. Greater patient empowerment: The government saw patient choice of provider as leading to patient empowerment, by putting patients 'in the driving seat' of reform.
- 3. Shorter waiting times: in addition to giving patients more choice, the initial pilots also aimed to reduce what were then long waiting lists for elective surgery.
- 4. Quality (effectiveness and responsiveness): the introduction of Payment by Results was designed to add an incentive to improve the quality of the service by encouraging hospitals to compete to attract patients and thence revenue.

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5. Equity: the government has argued that choice of provider would will lead to improvements in equity, by extending to all NHS patients a choice that was previously only available to people with enough money to opt for (faster) care in the private sector.

However, choice policy within the UK varies between England, Northern Ireland, Scotland and Wales suggesting that while broader concepts of consumerism and personalisation of welfare are key elements of UK government rhetoric and New Labour ideology the influence of central government policy on health and welfare is not translated in the same way across the different health systems within the UK.

The devolution of responsibility for health policy has resulted in divergence in terms of the way in which choice is emphasised and the kinds of choices that are promoted for health service users in the four countries of the UK. 

The divergence has been particularly striking since policy makers in Scotland and Wales have regarded choice between health care providers as an issue on which they can fulfil a political commitment to policy difference with reference to England. 

This report sets out the key policy background to patient choice in the UK and how it was being implemented drawing on official documents and interviews with those involved in the policy process and the delivery of choice policies in the NHS and with patients.

## 1.2 Aims and objectives

The main aim of the study was to examine the content and operationalisation of the different policies in respect of patient choice in the four home countries and to assess their impact on health system performance, including responsiveness to patients. The objectives of this project were

- to determine the political and ideological origins of the policies on choice within each nation
- to identify the essential elements and objectives of policies on choice and their relationship with other health policies in England, Wales, Scotland and Northern Ireland,
- to investigate how, under the New Labour government<sup>i</sup>, policy makers and patients understand and use the concept of choice, and how patient choice is managed in the National Health Service,

<sup>&</sup>lt;sup>i</sup> The context was the national UK Government. During the study the governments in Scotland and Wales changed and different direct rule and devolved rule periods occurred in Northern Ireland.

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- to illuminate the range of ways in which patient choice is implemented and managed by comparing the divergences which are developing between England, Wales, Northern Ireland and Scotland,
- to identify the effects of the different policies on choice on access to care, responsiveness to patients' wishes and efficiency of resource use in the national health system in each of the four countries.

## 1.3 This study

The basis for this study was, therefore, to examine how choice has developed in the UK and examine what differences exist in the way policy was interpreted and implemented within (and between) the four UK health systems. The key aims were to examine policy differences and the relevance of such differences in how choices, if any, were offered to patients. The specific focus of the study was to explore the nature of choice policy and how policy makers and those implementing policy and providing choices interpreted and understood patient choice policy in each of the four health systems in the UK. In order to explore the policy in depth we designed a study that would examine the process of policy making and implementation. It was not our intention to evaluate the policy process process, nor indeed to evaluate the impact of patient choice policy, but rather to gain some understanding of how and why policies were developed, what impact the policy had on processes of decision making in health care providers, general practice and by patients.

In order to provide an in-depth exploration of the nature of policy at these different levels we designed a tiered or layered study. Our approach drew on developments in contemporary policy analysis that suggest that a narrative approach yields richer and more relevant insights to policy processes than traditional approaches to policy analysis. 14,15,16,17 This approach has already been used to explore consumerism in health care. It draws on a policy-as-discourse approach to identify the ideological underpinnings and institutional development of the different choice policies as well as the roles of actors and relationships between key stakeholders. 18 The analysis incorporated thematic content analysis of policy documents and interviews and data collection at national and local levels. The aim was to develop 'policy narratives' for each of the four countries within the UK. Our intention was to identify dominant discourses within the policy process that clearly identified the political and ideological basis of patient choice policies. These discourse analyses explored the policy variants emerging from the historical analytic narrative and thus should not be interpreted as detailed discourse analysis of documents or interviews. The research was therefore structured to examine policy development and policy

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implementation by collecting data at national (macro) policy level, local organisational (meso) level and at the patient (micro) level.

While data collection was undertaken at three different levels and is reported on in this paper by level our analysis focuses on the synthesis of the main themes from each level. We were interested in the way patient choice policy was viewed at each level and whether there were commonalities in the way choice is perceived at different levels and between countries. As such our specific research questions were:

- 1. What were the sources and bases of argument (ideological, theoretical, evidential, stake-holder driven etc) for choice regimes in each home country? How have policies shifted over time and what were the putative mechanisms by which stated policy intents were to be achieved?
- 2. How do the different choice policies, together with the structure of the service, influence the range of choices offered to patients?
- 3. In what ways do service providers provide patients with choice? What influences the range of options that GPs offer to patients and how?
- 4. How do patients understand, experience and value choice (of secondary care service provider and of treatment options) and to what extent were they willing to exercise it within current policyformulated choices?
- 5. What is the relationship between choice regimes and how choice is experienced by patients in each country?
- 6. What impacts does patient choice have on the efficiency of local health services in terms of capacity and volume of services provided?

In order to explore these questions we developed objectives for each element of the study. Thus our research examined:

#### At the Macro level:

- the political and ideological origins of the policies on choice within each nation
- the essential elements and objectives of policies on choice and their relationship with other health policies in England, Northern Ireland, Scotland and Wales
- how, under the New Labour Government in the UK, policy makers understand and use the concept of choice, and how patient choice is conceptualised in the four UK national health services.

At the Meso level:

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- how choice at point of referral policy is operationalised in England,
   Northern Ireland, Scotland and Wales
- the organisational structures and processes supporting choice in each country
- the impacts of patient choice on the organisation and delivery of health care services in each country
- the impact of the delivery of patient choice on government objectives for choice policies
- a comparison of the operationalisation and impact of choice policy between case study sites and between countries

Originally we intended examining not just the impact on the way services organise patterns, service capacity etc. Our initial discussions with case study sites was that such data would be easily obtainable. However, obtaining useful and comparable data proved to be more complex than this and we were unable to obtain data of sufficient quality. Thus our analysis of impact is restricted to an examination of processes within provider organisations.

At the Micro level for patients referred for elective procedures:

 the effects of the different policies on choice on access to secondary care providers and responsiveness to patients' wishes in the national health system in each of the four nations

The study was undertaken between February 2007 and July 2009. Macro level data was collected during the latter part of 2007 and early 2008. The meso level data was collected mainly in 2008 and the patient data in 2009. Timing of the study is important given the continuing development of policy on choice in England and changing policy and organisational contexts in all four UK countries. Where relevant these changes are referred to in this report.

## 1.4 Background: patient choice in the UK

Choice is not a new concept in the NHS. In principle, patients have always had a choice of General Practitioner (GP), and an option to decline to consent to (most of) the treatments that doctors offered them. Until recently, however, choice of specialist was needs-based and largely determined by the GP on behalf of the patient. Patients could not refer themselves to hospitals without prior approval from the gatekeepers – a role that GPs fulfilled in the UK. Wider choice only existed for those with resources and access who could opt out of the NHS and obtain healthcare privately. Choice was also a central feature of the internal market,

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introduced into the NHS in the 1990s, to enhance efficiency and simultaneously tackle the main shortcomings of the former systems, such as rigidity, bureaucracy and unresponsiveness to patient preferences.

Most recently choice in healthcare has emerged as a popular policy in one form or another for all parties across the political spectrum in the UK although the rhetoric and emphasis differs between mainstream and smaller parties – especially the nationalist ones. Current choice policies pursued in the NHS differ from their predecessors' policies in many ways, but there are also many similarities. Central to policy developments post 1997 has been the emphasis on two key aspects of health care. The first is patient responsiveness and the second is improved health system performance. However, the route to achieving these goals is not uniform across the UK and is shaped by increasing political devolution. Secondly the articulation of the nature of choice also differs and since 2001 there have been increasingly distinctive approaches to how responsiveness is conceptualised and achieved. The development of choice and its focus on alternative routes of access and providing a choice of provider in England has dominated commentary following the introduction of the notion of choice in the NHS Plan in 2001.<sup>11</sup> It is this focus that has led to the commissioning of this study. However, it is important to set the study within the shifting context of devolution and the different ways of understanding or interpreting key concepts such as choice, responsiveness and access as these are relevant to understanding how policy develops and is implemented.

#### 1.4.1 Political devolution

Both the degree of choice and the choices made available to patients are determined by national and local policy makers, service commissioners and health care providers. Since the beginning of the NHS there have always been important distinctions between the organisation and delivery of health care services in England, Northern Ireland, Scotland and Wales. Essentially England and Wales operated the same structure and organisation, with Scotland having a similar structure, but with Health Boards rather than authorities, and Northern Ireland having combined health and social care Boards. Many elements of the system were, however, the same including the general practitioner system, the role and location of public health, and the delivery of community services. Since the Labour Government came to power in 1997 much has changed, with political devolution to the Scottish Parliament and, more recently, the Welsh Assembly and with political change now occurring in Northern Ireland with an emergent independent Assembly.

The Labour government's devolution of powers to a Scottish Parliament and the Welsh and Northern Ireland Assemblies has created the capacity for further spatial differences. <sup>19</sup> Moreover, other policies have supported

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greater diversity. The proposed NHS reforms, published in 1997 and 1998, incorporated different territorial policies. Although the capacity for policy diversity post-devolution varies in each territory, some policy uniformity might be expected as the UK operates as a unitary state with a parliamentary system (based at Westminster) and there are strong constitutional, institutional and professional forces for conformity within the UK health system. The Westminster Parliament retains sovereign authority so that the grant of devolved powers rests on a Memorandum of Understanding not to make primary legislation without gaining the agreement of the devolved administrations.<sup>20</sup>

Similarities between health systems are exemplified by the existence of a national Welfare State and shared NHS values, UK wide professional bodies, the establishment of new institutions such as the National Institute for Clinical Excellence (NICE: England and Wales only) and the NHS Quality Improvement Scotland (NICE guidelines are applicable to Scotland and the two organisations work together). However, political devolution provides a context for greater diversity as it allows greater policy experimentation but it may also facilitate uniformity through 'policy transfer' - the sharing of policy developments between one country and another and the fact that the NHS across the UK has a shared institutional history.<sup>21</sup> Devolution has provided a dynamic context whose long term impacts are currently unknown but in relation to choice, the explicit differences in policy rhetoric and objectives and the mechanisms introduced reflect increasing policy divergence. Such differences reflect increasingly different institutional frameworks and political ideology as well as territorial features such as size and geography.

Currently the Department of Health (DH) (for England) is the responsibility of the Secretary of State for Health whereas, elsewhere, responsibility for the NHS lies with the Secretary of State for each territory. The DH (in London) takes responsibility for UK-wide issues and for international health policy issues (such as liaison with the European Union). 22, 23 This division of responsibilities is liable to change as devolved territories re-negotiate their relationships within and outwith the UK. Of central importance are the different relationships between the NHS and the elected assemblies. In England the NHS is overseen by the DH but the DH has split national and English functions as does Parliament and the government leading to less direct political control via Parliament. Scotland already enjoyed considerable administrative devolution which is complemented by devolution of limited law making powers to the Scottish Parliament.<sup>24</sup> Hunter<sup>22</sup> argued that the Devolution White Paper envisaged "greater flexibility... over the pace and detail of the primary care changes" (p.11). Hazell and Jervis<sup>24</sup> foresaw the possibility that the Scottish Parliament could introduce radical changes such as adding greater democratic input into health care commissioning or

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ending the independent contractor status of GPs but this has not materialised, although significant policy differences have emerged such as the introduction of free personal care. The decision to provide long term care free of charge has had political and service ramifications across the whole of the UK not just in Scotland. The Welsh Assembly is responsible for allocating NHS expenditure in Wales but has no law making powers. However, it can introduce structural changes (such as transferring powers to the Assembly itself) or reorganising health care organisations as it has been doing over the last five years.<sup>24</sup> When first established the Assembly could not pass primary legislation and has no tax raising powers. However, by passing secondary legislation, Whitfield argued that it could "dictate the detail of health policy". 25 Revisions to the NHS in Wales include reducing the number of Trusts in Wales from 26 to 16 in April 1999 (which occurred before the Assembly was established), abolishing car parking and prescription charges and the more recent restructuring of Local Health Boards, centralising commissioning and developing integrated purchaser/provider regional bodies. 26, 27, 28 The Assembly was given a central role in health policy; for example, Health Authorities are held to account by it. The White Paper A Voice for Wales defined its health remit as monitoring the health of the population, determining the scale of financial resources for health and the identification and promotion of good practice (para.2.1). <sup>29</sup> In the early 2000's there was, however, ongoing criticism of the Welsh NHS performance in comparison to England as waiting times and other performance measures were substantially poorer. 30, 31 Recent progress towards achieving the Access 2009 target of 26 weeks total waiting time has brought Welsh waits closer to those of England. 32 The Government of Wales Act 2006 and the granting of powers for the Assembly to introduce 'Assembly Measures' (Welsh laws) in certain areas including 'health and health services' has increased the Welsh Assembly control over health policy and health service delivery.<sup>12</sup>

Choice is a common theme in UK health policy in all four countries and is represented as part of the consumerist project of New Labour, reflecting a wider emphasis on choice in public services. <sup>1,5,7</sup> Choice in public services is a key element of the 'modernisation' agenda and reflects a number of concerns about the need to meet individual needs with more responsive services, to challenge the power of professionals, to drive quality improvements and to improve equity as well as being seen as a good thing in its own right.<sup>2,3,7</sup> Similar objectives can be found explicitly in policies that support patient choice in England but also the emphasis on responsiveness is echoed in all UK health system policy although the focus of choice policies does differ across the UK. For example, in England the emphasis is on consumerism and the use of choice as a driver for improving quality and efficiency alongside other supply side developments to create contestability such as 'payment by results' and access to private sector treatment. This

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approach to patient choice is also seen to provide patients with opportunities for 'exit' in addition to policies that have emphasised 'voice' where patients engage with providers and commissioners to shape services provided. In contrast choice in Wales, Scotland and Northern Ireland focuses more on the demand side in less overtly competitive environments but, particularly in Scotland and Wales, with an increasing emphasis on patient and public 'voice' as emphasis is placed on shaping services to match patient expressed needs. <sup>5,30,31</sup> The emphasis is on patients and the public expressing their views and make choices about the type of service they want available to them.

Current health policy in England has focussed primarily on individual patient choice of provider although there are also developments supporting referral to specialists within primary care, developing alternative primary health care access points (eg walk-in centres) and treatment options. 5,23,34,35 While choice was also a prominent feature of previous market orientated reforms in health care there are distinct differences between the NHS internal market and more recent attempts to introduce choice. The first difference is that choice of secondary care provider has been introduced as a whole-scale entitlement for all users of healthcare and not just for the patients of GP fund-holders, and that patients, and not their agents (GPs), can now be the direct decision makers about this - with support provided by the commissioners of secondary care for those who need it.<sup>36</sup> Furthermore, competition among secondary care providers has been extended to include public, not-for-profit and private providers within or outside the patient's country of residence. Nonetheless, there are similarities in both language and aims with the pro-market reforms in the early 1990s. While the internal market was UK-wide, GP fund-holding had more limited uptake outside England and clearly current approaches to choice are also differentiated between England and the other countries.

Patient choice was seen as part of an approach to improve quality and performance by applying, in England, market incentives to attract or retain patients. Conversely in the other countries the emphasis was on the need to engage patients and the public to help improve services and performance through voice mechanisms. These distinctions were very apparent in the process of the research both at a policy levels but also when examining NHS processes.

At the start of the study there was a common concern about the need for improving system performance – particularly following substantial resource increases after 2004. In England the approach was to combine supply and demand reforms alongside the use of central targets to improve performance and shorten waiting times.<sup>37</sup> The approach in Wales and Scotland was to use a combination of collaborative approaches and suggested targets to achieve similar outcomes. However, in Wales in 2004

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the Audit Commission highlighted aspects of poor performance and there were concerns about whether LHBs had the capacity to lead service improvements and shape local services. In Scotland concerns were also being expressed by politicians and senior NHS Scotland managers about why the Scottish NHS seemed to be lagging behind the English system – especially in relation to waiting times. Stevens (2004) has described the successive waves of reform in English policy post 1997 as being layers of policy producing a three-pronged approach to improving NHS performance incorporating elements of cooperation, command and control, and competition. Repair of policy producing a three-pronged approach to improving the performance incorporating elements of cooperation, command and control, and competition.

This project focuses on choice as it has been introduced within England –on choice of provider. Other projects commissioned by SDO (PC144 ,171,172) were addressing wider aspects of patient choice and the provision of information for patients to make choices. Patient choice raises important questions about the way health care is accessed, delivered and experienced. This study examined the way choice policy in health care developed in the UK, focusing on the construction of policy, the delivery of patient choice, the way choice is experienced by patients and the impact this has on the range and structure of health care systems.

Patient choice needs to be seen within a web of factors that influence access to and use of healthcare services and which affect the provision of health care services. <sup>39,40</sup> Access describes the 'degree of fit' between clients and the health system. <sup>41</sup> With regard to choice of provider it is therefore important to explore the way choices are constructed (in terms of the types of choices made available), in what ways they are offered to patients (what is the process of providing patient choice) and the impacts choice has (on patients and the health system).

#### 1.4.2 Constructing choices

Health policy on choice differs between England, Northern Ireland, Scotland and Wales relating to differences in ideology. In England the government has introduced policies to increase patient choice to enable users of NHS services to participate directly in decisions about the place, time and the way treatment is offered and provided to them. <sup>3,10</sup> English policy has developed apace since the NHS Plan in 2001 which promised booked appointments to provide elective patients with the date and time of their choosing by 2005, <sup>11</sup> followed by nine patient choice pilot projects and then the country wide introduction of choice for all elective referrals in 2004. <sup>3</sup> From January 2006, where care could be planned, NHS patients were offered a choice of five providers at the point of referral of which at least one had to be from the independent sector.

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Patient choice, based on appropriate information was central to government plans to achieve greater responsiveness to patient needs, to increase technical and allocative efficiency, to enhance quality of services and most contentious of all, to improve equity. 1,11 Patient choice, together with two other major government policies, Payment by Results and Practice Based Commissioning, was aimed at introducing a market-type competitive environment in NHS healthcare provision to provide the context within which health service improvements would be achieved. Elements of choice existed already within the English NHS through NHS Direct and Walk-in Centres and alongside these developments current policies for increasing the range and type of providers (such as private and voluntary hospitals, GP specialists) and offering patients additional forms of access (eg self referral to physiotherapists) creating the potential for an increasingly diverse health system within which choices are made, but aimed at making the English NHS more responsive via competitive mechanisms. 3,42,43 At the start of this study the Department of Health was exploring the extension of patient choice to other areas of health care beyond referrals for elective surgery (See chapter 3).

Governments in Northern Ireland, Wales and Scotland have not been so determined to widen choices of service providers and have tended not to be in favour of introducing a market style approaches to healthcare. In Wales the NHS Plan identified the need to develop health services that comply with patient preferences and in 2004 a 2<sup>nd</sup> Offer Scheme was introduced where patients can be offered a second choice of treatment and/or location if they have exceeded the national waiting time limits (generally 18 months, but eight months for cardiac and four months for cataracts). In addition the emphasis in the Welsh government's strategy is to "... empower the community to have its voice heard and heeded, rather than simply being given a choice of treatment location.".44 The Welsh Second Offer Scheme is centrally driven and is specifically aimed at reducing waiting times following criticism about the poor performance of the Welsh health care system. 30,31 In Scotland the NHS Plan also stressed the need to be responsive to patients' views. The emphasis here has been on providing information for clinical choices to be made in consultation with patients, 45 but patient choice of secondary provider is now facilitated by the National Waiting Times Database which provides service users and their GPs with information to support GP referral decisions. In addition, the recent introduction of GP specialists and the establishment of the Referral Information Service have increased the availability of alternative routes to treatment and information aimed at increasing patient choice. 46 Finally, in Northern Ireland the opportunity for choice is more limited given the size of the health system. The introduction of a 2<sup>nd</sup> Offer Scheme (similar to Wales) has been welcomed and a recent review of health and social care services recommends further expansion of choice for specific treatments and

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specialties.<sup>47</sup> As in the Welsh scheme, the Northern Ireland scheme introduced choice of one alternative provider for patients waiting nine months or more for hip and knee operations and six months for cardiac and cataract operations.

How patients, and the public, are engaged in processes that structure choices are relevant and constituted a strong theme in this research – particularly in Northern Ireland, Scotland and Wales. In England there has been a long debate about public and patient involvement but policy and the re-organisation of public and patient involvement structures has taken place alongside of, rather than as part of policies on patient choice. A8,49,50 This contrasts with the situation in Wales where patient and public involvement is seen as central to the wider choice agenda. A1,25,51 In Scotland NHS Boards are legally required to involve members of the public in decisions about service planning and this is monitored by the Scottish Health Council. Thus choices can be seen as being derived from policies aimed at 'voice' through patient and public involvement and 'exit' through individual patient choice. Reconciling these different aspects of 'voice' and 'exit' provides a challenge for health care services.

While the main focus of patient choice would appear to be on location of choice, actual choices are constructed in a number of other ways. Surveys have shown that nearly a third of primary care patients and nearly 50% of inpatients want more involvement in decisions about their care and studies suggest that doctors tend to focus on technical issues rather than discussing issues more important to the patient including treatment options. While not an explicit element of choice policy in England the Department of Health has been promoting the concept of patient partnership for a number of years and there is a clear policy focus on patient centred care, supporting patient involvement and increasing patient autonomy and responsibility for their own care. Similar concepts are promoted in Scotland, Wales and Northern Ireland. The relationship between choice of treatment type and location of care has been largely neglected to date.

#### 1.4.3 Providing patient choice

Provision of choices for patients can be categorised in terms of provider, treatment, time and access dimensions - which represent (respectively) questions of where, what, when and how. The menu of service options varies between countries in both range and process of choice. However, in all cases at the start of the research in 2007 the offer of choice was normally between a limited number of options and choice policy was predicated on the assumption that a proportion of patients will be willing to travel to non-local providers or different treatments, raising questions about trade-offs between the different dimensions of access. The situation changed in 2008 in England when free choice was introduced initially for

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orthopaedic elective surgery and then for any elective surgery (see Table 1 for a chronology of the introduction of patient choice of provider in England).<sup>56</sup>

In Wales and Scotland the issue of choice is particularly affected by geography and distance with the areas of Wales with local monopoly providers being generally on the west coast (e.g. Aberystwyth) and similarly in the Highland and northern areas of Scotland. The majority of the English population lives within

Table 1. Implementation of patient choice of provider in England

April 2002	Introduction of Payment by Results (prospective casebased payment for NHS hospital services).
July 2002	Patients waiting six months or more for a heart operation offered the choice of faster treatment at an alternative hospital.
October 2003	Introduction of NHS and Independent Sector Treatment Centres
August 2004	Patients waiting more than six months for elective surgery offered the choice of moving to another hospital for faster treatment
January 2005	Choice at the point of referral for cataract patients
December 2005	Choice at the point of referral for all patients requiring surgery. An electronic booking system ('Choose and Book') introduced to enable all patients requiring elective care to be offered a choice of at least four providers.
June 2007	'NHS choices' website launched to provide information to support patient choice.
January 2008 (introduced April 2008)	For non-urgent treatment, patients given the right to choose any provider that meets NHS standards and can provide the service within the maximum price the NHS will pay ('Free Choice').

30 minutes travel (by car) of 2 hospitals while the areas with least `choice' of hospitals include the Scottish and Welsh borders, parts of East Anglia, Lincolnshire and south-west England. 55,57

At the start of the study choice of provider was offered to patients in England within a specific set of options (a range of 4-5 providers as defined by local commissioner PCTs or practice based commissioners) and provided by the GP/practice supported through the Choose and Book system installed in GP surgeries and hospitals across the country as part of the National Programme for IT (information technology). The policy was introduced following a number of pilot projects on choice. However, the policy introduced nationally differed from the pilots in a number of key respects, in particular, in the level of support provided to patients. In the initial pilots for patient choice, all patients were contacted by a patient care advisor (PCA) and those patients opting for an alternative hospital were offered free

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transport. In the policy roll-out, patients were to be provided with information on alternative providers and supported in making their choice by their general practitioner (GP). Primary Care Trusts (PCTs) are expected to provide PCAs for patients requiring additional support and only certain patients are eligible to have their travel costs met. Pilot projects also focused on those waiting over 6 months when overall waiting times were longer before the introduction of waiting time targets (now as low as 18 weeks from referral to treatment). Two mechanisms were put in place to support choice – Choose and Book (the system designed to identify and provide patients with choice of appointment) and the NHS Choices website (designed to provide patients with information upon which to make their choice).

Use of Choose and Book varies across England and in September 2009 only half of eligible appointments were booked using Choose and Book. 61 Use has fluctuated over time. For example, one of the English case studies examined in this research was a pilot area with 90% use but after the scheme was introduced nationally usage fell rapidly to just over 20% in this site. Low levels of usage have partly been due to the reluctance of some GPs to use the system, meaning a paper-based referral system is running in parallel, and there have also been technical problems. <sup>62</sup> In a recent study on patient choice a survey of outpatient clinic attendees found that 49% had been offered a choice. 63 This figure is similar to the latest national patient choice survey conducted in March 2009 which found 47% of patients recalled being offered a choice. 64 Both surveys found that about 50% of patients were aware of choice policy and those who were aware were more likely to recall being offered a choice. The level of use of the Choices website by patients seeking information about hospitals is low with only 4% of the King's Fund respondents and 6% of the 2009 National Patient Choice Survey. 63,64

In Wales the Second Offer Scheme gives patients the option of attending another hospital (often within England). The offer is made not by the local health commissioner (the Local Health Board), but by a centralised 2<sup>nd</sup> Offer Commissioning Team and limited to an offer of one other provider. The Northern Ireland scheme operates in a similar way. In Scotland, choices are clinically led by the GP, although as this study found, there has been an increasing policy emphasis on choice in recent years (see Chapter 3).

Clearly availability of information and knowledge about alternative providers are key to how choice is exercised. The differing approaches in each country place the need for information and knowledge and the point at which decisions are made about different providers at different levels in the system and involve the patient in different ways. In England, the pattern of local services and the degree of involvement of local patient and public representatives is structured around local commissioners (PCTs and practice-based commissioners). While the policy focus, and the principle of

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the Choose and Book system, suggest that patient choice occurs at the point of referral, in reality, choices are also shaped by the prior actions of commissioners and providers and the introduction of referral management services and intermediate assessment services means that choice decisions are not always centred at the point of referral and in England where there are interim primary care service in place, such as a clinical assessment or referral management centres, the PCT is responsible for making arrangements to ensure that the patient still gets a choice of provider for their elective care. <sup>65,66</sup> In contrast, in Wales and Northern Ireland, the focus is more on one-off decisions about individual patients made by the central commissioning team. In Scotland, GPs retain the major role in providing choices. The extent to which patients are supported in their choices will therefore differ. Since access to support, including relevant and appropriate information and support for decision making is crucial, these differences have important implications. <sup>5,58,59</sup>

Patient choice has introduced the potential that hospitals would lose patients and, through the recently introduced payment by results mechanism which sets universal price tariffs, lose resources. Thus the aim was that providers of all types (public and private) would compete to attract patients on the basis of the accessibility and quality of their services since there is no price competition. In the choice pilots choice was exercised by the majority of patients but this was in specific circumstances and with more support. At the start of the study there was no indication whether similar numbers of patients were exercising choice in the national choice system.

In summary then patient choice has been linked to three broad developments. The first is the link between choice and the introduction of market approaches to co-ordination within the English NHS. Choice is seen in this case as an incentive for providers to attract patients and increase their revenue or at least to improve services to ensure they retain patients. In this case choice is linked to payment by results so that patient choices of provider equate to payments to those providers.<sup>67</sup> Patient choice has also been promoted as an incentive to improve service quality and performance.<sup>5</sup> Finally patient choice has been linked to wider changes in the welfare State. 5,10 The shift here is to developing welfare services such as health, social care and education, that are more responsive to the users and are more personalised. Patient choice, therefore, is a response to providing more individually designed services that meet patient needs. 5,10 It was also clear that while there were distinct differences in policy between the four health systems the concept of choice was not completely alien in any system. While English policy was far more explicit about the nature and scope of choice in terms of Choose and Book, patient choices for elective surgery and selection of providers elements of choice had also been

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introduced in the Scottish (booking systems) and Welsh (Second Offer process) systems and was under discussion in Northern Ireland following the Appleby Report. 47,68

Pilot studies undertaken on the London and national schemes for patient choice in England suggested that patients would take up choices and choose alternative providers. However, at the start of the study there was little available information on whether patients more generally were expressing choices about location of provider and patient awareness of choice was still under 50%. The January 2007 Department of Health survey of patient choice in England found that:<sup>69</sup>

- More patients recalled being offered a choice of hospital for their first outpatient appointment: 45% in January, up from 41% in the November survey and 30% in the first (May/June) survey.
- 36% of patients were aware before they visited their GP that they had a choice of hospitals for their first appointment, up from 35% in November and 29% in the May/June survey.
- 64% of patients who were aware of choice recalled being offered choice, whereas 34% of those not aware of choice recalled being offered it, compared with 60% and 31% respectively in the November survey.
- Location or transport considerations were again given most often, by 64% of patients, as an important factor when choosing a hospital.

Choose and Book usage was also limited. A survey undertaken in the Autumn of 2006 by Medix on the national IT programme found that 80% of GPs had some experience of Choose and Book and that their support for the service had improved from 17% at the beginning of this year to 26%. However, of those with such experience, only about half used it for more than 40% of referrals. Of these, over 90% said that it increased the time of dealing with a referral and over 70% thought it either made no difference to or was detrimental to patient outcomes.

# 1.5 Outline of report

The study commenced in 2007 when choice of provider was on the point of being extended in England to provide free choice for orthopaedic surgery and then free choice for any elective procedure. Thus the study was undertaken at a time of rapid policy change. However, policy was also changing in the other countries with the 2<sup>nd</sup> Offer system in Wales initially stopped and then started again, organizational change consolidating and merging services in Wales from 2009 and organizational change in Northern

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Ireland leading to unification of the Health Boards. These circumstances provided a fluid context within which the study was undertaken.

In presenting the findings of the study we have chosen to present the data by both level of data collection – the macro level discussing national policy (Chapter 3), the meso level examining provider organizations and referral processes (Chapter 4), the micro level reporting on how patients experienced the offer of choice (Chapter 5) and then within these sections by country and where relevant by individual area case study. Each chapter provides a summary of the findings with supporting quotes, vignettes or descriptions of referral processes to illustrate key points. The findings summarised in each chapter relate specifically to exploring the nature of choice policy, how provider organizations managed the processes of choice of provider and how these were experienced by patients.

Chapter two provides a brief overview of the main study methods setting out our study design and rationale together with details of the foci of the different levels of the study. Chapter six provides a synthesis of the main findings of the study together the conclusions and recommendations for policy, practice and further research.

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# 2 Methods

### 2.1 Introduction

This study explored the relationship between choice, access, responsiveness and, while not a specific focus of the research, efficiency (by obtaining quantitative data related to service utilisation) drawing on Penchansky and Thomas's access framework (see Table 2).<sup>41</sup> While information about making choices and the factors influencing those choices right from the initial decision to seek help is important, this research was focussed on the choices about service offered to and made by patients within the different policy frameworks of each of the four countries. It examined patient pathways to specialist appointments through referral choices/decisions rather than patient experience per se. Table 2 identifies the relationship between the dimensions of access and patient choice and the subsequent system and patient impacts and outcomes. These were used to inform the development of our research questions and data collection.

Table 2. Patient choice: access, responsiveness and health services efficiency

Access dimension	Relationship to choice agenda	System and patient impacts/outcomes			
Acceptability	How do patients get information about the different services/ treatments in order to base their perceptions of that service regarding quality? Do patients know how to access the service and do they use the service? Is the service socially and culturally acceptable?	Changes in patient satisfaction Range of different types of services available Changes in use by traditionally excluded populations Increased social/cultural acceptance			
Affordability	Who bears the cost of `Patient Choice'? Does Patient Choice escalate health-care costs?	Cost shift from NHS to patients in terms of direct fees and out of pocket costs. Changes in commissioner costs			
Availability	Is there sufficient spare capacity to offer choice? Do the choices enable all patients to get appropriate services and to be satisfied? Do patients and public have choice in types of services made available? How does the availability of different types of health care service affect	Service utilisation  Range of services with capacity Patient/public involvement in service and commissioning decisions  Impact on service delivery of increased/decreased volumes of patients			

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	choices? What impact will supplier-induced demand have on the choices patients make?	
Physical accessibility	Can patients get access to the service and can they physically use the service?	Location of services Accessible by public/ private transport
Accommodat ion	What differences exist between services in terms of waiting times, amenities, quality of care? How do patients trade off these differences against other dimensions of access?	Waiting times Quality of care

Adapted from Pechansky and Thomas (1981)

This investigation into the provenance, development and implementation of the policies concerning choice by patients in the NHS was designed as a multi-level study, with selected case studies within each of the 4 constituent nations of the UK. There were three levels corresponding to the overall policy formulation (*macro*), the implementation of policy through the managerial agencies and service providers of the NHS (*meso*), and the operationalisation of the policy with patients (*micro*).

The cases comprise the 4 nations at the macro-level, selected NHS organisations and GP practices at the meso-level and patients being referred for hospital treatment for orthopaedics or ENT surgery at the micro-level. This research design allowed both a context-contingent understanding of how policy on this issue was constructed and put into practice in ways that reflect the varying politics and policy goals of each nation, and an insight into how such policies impact on patients.

As described in Chapter One our methodological approach drew on a narrative approach to policy analysis 14,15,16,17 Central to such an approach is the idea of policy-as-discourse in which the aim is to identify the ideological underpinnings and institutional development of the different choice policies as well as the roles of actors and relationships between key stakeholders 18 The aim was to develop 'policy narratives' for each of the four countries within the UK that were constructed from data collection at different levels of the policy process – the macro, meso and micro. These analyses explored the policy variants emerging from the historical analytic narrative and thus cannot and should not be interpreted as detailed discourse analysis of documents or interviews. Nor does such an approach set out to evaluate the policy process in terms of whether the policy was appropriate or an evaluation of the policies impact on patient outcomes.

It was intended to combine this approach with more traditional methods of analysing the policy process that draw on policy process and institutional

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frameworks <sup>71,72,</sup> However, it became clear in early interviews that concepts of policy networks or advocacy coalitions were not appropriate approaches to the analysis of policy development on patient choice as in England there was no evidence of a network or policy community with very few key individuals involved. In Northern Ireland, Scotland and Wales this approach to the analysis was not relevant as patient choice policy was not being developed. The full research team met on two occasions in the first year to discuss this and decided that focusing on developing the 'narrative histories' of particular policy initiatives was a more useful approach to reflect differing policy foci in each country.

# 2.2 Identifying case studies for comparison

The SDO brief explicitly called for study examining the policies, processes and effects of the different policies in respect of patient choice in the four home countries. The emphasis was on identifying the essential elements and objectives of the four different policies on choice and how do they relate to other differences in policy between each country. Our approach to the research was to explicitly structure our data collection to examine the national policy and its implementation in each country. The intention was then to compare across countries to identify key policy differences and differences in the way choice was put into practice – if at all – in each country. Our approach was essentially to develop a comparative case study design exploring the contemporary phenomenon of specific choice policies – in this case choice of elective referral – within real-life contexts – the national policy, service organisation and delivery contexts.<sup>73</sup>

Our design provided for country specific case study sites where meso and micro level data collection was undertaken (As shown in Table 3). The aim was to select case study sites to explore how patient choice policy in terms of referral for elective surgery was being 'operationalised'. These sites were selected to provide illustrative examples of how choice was 'managed' by NHS and general practice' services and how the implementation of choice was experienced by patients. Case study sites were selected to reflect rural and urban differences as evidence on health services access and patient choice suggests that there are key differences in the availability of choice between such areas. <sup>54</sup> In each selected case study area there was one clearly identified NHS acute provider (including in England a Foundation Trust) and additional NHS and private providers within one hour travel time <sup>55,57</sup>

However, our 'cases' were not simply geographical sites. The definition of the case is often complex and unclear and in practice the case or cases for analysis emerge during the research process.<sup>73</sup> This study presented a number of challenges in terms of identification of the case. The potential

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cases include policy, countries, Meso level areas and individual patient experiences. In addition we selected tracer conditions – orthopaedics and ENT – and these could also constitute cases. Comparison between cases is a normal approach in multiple case studies and the research team were faced with an array of potential comparisons that could be made within this study.<sup>74</sup> These included:

- 1. Between country England, Northern Ireland, Scotland, Wales
- 2. Between levels Macro, Meso, Micro
- 3. Between areas PCT, LHB, and Health Board areas comparing health care purchasers and providers
- 4. Between practices
- 5. Between patients
- 6. Between conditions orthopaedics, ENT at Meso and Micro level
- 7. Combinations of the above

The study design meant that project resources were spread across countries, levels and case studies limiting the depth of study at each level in each case. However, the strength of this design rested on the sysnthesis of data highlighting whether there were distinctive differences in policy in each country.

Table 3. Structure of data collection sites

Country				
England	Primary Care Trust A	GP practice A	Six patients referred for ENT elective procedures	
			Six patients referred for orthopaedic elective procedures	
		GP practice B	Six patients referred for ENT elective procedures	
			Six patients referred for orthopaedic elective procedures	
	Primary Care Trust B	GP practice C	Six patients referred for ENT elective procedures	
			Six patients referred for orthopaedic elective procedures	
		GP practice D	Six patients referred for ENT elective procedures	
			Six patients referred for orthopaedic elective procedures	
Nothern Ireland	NHS board C	GP practice E	Six patients referred for ENT elective procedures	

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			Six patients referred for orthopaedic elective procedures
	NHS Board D	GP practice F	Six patients referred for ENT elective procedures
			Six patients referred for orthopaedic elective procedures
Scotland	NHS Board E	GP practice G	Six patients referred for ENT elective procedures
			Six patients referred for orthopaedic elective procedures
	NHS Board F	GP practice H	Six patients referred for ENT elective procedures
			Six patients referred for orthopaedic elective procedures
Wales	Local Health Board G	GP practice I	Six patients referred for ENT elective procedures
			Six patients referred for orthopaedic elective procedures
	Local Health Board H	GP practice J	Six patients referred for ENT elective procedures
			Six patients referred for orthopaedic elective procedures

Further details of the meso case studies can be found in chapter four and details of the interview samples are included at the start of each of the chapters presenting the findings (chapters 3-5).

# 2.3 Challenges faced in the research

The research across the four policy and health care systems presented a number of challenges. First there was a problem of language. Specific 'choice' policy only existed in England. It was difficult to frame questions in the other countries around the concept of patient choice as this was only associated with English policy and not perceived as relevant to the other systems by participants. In order to explore the extent of choices about decisions relating to elective surgery it was necessary to talk in terms of referral decisions. This was particularly true at the macro and meso levels, where outside England, choice was seen as an English health system term and not applicable to the contexts of the other health systems. This was less of a problem for patient interviews, but we did ask within these about experiences of referral and choices relating to this.

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Second, there was the need to ensure comparability between data collection in each country. The research team spent a substantial amount of time developing comparable frameworks for interviews and analysis – especially for the meso and micro levels of the study. All interviews were semi structured but the policy level (macro) interviews were more loosely structured than the interviews at the meso and micro level. All interviews were recorded but, as agreed in our original proposal and subsequent submissions to research ethics committees, only the policy (macro) interviews were fully transcribed. Data was extracted from the meso and micro interviews into structured frameworks that we developed to reflect our research questions and topic guides.

The full research team met regularly to discuss data collection and analysis. In order to ensure comparability between sites we approached data collection and analysis in an iterative way. The whole team developed and piloted topic guides for the macro and meso levels and a more structured interview schedule for the micro level. Initial interviews at each level were fully transcribed and jointly discussed by the research team. Amendments to data collection tools were agreed where necessary. For meso and micro level interviews the research team developed structured frameworks as mentioned above. These had both 'fixed response option' and free text formats to facilitate comparisons across countries and allow more nuanced comments and observations to be recorded and reflected in the analysis. The researchers extracted data into the forms while listening (often several times) to the recorded interviews.

To ensure validity and reliability of data and analysis data collection and analysis was triangulated.<sup>73</sup> We used a combination of researcher and methods triangulation for data collection with team members making data from interviews available to all team members. Similarly analysis of data was undertaken initially on a country by country basis but then shared and discussed by all team members. Transcripts for macro interviews were read and coded by at least two research team members. Data extracted from documents was tabulated and discussed by the full research team.

In presenting the findings in this report a key challenge has been to structure our findings in a way that synthesises the substantial amount of data collected in a way that directly addresses our research questions. While each level and country could have provided a study in their own right this research was not designed to asses or evaluate choice policy implementation or patient experiences of choice. The level of analysis is the total data set - across countries and levels. In total we conducted 267 interviews, attended meetings, examined several hundred primary and secondary documentary sources. Within the confines of this report the focus of data presentation and analysis is on comparison of the choice regimes in each of the four UK countries in accordance with our research protocol.

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The following framework will be used to describe the research design in more detail within each level. Within the broad aim outlined above, we will indicate the corresponding objectives of the investigation as a whole and the purpose and scope of this part of the research, before identifying the data constructed from the various sources of written information and key informants at each stage. We then outline the various types of analysis carried out to produce the findings on which the conclusions are based.

# 2.4 Research ethics and R&D approval

Ethical approval for the project was sought for the meso and micro level aspects of the research project in respect of interviews with NHS staff and patients. Ethical approval was sought in the Spring of 2007 once data collection for the macro level stage of the project was underway. We submitted the project protocol as agreed with SDO to the London - Surrey Borders Research Ethics Committee. Approval for the project was given on 24th August 2007 – Reference 07/H0806/65. A copy of the ethics approval letter is included at Appendix 1. The project registered with primary care research networks in order to help facilitate practice recruitment and R&D approval was sought from individual study sites.

# 2.5 Macro level: choice regimes in the UK

# 2.5.1 Objectives

The key aim of the macro level study was to understand the way patient choice, in terms of referral for elective procedures, was articulated in national policy. We aimed to examine the basis of policy in each country and compare different ways that such choices were articulated within policy discourse. This element of the research study involved the analysis of policy through documentary research, looking at debates, official documents, interviews with key policy makers and other stakeholders to identify the 'choice regime' in each home country and framework within which choices policies were implemented. Our objectives were to:

## 2.5.2 Purpose and scope

The focus was on constructing narratives of the past, present and future of choice policy in each country, through an understanding of:

- the development of policy, in terms of the sequence of steps leading to the current policy rather than a detailed account of who said what
- the ideological roots of policy and rhetoric
- how policy was structured, in terms of its focus, purpose, etc.

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- the dominant discourses of interviewees, in terms of how interviewees describe policy
- institutional discourses, to ascertain what was the formal government/ department assessment of policy.
- determine the political and ideological origins of the policies (the discursive frame) on choice within each nation
- identify the essential elements and objectives of policies on choice and their relationship with other health policies in England, Northern Ireland, Scotland and Wales
- investigate how, under the New Labour Government in the UK, policy makers understood and used the concept of choice, and how patient choice was conceptualised in the four UK national health services.

The starting point for the policy analysis was 2000/2001, as this was when patient choice first became a key issue with the implementation of the NHS Plan in England.<sup>11</sup> However, reference was also made to policies between 1997 and 2001, since this provided a useful pre-devolution starting point at the beginning of the New Labour Government in the UK.

### 2.5.3 Case selection

While patient choice was essentially a policy emanating from the Department of Health for the NHS in England, each constituent nation of the UK has been included to provide comparative understanding of the extent to which patients were offered some say in the services they used. The lack of specific policies on individual choice outside England does not necessarily imply that choice of some kind was not available elsewhere, but that it might take a different form or be located within other policies that prioritise other goals. The research team also wanted to examine policy without any predetermined assessment of the basis of choice within policy. Thus while choice policy has been linked to concepts of marketisation in the English health care system we began with a neutral view of its roots in policy. <sup>75,76</sup>

### 2.5.4 Data

In order to examine choice policy we examined the following sources for written information:

 policy documents, including formal government policy papers (White Papers), Departmental publications, guidance from government and from the NHS

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- other sources of policy statements; e.g. published accounts of policy in press releases, committee hearings, newspapers, accounts in Parliaments/ Assemblies, interviews
- political rhetoric; e.g. party political information/policy, interviews
- secondary literature, including reviews, commentaries, etc.

We searched Departmental databases for policy documents and official publications, searched more generally across government websites, political sources and key newspapers for references to choice policy. Searches were conducted between April 2007 and April 2008 with additional key policy documents identified where relevant after April 2008 and included in our analysis. In total we identified several hundred document sources which we then examined more specifically for reference to patient choice in terms of elective care. Each country based research team identified key, relevant documents for developing country specific narratives of the development of patient choice policy. Table 4 summarises the totals of documents used for the analysis of policy and a list of documents examined is included at Appendix 2.

Table 4. Summary of types of source material for documentary analysis

	England	Northern Ireland	Scotland	Wales	Total
Policy documents	22	10	20	12	64
Policy statements	8	2	4	9	21
Party political sources	0	0	0	1	1
Secondary literature	0	6	1	4	11
Total	30	18	25	26	97

In parallel with the documentary analysis, a number of key policy informants were interviewed in each nation, amounting to 42 in total between May 2007 and September 2008. Interviewees were selected from those involved in policy development including politicians, civil servants, policy advisers, representatives of national patient organisations and senior NHS personnel in each country. Further details of respondents from each country are given in Section 3.1 of Chapter Three (p55). A copy of the interview topic guide is included at Appendix 3.

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### 2.5.5 Analysis

We originally explored the documentary and interview data through a range of frames to identify key narratives, but the most relevant approach was to adopt a comparative description and thematic analysis. We focused on the development of policy and the key influences (political, ideological, etc.) that shaped policy identifying similarities and differences between the four countries. We also examined whether there were particular policy champions or networks of individuals/ organisations, including both those actively engaged and those who may have shaped policy by setting the wider policy agenda, or by limiting policy options. The research team met on three occasions to discuss policy development. A key focus of discussions was to determine our analytical strategy regarding what would constitute the case for analysis and what comparisons would be made. We also held meetings with other researchers undertaking policy comparison within the UK in areas such as health, education and social care.

Given the focus requested by SDO we examined three key aspects of policy in each country:

- 1. Policy rationale why was choice introduced
- 2. Policy objectives what was choice meant to achieve
- 3. Policy mechanisms how was choice to be implemented

We used this as a framework to analyse and present data from the documentary analysis and from interviews. We initially developed four individual country analyses based on the documentary research and interview data. These 'narratives' were then discussed by the research team to identify key themes and to compare these for similarities and differences between the four countries. While the focus of the SDO brief was on choice in relation to referral for elective care, the research team also explored to some extent the way choice was articulated in policy. This was particularly important in drawing comparisons between the four countries given the lack of explicit choice policies in Northern Ireland, Scotland and Wales.

# 2.6 Meso level: implementation of choice policies in the NHS

# 2.6.1 Objectives

This element of the study examined the implementation and operationalisation of patient choice policy in each country. The focus was on how NHS agencies put patient choice into practice. We aimed to capture health organisational perspectives on patient choice, and explore how

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organisations understood and operationalised choice policy to determine the way choices were offered to patients. We undertook a number of case studies across the UK to allow inter country comparison. We examined the relationships between different levels of the NHS and the choice pathways offered to patients. In total eight case studies were undertaken (two in each country). PCTs, Unified Health Boards, Local Health Boards and Health and Social Care Boards areas will form the focus of each case study and we identified the main providers (NHS and non NHS) in each area and selected a sample of general practices. Our key objectives for this element of the study were to:

- identify how choice at point of referral policy is operationalised in England, Northern Ireland, Scotland and Wales
- identify the organisational structures and processes supporting choice in each country
- identify the impacts of patient choice on the organisation and delivery of health care services in each country
- identify the impact of the delivery of patient choice on government objectives for choice policies
- produce data to allow comparison of the operationalisation and impact of choice policy between case study sites and between countries

# 2.6.2 Purpose and scope

The primary interest at this level was in the mechanisms for choice of secondary care services within a number of case study sites and the effect any change in policy had had in the recent past (such as the introduction of the patient choice system in England). The focus was on changes from 1997 onwards. The meso study analysed the 'operationalisation' of policy concerning choice made when accessing secondary care services (choice of location/provider) in England, Northern Ireland, Scotland and Wales. The analysis focused on two case study sites in each country, consisting of local providers, purchasers and referrers relating to two tracer conditions (ENT and Orthopaedics). The research consisted of interviews with commissioners, providers, practice staff (GPs and practice managers), relevant regional representatives and patient and public representative groups within each case study area. We also sought quantitative data and organisational documents to identify indicators of the effects of different choice policies relating to referral to secondary care on access to care, responsiveness to patients' wishes and efficiency of resource use. Quantitative data was intended to provide a supplementary analysis as it

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was not known if it was possible to obtain it on a comparable basis across sites. As explained

### 2.6.3 Case selection

In order to examine how choice policy was implemented in each country it was essential that contextual factors were addressed by exploring policy implementation in different areas in each country. Within the resources available for the project we were able to select two case study sites in each nation centred on the local commissioning body (or equivalent) and within which general practices were selected as exemplar cases: 2 per case study site in England and 1 per case study site in Northern Ireland, Scotland and Wales, giving a total of 10 (see Table 2 above). A more detailed description of the case study areas is given in chapter 4 (section 4.1) with additional descriptive information at the start of each country section in chapter 4.

The criteria for the selection of case study sites (and GP practices within them) were as follows:

- Large enough practices within case study area to have sufficient volume of referrals in the tracer conditions selected for the microlevel phase (n≥12) over a period of six months.
- Mix of urban/rural population
- Choice of local providers, including a Foundation Trust in the English case study sites
- Research friendly, in the sense of being positive about being involved in the study, in order to minimise delays in delivering the sample.

Case study sites were selected to reflect rural and urban differences as evidence on health services access and patient choice identified key differences in the availability of choice between such areas. Selected areas had one main NHS acute provider (to include an English Foundation Trust) and additional NHS and private providers within one hour travel time. Selected areas case study recruitment commenced in early 2008. Difficulties in case study recruitment were experienced in England and Wales where, in each case, one site was recruited very quickly, but the second sites took several months to identify and agree to participate.

We also experienced general practice recruitment problems in England, Northern Ireland and Wales. The project was registered with local primary care research networks but even with their help recruitment was slow involving discussions with practices who then decided not to participate for a number of reasons including excessive workload, other research etc. For example in one case study site discussions were held with eight practices before securing access. This involved substantial researcher time.

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Securing the full quota of general practice sites involved 22 additional site visits with practices to encourage recruitment, attended GP events, liaised with local primary care networks as they have developed to discuss recruitment and visited PCT and other health organisations to identify practices and discuss recruitment. Visits to practices normally involved meeting with the practice manager and then a GP principal to explain the research and what would be involved. Some practices initially indicated that they would be involved but with the practice subsequently withdrawing their consent to participate. However, in the meantime, material was prepared for the practices for interviews with practice staff. Recruitment of practices also involved discussing aspects of patient recruitment and preparing patient material for sending out to patients. This was time consuming and involved additional travel, numerous phone contacts etc.

### 2.6.4 Data

The sources of information included the following types of interviews, which varied in content slightly according to their relevance within each nation:

- Interviews with representatives of NHS organisations (eg. PCTs, LHBs, Hospitals, general practices), regarding the operationalisation of choice
- Interviews with representatives of local patient groups (eg. Community Health Boards, LINks), regarding patient/public involvement in service and commissioning decisions, and opportunities for these groups to influence choice processes

Interviewees were identified by researchers in each country research group. We initially drew up a purposeful sample frame of potential interviewees and the contact was made with key informants in local organisations. We then used a snowballing technique to identify additional interviewees in each location. The research team also discussed who was being interviewed which led to the identification of further interviewees (eg administrators in charge of patient referrals in hospital trusts). In total 125 people were interviewed for this element of the research. Further details about the interviewees by informant category, agency/organisation and nation are given in section 4.1, Table 10 in Chapter 4.

Most interviews were conducted face-to-face at the interviewee's place of work with a few being conducted by telephone where necessary. The interviews were audio-taped using a common, semi-structured interview schedule for the NHS organisations across all sites and nations as shown Appendix 4. The interview schedules were developed jointly by the country research teams. Following initial interviews researchers transcribed interviews and shared these across the research team. Interviews were jointly discussed and adjustments made to interview schedules. These

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discussions also led to the development of a common approach to data analysis and construction of referral pathways. Interviews were conducted between April 2008 and September 2009.

In addition to the collection of qualitative data, it was intended that quantitative data on referral flows, volume of services provided, patterns of service provision, waiting times, and change in commissioner costs would be collected from participating case study sites. The aim of the collection of this data was to provide descriptive statistics to aid the identification of, and comparison of, trends and patterns in the above areas rather than a specific analysis of the efficiency and quantitative outcomes of choice policy. An outline of the data requirements which were developed by the project team can be found at Appendix 5.

Participating organisations were approached to supply quantitative data to support the interviews. Responses to requests were variable. Some organisations did not provide the requested data, and those organisations which supplied data often did not supply data which matched the requirements which were agreed by the project team. This was often indicative of the fact that some of the required information did not exist in organisations, and a lack of willingness on the part of participants to produce the data. Whilst it has therefore not been possible to collect comparable data across the four countries, or indeed within countries, it was not intended to produce a stand-alone analysis using the quantitative data. Instead the quantitative data were used to support the qualitative study, and where relevant, reference to the quantitative data which has been gathered has been included in the analysis of each country. Where possible, quantitative data which had already been gathered were used as a prompt within interviews in order to generate and inform discussion.

With reference to patient choice in England we have used two sources of externally available data to give an additional perspective on the impact that patient choice has had on our case study organisations. Firstly, we have obtained some information which provides an indication of the market position of the organisations. This has been developed by Professor Carol Propper of Imperial College, London, who has calculated Herfindahl-Hirschmann competition indices (HHI) at the NHS trust level for the fiscal years 2003/04 and 2007/08 for a study of competition in the NHS. These HHIs have been constructed using actual patient flows to the trust in a given year, for all elective services. Secondly, we have referred to the Care Quality Commission ratings for the English case study organisations in order to give an indication of organisational performance during the period the interviews took place. An analysis of this data with regard to patient choice can be found in Chapter 4.

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### 2.6.5 Analysis

Documents and observations were filtered to identify the relevant material relating to patient choice policy and implementation, prior to undertaking interviews in each case study site. Descriptions of each of the case study sites are provided in chapter 4 in the country sections. These provide background details about the case study sites including relevant providers.

Interviews were selectively transcribed and the transcripts read by at least two team members. The content was organised into pre-determined and emergent themes. Pairs of transcripts were exchanged at the initial stage to compare inter-rater reliability, and discordant interpretations were discussed between raters, with the aim of resolving the differences and agreeing a protocol for subsequent analysis. Researchers agreed an analytical framework and selectively transcribed from interview data. Comparison between and within themes, case-studies, organisational types and over time has been carried out. The research team identified similarities and key differences across case study sites by type of organisation, case study area and country. Commonalities across case studies in all countries were identified and synthesising the data it was clear that comparison between country was the most appropriate analytical structure and is presented in Chapter 4. Key similarities and differences in patient referral pathways emerged and these have been used to structure the presentation of data. In addition, detailed referral pathways were produced for ENT and orthopaedics in each nation to identify the points at which choices were made. These were shared between researchers and compared in order to develop common methods of presentation. These are included in Chapter 4.

Researchers provided summaries of data collection with key themes identified. These were jointly discussed across country to develop a common framework for data analysis. The focus was on identifying how organisation provided and managed patient choices. The research team agreed a common framework for structuring data to identify:

- How choices were shaped by purchasing/funding organisations and providers
- How choices were administered within provider organisations
- How choices were offered to patients

The findings are presented as summaries of processes in each country. Summaries were read by members of the research team and final versions were agreed by the whole team. Each country based research group identified key examples drawn from their case study material. The research team discussed which should be included for illustrative purposes in the report.

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# 2.7 Micro level: patients' experiences of choice relating to referrals (or access) to specialist care

### 2.7.1 Objective

This element of the research was nested within the meso level elements of the research and was designed to provide insights into the operation of patient choice at the patient level. We used the general practices that served as cases for the meso level for patient recruitment. The micro level study aimed to examine referral processes, and particularly any choice offered within those, from patients' perspectives, and to identify any qualitative differences in the effects of the four nations' different 'choice' policies on patients' perceptions of access to care and the responsiveness of services to their needs and preferences.

### 2.7.2 Purpose and scope

The intention at this level of the study was to understand, by considering illustrative examples, how the operationalisation of 'choice' policies had affected patients who had recently been referred by their GP to hospital for orthopaedic or ENT surgery. These two specialties were chosen because they both have a relatively high volume of referrals, so we could anticipate recruiting sufficient patients within the available time frame from medium sized practices. The sampling period was from October 2008 to October 2009.

### 2.7.3 Patient recruitment

The research protocol provided for the recruitment of patients to the study after they had been referred by the GP for further treatment. Patients were recruited by liaising with practices to identify all those referred in specific periods based on referral rates. We then sought to quota sample the referred patients to ensure they included men and women from each of three broad age bandings (18-40, 41-60 61+) and who had consulted with different GPs. We aimed to recruit a total of 12 patients from each practice.

Our original plan was to undertake two interviews with each participating patient: one immediately after referral and a second , by telephone if possible, 6 – 9 months later. However, the research ethics committee required that patients 'opt in' to be contacted by the research team, which meant we were dependent on practices to send invitations to participate to eligible patients. In addition, there appeared to be substantial non return of the invitations sent out by practices. These circumstances precluded interviews immediately after referral. Therefore, following discussions with GP practices and with agreement of the ethics committee we changed the

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protocol in early 2009 and agreed with SDO that we would only undertake one interview per patient at a point within six months from the referral consultation with the GP.

Practices chose for practical reasons to send invitations to all consecutive adults who met the referral criteria until the research team informed them that the target sample size and composition had been achieved. Adults who were interested returned a form indicating agreement to direct contact with a member of the research team to discuss possible participation in the study. These discussions were arranged on a country-specific basis and were usually held by telephone. Due to delays in recruiting practices (explained above) there were subsequent delays in recruitment of patients. Recruitment of patients commenced in November 2008 but initial recruitment seemed slow. (Practices did not all keep records of the numbers of patients they sent invitations to, so we were unable to estimate 'opt in' rates, but we know that some practices sent over 100 invitations before we secured 12 interviews). In total, we interviewed 99 patients within the time frame of the project (recruitment stopped in July 2009). Details of the patient sample are included in section 5.2 in Chapter 5.

Interviews were conducted by country-specific researchers either in participants' homes or by telephone if travel requirements for the researchers were unduly impractical or costly. When interviews were conducted over the telephone, interviewers had discussed the consent form with the interviewee when setting up the interview date. Two copies of the consent form were sent to the interviewee in the post, with one copy to be signed and returned to the interviewer before the interview. When the interview commenced, whether face to face or over the telephone, researchers reminded participants about the aims of the study and the key points on the consent form. They also stressed that the study was not trying to evaluate their GPs.

### 2.7.4 Data collection

The researchers who conducted the interviews were supported by an interview schedule (see Appendix 6). This was organised chronologically, so participants were encouraged to tell: the story of how they got to a point that a referral was made for them to see a specialist about their ENT or orthopaedic problem; what happened in the consultation during which their GP made (or agreed to make) a referral to a specialist; and what had happened since the consultation in which the referral was made. They were asked to comment particularly on issues of choice and involvement, and then to look back on the process and say what they felt about it all, and whether they had any suggestions for improvement. Broad opening questions in each of these domains were followed up by further conversational probes to check the researchers had understood, for

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example, what were the main symptoms, problems or concerns that the referral was intended to address, or what the sequence of events was.

In an attempt to compare the experiences and evaluative judgements of patients in the four countries in a more structured way, we included two short blocks of precisely scripted questions with fixed response options. The first block of questions, asked after the patient had described what had happened in the consultation during which the referral was made or agreed, sought to check whether or not the referring GP had discussed with the patient where (e.g. which hospital) to whom (e.g. which consultant) and for what (e.g. tests, procedures) the referral would be for, and when it would be. The second block, asked after they had made their open reflections on the process, considered whether they had wanted to be involved in the decision about their referral, whether they had been involved in making the decision about their referral, whether they had been given sufficient options in terms of where, to whom, for what and when their referral would be, and whether enough attention had been paid to their views about where, to whom and for what they were referred and when their referral appointment would be. We had intended to compile simple frequency counts for responses to these questions, and to look for any striking differences in patterns of responses across countries that might warrant further investigation. However, it became clear during interviews that some respondents had difficulty with some of these questions, and comments they made elsewhere in the interviews revealed inconsistencies in their interpretations of these questions that would render the presentation of frequency counts misleading. We therefore summarised responses to these questions descriptively in the context of the broader comments that participants made on the same issues. We also noted the kinds of interpretative issues that arose, because these have salience for the design and interpretation of larger scale surveys of patients' experiences of referrals and 'choice' relating to these.

Some participants told us about their experiences with previous referrals to specialists as well as with the referral that had triggered their invitation to take part in this study. We asked them to focus on the trigger referral, but made use of what they told us about previous referrals that were clearly linked to the most recent one, and also of reflective and comparative comments that shed light on their evaluations of choices and involvement relating to the use of specialist services.

### 2.7.5 Analysis

The interviews were digitally recorded. In accordance with our research proposal, recordings were not fully transcribed (budgetary constraints did not permit this). Researchers exchanged notes or self-made transcriptions of their first few interviews and met to discuss the interview questions and

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responses. As proposed in our research protocol and in order to facilitate cross-country comparisons and data analysis, the research team developed a data extraction framework in the form of a Microsoft Access Database (with a record for each interview) that could record both 'fixed responses' and summaries or partial quotations of more discursive responses, following the structure of the interview guide (see Appendix 6). The researchers who conducted the interviews listened to the recordings (sometimes several times) and completed the data extraction accordingly. The database entries were analysed on both a 'within person' and 'by topic' basis. The researchers also prepared initial country-level summaries presenting the response frequency 'counts' for questions with fixed response options and descriptions of the key themes and issues they had identified in response to more open questions. The research team considered the most appropriate approach to presenting the data, taking into account the fact that there had been no scope to transcribe all the interviews. We agreed after discussions to prepare brief individual summaries of cases selected to illustrate both typical and unusual accounts of experiences of referral processes and views about choice or involvement. Edited versions of these are included within the analysis presented in chapter Five.

### 2.8 Limitations of the research

During the project we made one major change to the research protocol. Our original intention was to interview patients immediately after referral by their GP and before their elective procedure, and then to follow this up 6-9 months later to identify what had happened. This was changed to one interview for two reasons. The research team was concerned that there would be attrition between the first and second interviews which would limit the usefulness of the data. Second, it was clear from discussions with practices that the feasibility of gaining consent and access to patients within a short period following the referral consultation would be unrealistic.

This latter point was verified in practice. While we had agreement with practices to send invitations to participate to all patients when they were referred for elective procedures in reality practices did this in different ways. Often invites were sent to patients in batches, so for some patients they did not arrive until a number of weeks after referral. Given subsequent delays in patients' responses and the need to arrange interviews at times convenient to patients, all had experienced some form of 'progress' or 'delay' with their referral by the time they were interviewed. Undertaking a second interview to explore 'what had happened since' was thus rendered inappropriate. This did mean that some patients were interviewed some months after their referral was agreed, and this of course could have implications for their ability to recall communication relating to choice

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around the time of the referral. However, most participants were able to give quite vivid accounts of what happened.

The other major limitation of the research was the focus on patient choice of provider for elective referrals. This focus was stipulated in the original brief due to the current policy context in England at the time of the research. Towards the end of the research the scope of choice broadened. Two potential limitations arise from this. The first is the imposed focus on choice of elective referral provider presented challenges in constructing data collection tools across the four countries. In order to operationalise the concept we focused on discussing choices in patient referral pathways. Second, the widening of choice after April 2008 in England was implemented towards the end of the research. However, the findings of this report provide some relevant insights to the current context of choice.

Changing policy was an issue across all four countries, and as with many analyses of policy, it is difficult to both identify a specific policy and to examine its implementation while the wider policy context is continually changing. The late introduction of limited choice in Northern Ireland and increasing reference to choice in Scottish policy documents are examples of how policy contexts change. Identifying the specific roots of such changes is complex and open to multiple interpretations.

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# 3 Patient choice policies

### 3.1 Introduction

As discussed in Chapter 1 choice has become an increasingly important element of New Labour's approach to the Welfare State. Choice casts the public service user as a consumer choosing between different welfare services.<sup>1,78</sup> While there is clearly a UK wide context to welfare state provision the increasingly devolved nature of the UK's political system and public service provision has led to the emergence of clearer differences in health policy and the organisation of health care services between the four UK countries. We undertook an analysis of policy and quidance documents and interviewed people involved in policy development and implementation in each country to explore the nature of choice policy within each of those health systems. The focus on patient choice presented some difficulties when interviewing outside England. For example, the extent to which non-English respondents related to the concept of patient choice varied with some politicians and policy makers being very explicit that choice was an English concept and did not have any relevance in non-English systems. The framing of the research study around patient choice also led to respondents framing their responses in relation to England, with some respondents - particularly in Scotland and Wales – reflecting on the English system in response to questions about choices in their own health systems and policy development. In the confines of this report, it has not been possible to fully reflect these aspects of the analysis, but the research team intends to publish these data elsewhere.

This chapter presents the key findings from the documentary analysis and interviews. The documentary analysis included policy documents published from 2000 onwards until 2009. Interviews were conducted in the second half of 2007 and the first quarter of 2008. Key questions were the extent to which 'personalisation' and 'responsiveness' were embedded within the policy discourses of each UK country. The data are presented both as a narrative for each country and analysed by theme. Our aim was to identify dominant policy discourses related to patient choice. This includes the extent to which patient choice was explicitly referred to in policy, the development of key policies to address choice and policy mechanisms put in place to deliver choice in health care. Data are presented for each of the four countries in turn drawing on the analysis of policy documents and interviews with policy makers, advisers and politicians. A fuller analysis of policy documents was completed in February 2009 and is available as a separate document. A timeline of documents and key guidance and actions is included as Appendix 2.

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Table 5. Respondents at the macro level, broken down by informant category and nation

Informant category	Agency/ organisation	England	Northern Ireland	Scotland	Wales	TOTAL
Politicians and political advisors	UK Govt, Scottish Parliament, Wales Assembly Govt.	7	5	2	3	17
Senior civil servants and health service executives	DH, WAG Health and Social Care Dept., Scottish Executive Health Department, NI Dept Health and Social Services.	4	1	7	8	20
Health specialists	Think tanks/ unions	4	0	2	0	6
TOTAL		15	6	11	11	43

# 3.2 England

### 3.2.1 Introduction

In the English NHS, 'Patient Choice' policy has been a central element of recent health care reform that has focused on patient choice of secondary care provider.<sup>4</sup> Patient choice represents one of the demand-side reforms introduced since 2001 and complements policies aimed at giving patients a stronger voice in the.<sup>36</sup> Policy makers in England have promoted patient choice (including options for patients to 'exit' from one provider and transfer to another) as a key driver for improving quality and efficiency, and particularly for the reduction of waiting lists and lengths of wait for secondary care. Policy officials and political advisers in the Department of Health emphasised the use of patient choice as a way of specifically cutting waiting list times:

From a managerial perspective, the patient choice and Payment by Results [policies], and the introduction of new providers were also being introduced for instrumental reasons, which is that certainly when we looked at the data for elective activity growth in 1999, 2000, 2001, it had effectively stalled despite apparently injecting more cash specifically for elective activity growth. So that in turn meant that there was great interest in some of the

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international experience around how waiting times had been reduced, and the patient choice mechanisms that were beginning to be tested in Sweden, Denmark and Spain, (DH political adviser A)

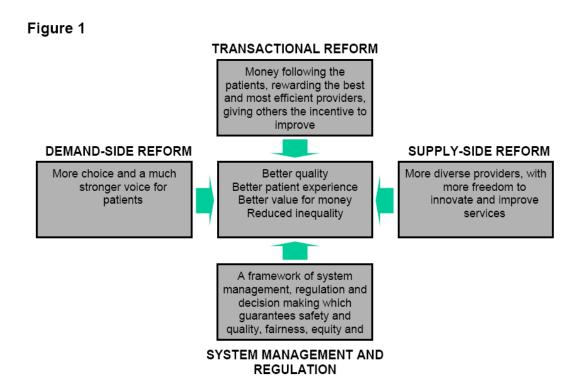
In 2003, the DH introduced nine pilot projects offering patients choice of provider. The experience of these pilots was seen as very positive from both a patient perspective and at a policy level as they had a marked impact on waiting lists:

This was at a time when there was a concern about waiting lists. We have not talked about the choice pilots. The great thing about choice and the pilots was that it made much better use of existing capacity. (DH political adviser B)

Building on the perceived success of the pilots, the choice policy was first introduced as a means of providing patients who were facing a long wait for surgery with the option to choose a provider with a shorter waiting list. Thus choice became one of the key mechanisms for addressing NHS productivity as shown in Figure 1. One senior policy official in the Department of Health described choice as "an essential driver for addressing capacity problems in the NHS – first priority and then tackling waiting lists. Choice as an internal management or systems driver. The threat of patient's making preferences acts as a driver for organisational change."

Figure 1. Relationship of patient choice to the English health service reform programme

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Source: Creating a Patient led NHS: Delivering the NHS Improvement Plan<sup>79</sup>

There was a strong emphasis in the *NHS Improvement Plan* on developing a 'personalised' service and 'personalisation' remains a key component of the rhetoric of policy. Since 2001 there has been an increasingly explicit emphasis on increasing the range of health care providers (including private providers) and presenting patients with options in order to create a market for health care provision in England.

Patient choice of provider remains a central plank of health policy but it is also closely related to other policy goals relating to health and social care. However, it is clear that the policy commitment to expand the range of choices available remains a key government objective and enjoys cross Party political support.

I think we should empower people, and choice mechanisms in other contexts like education have tended to demonstrate that if you empower the public, the consumers of public services, quite often it's people who have literally not known how to challenge the services that you provide to them who suddenly find that they get a voice, an influence and they begin to shape the service far more effectively in the future. (Conservative Party Health Spokesperson)

I certainly favour people having the right to choose between different providers..... But its more than just that, it's also giving the patient a right

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to have a say in which clinician they get to go to (Liberal Democrat Health Spokesperson)

In 2007, universal choice was made available for patients referred for orthopaedic surgery as a pilot for national choice policy and since April 2008 patients in England have been able to choose from any of the providers that meet national criteria. The emphasis on choice is highlighted by the recent *Next Stage Review* which advocates information and choice, informed choices, introducing personal health budgets and embedding the 'new' right of patients to make choices about their care in the new NHS constitution. <sup>80,81</sup>

# 3.2.2 Policy rationale (why)

In the NHS Plan,<sup>11</sup> the Labour Government articulated a diagnosis of NHS problems around four keys areas:

• **Responsiveness** - allowing patients to individualise certain aspects of the delivery of their care was seen in policy terms as a key way to ensure the NHS became responsive and 'shaped around the convenience and concerns of the patients'. 11 Patients should be able to choose *how, when and where* they are treated" (2.17) and this is enshrined in the new NHS constitution. 36,81

We were moving from an NHS that was being run like an old nationalised industry, into this new world that we were calling the patient –centred, patient-focused NHS, a patient-led NHS, where essentially all the incentives within the system would lead the NHS constantly to improve the quality and the speed of care that they gave the patients (Former Secretary of State for Health)

- Waiting times One of the highest priorities of the NHS Plan was to reduce waiting times from a level which was unacceptable to patients. Concern with waiting times was both absolute in terms of reducing all waiting times but also it was recognised that waiting times differed between areas creating further inequality of access. Later policy documents such as the NHS Improvement Plan positioned choice as a mechanism for allowing patients to access the shortest waits, leading to the reduction in waiting times which was a prerequisite for implementing wider choices for patients. <sup>36</sup> One senior Department of Health official described choice as part of the 'war on waiting' and a key mechanism in achieving 18-week waiting time targets.
- **Performance** Performance between providers has always varied and while responsive to central targets, these were felt to be a blunt instrument for improvement. The belief was that consumer-led choice

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in a competitive market place was the mechanism which best facilitated continuous performance improvement to deliver services in line with patient demand, and without requiring direct central intervention.

Patient choice would in itself lead to a change of incentives within the system, because once cash was following choice then there was a sharp reason, it introduced a sharp reason, for organisations to think about their performance, to think about whether or not they were capable of attracting extra patients and therefore extra income .... As part of a broader range of drivers that we were seeking to introduce, to improve performance in the system. (Former Secretary of State for Health)

• **Equity-** choice in the English NHS was positioned as a way of replacing the current inequitable service, with a mechanism which would 'universalise the best'. Patient choice was presented as a mechanism for achieving the fairer allocation of health care resources; improving patient experience (by promoting individual involvement in care), and; increasing efficiency and system responsiveness. As such patient choice was presented within the key core values of the UK NHS of fairness and equity. Equity was used within the Labour Party to 'sell choice to the backbenchers' based on the argument that it would reduce waiting times, improve quality and give everyone the sorts of choices enjoyed by the middle classes:

I wanted every individual NHS patient to be able to exercise choice over where they were treated and over their form of treatment. That was the explicit objective, now, and I very well remember being told at the time by one or two senior policy makers within the department, that people didn't want choice, based upon this rather quaint notion that because it was alright for them on their six figure salaries to exercise choice, but people in my constituency who unfortunately were on five figure salaries that they didn't want to have choice. (Former Secretary of State for Health).

# 3.2.3 Policy objectives (what)

Patient choice was designed to achieve a number of objectives including:

- Shorter waiting times
- Choice of where and when patients are seen/treated
- Improved quality
- Increased information for patients on services provided.

Choice was first introduced to the English NHS to reduce waiting lists for elective patients, first for the longest waiters and then for everyone else, and then to keep waiting lists low. The aim of letting patients choose their

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secondary care provider was firstly to decrease waiting times but also to create a 'self-improving NHS',<sup>73</sup> in which patients' choice of secondary care provider created a competitive environment for providers, where elements of performance, such as shorter waiting times, were incentivised.

Overall the context was that we were trying to fundamentally change the way that the NHS was run, organised, what was driving decision making within it. (Former Secretary of State for Health)

In order to enable this system to flourish, the Government believed that capacity needed to be increased and health providers given more freedoms. Thus there was the development of private and third sector providers and promoting new organizational forms, including the creation of Foundation Trusts and the provision of NHS services by private sector organizations. The adoption of a fixed price tariff was also introduced to ensure that providers would compete on quality rather than price. This establishment of a consumer-led market was part of a set of supply side reforms aimed at improving NHS performance.<sup>36</sup> Choice was seen as a lever for quality improvement with service providers competing on quality (rather than price) to attract patients.

Choice within the English scheme was based on location of treatment, with the choice made after agreement about the need for treatment has been made by the GP in consultation with the patient. Patient choice policy does not address issues of treatment choice. Choice was also limited to choices paid for and offered by the NHS and while independent providers were included they have to be NHS-accredited. These initiatives were also supported by schemes that addressed 'when' as they were designed to make the appointments process more service-orientated, offering patients a choice of date and time for treatment and improving methods of booking appointments. Choice was initially restricted to elective care at a time and location of the patient's choosing, but since 2008 choice has been extended across a wider range of treatments although still predominantly elective, surgical treatments. The policy objective appears to have developed from an explicit focus on waiting times to embrace a stronger focus on responsiveness to the patient.

The initial choice policy was actually more around, if you like, the consumerist bit, in actual fact of Choosing and Booking, it's the convenience things and so on. I'd have said almost, at that stage, choice of hospital was actually largely an after-thought, 'you might as well choose your hospital', that kind of thing. Coming out of the stable of Choose and Book and then very much an issue around 'we need to develop the systems for choice', but actually the focus had to be inevitably on building the capacity, a) because you needed to bring waiting times down .... That's shifted now in two or three ways. [and now] being actually quite an important end in itself, in terms of patient empowerment. (Senior DH Official)

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In *Building on the Best*, <sup>2</sup> the government argued that the 'culture of choice needs to be widened and deepened' and the paper contained plans to increase the choice of access points to primary care and medicines, and widen the choice of treatment and care in maternity services and care at the end of . Later proposals included widening choice within mental health services, care choices for patients with long term conditions, increasing choice of access points to emergency care, and encouraging patients to make healthier and more informed choices regarding their own care. <sup>32,73,82</sup>

The fourth objective was to ensure equity by providing information to support the patient in making choices – offering information about waiting times, quality of services and ensuring support was offered for patients who may be disadvantaged in making choices. In 2004, the Department of Health published an information strategy, *Better Information, Better Choices, Better Health*, which outlined its three-year programme to improve information for patients and promote shared decision-making between clinicians and patients, on the basis that the availability of good quality and meaningful information 'is fundamental to choice and making informed decisions. Without information there is no choice'. Information was also seen by the government as being key to supporting free choice.

I think the information bit of it is absolutely vital, it says that in 'Building on the Best'... Once we start, and I hope we will, once we start really opening up what you might call contestable, arguable information that people can see is not just about 'in this hospital they provide these services', but 'in this hospital they provide these services better than this hospital, and they have lower MSRA rates, and they have better outcomes, and you can see it', and its one of the things that makes me cross of course, is that doctors have always had choice for themselves and their families. My father was a doctor, he knew who was good and who wasn't, who was nice and who wasn't, who was quick and who wasn't. (Ex Senior DH Official)

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Table 6. Chronology of policy documents: England

Year	Policy documents	Initiative	Type of choice
1948		Launch of NHS - right to choose their own GP, optician and dentist	Gatekeeper
1998		National booked admissions programme launch[1]	Appointment date and time
2000	NHS Plan: A plan for investment, a plan for reform (Cm 4818). (White Paper)	Introduction of a system for patients to book time and date of appointment	
2001	Extending choice for patients (DH publication)		
2002	Delivering the NHS Plan: next steps on investment, next steps on reform (Cm 5503) (White Paper)	"CHD Choice" pilot. Patients waiting for more than 6 months for heart operations get choice of provider (a pilot was also conducted for patients waiting for elective surgery in London)	Provider (cardiology)
2003	Choice, responsiveness and equity in the NHS and social care. (National consultation) Building on the best: Choice, responsiveness and equity in the NHS (Cm 6079) Fair for all, personal to you (Consultation)	9 choice pilots in operation across England offering patients waiting more than 6 months for surgery a choice of provider [2]	Provider (elective surgery)
2004	NHS Improvement Plan: Putting people at the heart of public services (Cm 6268) (White Paper) Choosing Health: Making healthy Choices easier (Cm 6374) (White Paper) Better Information, Better Choices, Better Health: Putting information at the centre of health (DH Publication) Choose and Book - patient's choice of hospital and booked appointment.' (DH Publication)	"Choice at 6 months" launched. People who have been on an elective waiting list for 6 months choose another hospital (excluded ENT and Orthopaedics until August 2004)  Pharmacy choice. Patients can pick up repeat prescriptions from a pharmacy of their choice.  "Choose and Book" online booking system launched [3]  "Choice at 6 months" pilot. Choice of location of ophthalmology treatment in six SHAs	Provider (elective surgery)  Provider (pharmacy)  Appointment date and time Provider (ophthalmology)

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		"Choice at 6 months" pilot. Choice of location of orthopaedic treatment in six SHAs	Provider (orthopaedics)
2005	Creating a patient led NHS: Delivering the NHS improvement plan (DH Publication)	"Choice at referral" Introduction of choice of at least two providers for cataract surgery from January 2005.	Provider (ophthalmology)
		"CHD Choice" All patients requiring a coronary artery bypass graft, angioplasty, or heart valve operation, given a choice of hospital at the point of referral by the cardiologist. [4]	Provider (cardiology)
2006	Our health, our care, our say: A new direction for community services (Cm 6737). (White Paper)	"Choice at referral" All patients offered a choice of 4 or 5 providers when they are referred for elective treatment by their GP	Provider (elective care)
	A Stronger local voice: A framework for creating a stronger local voice in the development of health and social care services (DH Publication)	'National menu' Choice widened to include NHS Foundation Trusts, Independent Sector Treatment Centres and Independent providers [5]	Provider (elective care)
2007	Generic Choice Model for long-term conditions (DH Publication)	"NHS Choices" online information service launched. Includes information about healthy lifestyle choices as well as information to aid decisions about health care providers.	Decision support
		"Free choice" of secondary care provider phased in on a speciality basis, starting with orthopaedics (based on the "extended care network" of mixed economy of providers, including independent treatment centres).	Provider (all specialities)
2008	High Quality Care For All: NHS Next Stage Review Final Report (DH Publication)	"Free choice for all" covers all specialities, excluding maternity and mental health. Patients can choose any provider in England.  Terminally ill people can choose where they are cared	Provider (all specialities)  Location
		for.	

<sup>1.</sup> See "Historical Review", at: <a href="https://www.dh.gov.uk/en/Healthcare/PatientChoice/Waitingbookingchoice/DH 4083787">www.dh.gov.uk/en/Healthcare/PatientChoice/Waitingbookingchoice/DH 4083787</a> (accessed 30.6.08)

<sup>2. &#</sup>x27;Choice of Hospitals: Guidance for PCTs, NHS Trusts and SHAs on offering patients choice of where they are treated' (DH, 2003)

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3. Connecting for Health (2005) "Choose and Book Progress to Date" Submission to the Public Accounts Committee on Choice. Available at: <a href="https://www.connectingforhealth.nhs.uk/newsroom/news-stories/public accounts committee and choice/">www.connectingforhealth.nhs.uk/newsroom/news-stories/public accounts committee and choice/</a> (accessed 30.6.08)

4. CHD Choice website, at:

www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Coronaryheartdisease/DH 4097969 (accessed 30.6.08)

5. 'Choice Matters: 2007-8' (DH, 2007)

**Note**: Only documents that set out new policy are listed here, there are many other documents providing information and guidance on implementation. A more comprehensive listing of documents can be found in Appendix 2.

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# 3.2.4 Mechanisms (how)

To support patient choice of location of referral and time and date of appointment a number of mechanisms were implemented including pilot choice of provider schemes, computerised booking schemes and information services to support choice including a choices website (See Table 6 and Appendix 2).

Choice was first introduced in England in 2002 to reduce waiting times for operations, whereby long waiting patients were offered earlier treatment at an alternative provider. As described in Chapter One there was a gradual development of policy over the next seven years following initial pilot programmes, the inclusion of all patients waiting over six months for elective surgery, the provision of a choice of 4-5 providers and then in 2008 free choice. Processes offering choice at the point of referral were underpinned by new booking mechanisms including a booking technique ('partial booking') designed to offer patients a choice of date and time when booking outpatient appointments in secondary care and a web-based booking system 'Choose and Book' to facilitate patients' choice of provider. This latter system, which was the central instrument in the delivery of choice of provider policy, allows choices of provider to be registered over the internet, and eventually will offer all patients and GPs the opportunity to directly book an appointment of the date, time and provider of their choosing over the internet. Support was offered to patients to make the choice either by GP support in the surgery, or via web-based waiting time and quality information on the NHS Choices website (www.nhs.uk), a means-tested Patient Choice Adviser, or the national appointments telephone line. Whilst the system facilitates choices made by the patient in consultation with the GP, it also allows the patient to choose the preferred provider and make a booking after they have left the GP's consulting room. In this way, in theory, the onus for making a choice about where to receive treatment was ultimately taken out of the hands of the clinician, or indeed the bureaucrat, and given to the patient.

Choice of provider also exists within other areas of the NHS, most notably the development of alternative first contact primary care for the patient in the form of NHS Direct and NHS Walk-in Centres. It was envisaged that in the future patients will also have increased choice of provider in primary care, including the development of new GP-led health centres, and increased choice over appointment time, including weekend and evening access. The primary care proposals in *Our Health, Our Care, Our Say* also provided for extended pharmacy services providing alternative first points of access for

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common and easily managed conditions and a range of alternative community health services.<sup>3</sup>

Over the last six years the choice agenda has been expanded beyond just choice of provider, with an increasing emphasis on the opportunities created by patients and health care professionals working in partnership.86 Expert Patient programmes were designed to widen patients' choice of treatment and care -using generic skills including self management and more effective use of health services.<sup>87</sup> These initiatives began with maternity, but have been expanded to include care at the end of life.<sup>2</sup> Similarly, it is envisaged that mental health service users will also have increased choice over their care and treatment options.<sup>79</sup> Best practice guidance has been issued to commissioners of care for people with long term conditions to support choice for patient through the development of personalised packages of treatment and care.<sup>88</sup> Our NHS Our Future clearly states the need to widen the choice agenda even further in the future in order 'to deliver the kind of personalized care we all expect'.85 The Department of Health has also developed a programme of information on patient choice (e.g. 'Choosing Your Hospital' booklets and the 'NHS Choices' website) to address problems of poor information available to patients about services provided in different locations. The latest expansion of this agenda is an initiative to use libraries and their staff as 'agents of choice' to provide an information support service for patients.82

### 3.3 Scotland

### 3.3.1 Introduction

Interviews that focused on individual patient choice were difficult given that many interviewees explicitly rejected of the notion of choice as framed by English health policy and, in addition to the differences between Scottish and English policy and NHS organisation predating 1997 and political devolution. This did lead some respondents to question the relevance of the research in the Scottish context. However, choice for patients is an integral part of Scottish health policy although increasing patient choice was not an explicit policy driver. The English emphasis on increasing individuals' access to a choice of NHS and private providers in a health care market was explicitly rejected in Scottish health policy.

I think it is quite important to stress there are two reasons why that mantra of choice has not been embraced and has not been at the heart of either the narrative or the substance of policy in Scotland in

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the way that it has been at UK level. One is, if you like, a political reason, the other is a practical reason. At the political level, it is a statement of fact that Scotland does not, has not, and shows no particular indication that it intends to embrace the market or the mixed economy either with the same enthusiasm and certainly not with the same mechanisms that has been done South of the Border ... [and at the practical level] ... the population distribution of Scotland just does not lend itself to the models of health care delivery now being pursued in many parts of England. (Former Scottish Government Minister)

The overall policy approach emphasises single-system working, collaboration and partnership working, in place of competition and diversity:

"The fundamental reason why we will not have foundation hospitals in Scotland is that we have our own reform agenda, which is based on the principle of single-system working within a decentralised context. I believe that that is the most patient-centred approach, because patients see one system....We want a system in which, rather than compete with each other, health care professionals cooperate and collaborate." (Malcolm Chisholm, Minister for Health, Scottish Parliament Health Committee 23 March 2004)

Scottish health policy did seek to ensure that patients were provided with the opportunity to make choices about their own treatment (e.g. whether to have surgery or to opt for drug treatment). Policy documents make frequent references to the need for a patientfocused service (i.e. that the health care an individual patient receives should be informed by their needs, wishes and preferences; e.g. Patient Focus and Public Involvement 2001 and this emphasis was particularly strong (with caveats) in policy documents on maternity services. 89 Patients also have the opportunity to choose where to go for surgery (e.g. patients whose local NHS cannot provide elective care within the National Guarantees on waiting times can choose to receive that care outside their local area) and, under patient-focused booking, to choose the date and time of their outpatient appointment from a range of available dates and times. In addition to the availability of choice for individuals, it was also a key recurring theme in Scottish health policy that the public and patients should be involved in decisions about national and local services; i.e. that they should be involved in making the wider choices about which services were available.

Well I think there are some differences and there are some similarities. I guess we start from the perspective that patient choice is part of every engagement between a clinician and a patient. And it

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is about understanding what patient needs are and responding to them, and where there's a choice making that clear. So you know if you look at some of the recent policy developments, for example around extended access to primary care, that's only about choice. If you look at some of the work we've been doing recently with the Scottish Consumer Council around the, 'It's OK to Ask' programme, that's really about informing that clinical interaction and therefore about informing choice, encouraging people to ask the right kind of questions to enable them to make the right kind of choices. And of course there is also, you know, I guess some of the more readily recognisable choices and initiatives like patient-focused booking etc (Senior Scottish Government Official)

The policy emphasis was on the need to provide *certainty* in health services: high quality services that are provided as locally as possible ("safe, high-quality services that are as local as possible and as specialised as necessary". 90 Patient choice was most often referred to as a loosely-defined benefit which results from achieving other objectives (e.g. 'patient choice will be enhanced as services are improved', rather than as an objective in itself or as a mechanism by which other objectives might be achieved (e.g. patient choice as a means to drive quality improvements). However, patient choice in the form of choice of provider was described as a means to tackle uneven waiting times across providers, (e.g. *Partnership for Care 2003)*, 91 and 'patient focused booking' (choice of outpatient appointment) was described by interviewees as one of the factors that has helped to reduce waiting times (by reducing DNA rates and hence wasted 'slots').

The change in government from Scottish Labour to the Scottish National Party following the election on 3 May 2007 did not lead to a dramatic change in policy in relation to patient choice. Their first major policy document *Better Health Better Care – Action Plan* emphasised several aspects of care (e.g. safety, patient involvement in their care, better information for patients, more flexible access to primary care, best practice in relation to long term conditions, reducing variation in practice, modernising the NHS through better use of technology and delivering treatment quickly), but the word choice rarely appeared. One explicit reference to choice in this document was in the context of maternity services, where 'informed choice' for women was emphasised as a key principle." What was

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<sup>&</sup>lt;sup>ii</sup> The emphasis in the Scottish policy documents on informed choice in relation to maternity services in particular (as opposed to in other health care services) may reflect the nature of and strength of debates around maternity services and their comparatively long history in terms of consumer involvement. The term is certainly widely understood to be appropriate in other clinical domains.

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different about *Better Health Better Care – Action Plan* compared to earlier documents was an even stronger emphasis on rejecting the market model and considerable emphasis on a more *mutual* approach - partnerships between agencies rather than internal competition - to health care and to public ownership of the NHS: "(The NHS) will remain firmly in the public sector. In stressing public ownership through a more mutual approach, we distance NHS Scotland still further from market orientated models" (Foreword by Nicola Sturgeon, Deputy First Minister and Cabinet Secretary for Health and Wellbeing). 92

# 3.3.2 Policy rationale (why)

National identity and the desire to differentiate Scotland's health policy from that of England formed the ideological backdrop to health policy in Scotland. The rhetoric emphasises the need to provide Scottish solutions to Scottish problems, taking into account the ways in which Scotland's health services needed to respond to particular circumstances (notably levels of chronic ill health, deprivation and geographical issues relating to remote and rural locations).

Other explicit drivers of health policy were the need to respond to broader demographic and epidemiological changes (e.g. ageing population, increasing prevalence of chronic conditions).

'To meet the needs of the Scottish people, we must have a different solution from the solution down south [i.e. foundation hospitals]....establishing foundation hospitals in competition with each other to serve the population of Grampian would be completely irrelevant....For many people in rural Scotland, there is no choice.' (Mike Rumbles, Liberal Democrat MSP, Scottish Parliament Health Committee 23 March 2004)

There was a marked emphasis on the extent to which health service policies were being formed in response to public consultation (e.g. in the regional public meetings that informed the 2005 *National Framework*): "One of the most important components of our work was to give voice to the public and healthcare professionals working in the clinical front line so that we could understand more fully the dominant issues that were causing concern"(1).<sup>49</sup> Again this fits with the largely collectivist rather than individualistic approach to improving quality of care that ran through the Scottish health policy documents. Scottish policy was influenced by the opportunities political devolution offered to design a Health Service with a national identity built around the differences in geography and health needs which placed Scotland apart from England:

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'Our model is different from the English model... We are trying to create a more integrated way of working in Scotland – single-system working, with the different parts of the health system working together collaboratively.' (Malcolm Chisholm, Minster for Health, Scottish Parliament Health Committee 23 March 2004)

The vision was of a Health Service that offered fair and equal access for the people of Scotland '...the treatment they need, where they want it, and when'. Emphasis was given to the need to provide certainty in health services through 'safe, high-quality services that are as local as possible and as specialised as necessary'. <sup>92</sup>

What also emerges from policy documents was the belief that the planning of health policy should be based around the wishes of the people of Scotland and this was echoed strongly in the interviews with politicians and civil servants.

it's actually quite difficult to find Scottish policy on choice and that's because it's embedded in a whole host of other documents. We don't have that, it is not something that's separately about choice or about patient experience, it's more about public engagement, but rather we try and pull all of those things together all of the time. (Senior Scottish Government Official)

The National Framework *Building a Health Service Fit for the Future* (2005) imagined 'strong, cohesive health communities...collectivism and engagement with both the public and clinicians'.<sup>93</sup> There was an emphasis on engaging with the public as a collective, and allowing their opinions to shape policy direction. Much of the policy was therefore based the results of consultation exercises such as the regional public meetings that informed the National Framework. This was in itself an approach to offering choice, but also provided direction for other, specific, choice policies.

However, policy also became increasingly contradictory in relation to patient choice. *Building a Health Service Fit for the Future* opened with a statement of guiding principles that, specifically deemphasised patient choice in favour of other objectives:

"Patient choice is important, but the people of Scotland sent us a strong message that certainty carries greater weight—if we make a commitment to see or treat a specific patient on a specific date, we must honour this, and ensure the quality of care delivered. ... I believe that Scotland is better suited to health improvement through collaboration and internal cohesion, making us externally competitive" (p.2)<sup>93</sup>

The report highlighted the limitations of focusing on access to elective services, acknowledging that while this was an important

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area where choice could be exercised, with the potential to increase efficiency and reduce waiting time, it was only one area of choice. Other choices were also important:

- Choice over whether, where and when to seek care;
- Choice of care or treatment offered, and involvement in decisions about their conditions/illness or treatment;
- Choice in appointment date/time;
- Choice of hospital/doctor. (54)<sup>93</sup>

The report then recommended that "The Scottish Executive and NHS Boards should establish a clear policy about what patients in Scotland want in the way of choice" (55) and recommended that it did so by developing 'values' (building the service around choice was more likely to meet more what users wanted and to have higher levels of satisfaction), 'information' (as real choice required good information) and 'systems' (to ensure that policies and strategies on choice were turned into action and that "services reflect and offer the choices that patients and carers want").

This recommendation that the Scottish Executive and NHS Boards should establish a clear policy about what patients wanted in relation to choice emphasised the need to engage patients in determining the 'choice set' or menu of services made available. It contrasts with the strong opening statement about the preference of patients in Scotland for certainty over choice and suggests some uncertainty at policy level about the views of patients and the public in Scotland in relation to choice. Two years later, the newly elected Scottish government headed by the Scottish National Party carried out a public consultation on the NHS which was followed by the publication of Better Health Better Care: Action Plan. 94 In common with earlier consultations, there was no indication here that the Scottish public was seeking more choice in health care. Better Health, Better Care placed a strong emphasis on mutuality, on the Scottish people and NHS staff as partners or co-owners in the NHS, and explicitly sought to distance NHS Scotland from the market. In common with earlier documents, the aspirations for the NHS emphasise a range of aspects of care, including improving patient experience, patient rights, public participation, enhanced local democracy and a more mutual approach to health care but did not mention choice.

Table 7. Chronology of policy documents: Scotland

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Year	Policy	Initiative	Type of choice
	documents		
2001	A framework for maternity services in Scotland	The document was explicitly defined as setting out a broad philosophical approach – an outline of a set of broad principles to inform local maternity planning – rather than as a strategy document or a model service specification.	Decision support, choice of lead professional, choice of birth place
		"Women have the right to choose how and where they give birth. This choice should be supported by high quality information and evidence-based clinical advice that allows them to take part in the decision-making process" (Principle 11)	
2003	Partnership for Care (White Paper)	Expansion of the National Waiting Times Database.	Decision support
		Patients to have the right to receive elective care elsewhere if not treated by their local NHS within the National Guarantee.	Trovider
2004	Fair to all, personal to each: The next steps for NHS Scotland	Patient-focused booking systems	Outpatient appointment date and time (when waiting list was at least six weeks)
2005	A National Framework for Service Change in Scotland: Building a health service fit for the future (the Kerr report)	Referral Management Centres to develop new patient referral and diagnostic pathways, extend referral options (e.g. to GPwSIs) and facilitate patient choice	Provider

# 3.3.3 Policy objectives (what)

The policy documentation in Scotland post-1997 articulated an explicit rejection of the model of the internal market and of consumerist mechanisms as a means to achieve the responsiveness and equality of access envisaged for the Scotlish NHS. In Scotland

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the aim was to restore the NHS as a public service working cooperatively for patients, 'not a commercial business driven by competition'. The vision within this document was of a service which delivered clinically-effective care quickly and reliably through high quality facilities which were available throughout Scotland when patients needed them.

Building a Health Service Fit for the Future rejected the notion that the 'invisible hand' of the market could function well within health services, and instead envisaged the main influence on provision being exerted 'by government, by providers, by clinicians and by patients' (4).<sup>93</sup> Consumer mechanisms were rejected in favour of 'certainty', defined as honouring treatment commitments and ensuring quality of care for all patients.

In the main, the NHS Scotland position has been that Scottish patients do not place a high priority on choice *per se* and were not willing to sacrifice collective ideals and other objectives (e.g. certainty) in order to secure more choice:

"At risk of seeming overly sentimental, I believe that a more truly Scottish model of healthcare would be to take a collective approach in which we generate strength from integration and transformation through unity of purpose. Patient choice is important, but the people of Scotland sent us a strong message that certainty carries greater weight – if we make a commitment to see or treat a patient on a specific date, we must honour this, and ensure the quality of care delivered" Building a Health Service Fit for the Future (2). 93

Where options were available, the government argued that patients wanted robust information to give them a degree of security about the choices they were making:

'Feedback from the public repeatedly emphasises a need for better information about their health, their treatment, the options for care, and the availability of health services. Without this information it is impractical to expect patients to make informed choices or take more responsibility for their own health' (7)<sup>93</sup>

The policy did envisage choices being made by informed patients involving decisions about their care but was clear that these choices should be made in conjunction with health professionals.

Although patient choice was not a key instrument of policy in Scotland in the way that it was in England, a choice of provider policy was adopted as one of the mechanisms for tackling uneven waiting times across providers, and ensuring that patients were not disadvantaged by long waits with their local providers. The White

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Paper Partnership for Care stated that under the National Guarantee, patients will have the right to be treated elsewhere (e.g. elsewhere in the NHS, in the private sector or exceptionally elsewhere in Europe) if they were not treated by their local NHS organisation within the National Guarantee period. Patient focused booking was also later referred to by the Chief Executive of NHS Scotland as one of the factors that has helped to drive down waiting times (by reducing DNA rates).

### 3.3.4 Mechanisms (how)

There were various initiatives associated with policies relating to choice as they were articulated by NHS Scotland. Firstly there was a raft of mechanisms relating to public involvement, both in relation to the planning of services and policy and to decisions relating to individual care pathways. These included the introduction of local service improvement projects based on joint work between service users, carers and providers (Partners in Change), the inclusion of patients as integral members of linked groups to ensure equitable provision of high quality clinically effective services (Managed Clinical Networks), and the development of Patient Information Networks across Scotland.

In 2003, the web-based National Waiting Times Database was introduced to provide information on waiting times for a first outpatient appointment with a consultant. The database was intended as a tool for GPs to make the appropriate choice of referral, in consultation with patients.

In order to achieve equality of waiting times for elective procedures, in 2003, NHS Scotland introduced the National Guarantee, that a patient should be offered treatment 'elsewhere in the NHS, in the private sector in Scotland, in England, or overseas' if the patient's host NHS Board was unable to provide treatment within the target time. However, the choice offered to patients as described in the patient information leaflet, *The NHS and You* (2005) was limited to receiving treatment elsewhere in Scotland and did not mention patients having the choice to travel elsewhere in the UK (or Europe) for treatment. "Sometimes, hospital services in your local area might be so busy that it will not be possible for you to get treatment within the national target times. If this is the case, you will be given the

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The wording of the later patient information document, *The NHS and You* (2005) suggests that in practice, patients will be offered a choice of provider elsewhere in Scotland.

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opportunity to travel to somewhere else in Scotland to get treatment within the target time."  $(13)^{96}$ 

The impact of waiting time limits could be seen in the use of the National Waiting Times Database:

... in 2003 ... we launched our product called the National [Waiting Times Database] which gave the average waiting time to see a consultant for routine conditions if you like, well in the main specialties, so that person can go to their GP, the GP says yes you need a cataract, you could go to your normal hospital but you could also go on the internet and check this database and if you find somewhere with a shorter waiting time then perhaps you can be referred there. And that was quite successful initially but since then we have reduced waiting times quite dramatically to the extent that the variation between waiting times in hospitals is pretty minimal, so you don't get a choice of oh well it's 6 weeks here but 26 weeks there, there's not that variation now. Everyone is within 18 weeks or below. So is it worth travelling a longer distance just for a week earlier? (Senior NHS Scotland official)

NHS Scotland also launched 'patient focused booking' in 2003, (initially in pilot areas with subsequent roll out in stages to all areas), allowing patients awaiting outpatient treatment to choose their preferred appointment from a range of dates and times. 90,95

In summary, patient choice for individuals played a much less obvious role in policy in Scotland than it did in England during the period of the study. Although Scottish patients did have choices, and there was a strong emphasis on patient and public involvement in services, choice was not a key term in the policy rhetoric. Choice-related initiatives were one of a range of mechanisms used to bring about service improvements but they were not a dominant feature.

#### 3.4 Wales

#### 3.4.1 Introduction

Like Scotland, the NHS 'choice' or 'voice' agenda in Wales in the period of the study was shaped by the Welsh national identity and was perhaps defined by both distinctive geographical and ideological landscapes. This perception of a national identity led to an explicit rejection of the consumerist English Choice model. As in the Scottish case, interviews that focused on choice were difficult given the explicit rejection of the notion of choice as framed by English health policy in policy documents and by the interviewers themselves. This also led to questions about the relevance of the research in the

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Welsh context. However, when phrased in relation to referrals, patient management and the role of patient and public involvement there is, like in England and Scotland, a clear policy agenda in relation to responsiveness in terms of meeting patient preferences.

The argument about geography was essentially one about the necessary conditions for a working health care market. Alun Michael, the founding Welsh Assembly Government First Minister, commented that Wales was characterised by "rurality, sparsity, mountains...". <sup>97</sup> Many geographically-isolated areas possess only a single NHS purchaser and single general hospital. Poor north/south links, mountainous terrain separating adjacent valley communities and thinly-populated rural areas accentuate reliance on local hospitals. Many commentators argue that the difficult transport links and the unwillingness of local people to travel, make provider competition and choice of treatment location infeasible. The idea that Wales' geography was a practical obstacle to implementing English-style NHS policies was expressed by several civil servants interviewed for the study.

As in Scotland issues of geography were often combined with ideological arguments, as when the First Minister, Rhodri Morgan stated that 'our geography does not encourage this social model, and I don't think out values encourage this model either'. 98 Two of the Welsh Assembly Government's special advisors on NHS reforms agree in highlighting ideology, more than geography, as the force driving the distinctive Welsh approach. 99 As far back as 2002, when the first details of the English policies on foundation trusts, ISTCs, Payment by Results and expanded patient choice were emerging, the First Minister coined the evocative metaphor of 'clear red water' to characterise the policy gap between Westminster and Cardiff Bay. The WAG, Morgan said, was "more interested in community values than consumerist values. Our attitude to the future of the health service is not about how much competition, how much out-sourcing, how much consumer choice". 100 He ruled out the use of market mechanisms in Wales and stated his determination to restrict the role of private providers. These messages were repeated in a public lecture in which the WAG Health Minister approvingly quoted the words of the commentator Julian Tudor Hart: 'Though the market model may give patients a louder voice, this will be the shrill cry of consumer choice, not the sceptical thought and responsible voice of the citizen.'101 The formation of a Labour/Plaid Cymru coalition government in June 2007 led to a further distancing of Welsh health policy from the English market reforms. The 2007 policy document, One Wales: A Progressive Agenda for the Government of Wales set

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out plans to end the internal market in Wales, which resulted in the removal of the purchaser/provider split from October 2009. 102

## 3.4.2 Policy rationale (why)

The vision for Wales set out by the Welsh Assembly Government in 2001 was 'to create a confident, joined up, co-operative, sustainable, healthy and listening nation'. Like other countries, the vision for NHS Wales was based around a service which was patient-centred. However this was envisaged in terms of citizens rather than consumers. In Wales, 'voice not choice' has emerged as a consistent strand of Welsh policy from the 2001 plan for the NHS in Wales to the present time. *Improving Health for Wales* outlined a rights-based agenda in which the NHS was accountable to communities, and the public have influence through inclusion in the structure of the NHS, and corresponding responsibilities, including shared responsibilities for continued health development. In the ten year strategy, *Designed for Life* explained that the intention was to: '... empower the community to have its voice heard and heeded, rather than simply being given a choice of treatment location'. (14)

The more recent *Beyond Boundaries* plan (The Beecham Report) developed for the Welsh Assembly Government examined the possibilities of the citizen model in Wales and advocated an adoption of 'co-production' rather than consumerist policies.<sup>104</sup> A priority for the Welsh NHS therefore was to support communities and citizens, and create a socially inclusive NHS through an 'opening up' of the policy making process in order to 'enhance the citizen's voice at the heart of policy'.<sup>103</sup> This vision was articulated as a less simplistic version of the consumerist choice agenda, which replaced 'exit' with 'different forms of choice, personalisation and the opportunity to express preference and influence provision'.<sup>104</sup> In this way, 'choice' was seen as an outcome of better, more responsive services, rather than as a mechanism for improving performance of the system.

Although many Welsh policy makers used the word 'choice' with caution, perhaps - as one senior policy advisor told us - 'because it might dilute the clear messages associated with the concepts of 'voice' and 'engagement', Welsh policies were constructed to support certain kinds of choices. The Assembly First Minister, Rhodri Morgan, has articulated the notion of 'equality of reach':

What the [Second Offer] scheme does not do is to privilege the choice of some over the choice of others ... [it] does not depend upon being articulate, or advantaged, or able to work your way around a complicated system. The system comes to you – whoever

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you are, wherever you live, we take the initiative in making sure that an offer is made. (Morgan cited by Drakeford, 555). 105

Welsh policies were thus designed to reach both those able to help themselves and more disadvantaged people who need the support of a public service. A Cabinet advisor on health and social services, explained that this represented an attempt to reconcile choice with equity:

the fundamental principles on which that was based was a good standard of service for people, the removal of inequalities, so there's a very heavy thing and theme about everybody must have access, proper access to care of a high quality in Wales, bearing in mind in terms of sustainability and communities and that sort of thing there were great, great inequalities in Wales and many people who required care, well you know it was all based on the Inverse Care Law, many people required care could not access it, cos they .. didn't know how to or didn't choose to (Welsh NHS Special Adviser)

Although public 'voice' was an important component of Welsh policy, it was not necessarily the primary driver in a service designed to maximise the collective good. The First Minister told the Welsh Affairs Committee that a trade off existed between patient access, quality and affordability of services and has suggested that clinical safety and clinical quality should be the main drivers: 'the issue is always whether what you want is excellent services provided as close as possible to your home or services which are as close as possible to your home which are provided as excellently as possible. I think it has to be the first of those: excellent services provided as close as possible'. <sup>106</sup>

Alongside ideas about citizenship, community engagement and better connections between local service delivery organisations, policy makers articulated a 'small country governance model' that gave a new twist to integrated public service delivery. *Making the Connections* set out the case for an integrated, collaborative approach to public sector service organisations, better suited to Welsh conditions than the English model of autonomous provider units in a quasi-market. <sup>107</sup> The 2006 *Beecham Report* discussed implementation options and suggested how greater citizen engagement might be a component in a distinctive 'small country governance model'. <sup>104</sup> This was significant because it meant that Wales' rejection of the market was not presented in terms of a return to the discredited centralised provision of public services that characterised the pre-quasi-market era, but represented a

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vitalized approach to public service organisation made possible by small scale.

# 3.4.3 Policy objectives (what)

The citizenship model was concerned with making better connections between stakeholders and agencies and a weakening of organisational boundaries. Thus policy did not concentrate on opportunities for 'exit' from the system (see Table 8) but, instead, 'the model relies on voice to drive improvement'. 104

Table 8. Chronology of policy documents: Wales

Year	Policy documents	Initiative	Type of choice	
2001	Improving Health in Wales. A Plan for the NHS with its Partners.			
	Signposts - A Practical Guide to Public and Patient Involvement in Wales			
2003	Review of Health and Social Care in Wales (Wanless Report).	Expert Patient programme started as pilot project in 2 LHB	Capacity of patients and carers	
	Signposts 2: Putting Public and Patient Involvement into Practice in Wales.	areas		
2004	Making the Connections: Delivering Better Services for Wales.	Second Offer Scheme introduced to give second option to patients waiting more than 18 months.	Provider elective surgery	
2005	Designed for Life: Creating World Class Health and Social Care for Wales in the 21 <sup>st</sup> century.	Second Offer Scheme extended to those waiting more than 12 months.	Provider elective surgery	
		Best Practice Guidance: Elective Services	Patient-focused appointments – time and perhaps place	
2006	Beyond Boundaries. Citizen-Centred Local Services for Wales.			
2008		EPP rolled out to all Welsh LHBs	Capacity of patients and carers	

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It was envisaged that this would be achieved through a high level of involvement of citizens in planning, for instance, by 'engaging the public with the competing priorities for public investment within a constrained overall budget'. A key element of this policy were strong mechanisms for patient and public involvement to allow high level choices to be made:

'The new NHS will enter into a partnership with the people of Wales so that each citizen and each community is helped to play a role, directly or through bodies representing them, in the development of health policy, the setting of aims for the NHS, the improvement of health and well being and the narrowing of health and social inequalities' 103

Although policy documents favoured 'voice' as a mechanism for steering the development and delivery of services, there was also an increased emphasis over time on the need for performance management mechanisms to improve performance. The 10-year strategy contained detailed performance targets designed to improve performance.44 As mentioned in Chapter One, Wales' poor performance, compared with England, in meeting waiting times targets meant that the WAG came under severe pressure on this issue, resulting in the Access 2009 initiative. The Access 2009 delivery plan for the reduction of waiting lists, initially set a target of a maximum wait between referral and treatment of 26 weeks (the '2009 access target'), as well as a series of interim waiting times targets. 108 This total waiting time limit superseded previous (separate) targets of 18 months for first inpatient appointment and 18 months for inpatient/day case treatment. Subsequently, a revised target was set stating that, by the end of March 2008, waits for inpatient or day-case admission, or outpatient appointment, should not exceed 22 weeks. More recently the targets for March 2009 changed to a maximum wait of 14 weeks for inpatient or day-case treatment, and 10 weeks for a first outpatient appointment. The Audit Committee's (2005) report on Welsh waiting times contained 13 recommendations for achieving WAG's Access 2009 target, and these were incorporated into the strategy then adopted. 109

So the inequalities then became inequalities compared with England rather than inequalities within communities in Wales, the focus had to shift. So we had to sort that out before you could go any further. So that over the last three years has been sorted with the government putting extra money into what they call their 2009 project which is 26 weeks by now and indeed that's all being delivered, that's fine, it's all going through. (Senior Welsh NHS Official)

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Thus although Wales had rejected consumer choice of provider as a policy aim, the establishment of the Second Offer scheme to reduce waiting lists has opened up a more limited choice for patients. As we shall see below, Wales also provided some degree of choice of location of treatment via a patient-centred booking system.

# 3.4.4 Mechanisms (how)

Welsh policy makers put in place a number of mechanisms to involve the public in the running of the NHS between 2000 and 2009. These included local representative bodies in the form of Community Health Councils (CHCs) and Local Health Groups (later reconstituted as Local Health Boards (LHBs)), a variety of forums and other initiatives within NHS Trusts and LHBs, and a range of community-based programmes and projects aimed to address the wider policy agenda of reducing social inequalities and local regeneration. CHCs were retained in Wales with increased powers. At the time of the study there were 19 CHCs (now merged mostly matching the new health board boundaries) and their links to local communities through local authority and voluntary agency representation were seen by Welsh politicians as part of a conscious strategy to strengthen local democratic accountability. Local Health Groups were introduced in 1999 as stakeholder groups which included lay people, with the aim to shape and improve the quality, delivery, accessibility and coordination of health and social care. These were strengthened in 2003 to become Local Health Boards, autonomous bodies in a close working relationship with local authorities, with membership extended to include local authority representatives. This was the basis of the 'new localism' of the NHS in Wales. 110

What happened with that policy was, I mean it had lots and lots of good things about it in terms of structural, it had to have structural reform to get more localism so that the Health Service could be more attuned with its partners, to the local community and what their health needs were and commission effectively (Senior policy adviser)

The Public Services and Performance Department (PSPD) coordinated engagement policies across the different public service sectors and oversaw the inspection bodies concerned with health, social services and education. NHS Trusts and LHBs were required to undertake a baseline assessment and annual reports on progress regarding patient and public involvement (PPI), and a number of performance standards concerned with 'patient experience' were monitored by the WAG (through Health Inspectorate Wales). Practical suggestions for the elaboration of Welsh PPI policies were set out in the guidance papers, *Signposts* and *Signposts* II, and

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many of these ideas were then developed in local forums and schemes of other kinds. At the community level, a number of umbrella social development programmes provided project-based funding for schemes initiated by local organisations. Examples included: Communities First, a project to support bottom-up social development projects launched by the WAG's Department for Social Justice and Regeneration in 2002; Local Health Alliances, which required local authorities, NHS bodies and other stakeholders to come together to deal with health issues in local communities; and Sustainable Health Action Research Programmes, an initiative to support action research projects in the areas of health, housing, unemployment, social distress and poor access to services. Although questions were raised about the sustainability of individual projects when core funding ended, and a degree of disconnection between micro level projects and macro policy, Welsh policy makers continued to see these programmes as 'slow growth', long term ventures to produce learning over time.

The 'second offer of treatment guarantee', mentioned earlier in the chapter, was introduced in 2004. This was a centrally managed system in which patients waiting over the maximum time limit for their operation were offered earlier treatment elsewhere. This could be at a different provider or at another site within the same NHS Trust. Initially, the scheme covered patients waiting more than 18 months, but in March 2005 it was extended to include those waiting more than 12 months. In their annual review for 2005 the Healthcare Commission stated that by that year nearly 11,500 patients had opted to be treated in an alternative hospital under the scheme. <sup>31,iv</sup>. By January 2006 the figure had risen to 19,700. <sup>110</sup>

The policy line on this mechanism was that it was not a choice mechanism, as the decision was not left to the individual but was centrally managed. This was consistent with the philosophical position, set out by Morgan in an earlier section, that the option provided was offered on an equal basis to all patients and thus not affected by their skill as consumers in a market place. Second Offer' played a much less central role in the NHS commissioning process than does 'Choose and Book' in England. There was no attempt in Wales to develop a patient choice mechanism that would shape initial referral pathways and patterns of service purchasing. The Second Offer scheme was not about allowing patients to choose between alternative providers, but a means of achieving waiting times targets.

iv Interestingly the Second Offer Scheme was discussed in this Report under the heading of 'A Choice for Patients'.

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Patient choice was restricted to exercising the option of stepping out of a long queue into a shorter queue at a different hospital. WAG Health Department guidance stated that routine use of the scheme should be avoided through a combination of effective commissioning and effective delivery. 111,112

When Access 2009 was launched it was stated that, as waiting times reduced, the Second Offer scheme would be wound down. From 2006 to 2008, the Second Offer scheme fell into disuse. This occurred against the background of falling waiting lists, but also a major scandal that had arisen because problems affecting some of more than 600 patients who had been referred for joint replacements to an NHS treatment centre in the South West of England. A review established that operations performed there, mainly by foreign surgeons, had led to a higher than normal complication rate. 113,114

In late 2008 the Second Offer scheme was reactivated because of an unexpected rise in waiting times at hospitals in South East Wales. It was reported that the region's largest NHS trust had over 700 orthopaedic patients breaching the new 22-week referral to treatment target. Despite the Assembly Government having reportedly instructed commissioning LHBs to exhaust capacity in the English NHS before using the private sector, a number of LHBs entered into contracts with English ISTCs for some of this work.

In line with the wider access 2009 delivery plan and the Audit Committee's recommendations on waiting time reduction, a number of other initiatives to streamline the referral process were introduced. Four pilots were launched in 2005 to develop the idea of referral management centres, which would assess and filter GP referrals. Such schemes were being implemented in most LHBs, though in some cases they were not fully operational in the period in which we undertook the study or only covered certain conditions.

Other recommendations acted upon by WAG, included the implementation of the Audit Committee's recommendation to publish data which could be used to analyse GP referral patterns and to target demand management activities, and greater attention to delays in hospital discharge arising from patient choice of subsequent placement.

In 2002, NHS Wales issued best practice guidance about offering patients a choice of appointment date when making outpatient, inpatient and day case appointments. During the following year, a Guide to Good Practice was first published by the Innovations in Care Team, and this was further expanded in 2004 and 2005. The National Leadership and Innovation Agency for Health Care (2005) published

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a revised *Guide to Good Practice: Elective Services*, which the Assembly Government adopted as policy.<sup>117</sup> This was supported by a Welsh Health Circular which required NHS Trusts 'as a matter of policy, to implement now the systems and processes related to the new ways of working in line with the 2005 edition of 'A Guide to Good Practice'. <sup>118</sup> The Health Minister's Introduction to the guide stated that the 'overall aim is to ensure patient appointments reflect clinical priority. Patients will be seen in chronological order and given an opportunity to choose a convenient date. This will minimise non-attendances and cancellations.... Patient cancellations and non-attendance rates will be reduced by promoting shared agreements between patients and the trust and applying new ways of communicating with patients' (iii).

The first of six core principles in the document was 'Patient Choice':

The patient should always be offered reasonable choice in their appointment. Choice means that the patient can choose the location, the date and time, and the consultant. The reasonable nature of the choice means that choice may be limited to those locations where clinics and/or theatre sessions are held, dates and times that clinics and lists are scheduled, and consultants or other staff that are qualified to perform the procedure or see the patient. Reasonable patient choice means that where an option is available, the patient has the right to choose that option (1).

Choice of location in this context normally meant choice of sites within the NHS Trust to which a referral was made. The guidance stated that 'In no case should an appointment time be notified to a patient who has not been involved in the choosing of the date and time' (2) It noted that there might be instances when patient choices could lead to the breaching of waiting times targets and stated that the guiding principle should be that ' patient choice was respected but that Trust performance was not adversely affected' (2) The guidance allowed that where patient choice was the only reason that a target was breached, that case could be excluded from the performance figures. Choice in this context was likely to be limited to choice between hospitals where a local NHS trust offered the same service on more than one site. Additionally practices were required, where possible, to allow patients to see the GP of their choice, and to communicate in their choice of the Welsh or English language.

For most patients, opportunities to express preferences regarding referral related to a choice between two sites. At the time of referral, the patient's preferred hospital could be discussed with the GP in the surgery. But this issue might also come up when the appointment was arranged with the provider Trust, if it offered the treatment at

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multiple sites. When GPs referred to pooled waiting lists, as was the norm in Wales, they would usually not be able to specify the consultant involved. Where the Trust included several hospitals, the GP might also be unsure of the treatment site. For a proportion of patients, an additional opportunity to exercise limited choice arose if they were deemed eligible for the Second Offer Scheme, and given the opportunity of earlier treatment at a hospital other than the one where an appointment had been arranged.

The possibility of enhanced opportunities for 'voice' and limited 'choice' raises the issue of the capacity of patients to make judgments. There appeared to be no Welsh initiatives explicitly designed to support the expression of patient preferences in the referral process in the period of this study.

## 3.5 Northern Ireland

#### 3.5.1 Introduction

Whilst the concept of 'choice' resonated with Northern Ireland politicians and other policy makers, it was a term that only truly appears in the context of the education (school selection policy) agenda. The term barely figured in political or policy discussion with regard to the Health Service during the period of this research and has only a marginal influence. During the period 2000-2009, at an organisational level, the emphasis was on reconfiguration of the Trusts and the Health and Social Services Boards (HSSBs). At the level of service delivery, the emphasis was on access to services, waiting times and reducing inequalities in service provision. The keywords for health policy in Northern Ireland seem to be: access; (in)equity; and waiting times.

An important point of change in Northern Ireland occurred with the establishment of the Northern Ireland Assembly in May 2007. At that point, responsibility for all policies and services (excluding those relating to law and order) were devolved to the assembly. In January 2008, a Draft Programme for Government (PfG) was approved by the Assembly. The programme was built around 23 public service agreements (PSAs) each of which specified objectives, priorities and targets for specific service areas. Much of current policy in health and social care was driven by the objectives of the PfG, and the Department of Health and Social Services (DHSSPS) was responsible for the implementation of four PSAs - of these, two were directly related to the provision of health care.

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PSA 18 was directed toward the delivery of "high quality health and social services". In the opening paragraph to the section concerned with PSA18 the document stated: "....... we will ensure that services are built around the needs of the individual. We will reduce avoidable reliance on acute hospital services and institutional care through a range of flexible and more responsive care services closer to home. We will reduce long waiting times for care packages and delays in discharge from hospital for want of a care package". That statement sums up in a succinct manner the essential focus of health services policy in NI during the period of the research, and the key terms to note are: inequality of access, waiting times, and care 'closer to home'. The word 'choice' appeared only twice in the entire DHSSPS PfG statement and in neither case did it relate to any aspect of patient choice.

The key concerns above were also highlighted in the interviews with the members of the Health Committee of the Northern Ireland Assembly and with political representatives of the major parties – many of whom were puzzled by our enquiries concerning a policy for 'patient choice' which was seen as an 'English' policy. Rather, a focus on access, waiting times, inequality, and care and treatment 'closer to home' were seen as at the core of recent policy decisions made by the Department of Health in Northern Ireland and made manifest by major investment in new health and care centres – 'one-stop-shops' to meet the needs of individual families in their local communities – and to a certain extent in the decision to abolish prescription charges by April 2010.

### 3.5.2 Policy rationale (why)

The major review of public administration (RPA) launched by the Northern Ireland Executive in 2002 has been central to organization of the Health Service in NI in the period examined in this study. During our interviews with professionals in NHS organisations, the RPA was considered to have been the biggest change ever to have occurred within health and social care. The purpose of the RPA was to review Northern Ireland's system of public administration with a view to putting in place modern, accountable and effective arrangements for public service delivery in Northern Ireland. The review covered almost 150 bodies including the District Councils, the Health Boards and Trusts and the Education Boards. Following the suspension of devolution in autumn 2002, RPA was taken forward by direct rule Ministers, with the final outcome announced by the Secretary of State for Northern Ireland, Peter Hain, in 2005. On the same day, the then Minister for Health, Social Services and Public

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Safety, Shaun Woodward, announced the reorganisation of Northern Ireland's health and social services as part of the RPA. The main reasons given for the reforms were couched in terms of improved efficiency and performance so as to deliver a high quality Service which focused on the health needs and well-being of the individual patient and wider population. The reforms were to result in:

- a reduction in the number of existing Trusts (from 19 to 6);
- replacement of existing Health and Social Services Boards with a single Health Authority with Local Commissioning Groups replacing Local Health and Social Care Groups; and
- the establishment of a single Patient and Client Council to replace the four health and social services councils.

Central to this 'programme of reform, modernisation and delivering a first class system for patients in Northern Ireland' was the drive to 'put patients first' by making the Health Service 'patient led' and 'patient responsive' and giving a stronger voice to patients as seen through the establishment of a single Patient and Client Council (PCC).

"An effective system must ensure that the voice of the patient can be heard loud and clear. The four Health and Social Services Councils will be replaced by a powerful single health and social user's body." 120

"The PCC will have a critically important role in **engaging with the patient**, the client and communities in promoting their health and wellbeing; in getting the best from the service; and in providing effective advocacy when the service is not doing what it should be to meet patients' just needs and demands." (:our emphasis)

Implementation of the RPA was to take place in two major phases. The first phase established the new streamlined Trusts and took effect from  $1^{\rm st}$  April 2007 with the second phase planned for completion by April 2008.

Concerns about 'inefficiency' and 'excessive bureaucracy' were also echoed in the Independent Review of Health and Social Services in Northern Ireland, undertaken by Dr John Appleby (an English health policy analyst from the King's Fund in London), published in August the same year. <sup>47</sup> In fact, the Appleby review was somewhat dismissive of the proposed organisational reforms outlined within the RPA and questioned whether or not the RPA reforms would be adequate to tackle the deficiencies, particularly in performance management systems. The Appleby argument was that the RPA ruled out competition: '...current recommendations from the Review of Public Administration explicitly rule out one option for sharpening the

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current performance management system - namely, competition.' (171)<sup>47</sup>

The RPA recommendations for reconfiguring health and social care organizations were considered by Appleby to represent a reinvented 'pre-1990 English NHS model in which health authorities received weighted capitation allocations, planned services and directly managed (and set budgets for) the hospital providers in their area.' Appleby argued that 'while partnership and integration can generate good things for patients and users, there is a distinct danger that the performance model implied by the RPA's structural reform could fail to provide the necessary incentives and sanctions - or 'bite' - to encourage providers of services to continually seek out new ways to improve their performance.' (171)<sup>47</sup>

Appleby consequently highlighted a number of mechanisms which could support a more robust performance management regime within the Northern Ireland health care system. These included, 'the most appropriate form of separation' between purchasers and providers, long-term target setting with rewards and sanctions, an 'activity-based prospective reimbursement system' for providers similar to the 'Payment by Results' scheme in England and 'careful expansion of patient choice'. However, Appleby recognised that in a relatively small and restricted 'market place' there was very limited room for patient choice of provider. This latter point was one that was also emphasised in our interviews with the members of the Assembly Health Committee. In practice, the Health and Social Services reforms alluded to in our opening paragraph were to operate on a different timetable to the RPA, and the first reform that was seen as 'putting patients first' was a dramatic reduction in the waiting times for in-patients seeking hospital treatment.

#### 3.5.3 Objectives (what)

Reducing hospital waiting times was one of the highest priorities for the DHSSPS in the period of the research. The duty to deliver access waiting time targets, and the implications this had on the way Trusts operated was a recurrent theme throughout our interviews with key Health Service personnel. Many of our respondents discussed how meeting the waiting list targets changed relationships both within and between NHS organisations and other external organisations. Since July 2005, there has been significant improvement in the inpatient/day case waiting time performance. In fact, by the start of June 2006, with the exception of only three patients, all the targets for in-patient waiting lists had been met. This improvement was achieved through major changes to the way hospitals manage

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waiting lists – chronological management, pooling of lists, improved theatre utilisation and performance management arrangements whereby progress towards targets was monitored. In cases where Trusts did not meet their targets, patients were offered the opportunity of a transfer to an alternative provider under the Second Offer scheme, with the cost of the treatment being met in full by the original provider. This was not, however, a mechanism to allow patients to choose a provider, but was an incentive for providers to meet their waiting list targets. Second offer gave patients the opportunity of being seen more quickly but also placed a strong onus on the patient to accept a reasonable offer of treatment or risk their waiting time being set at zero to begin again or being taken off the waiting list altogether and being referred back to their GP.

In January 2006, the second stage of the reform programme was specifically aimed at addressing out-patient waiting times. The main levers were drawn from an approach used in Manchester Strategic Health Authority. (The elective care programme director from the Manchester Authority worked with the DHSSPS in Northern Ireland). The main elements of the out patient reform included:

- Integrated Clinical Assessment and Treatment Services
   (ICATS) essentially a triage system provided by integrated
   multidisciplinary teams of health service professionals in a
   variety of primary and secondary care settings.
- Electronic Referrals Management System all primary care referrals registered on a central referrals management system to be clinically assessed and responded to within seventy-two hours.
- Improved management of outpatient services including the introduction of partial booking systems which gives the patient a degree of choice regarding a suitable date and time for their appointment.

The introduction of these services was aimed at reducing outpatient waiting times by referring to hospitals only those patients who would benefit from seeing a consultant. Waiting times for ICATS appointments were subject to existing outpatient waiting times targets. The partial booking systems offered the patient a degree of choice, but - as was explained to us by a number of respondents during interviews with managers and professionals - the key motive behind its introduction was to reduce rates of non-attendance at outpatient clinics and increase efficiency.

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Following devolution in May 2007, the Direct Rule proposals for reform to the health and social care system that had been planned before that date but were not due to be implemented until April 2008 were reconsidered and put forward for public consultation by the Northern Ireland Minister for Health, Michael McGimpsey.

"...when I took up office in May, I inherited a raft of proposals for reform which had been drawn up by Direct Rule Ministers for a Direct Rule administration. I believe that the return of devolution with local Ministers and a local Assembly scrutinising their work presents a real opportunity to deliver a local solution which meets our local needs." 121

The main points of focus, however, were on putting patients first, giving the patient a 'voice' – in addition to tackling various kinds of health inequalities.

"I want a modern health service which tackles health inequalities and puts patients at the heart of its thinking. I want efficient, forward looking, innovative, health and social care organisations, which deliver on targets and constantly strive to improve their performance for the benefits of patients. Quality and standards must continually be driven up without compromise. Patients must be given the opportunity to voice their concerns and be sure that they are listened to." 121

Outlining his proposals, the Minister has also put emphasis on 'partnership' with local government and providing a 'voice' to the local community. 'Partnership' evolved to become a pivotal term in the design of various kinds of services – including the health services.

"Closely linked to this new organisation will be the five Local Commissioning Groups (LCG's). These bodies will be strongly rooted in their local communities and actively engage GP's and other primary care professionals in the planning and redesign of services to secure better services for the communities they serve. Previous proposals did not include any input from elected local representatives. I feel this was a missed opportunity therefore I be seeking views on the memberships of the LCG's as I want to ensure that local people and councillors are given a strong voice in the system.<sup>121</sup>

Interestingly one of our NI Assembly Health and Safety Committee respondents had told us that, if anything, there was no clear 'voice' in his constituency concerning health provision. Rather, there were many voices and it was not at all clear to which he should listen.

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# 3.5.4 Mechanisms (how)

During the period of the research the introduction of the Health Social Care (Reform) Bill was one of the most significant pieces of legislation affecting the Northern Ireland Health Service in recent decades. The subsequent 2009 Health and Social Care (Reform) Act provides the legislative framework within which the proposed new health and social care structures now operate. Under the legislation the PCC is the mechanism through which the patient voice is heard. It would also appear to be a mechanism by which patient choice was to be enhanced although it was not clear what was meant by such enhancement. In evidence presented to the Health Committee in regard to 'Proposals for Health and Social Care Reform: Consultation Report' (DHSSPS, September 2008), representatives from the DHSSPS explained:

Clauses 16 to 20 deal with a broad range of "Patient representation and public involvement". The five clauses deal primarily with the establishment of the patient and client council. They also deal with enhancing patient choice; meeting the needs and expectations of patients, clients and carers; and ensuring that their views are heard and listened to at all stages in the planning and delivery of services. The patient and client council will replace the four existing health and social services councils. It will build on the excellent work that those councils have carried out in the past, and it will combine the strong local focus that the councils provided with a powerful regional voice — a voice that has been missing in the current set-up. (Committee for HSSPS, 2008; our emphasis).<sup>122</sup>

A duty was placed on all health and social care organisations to cooperate with the PCC in the execution of its responsibilities. That was an additional authority that gave the PCC influence to a greater extent than the previous Health and Social Services Councils had.

Clause 21 dealt with the duty on HSC Trusts in relation to improvement of health and social well-being. Legislation included an additional statutory duty on Trusts in relation to improving health and social well-being. Clause 21 was subsequently amended to include a reference to health inequalities:

"It is the duty of an HSC Trust to exercise its functions with the aim of improving the health and social well-being of, and reducing health inequalities between, those for whom it provides, or may provide, health and social care." (15)<sup>122</sup>

Despite rhetoric about 'putting patients first', listening to the 'voice' of the patient, meeting the needs of patients and of 'enhancing patient choice', but the mechanisms through which such voices,

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needs and choices were to be made manifest was not to be the mechanism of the market.

No we don't have choose and book; we don't have payment by results yet, and in fact, within the last two to three years far from there being competition for patients there has been a pooling of the resource in NI so that patients could be treated more expeditiously. For instance, there are some hospitals in NI who have very long waiting lists for certain procedures. Other hospitals had spare capacity, and in the context of patients waiting for a very long time this didn't make sense, and so patients were then offered the opportunity of having their condition treated much more quickly, but in another hospital than the one to which they had originally been referred; so its collaboration rather than competition that has ruled the day here. (Senior NHS Official)

Rather those voices, needs and choices were to be reflected through the deliberations of the Patient Client Council (PCC). It was perhaps more of a *dirigiste* than a market driven model of service planning and service delivery.

# 3.6 Conclusion – a comparison of choice policy in England, Northern Ireland, Scotland and Wales

The macro level study sought to examine the development of choice policy across the UK and its ideological origins. Our analysis of the interview data focused on two key approaches. We sought to establish whether there were any dominant policy networks or coalitions of policy agents (politicians, policy advisers, patient organisations etc) advocating or driving the development of policies providing patient choice. Alongside this we also sought to develop a narrative of the way policies relating to choice emerged within the general development of health policy within the devolved government and NHS structures of the UK. While we had anticipated that choice was not a dominant discourse outside of England, language was an important factor within discussions with policy informants leading to the development of guestions that more directly focused on referral decisions. However, given the strong dominance of the UK wide Welfare State and recent institutional, political and organisational structures that were UK wide we anticipated similar influences relating to changes in ideas about the delivery of public services would create some similarities in policy.

However, there was no clear UK wide policy coalition or network across the four countries and even in England there was no evidence of a strong policy coalition or network advocating increased patient

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choice. In fact patient organisations and political groups were not pressing for the introduction of patient choice of provider although other types of choices were rated as important in responses to the Department of Health's consultation on patient choice in 2003. Our interviews clearly demonstrated that patient choice of provider policy emanated from the Department of Health and from the Prime Minister's Office with key policy advisers being important in framing the policy. There was little contact between the four countries although in 2008 greater attempts at co-ordination between Northern Ireland, Scotland and Wales were being developed.

# 3.6.1 The political and ideological origins of the policies on choice

There was little ideological discussion of choice either in policy documents or by interviewees. The key exception were the two English policy advisers closely associated with patient choice policy who saw choice as both a system driver within a market style form of competition between providers for patients and also as a way of providing greater equity between patient groups. While equity was mentioned by a few other English politicians it was not identified as a key policy driver. There were clear political contexts to policy on choice outside of England – especially in Wales and to a certain extent in Scotland where policy and political difference were identified as key factors by interviewees. Health ministers from Scotland, Wales and Northern Ireland met in April 2008 and agreed a joint statement of core NHS values. There was no explicit reference to patient choice in this statement; instead, emphasis was placed on partnership working to improve quality of care within health care services. A significant finding was the contrast between England dominated by policy on individual choice of provider, and the emphasis in Wales and Scotland, and to a certain extent Northern Ireland, on public and patient engagement and the importance of voice as necessary for choice. Engagement at a community level was seen as central to improving quality and meeting patients needs in a more responsive way.

#### 3.6.2 The objectives of policies on choice

Two consistent themes emerged from the policy documents and particularly the interviews. The first was the central importance of tackling waiting lists. Choice in England, Wales and Northern Ireland was very closely linked to initiatives for reducing waiting times for patients. The second aspect was in relation to quality. In England choice was part of a set of policy drivers that was also initially seen

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as a way to drive up provider quality. Broader objectives relating to choices beyond provider choice were less well articulated in all four countries but increasingly recognised as important. Policy objectives also differ in relation to the objectives relating to mechanisms for individual choice (eg the choices website in England, *Choose and Book*) and objectives in Wales for example, relating to public and patient involvement.

# 3.7 How patient choice was conceptualised

In all four countries choice for patients remains a limited concept. Table 9 compares the choices available in each country in relation to choices offered to individual patients. Other ways of conceptualising choice were raised in interviews – particularly outside of England where interviews around choice had to be approached in a different way as choice was seen as being closely associated with English policy and not part of health policy in the other countries. Interviews with non English respondents often, therefore, reflected how their policy differed to England or explored notions of choice through discussion of referrals (an issue that was also seen in the next chapter when choice was discussed with service providers) or by emphasising voice and PPI as integral to providing relevant choices of quality services.

Table 9. Comparison of patient choice within the UK

Policy area	England	Scotland	Wales	Northern Ireland
Choice of treatment	In conjunction with GP	In conjunction with GP	In conjunction with GP	In conjunction with GP
Choice of appointment date and time	Yes	Yes	Reasonable choice offered	No
Choice of provider	Yes	Yes	Reasonable choice offered	No
Choice of location	Yes	Yes	Within provider sites	No
When choice is made	At general practice	At general practice	At offer of appointment	N/A
Who is the main chooser	Patient	Patient	GP/provider	GP

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#### 3.7.1 Future directions

While the impact of choice on elective care was not yet universally embedded in policy in all four countries the concept of choice as an important element of health care provision is. Policy documents and interviewees provide a picture that suggests choice was now embedded in the language of health policy and health service delivery. During the period of the research the dominant focus of patient choice was on the date and timing of appointments in secondary care although the extent to which the emphasis on choice was proactive or reactive varied. Only England had specific policies in place to offer choice of provider. While developing opportunities for patient and public engagement (voice) was more dominant outside England there has been an increasing emphasis on patient and public engagement in England and is explicit in the proposals for extending choices to people with long term conditions. Choice has become a dominant discourse in health policy across the UK although the degree to which it is a primary focus of policy, what types of choices are developing and how such choices are to be achieved varies. The following encapsulates what was perhaps the main legacy of the introduction of choice in health care not just in England but across the UK.51

I think that if we're having this conversation in 10 or 15 years time, I think it will be not, I would never say never, as you can never say ever or never, I would be surprised if the model of healthcare hadn't evolved towards what I think it should evolve to, which is precisely patients exercising more choice, greater diversity in systems, backed by some core standards, core ethics, core values, core system of funding, but which is much more diversified, fluid, open and flexible, and where power is far more disaggregated. (Former Secretary of State for Health).

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# 4 Shaping and managing choice

This chapter examines the way organisations designed and delivered choices to patients who were being referred into secondary care in England, Scotland, Northern Ireland and Wales. It will be noted that the English section examines the systems for delivering choices in more depth than the sections looking at the arrangements in Northern Ireland, Scotland and Wales. This is reflective of the centrality of the choice of provider system in England, situated as it is within wider policy initiatives such as Payment by Results.

The methods used to gather the data about the organisational delivery of choices to patients are described in Chapter 2. This chapter begins with a brief description of the interviewees recruited for this element of the study. The arrangements in each country are summarised through a two part framework which examines firstly how the choice agenda for organisations was shaped in each country and secondly how organisations manage the delivery of choices to patients. 'Shaping choice' sections outline staff and organisations' understanding of choices which were available to patients during the referral pathway in each country, their roles and responsibilities for delivering choices to patients, and the resources which were in place to deliver choices to patients. 'Managing choice' describes how choices were delivered to ENT and orthopaedic patients in each country, by describing the points on the referral pathway at which choices were available, the impact of administrative systems on the delivery of choices and the impact the delivery of choices has on services. Each country section begins with a description of the case study areas which participated in the study.

# 4.1 Case study site and interviewee selection

Once case study areas had been identified, and the key organisation (Primary Care Trust or equivalent) had agreed to participate in the study, local GP practices were approached to participate in the study as were the secondary care organisations which received their ENT and orthopaedic referrals. An overview of the case study sites is given in Table 10. A description of the case study areas in each country can be found at the start of each country specific section in this chapter.

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Potential interviewees in participating organisations were identified according to their role in the organisations. The initial aim was to interview staff members at Board level in each organisation, service managers for ENT and orthopaedics and business managers. Interviewees were also selected using snowballing techniques as the research progressed. See Table 11 for a summary of interviewees.

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Table 10. Overview of participating organisations within case study sites

COUNTRY		CASE STUDY 1	CASE STUDY 2		
<u>ENGLAND</u>		HAMPTONSHIRE AREA	NORTH GORINGHAMSHIRE AREA		
	Commissioner	Hamptonshire Primary Care Trust	North Goringhamshire PCT		
	Secondary Care	Seahaven District General Hospital St Stephen's Specialist Foundation Trust Ridgeway District General Hospital Coast City Teaching Hospital	Goringhamshire Foundation Trust North Eastingshire Foundation Trust Newtown Foundation Trust Goringham Independent Sector provider		
	Primary Care	Practice A Practice B	Practice A		
SCOTLAND		THISTLE AREA	HEATHER AREA		
		Thistle Health Board	Heather Health Board		
	Primary Care	Practice A	Practice A		
WALES		PORTH AREA	DRAIG AREA		
	Commissioner	Local Health Board	Local Health Board		
	Secondary Care	Appleton Trust	Rural NHS Trust Urban NHS Trust		
	Primary Care	Practice A	Practice A		
NORTHERN IRELAND		PARK AREA	BOROUGH AREA		
	Commissioner	Park Health and Social Services Board	Borough Health and Social Services Board		
	Secondary Care	Park Health and Social Care Trust	Borough Health and Social Care Trust		

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Primary Care	Practice A	
Patient representative organisation	Park Health and Social Services Council	Borough Health and Social Services Council

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Table 11. Numbers of interviewees by country, organisation and role

Informant	Agency/	England	N	Scotland	Wales	TOTAL
category	organisation		Ireland			
Chief Executive/Executive Director	PCT/UHB/LHB /HSCB	2	1	2	4	9
Medical Director	PCT/UHB/LHB /HSCB	0	1	1	2	4
Lead commissioning manager	PCT/UHB/LHB /HSCB	2	1	0	2	5
Service Manager	PCT/UHB/LHB /HSCB	2	0	5	1	8
Administrative Managers	PCT/UHB/LHB /HSCB	1	0	0	0	1
Chief Executive/Executive Director	Providers (NHS / non- NHS)	5	1	0	8	14
Clinical Director/Lead consultant	Providers (NHS / non- NHS)	1	5	2	9	17
Contracts / business manager	Providers (NHS / non- NHS)	4	2	0	0	6
Service Managers	Providers (NHS / non- NHS)	11	1	0	2	14
Administrative Managers	Providers (NHS / non- NHS)	2	1	0	4	7
Chief Executive / Senior Manager	Regional Health Body (SHA/HB/UB)	1	0	0	0	1
Lead representative	Local patient groups (PPIF/PIGs/CH Cs/local patient forum)	0	2	0	4	6
GPs	GP Practices	6	1	9	7	23
Practice Manager/administra tor	GP Practices	4	0	3	3	10
TOTAL		41	16	22	46	125

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# 4.2 Shaping Choice - England

### Box 4.1 Case study description

Case Study 1 is based around Hamptonshire PCT. Hamptonshire PCT is a large rural PCT (population over 500,000). The population is predominantly well off and healthy, but there are pockets of deprivation. The PCT was formed from a merger of 5 smaller PCTs in 2007, and is currently undergoing a public consultation on the reconfiguration of the main providers in the area.

The main providers of ENT and orthopaedic services in the area are

**Seahaven DGH** – Seahaven DGH operates on a split site to the south of the Hamptonshire PCT patch, with 600 beds providing the general health care for a district of 250,000 population. The Trust received a 'fair' rating in the 2008/09 assessment for quality of services, and a 'fair' rating for financial management. The PCT is the lead commissioner for this Trust. The Trust does not operate direct (internet) booking.

**St Stephen's Specialist Foundation Trust** – As a regional centre of excellence the Trust provides specialist services, and community services to the local population. The Trust is a Foundation Trust and was rated 'excellent' for quality of services and financial management in the 2008/09 assessment rating. The Trust is situated in the northeast of the PCT patch. The Trust is not yet direct booking.

**Ridgeway DGH** – Provides services in the northwest of the PCT and the neighbouring county. The hospital has a single main site, and serves a population of around 350,000 people. The Trust received a 'fair' rating in the 2008/09 assessment exercise for quality of services and financial management. The Trust is not yet direct booking.

**Coast City Teaching Hospital** – is the regional teaching hospital based in a large coastal city and provides general and specialist acute hospital services working as one teaching hospital across two sites. The city has its own PCT, which is the Trust's lead commissioner. The Trust was rated 'good' for quality of services and financial management in the 2008/09 assessment. The Trust is direct booking in all services except Orthopaedics.

The two GP practices participating in the case study were based in Hampton town. Hampton has a population of approximately 50,000, with a high proportion of career professionals and a low proportion of low income families.

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#### 4.2.1 Definition of choices available during referral

#### **Box 4.2 Case study description**

**North Goringhamshire PCT** covers a population of around 500,000. The area consists of a large city, two small cities and a rural area. The large city has a larger than average ethnic population. Whilst levels of deprivation in the PCT overall are lower than the national average, there are pockets of high deprivation in the city areas. The area has good transport links. The PCT has a high level of choice awareness within the population. The PCT and surrounding area contain a high number of Foundation Trusts and independent sector provider.

The main providers of ENT and orthopaedic services in the area are:

**Goringhamshire Foundation Trust** – a large general hospital with over 800 beds, based in the largest city in the PCT area. The Trust was rated 'good/excellent' in the most recent rating exercise. The Trust runs services from the main hospital site in Goringham and from a community hospital. Goringhamshire FT is the lead provider for the PCT

**North Eastingshire Foundation** Trust – is based in the neighbouring county to the west. It is a 450 bed general hospital, which also provides a small range of specialist services. It has an excellent/excellent rating.

**Newtown Foundation Trust** – is based in the neighbouring county to the east. It provides services from two main sites, and manages outpatient services across another four sites. It has a good/excellent rating.

**Goringham Independent Sector provider** – an independent sector provider based in Goringham. The hospital is part of a national chain.

The GP practice participating in the case study is based in a deprived area of Goringham city.

All the NHS Trusts in the case study operated direct booking of referrals (patient/GP can book directly into a clinic slot over the internet).

Choice available to patients during the referral process in the English NHS was described by interviewees primarily in the context of choice of provider policy. The policy rules governing choice of provider and how it should be delivered gave interviewees a shared understanding of what choice should be. For many, especially those in primary care, choice was synonymous with the use of the Choose and Book system.

Patient choice of provider policy was clearly situated within a programme of system reform in the English NHS. Most often interviewees referred to the national tariff for activity (Payment by Results) as a key part of the choice agenda. When discussing the impact of choice of provider policy at an organisational and service level, interviewees found it difficult to disentangle constituent parts of the policy to say what the effects of

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choice of provider had been, and the relevance of 'choice' itself as a driver for their behaviour (as opposed, for instance, to waiting time incentives, financial incentives, Foundation Trust status).

Although national choice of provider policy was the most prominent type of choice available during referral described by interviewees, other choices for patients were also identified. In particular, interviewees often mentioned choosing the date and time of a particular appointment. Other choices identified by interviewees, although less often than choice of provider and appointment were choice of consultant, site, or treatment. These last choices were choices which were locally shaped rather than centrally prescribed by policy.

The choices available during the referral process were often discussed in relation to their limitations. There were differences of opinion between interviewees about the degree of choice offered by choice of provider policy, which was seen by some to be limited by factors such as geography, the distribution of providers, and the tendency of patients to use their local provider. The other potential choices during the referral pathway were often defined by their limitations, most commonly the need to give patients appointments within waiting time targets, and the finite nature of staff and physical resources.

### 4.2.2 Roles and responsibilities in relation to choice

#### **Primary Care Trusts**

Interviewees working in Primary Care Trusts described a clearly defined role in relation to their responsibilities for patient choice. They outlined a short term project management agenda which was associated with the implementation of the Choose and Book system ensuring that Information Technology systems were in place and that GPs and providers were using Choose and Book. They were also concerned with ensuring that the local health organisations attained national targets for use of the Choose and Book system. In addition some senior staff outlined a long term aspirational role in which the Primary Care Trust was working to create the appropriate environment in which patient choice would flourish, such as ensuring that the public were aware of the availability of choice of provider, and that a diversity of provision was in existence. In this context primary care trusts' roles were focused on making NHS choice policy 'work' in the local context, whether this was trying to reconcile messages of consumer choice with the need to rationalise local services to make them viable, or attempting to create diversity of provision when faced with a monopoly of a local provider.

Interviewees in both primary care trusts identified their commissioning team as key to the choice agenda, together with project management

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posts responsible for the implementation of the choice system and technical implementation of the Choose and Book system.

#### **Box 4.3: Two contrasting Primary Care Trust choice roles**

Hamptonshire Primary Care Trust felt their task was largely to understand the services which existed in the patch following the merger of local primary care trusts, and were concentrating activity on understanding the services which currently existed in the area. They had chosen not to pursue an aggressive choice marketing strategy as they felt it was in tension with the ongoing public consultation about local hospital configuration.

North Goringhamshire Primary Care Trust thought choice of provider policy was not meaningful to all citizens and saw their role to develop different types of services which patients could choose between, for example through the development of 'tier two' services, primary care based services that provide an alternative to conventional secondary care outpatient services.

#### **Interface services**

Primary Care Trusts had set up services to administer referrals between primary and secondary care. There was a variety of such services in existence across the Primary Care Trusts, consisting of both administrative centres which processed referrals and services which clinically triaged patients. Table 12 gives a summary of those interface services which were referred to by interviewees as existing for the tracer conditions of ENT and orthopaedics in the case study areas and Box 4.4 gives contrasting examples of services in each case study site.

Understandings of the nature of the relationship between these services and choice for patients varied between interviewees and was subsequently often unclear. There was a particularly high degree of confusion concerning the role of musculo-skeletal services in relation to choice. For some interviewees, including the member of staff interviewed for the Hamptonshire musculo-skeletal service, these services had a clear and important role in delivering choices to patients, for others the primary responsibility of the services were to 'demand manage' entry into secondary care.

Table 12. Summary of Interface Services in English Case Study Sites

Role
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Hamptonshire PCT	Musculo- skeletal service (west area)*	Clinical triage of orthopaedic patients	To offer choices to orthopaedic patients and manage entry to secondary care
Hamptonshire PCT	Musculo- skeletal service (central area)	Clinical triage of orthopaedic patients	To offer choices to orthopaedic patients and manage entry to secondary care
Hamptonshire PCT	Musculo- skeletal service (east area)	Clinical triage of orthopaedic patients	To offer choices to orthopaedic patients and manage entry to secondary care
Hamptonshire PCT	GP with Special Interest in ENT*	To offer GPs a specialist opinion	None
North  Goringhamshire PCT	Referral Facilitation Service	Enter referrals onto Choose and Book.	Administration of Choose and Book system.
North Goringhamshire PCT	Musculo- skeletal service (PCT area?)	Clinical triage of orthopaedic patients	To offer choices to orthopaedic patients and manage entry to secondary care

<sup>\*</sup>Indicates that a representative of the service was interviewed for this study

#### **GP** practices

Whilst occupying a central position within the choice agenda as the delivery point of choice of provider to patients, the GP practices who participated in the English study did not describe an extensive role in relation to choice,

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and generally outlined activities which ensured compliance with local and national policy about choice of provider. They described a duty to administer the Choose and Book system within the practice (or comply with locally agreed procedures of sending referrals via the Referral Facilitation Centre) and to have a conversation with patients concerning choice of provider. The introduction of the Choose and Book system was reported by interviewees as a challenging process. GPs often delegated the tasks associated with the Choose and Book system to the administrative team. GP practices were incentivised to put referrals through Choose and Book, and meet targets regarding the percentage of referrals put through Choose and Book. It was this aspect of the choice system that GPs often identified as the most discussed aspect of choice in the practice. GPs were sceptical about the extent to which choice of provider policy and the Choose and Book system had increased choice for patients, and suggested that the formalisation of choices in policy had led to their restriction (i.e the discussion of choice with patient had become stilted, and the formalisation of choices into an electronic menu was restrictive).

#### **Box 4.4 Contrasting uses of interface services**

The Hamptonshire musculo-skeletal service was closely associated with the provision of choice by the Primary Care Trust and those running the service as a means of ensuring choices to patients when making decisions regarding physiotherapy, osteopathy and secondary care. The service had been set up using choice funds with the aim of ensuring equity of choice for orthopaedics in the area.

North Goringhamshire Primary Care Trust had established a referral facilitation centre. The function of this centre was to enter GP referrals onto the Choose and Book system and send letters to patients to enable them to book their appointment. As such their role concerned the administration of Choose and Book rather than the direct provision of advice regarding choices to patients.

In terms of discussing choice of provider GPs saw their role as complying with the letter of the law - having a conversation of some sort because they were required to. However this did not generally extend to a responsibility to explore choice of provider in depth with patients unless patients pursued this. The individuals having the choice conversations with patients (both GPs and other referral advisers such as professionals in interface services) had access to 'soft' information about services, based on interpersonal relationships and trust of particular consultants based upon long term working relationships. However some of those having choice conversations with patients expressed an uneasiness about sharing their personal subjective opinions with patients, and thought they should remain impartial. This need for impartiality on the part of choice advisers, was in

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tension with the support often requested by patients when they were choosing providers ('Tell me who is the best').

Generally the GPs interviewed found the attempt to dictate in policy what they should discuss with patients unhelpful, often describing awkward and laboured conversations with patients in which their attempts to raise the issue of choice of provider was met with bewilderment or disinterest from patients. They cited numerous possible barriers to a full and frank discussion of options with patients, including lack of time in the consultation, lack of patient interest in choice of provider, and their own lack of knowledge about non-local providers. Conversely there was also a view that choice policy had not greatly changed their choice conversations, and that they had always offered a choice of providers to patients where this was appropriate.

#### Secondary care

Interviewees working in secondary care provider organisations described clearly defined roles in relation to their participation in the choice of provider system which they were required to fulfil, such as entering information about their services onto the Directory of Services, and participating in the booking systems. Above and beyond these mandatory responsibilities, interviewees outlined further choices which provider organisations aspired to provide to patients who were being referred to them, such as choice of appointment date and time, choice of site and choice of consultant. Many providers, especially Foundation Trusts, had developed their marketing activities and resources in order to attract more patients, and take advantage of the opportunities for expansion offered by the choice of provider system. A further role in provider organisations was a day to day reconciliation of the requirement and aspirations to offer choices to patients, with the requirement to meet waiting time targets within the finite resources available.

In provider organisations key staff roles in the delivery of choices were the administrative and managerial roles concerned with the operational management of services and waiting list management. Some providers had developed dedicated Choose and Book posts concerned with the information put on the Directory of Services and booking processes. Other key roles were a number of GP liaison posts found in Foundation Trusts. Providers had also developed business and strategic development posts which had responsibility for planning strategy for attracting patients into the Trust.

#### 4.2.3 Resources

Resources had been put in place at all levels of the NHS to implement and manage choice policy. Table 13 summarises those resources referred to in

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interviews. There was much more reported investment by the independent sector provider interviewed in the North Goringhamshire area, including investment in Information Technology at a national level, staff training in coding and referral management and investment in booking posts.

Table 13. Resources put in place in case studies to deliver choice of provider policy

# 4.3 Managing Choice in England – the administration of choice for ENT and orthopaedic patients

Level	Human Resources	Other resources	Governance
National		Telephone Appointments Line (NHS Direct)	Department of Health monitoring meetings
Regional (Strategic Health Authority)	Choice lead posts at Strategic Health Authority		Choice targets monitored at Strategic Health Authority Board
Local (Primary Care Trust)	Choose and Book/Choice implementation post(s) Choice and Access Manager	Incentive payments to GPs Referral Facilitation Centre Musculo-skeletal service IT systems for Choose and Book system across area	Discussion at PCT Board Meetings Health Community group to implement Choose and Book
Providers	GP liaison post Commercial Director Choose and Book/Directory of Services Managers	Marketing databases	Provider information Directory of Services Participation in health community meetings
GPs		Training in use of Choose and Book system	Participation in Choose and Book implementation meetings

#### 4.3.1 Referral options (choice of provider)

The free choice policy in England which wasintroduced from April 2008 meant that there was in theory a choice of any accredited secondary care provider in England for patients when they were referred from primary care. However in both case study areas, when the interviews were

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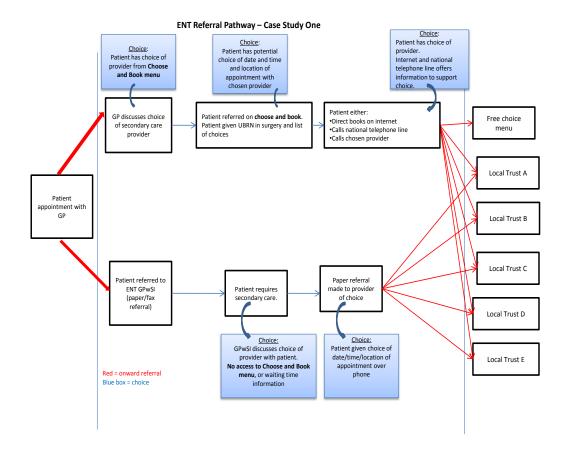
conducted (May 2008 onwards) the choices reported by referrers to be presented to patients consisted of the nearest secondary care providers. The difference between providers was seen by the referrers interviewed as geographical and relating to waiting times rather than including different treatment choices. Local options in North Goringhamshire PCT also included two independent sector providers, who offered limited services.

In addition to secondary care providers, further referral options for patients were provided by interface services. It was unclear from interviews with referrers to the musculo-skeletal services whether these services were mandatory referral pathways, or represented referral options. As described previously, there was a variety of orthopaedic musculo-skeletal services in existence in the case study areas. Whilst commissioners emphasised the need to ensure standardisation of the choices available to patients, and to establishtreatment pathways in order to preserve equity for patients, in reality there was a patchwork of services in existence in each PCT area, which related to the development of services over a period of time based on historical organisational boundaries.

The referral choices for ENT patients were more restricted than those identified for orthopaedics. In addition to choice of secondary care providers, there was one GP with a Special Interest in ENT in existence in Hamptonshire Primary Care Trust area. Two examples of referral pathways indicating the stages at which choices were available to patients are given in Figures 2 and 3. A full set of referral pathways from case study areas can be found in Appendix 7.

Figure 2. ENT Referral pathway - Hamptonshire

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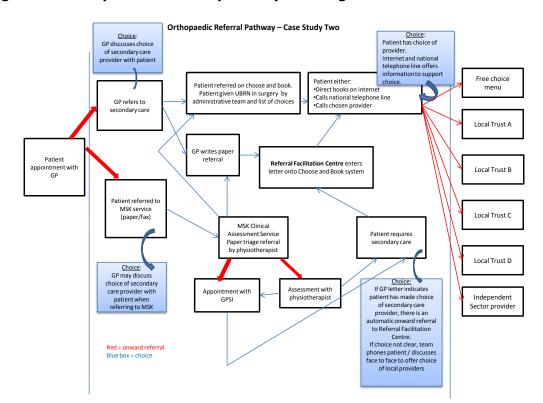


Figure 3. Orthopaedic referral pathway - Goringhamshire

#### 4.3.2 Administration of referral options

#### **Primary care**

The most important aspect of choice policy in GP practices appeared to be the Choose and Book system. GPs' experiences of the Choose and Book system were mixed. Commonly practices reported that whilst the system had originally been difficult to use and fairly unreliable, problems had now been largely resolved. Usage of the Choose and Book system varied greatly. Some GPs used Choose and Book during the consultation with the patient, others delegated the use of Choose and Book to the practice administrative team. However, one practice had stopped using the system completely due its perceived unreliability, and all their referrals were sent to the PCT administered Referral Facilitation Centre, who entered referrals on to Choose and Book. It was not clear how, or whether, these differences in administration led to differences in the options offered to patients when they were being referred.

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Although the 'free choice' menu was available to patients at the time of the interviews, those GPs who referred to the list of providers from the Choose and Book system during the consultation referred to using a list of approximately five local providers as a basis for their discussion with patients. There was confusion on the part of GPs and practice administrators about the options available on Choose and Book menus, most commonly concerning whether it was possible to refer to specific consultants, which suggested that in some instances choices were potentially being limited because referrers did not understand the system fully (See Box 4.5). There was also some perception that freedom to choose had been impaired as GPs felt that choices they would want were not on the menu, such as non local specialist services.

GPs had differing understandings of whether referral to an interface service was a choice or a mandatory pathway, with some referring orthopaedic patients automatically to the musculo-skeletal service, whilst others referred direct to secondary care if they were sure a consultant opinion was required.

#### **Box 4.5: Choice of Consultant at Practice B (Goringhamshire PCT)**

Administrators and GPs at Practice B were disappointed that they could not refer to a named consultant at North Goringhamshire Foundation Trust on the Choose and Book system as the option did not appear to be on the choice menu. It was not until a new GP joined the practice that they were alerted to the correct way to access this option on the Choose and Book system. However, the practice was still not convinced that choice of consultant would be 'honoured' through the Choose and Book system, and had therefore reverted to sending a paper referral direct to the consultant's secretary.

Similarly at other points in appointment booking process there were a variety of referral and booking routes open to patients, which delivered choices in different ways to patients, with different sources of advice. For instance, a GP could book a patient an appointment with their chosen provider over the internet whilst in the surgery, or the patient could leave the surgery and use Choose and Book website from home to book their appointment. Alternatively the patient could telephone the Telephone Appointment Line who would offer further advice about choice of provider.

#### **Interface services**

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There were a plethora of interface services between the GP and secondary care which the patient might encounter during a referral in relation to choice (see Table 14).

Whilst musculo-skeletal services had an important role in offering choice of services and providers to patients, due to the focus of choice policy on the GP as choice adviser, these facilities were not necessarily part of the Choose and Book system. This meant patients referred by these services to secondary care were in some cases referred outside the Choose and Book system, and the referrers did not have access to waiting time information, or the free choice menus (See Box 4.6).

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Table 14. Overview of possible choice advisers, types of choices and booking methods during the referral process

Choice advisers	Types of choice	Methods of booking appointment
GPs	Provider	Internet
Orthopaedic Musculo-	Date and time of	Telephone
Skeletal service	appointment	Allocation by letter
ENT GP with Special	Location of appointment	
Interest	Consultant or team	
Telephone Appointments Line	Treatment options	
Internet Choose and Book site		
DOOK SILE		

## Box 4.6: Choice of osteopath/physiotherapist in Hamptonshire Musculo-Skeletal Service

The musculo-skeletal service originally offered a choice for patients between seeing an osteopath and a physiotherapist. However the service found that the time taken to explain the differences between the physiotherapist and osteopath, and administer appointment changes between the two groups of professionals in line with patient preference led to the cessation of the provision of the choice. Instead letters were sent to patients offering them the next available appointment with the option to call to change the appointment and professional if they wanted.

#### Secondary care

Interviewees in provider organisations identified choices within the referral process which, unlike choice of provider, were locally rather than nationally prescribed. These included choice choice of consultant, and choice of location of appointment. In contrast with the efforts elsewhere in the organisation to encourage choice of provider for instance through the business planning of services, choice was largely viewed by the managers responsible for the day to day running of services as a complicating factor in the achievement of the 18 week target. Those providing services felt strongly that, although choices for patients should be supported as far as

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possible, the scope of choices (most commonly site, consultant, and the breadth of choice of date/time of appointment) were limited by the availability of resources.

The mechanism for communicating the available options to patients and referrers was the Directory of Services each organisation produced which detailed the options which appeared on the Choose and Book website, such as the number, timings and locations of appointments which were available, and whether referrals could be made to a consultant or to a generic service. In order to deliver waiting times within resources, the Choose and Book system itself was used in interesting ways to limit the choices available to patients. For instance, where providers had concerns that choice would lead to an imbalance of waiting times for consultants and endanger the 18 week waiting time target, Choose and Book was used to limit the availability of this choice. Whilst previously referrers were able to address a referral letter to whomever they chose, some providers chose to only give the option of a generic referral to a service through the Choose and Book menu, rather than a referral to a particular consultant.

Moreover the availability of other choices depended on the organisational or departmental policy of provider in that regard, or indeed the actions of individual administrators when such policy did not exist. In some instances the availability of options was limited by a lack of explicit explanation about the potential choices available (See Box 4.7).

#### **Box 4.7: Choice of site at Goringhamshire Foundation Trust**

Goringhamshire Foundation Trust ran orthopaedic services from the main hospital site and a local community hospital. However it was felt that offering patients a free choice of these sites would make the management of waiting times at each site unmanageable. In order to comply with waiting times the orthopaedic team decided that staff would not offer choice of site to patients up front when agreeing appointments, and would allocate appointments based on waiting times. If patients raised the issue of site during the appointment conversation, staff would then offer a choice of site to patients.

Offering choices to patients was seen as a complicating factor in booking processes. This was manifested in various ways. Providers were operating a variety of booking systems, depending on Information Technology systems available to them and in response to the variety of referral practices in primary care and interface services. However, regardless of the particular combination of booking system being used in each provider organisation, interviewees tended to describe a similar tension between the requirement to offer flexible booking processes to patients and the need to streamline

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### Box 4.8: Examples of booking practices in the case study areas Hamptonshire case study

The providers within the Hamptonshire case study had Information Technology systems which were largely non-compliant with the Choose and Book system, and so were operating a combination of booking methods rather than releasing slots for booking over the internet (direct booking). They felt their task of managing referrals had become more complex as referrals had a number of different routes into the system which made the task of managing the allocation of appointments in order of waiting times more difficult.

#### Goringhamshire case study

Most of the providers in the Goringhamshire case study were operating direct booking, and it was acknowledged that this real time booking system exposed any pre-existing capacity problems when the Choose and Book website ran out of slots. Whilst these capacity problems pre-existed choice, and had not been caused by choice itself, they were highlighted and exacerbated by the real time nature of the booking process. There were examples of the booking chaos caused in these cases as patients returned to their GPs to demand referrals via another route, leading to an avoidance of the Choose and Book system. Another reported response was attempts by the providers, against policy guidelines, to remove themselves temporarily from Choose and Book menus.

The tension between choice and waiting times was raised consistently in interviews. Providers often commented that choice of provider had the potential to make referral management difficult, because of the unpredictability of the number of referrals entering system. However it was noted that where fluctuations in referral flows were being experienced this was not thought to be as a result of changes of patient flows due to choice, but instead was due to an overall rise in referrals and natural variation.

Other types of choices along the referral pathway, such as choice of consultant and choice of site, were similarly perceived as threats to the achievement of waiting time targets, due to the general lack of the spare capacity necessary to accommodate choices.

One aim of the system reform programme in the English NHS was to create a system where organisations were paid for activity, and could

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consequently grow or shrink their business in line with demand from patient choice In spite of the theoretical flexibilities inherent in the Payment by Result tariff system, interviewees in providers generally felt that these changes in income did not alter resources which were fixed (e.g. consultants and their timetables, clinic rooms and theatre space). The capacity to manage any changes in referrals was therefore limited to 'squeezing' extra patients into clinics, paying staff for extra ad hoc activity.

#### 4.3.3 Change in activity

Whilst interviewees in provider organisations reported a growth in activity, there was no firm evidence provided by organisations of a change in referral or financial flows which could be connected to patient choice. The general view was that it was not possible to make inferences about changes in activity based on the information available within organisations. The reasons given for this varied: information systems were under-developed, providers had no way of knowing patterns across all providers, and the introduction of triage services had made it difficult to assess referral information. Whilst organisations had adopted the paraphernalia of a market system, with investment in market analysis packages, expansion strategies and strengthened teams in areas such as communications, marketing and business development, and a diversity of provision had been developed by commissioners, organisations presented no hard evidence that referral flows had changed since the introduction of choice of provider policy.

There was some anecdotal evidence of changes in referral flows given in interviews, for instance an increase in patients choosing a hospital due to parking problems at a neighbouring provider, or due to bad publicity for hospital acquired infections. One provider even reported a 26% rise in orthopaedic referrals in a month due to marketing activity. It was pointed out in both case studies that aggressive marketing was limited, both by the national 'Rules for Competition and Collaboration', and the appropriateness of spending NHS resources on marketing activity. Another view expressed by some interviewees was that whilst choice was desirable in financial terms, it was not always clinically appropriate. The potential impact of marketing activities was tempered by a common sense approach of the clinicians and managers involved in the running of services about what was in the patients' best interests, characterised by a scepticism about the appropriateness of treating patients from a long way away unless there was a clinical reason for the patient not receiving local care (for instance availability of specialist treatment).

However, we have obtained some information which provides an indication of the market position of the organisations. Professor Carol Propper of Imperial College, London, has calculated Herfindahl-Hirschmann

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competition indices (HHI) at the NHS trust level for the fiscal years 2003/04 and 2007/08 for a study of competition in the NHS. These HHIs have been constructed using actual patient flows to the trust in a given year, for all elective services. For each year, there is one observation per trust . HHIs vary from 0 (trusts facing the most competition) to 10,000 (monopoly).

The HHI indices suggest that all the NHS trusts within our case studies have been subject to more competition over the period 2003/04 to 2007/08.

Within the Hamptonshire PCT case study Seahaven DGH, which is the main provider for the Hamptonshire PCT, had an index of 7026 in 2003/4 and 6559 in 2007/08 indicating that that whilst at the start of the period they had a strong market share this is decreasing. Similarly, Coast City Teaching Hospital is in a very similar position to Seahaven with a HHI of 7321 in 2003/04, dropping to 7040 in 2007/08. The other two providers within the case study, Ridgeway DGH and St Stephen's Specialist Trust had both always been subject to considerably more competition with HHIs of 4455 and 4947 respectively, and again were in an even more competitive market in 2007/08 with scores of 3721 and 4359.

The position in the North Goringhamshire PCT area showed a similar overall pattern, although it appears that competition has increased to a lesser degree. Goringhamshire FT was not in a competitive market in 2003/04 (HHI 7151) and this has only changed slightly in 2007/08 (HHI 6985). This reflects the position outlined in interviews in which Goringhamshire FT was seen to be the major provider for the PCT, a position which had been relatively unchanged by the introduction of patient choice. Newtown FT was in a significantly competitive market in 2003/04 with a HHI of 4753, but this only increased slightly by 2007/08 to 4522. However North Eastingshire FT showed a considerable increase in the competitiveness of the market in 2007/08, with their market share dropping from 6459 to 5601. Interestingly this organisation had not seen a drop in performance rating in the period in question (2007/08) and interviews (conducted in 2008/09) showed no awareness that referrals were dropping.

These figures would suggest that organisations are not particularly sensitised to the increasing competitiveness of the markets in which they are operating. Interestingly, although Hamptonshire interviewees appeared much less alert to the possibility of a change in flows than those in North Goringhamshire, the area has seen a more significant increase in competitiveness. It may be that organisations were not sensitive to reductions in their market share because the volume of activity overall was increasing at the same time, a phenomenon that was noted by a number of interviewees. The decreasing market share across the board may relate to the introduction of new providers of care, for instance independent sector

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providers, or may indicate that more patients are choosing to receive care from providers outside the immediate area.

A further indicator of interest here is the Care Quality Commission performance ratings for our organisations for 2008/09 (the period the interviews were conducted). These show that in the main our providers were meeting the national targets for inpatient and outpatient waiting times and the 18 week target. We do not know what the relationship is between patient choice and the providers' success in meeting waiting time targets. The interviews with staff within provider organisations tended to frame the relationship between patient choice and waiting time targets as problematic due to the potential variability of activity.

There are two exceptions to the achievement of waiting time targets within the organisations studied, both within the Hamptonshire case study, where Seahaven DGH failed to meet their 18 week target and Ridgeway DGH failed to meet the inpatient target. Whilst both these providers had experienced a loss in market share according to the Herfindahl-Hirschmann competition indices it is not possible to make a link between failure to meet a target and patient choice as all organisations in our case studies experienced a loss in market share. Furthermore, there is no evidence from the qualitative data which suggests that these two organisations were experiencing patient choice any differently from the other organisations studied.

#### 4.3.4 Impact of referral choices on service provision

There was little evidence that choice of provider policy had impacted on the provision of services. Whilst it might be expected that service development under the patient choice system would be driven by patient pressure or by the desire to attract new business there was no evidence of this in practice, and service development was described as largely steered by clinician interest.

The Foundation Trusts in the Goringhamshire case study had substantially developed support and information for GPs through the development of GP liaison posts which were responsible for ensuring GPs had all the information they required about services, and providing a troubleshooting service to ensure that GPs access within the Trust was eased (See Box 4.9). This development was indicative of GPs privileged position as choice advisers, and suggests that some of the advantages originally envisaged for patients resulting from the choice of provider system (i.e increased responsiveness and influence) have developed for GPs instead. These developments may in turn benefit patients by proxy.

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#### **Box 4.9: GP liaison at Goringhamshire Foundation Trust**

The role of the GP liaison manager was to ensure GPs had knowledge about the services available in the Trust and could easily access services. A key element of this role was to act as troubleshooter in the Trust in line with GP feedback. A key success of the role was securing GP access to the hospital information system, so they could check easily on patient test results in line with feedback received, and securing direct GP access to a Trust screening service.

However there were a small number of examples where leading edge services had been picked up on by patients (See Box 4.10).

#### Box 4.10: Green light laser surgery at North Eastingshire FT

A clinician introduced a leading edge green light laser treatment for bladder cancer at North Eastingshire FT. Patients began finding the service on the internet and asking their GP for a referral. This initially caused difficulties as GPs were unwilling, or felt unable, to refer into a non-local service. The FT found it was increasingly acting as an advocate between GP and patient, to assure the GP they could refer.

#### 4.3.5 Cultural and strategic impact

Consumer choice was reported to have had a strong cultural and strategic impact in Primary Care Trusts and provider organisations. Rather than identifying specific activities or outcomes linked to choice, interviewees felt the desire to offer choice was embedded in the general working of the departments, and was reported to have impacted on the culture of the organisation even in those providers who did not think patients were likely to exercise their right to choose a non-local provider. Some organisations had incorporated 'choice' into their straplines, and linked it to an aspiration to be the best ('the provider of choice').

Whilst changes in activity were not felt to be occurring in any significant numbers, the threat of changes in referrals due to patient choice was seen as a driver for the achievement of good clinical standards, waiting time performance, and the provision of good hotel services such as food and cleanliness. Choice of provider policy did not appear to have impacted on culture or strategy in GP practices, where the impact was very much at an operational level around the administration of the Choose and Book system.

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#### 4.4 Shaping choice in Scotland

#### 4.4.1 Case Study descriptions

#### **Box 4.11: Case Study One**

Thistle Health Board employs approximately 15, 000 staff and covers a population of 535,000 people. NHS Thistle consists of acute services, corporate services and three Community Health Partnerships. NHS Thistle has a budget of around £760 million, and covers an area of over 3,000 square miles of city, town, village and rural communities. It contains one acute hospital, one District General Hospital and seven specialist hospitals. It also contains 14 community hospitals, 14 of which have minor casualty units. There are 53 GP health centres within the area.

#### **Box 4.12: Case Study Two**

Heather Health Board employs approximately 14,000 staff and covers a population of 394,160. NHS Heather has an annual budget of £750 million. The area contains 11 hospitals, 3 Community Health Partnerships, and 72 general practices.

#### 4.4.2 Definition of choices available during referral

Within the interviews it became quickly apparent that informants recognised that there was no specific policy or set of policies which deal specifically with 'choice' in NHS Scotland. Interviewees – especially those in management roles – mentioned several policy documents that at least implicitly had some relationship to their understanding of the 'choice agenda'. These included: Better Health, Better Care; The Patient Charter; New Ways; Shifting the Balance of Care. These were seen as underpinning patients' rights to participate in their individual healthcare and more generally in the delivery and design of services.

Several interviewees questioned the importance of 'choice' as a national, political, research or organisational topic. Some saw 'choice' framed as an 'English' problem, to do with 'Choose and Book'; others questioned why the research was being carried out at all, suggesting it had little relevance to Scotland and arguing that 'we don't want that type of 'choice' policy here'.

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Several mentioned the lack of an underlying 'choice' policy and lack of political or organisational 'will' for 'choice'.

Not unsurprisingly, then, the understandings of 'choice' that were apparent in the interviews were multiple and poorly delineated. Understandings were mobilised fluidly and participants moved rapidly from one understanding to another with little reflexive engagement.

'Choice' was variously discussed as referring to:

- clinical issues: treatment options and processes of choosing between these
- operational issues of health care delivery supply and provision of options in terms of who provides care (e.g. which consultant), when and where care will be provided
- involvement issues: public and patient more collectively/as representatives in service redesign and development

Both primary and secondary care providers made some links between issues of 'choice' and patients' involvement with service design and reconfiguration, via lay membership on committees or specific focus group work. This input was viewed as providing an 'insider' slant to service reconfiguration, for example, in designing patient pathways, patient experience could help identify bottle necks or annoyances which would not be readily visible to service providers. This was, however, balanced with discussion on limiting patient expectations of what was both clinically and organizationally possible to provide.

For interviewees from the Health Board and secondary care sector, the main focus of discussion relating to choice was the 18 week 'referral to treatment' waiting time directive. This has major implications for those designing and delivering services. Interviewees suggested their efforts were particularly focused on removing (administrative) inefficiencies in referral processes and in the movement of patients from primary care providers (GPs) to being assessed and subsequently treated (or not treated) by specialist services. The 'choice' agenda (in the sense of providing options for place, time and provider of specialist assessment and treatment) was seen as less important than the centralised waiting time target policy. However, paradoxically clinicians and managers noted that this may reduce the degree of choice that patients have as they become so effectively processed that there was no longer a 'reflective' space to consider options. In essence once the referral goes in the patient may be seen in clinic and booked in for treatment within a few weeks; there was little time to change your mind.

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At the time of the interviews, due to the imminent introduction of the 18 week waiting list policy, any significant increase in choices for patients was perceived as something which would have a negative impact on the access targets that were currently being worked towards. By increasing patients' choice, our interviewees particularly noted that administrative timelines would increase, meaning that patients would violate their targets. These violations were viewed as being seen unfavourably; it was unclear by whom but in all likelihood the Health Board and the Government's Health Department. There was also the issue of the population and its geographical dispersal. This has an impact on the amount of 'hard' resources (hospitals, staff, and equipment) available. Due to a finite amount of resource, choices were by their nature limited to what was available.

#### 4.4.3 Roles and responsibilities in relation to choice

Assumptions regarding responsibilities for choice were sometimes contradictory. For instance staff within secondary care providers tended to think that primary care clinicians were involved in face-to-face clinical discussion with patients, providing 'care' choice whereas GPs themselves tended to suggest that these types of treatment decisions were made by specialists in secondary care.

#### **Health Boards**

Health Board managers were not central to the provision of referral choices for patients in Scotland and were therefore not interviewed for this study. However the role of Health Boards in relation to referral choices for patients was referred to by interviewees in primary and secondary care, particularly in relation to their role in arbitrating decisions regarding out of area referrals.

#### **Primary Care**

GPs viewed themselves as more akin to 'gatekeepers' of service who had responsibility for having a working knowledge of possible referral protocols and options. 'Choice' was in the main associated with whether the patient wanted treatment or not; whether the patient had a preference for a named consultant; and whether patients wanted to be treated privately or on the NHS. GPs did not consider decisions about the timing of secondary care appointments to be under their control, but they did discuss trying to organise secondary care provision at sites that suited their patients' social conditions and needs (e.g. taking into account whether the hospital had a good bus service if the patient was known not to have a car).

There was, however, a reading of 'choice' provided by GPs that related it to ideas of 'involvement' and a responsibility on their part to enter into an

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informed dialogue with patients, for example, on the clinical evidence base of treatments (such as, whether primary based care could be used in the first instance e.g. physiotherapy for back pain as opposed to direct referral to orthopaedic surgery), in order to enable patients to decide which service route they would prefer.

#### **Secondary Care**

In the case of secondary care, the main discussion around forms of 'choice' were centred on those individual services which utilise a Patient Focussed Booking (PFB) system, whereby a patient was given a choice of appointment times and dates. There was general agreement that opportunities for patients to exercise choice and to choose between options were limited. Although the New Ways booking policy had introduced two reasonable offers of appointment, it was agreed that this was a relatively insignificant change against the push to streamline waiting times. In real terms the most meaningful choice that patients could exercise was whether to proceed to treatment or not; decisions on choice of treatment was in real terms decided by the specialist consultant. Secondary care, although acknowledging their expert knowledge base, appeared to view GP consultation as allowing a greater degree of 'choice' for the patient in terms of whether to treat or not and as providing alternatives to secondary care treatment. Choices then were mainly reducible to operational considerations, for example, to be seen at an out-reach clinic (where available) as opposed to centralised hospital setting and the date and time of appointment.

For those in secondary care, the current policy constraints regarding waiting time targets temper choices of how and where services were delivered. There appears to be a perceived pay-off between patients being given operational choice and meeting referral to treatment targets, as choice was seen as negatively impacting on waiting time targets by slowing down the patient pathway process. Secondary care professionals perceive their role as being directly involved in ensuring waiting time targets were met, which may or may not allow increased 'choice' options for patients.

Whilst there was not a strong policy drive to provide choice, practitioners and managers identified the main role of the organisation to be responsive to the needs of the patient more generally. The aspiration was to fit services around the lifestyles of the patient populations which were being served. For example, some out-of-hours clinics were provided. Although it was noted that these clinics were often initiated to ensure waiting time targets were met in the short term rather than to provide options for patients, it was highlighted that these clinics often had low DNA (Did Not Attend) rates and seemed to be viewed positively by patients, especially those who worked. There was a further perceived role for secondary care

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providers to provide local care, where operationally and functionally possible.

#### 4.4.4 Resources

The *New Ways* ('New Ways of Defining and Measuring Waiting Lists') waiting list policy was introduced in 31<sup>st</sup> December 2007 by the Scottish Government, to ensure that patients being referred were given a 'reasonable offer' of two different times of appointments.<sup>123</sup> In order to deliver this policy patient focused booking systems had been put in place. *SCI Gateway*, a centralised electronic booking system which allows a certain degree of choice of possible clinic sites and consultants via dropdown menus has been introduced as a means to improve the booking and transfer interface between primary-secondary care and in particular allowed attempts at reducing inefficiencies in the booking process which were previously inherent in the paper based system. At a local level, much organisational effort appeared to have gone into supporting electronic systems and protocols to speed up referral processing and reduce inefficiencies which were apparent within the paper system.

There were some noted resources which had been put in place to increase the responsiveness of services: the introduction of a *Scottish Regional Treatment Centre* (in one Health Board), an independent sector treatment sector designed in collaboration between the Health Board and an independent healthcare provider; changes to clinic delivery times, such as out-of-hours working; increased employment of Information Technology technical support staff to manage electronic referral pathways; and the increased need for appropriately designed software to deal with referrals and booking appointments.

# 4.5 Managing choice in Scotland – the administration of choice for ENT and orthopaedic patients

#### 4.5.1 Referral options (choice of provider)

In the main in both case studies, interviewees acknowledged that patients had very few options in terms of location of secondary care provision, mainly due to limited 'hard' resource (i.e. hospitals) and limited personnel. Both areas had only one main (tertiary) level hospital so there was limited 'choice' between sites of specialised care provision. Perversely it was suggested that those based within city areas had comparatively less 'choice' than those living in outlying areas because the latter could also access District General Hospital services for some specialties. GPs were supporters of local services and noted they would refer to more locally based outreach clinics, specifically to retain their provision (a 'use it or lose

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it' rational). There was the option to refer outside the Health Board area if seen as necessary (e.g. there was no specialist provision within the home Health Board), this would be negotiated in discuss within the appropriate Health Board Managers.

The options for orthopaedic patients were referral to the local secondary care services or referral to physiotherapy/osteopathy services. ENT patients were referred to the local secondary care services. Two example referral pathways are given in Figures 4 and 5.

HB 2: ENT Referral Pathway (90%) CHP 1: Patient screened and Consultant chosen based on clinical Time/Date URGENT Acute Hospital Central ENT CHP 2: Patient Referral sent directly [no Referral Medical administrative Clinician Records for appointment GATEWAY Service and Triage ROUTINE 18 Weeks RTT Non-ENT CHP 3: Patient appointme with GP Referral returns to location equested by GF GP Surgery Primary/Secondary Secondary

Figure 4. Example of Scottish ENT referral pathway

#### 4.5.2 Administration of referral options

#### **Primary Care**

Referrals were in the first instance raised by the primary care GP. The referral would then be processed by administrative support within the health centre, overseen usually by the Practice Manager. Referrals were increasingly being sent via a centralised electronic booking system, *SCI Gateway*, which allowed a certain degree of choice via drop-down menus of possible clinic sites and consultants. Some referrals were still sent in paper format although this was increasingly less common, however, it was still

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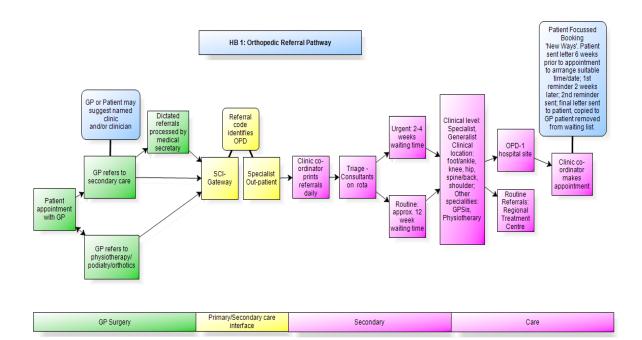


Figure 5. Example of Scottish orthopaedic referral pathway

Although it would appear that in process terms, there was a relatively straight forward protocol for referral, it become apparent that amongst the GPs interviewed, there was a great degree of confusion as to 'how to refer' (e.g. current codes noting urgency of referral), 'who to refer to' (e.g. consultants, clinics) and what happened after referral was picked up in secondary care. All staff commented that they were unclear about exactly what happened to a referral once it reached the centralised booking system and how decisions were made.

GPs were also unclear as to whether they would name a consultant or not. Some preferred to add in a name if they had some form of history or knowledge of that person, e.g. Consultant X does hands, Consultant Y does backs. Although admittedly they were moving away from naming a practitioner, there seemed to be a residual desire to maintain some form of control over where and by whom their patients were seen.

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#### Box 4.13: GP understandings of referral options

In the Heather area practice, GPs had strikingly disparate understandings of how referral systems work, and gave diametrically opposing statements on their referral practices. Some GPs claimed to refer to named individuals and specific clinics. In the case of one clinic, there were three different stories as to its current activity - it was now shut and no longer taking referrals; it was open for referrals; and one, don't know, maybe shut, may be open. The administrator and practice manager were clearer about the new system and tended to be the ones who ensured referrals were processed correctly.

#### **Interface services**

In the main referrals were sent directly from primary to secondary care. However one of the case study areas had introduced a *Virtual Referral Management Centre*, which was a centralised administrative service which receives all referrals for distribution. This did not function to offer referral options to patients, but its purpose was to streamline the referral process to ensure that referrals were sent to the correct speciality. In some cases referrals going through the Referral Management Care would be returned to the referrer or sent elsewhere if they were not suitable for secondary care.

#### Secondary care

There was a distinctly more unified understanding of how the referral system worked amongst secondary care interviewees than in primary care. The overriding concern in secondary care was to manage referrals within waiting time targets and choices were discussed in relation to this. The main referral choice offered in secondary care was the choice of appointment date and time. Staff were required to offer a patient two choices of date and time of outpatient appointment. If a patient rejected two choices their waiting list time was re-set. Alternatively the waiting time could be stopped in the case of holidays when the patient was unavailable.

There was a strong motivation to move away from naming a clinician as waiting time targets were adversely affected. More popular or well-established clinicians would have larger waiting lists than not so well-known or high profile practitioners. In order to flatten distributions, it was decided that the in-house disciplines were in the best position to review and distribute the referral to the most appropriate person. They could then make an informed judgement balancing the need for a high degree of subspecialism versus waiting time targets, for example, comparing non agerelated hip problems (needs high degree of sub-specialism) versus agerelated hip problems (does not high degree of sub-specialism). For those

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groups where a high degree of sub-specialism was unnecessary, they could then be added to the generic pool to reduce waiting time.

There was an assumption in secondary care that an option that patients wanted was that services were delivered as close to home as possible. However it was noted that this was difficult to achieve within the constraints of specialist resources, both hard resources such as scanners and soft resources such as consultant time.

#### **Box 4.14: Managing consultant workload Thistle**

Within surgery the Health Boards had to run outreach clinics less frequently than those located in the corridor where the majority of the population lived. More frequent outreach, consultant led clinics that enhance patient choice were seen to be economically unviable particularly when highly specialised (and paid) consultants had to spend huge proportions of their clinical time in the car travelling between rural clinics

#### 4.5.3 Impact of referral choices on service provision

There were some noted changes to service relating to the responsiveness agenda: changes to clinic delivery times, such as out-of-hours working; increased employment of IT technical support staff to manage electronic referral pathways; and the increased need for appropriately designed software to deal with referrals and booking appointments.

Service demand was often seen as the driver for service development. Changes in patient populations (such as increases in Diabetes Type 2 or an ageing demography), and development of treatment and care options, were seen to impact on how, when and where services were delivered. For example Diabetes being increasingly moved into primary care for monitoring and support, with associated clinical services, such as retinopathy and chiropody also being provided in out-reach. This was seen by practitioners and health service managers as a way of providing care locally for patients.

The move to sub-specialisation within the secondary and tertiary sector had also filtered down into primary care with one Heather area Health Board looking to recruit GP with special interests (GPwSIs). That is, GPs who could undertake certain procedures, for example, minor surgery, within their local area. Although arguably not directly motivated by any 'choice' agenda, it did have an implicit increased flexibility for patients in terms of where some services could be provided.

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#### 4.6 Shaping choice in Wales

#### 4.6.1 Case Study descriptions

#### **Box 4.15: Wales Case study Porth area**

Comprised of one secondary care provider (Appleton NHS Trust), one Local Health Board (commissioner) and one GP practice.

**Appleton Trust** was one of the largest in the UK with 16,000 staff covering a population of 600,000 in an urban setting with an annual budget of £770 million. The Trust has four major hospitals, 14 community hospitals, clinics and treatment centers with in-patient beds, and 46 community clinics and health centers, providing 2,800 beds. The present organisation was launched on 1st April, 2008, following a merger between two former Trusts. A new organisational structure had been introduced and a new management team was in place. However the patient administration systems (PAS) used by each Trust were incompatible which hindered further integration.

The **Local Health Board** was established as a statutory body in April 2003 to serve a population of 228,000 people. The community was served by 35 general medical practices, 48 dental practices, 61 pharmacy practices and 24 optometry practices.

The study **GP practice** consists of four GPs, one practice manager and administrative staff.

#### Box 4.16: Wales case study Draig area

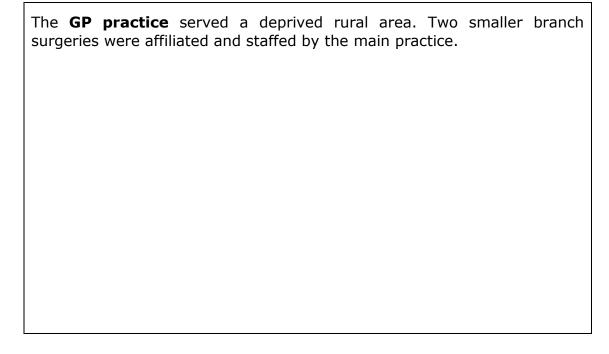
Comprised two NHS Trusts (urban, rural), one LHB and one GP practice.

The **Rural NHS Trust** was created on the 1st April 2008 following the integration of two previously autonomous Trusts; it comprised ten hospitals of which two were district general hospitals. The Trust had an operating income of over £300 million, employing 7,600 staff in total. The Trust delivered acute, intermediate, community and mental health services to a population of 330,000 residents in mainly a rural valley area. The Trust worked in partnership with four LHBs overall.

The **Urban NHS Trust** was one of the largest NHS Trusts in the UK and included eight constituent hospitals. It was the main tertiary referral point for Wales. The Trust provides health services for a population of around 500,000. In 2006/2007 the Trust's total income was £610m and it employed approximately 13,500 staff.

The **LHB** provided services to a population of 170,000 people in an area of high deprivation.

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#### 4.6.2 Definition of choices available at referral

Patient choice was not believed to be a relevant issue in the context of NHS Wales and interviewees saw patient and public involvement as the mechanism of ensuring the responsiveness of the Welsh NHS. Most interviewees felt that there was no equivalent of the English choice model in Wales, and indeed that effectively Wales had no choice policy. However patient and public involvement was a political priority and organisations were fully committed to undertaking consultation exercises and developing activities to engage and empower the public.

'Choice', where it was felt to exist within the referral pathway, was understood primarily in terms of micro choices. The choices identified which were open to patients included; choice of GP; choice to accept or decline specialist treatment or an onwards referral; choice of time and date of appointment; choice of consultant and choice to exit the NHS and enter the private health care system. Whilst there was no policy regarding the availability of these micro choices (with the exception of date and time of appointment) the understanding across the board was that individual patients were entitled to voice their preferences regarding hospital, treatment provided and other basic rights, including religious needs, gender preferences and that this wish should be met if possible.

Interviewees noted that a policy advocating choice of provider did not exist in Wales. An exception to this was the 'second offer scheme' in which patients had a choice to accept or decline treatment at a second hospital (in

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the main an English hospital or treatment centre) if they had waited an excessive amount of time for treatment at a local hospital.

It was also noted that due to recent Trust mergers, particularly in the Porth case study area, there were up to four different hospital sites within a single organisation, which created the opportunity for patients to attend a non-local site. Furthermore, it was noted that in some cases patients would be offered a choice of site when booking their secondary care appointment, if the consultant worked across more than one site. However, there was limited evidence of patients being offered a choice of site in practice in patient and staff level interviews, and in the main it was assumed by all parties that patients would be referred to their local site unless a condition required highly specialist treatment..

Treatment options were felt to exist but varied according to condition. Choice exists if a range of equivalent medical treatments are available for a specific condition and decisions are reached as part of the informed consent process beginning at the GP consultation and discussed at every stage of the pathway through secondary care. Informed consent was believed to form the backbone of all GP referrals based on good clinical practice.

More options were identified in low volume areas including maternity services where patients have the option to choose between a home birth, a mid-wife led service or a consultant led service, assuming no complications are expected. Choice was also offered at end of care, specifically choice of location of nursing home.

#### 4.6.3 Roles and responsibilities in relation to choice

When discussing their roles and responsibilities for choice most interviewees addressed the question on the understanding that choice does not exist in Wales as it does in England, as Wales has no 'choice' policy. Interviewees saw the equivalent responsiveness achieved in their roles and responsibilities for patient and public involvement activities.

#### **Local Health Boards**

Local Health Board staff understood their role to include responsibility for ensuring that the public and patients were engaged in the development and planning of health care services, to ensure clinically appropriate services were provided to meet the health care needs of the population, to arrange appropriate long-term service agreements and ensure quality of care was maintained where commissioning needs were identified, and to ensure services were efficient and cost effective. Issues of patient choice were not directly implicated in these core tasks, although it was noted that choice was provided through commissioning decisions.

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Local Health Board staff outlined their responsibility to provide detailed and accurate information to both patient and GP to ensure service providers and service users were informed of available treatments as they became available to the public. They believed they should ensure that patients were supported to make informed decisions about their care and were informed of developments in services and the community with the opportunity to engage in discussions.

#### **Primary Care**

Most GPs perceived they had limited responsibility to promote direct patient choice. GPs believed their role was to act in the best interests of the patient and guide them to the most appropriate services available. The GP was seen by all interviewees to have responsibility for advising on the best and most appropriate service available to patients, local or otherwise.

There was discrepancy in the perception of the extent to which GPs discussed treatment options with patients. The view from the Local Health Board was that GPs discussed with patients all the treatments routes and options available to them. Trust staff perceived that GPs had limited specialist knowledge of treatment options, supporting the view that secondary care staff led the way in outlining treatment options to patients.

#### **Secondary Care**

The view from the interviewees in secondary care Trusts was that staff had a responsibility to provide an elective service in a timely manner which was responsive to the needs of the individual and the service, to provide information and support to patients and ensure a safe journey through a care pathway whilst maintaining a balance between what was best for the community and the individual.

Interviewees perceived there was a requirement to ensure that the service was responsive to people's wishes and create a culture of service that enables this to be achieved. This responsiveness was generally framed within responsibilities for patient and public involvement rather than the delivery of choices for individuals. Choice within secondary care was seen to be limited by the resources available, particularly waiting times, and the difficulty of responding or adhering to patients' wishes to stop or alter treatment decisions once on a care pathway. However within these limits interviewees thought Trusts had a responsibility to talk to patients who were unhappy with the option they were given and make changes if possible.

#### 4.6.4 Resources

Interviewees reported that increased resources, administration staff and investment have been needed to achieve fully operational teams to

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implement the 'direct booking' systems which offer choice of date and time of appointment to patients. There was an increased financial cost associated with developing call centres and training staff, and asking staff to work longer hours.

## 4.6.5 Managing choice in Wales- the administration of choice for ENT and orthopaedic patients

#### Referral options (choice of provider)

There was general agreement across both case studies that patients wanted to be referred locally and a belief that people preferred treatment as near to home as possible. Historic referrals routes were followed across Wales, whereby patients were generally referred to their local provider. This was reflected in the long-term agreements that exist between Local Health Board and proximate provider Trusts in the local health economies. Patients may sometimes be referred to more distant providers in Wales, but typically only on the condition that a service is not available locally. Historically GPs in certain parts of a borough (on the edge) could refer to a Trust which was not within the Local Health Board boundaries. This typically occurs where another Trust is geographically closer to a GP practice, and in these circumstances long term agreements are often arranged between the Local Health Board and adjacent Trust. Referrals outside of Wales are usually declined by the Local Health Board.

Therefore the referral options for ENT and Orthopaedic patients within the case study areas consisted in the main of referral to their local hospital. In the Porth case study area the recent merger which formed the new Trust was believed by most to have increased choice for patients as more hospitals were included within the Trust. Two examples of patient referral pathways are given in Figures 6 and 7.

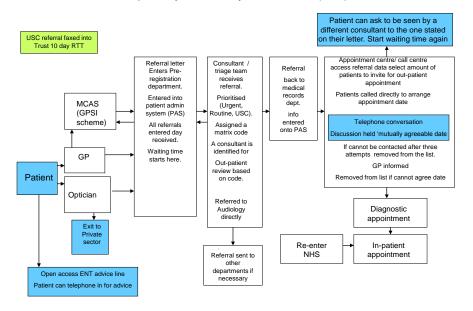
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Figure 6. Example of Welsh orthopaedic referral pathway

#### Referral pathway Case Study 1: NHS Trust (West) Orthopaedics Rules up to March 31st 2009 Component waits Patient can ask to be seen by a different consultant to the one state USC referral faxed into Trust 10 day RTT on their letter. Start waiting time again Referral letter Appointment centre/ call centre Consultant / Referral access referral data select amount of Enters Pretriage team registration receives referral. back to patients to invite for out-patient medical records dept. department. appointment and send letter. Entered into Prioritised Patient given a date and asked to ring to confirm / decline / re-schedule MCAS (Urgent, outine, USC). (GPSI system (PAS) info scheme) All referrals entered day received. entered onto PAS Discussion held 'mutually agreeable dat A consultant is identified for within 2 weeks or removed from the list Waiting time GΡ GP informed. Removed from list if Patient Out-patient cannot agree date GP informed can reinstate within 3 months review based on code. 17 consultants in dept inc physio-therapists Diagnostic appointment In-house physio service In-patient available ain NHS appointment some GP practices in the city Referral sent to other departments if necessary Discharged

Figure 7. Example of Welsh ENT referral pathway

Referral pathway Case Study 1: NHS Trust (East) ENT



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The Local Health Boards and providers had set up a number of triage teams in which a multi-disciplinary team assessed a referral and decided which route a patient could take (See Table 15). Triage teams were introduced as a means to reduce inefficiencies in the system and ensure only the most appropriate patients were accepted into secondary care. In the main these services were mandatory referral options consisting of musculo-skeletal triage teams which assess referrals from GPs to see if they were appropriate referrals for secondary care or whether they would benefit from physiotherapy. A further option had been put in place by one practice who provided their own physiotherapy service (See Box 4.17).

Table 15. Interface services in case studies

	ENT	Orthopedics
Porth area West	No GPwSI or triage	2 GPwSIs and 1 ESP
Porth area East	No GPwSI or triage	No GPwSI
Draig Urban Trust	No GPwSI or triage	1 GPwSI in community
Draig Rural Trust	No GPwSI or triage	No GPwSI

GPwsI - GP with Special Interest ESP - Extended Scope Practitioner

### **Box 4.17: In-house physiotherapy**

The GP practice which participated in the Porth area study had an inhouse physiotherapy team, to which GPs would refer their own patients for a short course of physiotherapy, prior to a referral into secondary care, when surgery was not thought to be necessary. The LHB have on a regular basis threatened to remove this service from the practice, on the grounds that they fund a physio-therapy service within the local secondary care Trust. However GP respondents favoured the in-house service because waiting lists at the practice were only two weeks.

### Administration of referral options

### **Primary Care**

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When a decision was made to refer for specialist care, a referral letter was dictated by the GP, typed up and posted by practice staff, or faxed if it was urgent. The decision to refer was described by interviewees as being made between the GP and the patient. GPs had the scope to refer to a variety of hospitals. In these cases, GPs would make a judgement in the best interest of their patients and stated that they usually followed traditional referral routes unless requested by a patient or if they were aware of a shorter waiting time.

The specific options available to patients when a referral was being made varied between Trusts and Local Health Boards, as each organisation worked independently to develop care pathways for the local area based on good practice guidance and Access 2009 guidance issued by the Welsh Assembly Government. In some instances referral templates for specific conditions have been introduced which dictate whether a referral can be made or not, for instance the Local Health Board and Trust stipulated that patients could not be referred for tonsillitis unless they have five episodes within one year. In such cases a tick box form was provided for referrals requesting specific information be supplied to the consultant. A less prescriptive approach was taken by one Trust who developed a hot line for GPs, manned by nurse practitioners for one hour a day, offering further information and advice prior to referral.

GPs identified choice of consultant as a potential option when the referral was being made, however some referrers were uncertain whether a named referrals were honoured by providers once they reached secondary care.

### **Secondary care**

When referral letters were received by providers they generally followed the same pathway of being centrally received into Trusts. In the Porth area case study, the main Trust uses two mechanisms, dependent on purchaser, to filter orthopaedics referrals – a referral management centre based in the Trust rheumatology department and a system based on triage by GPSIs. Neither case study area has a referral management system for ENT referrals.

Interviewees identified a number of areas in which Trusts have the potential to reverse choices which were made earlier in the referral pathway. Referrals can be sent back to the community triage team by the Referral Management Centre for further investigation and removed from the waiting list. Trusts have the ability to decline a referral from outside of their local area and return the patient to the appropriate Local Health Board. Similarly a GP could indicate urgent or routine on their referral letter but the referral could be down-graded or up-graded by a consultant according to their prioritisation criteria. The introduction of 'pooled waiting lists' was another measure used to manage referrals entering secondary

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care. Referrals to named consultants were not encouraged by Trusts and Local Health Boards and referrals were made to a department not an individual consultant in an attempt to manage waiting lists and distribute work load evenly. If a GP refers a patient to a specific consultant the referral will be 'pooled' when it enters the Trust and will, in the main, only be allocated to that consultant if this was deemed appropriate at Trust level (for example, to ensure on-going treatment by one consultant, or based on previous treatment by a consultant). Patients may request to be seen by a particular consultant and where possible staff indicated this would be respected.

It was possible to override decisions made at this stage, at a later stage to respond to patient wishes (See Box 4.18). For example one manager had authority to change a consultant code allocated to a patient in the IT system which allowed clerks the opportunity to offer the patient the option of appointments on alternative dates with a different clinician. However the ability of any given individual to offer such choices was understood to be affected by limited provider capacity and increasing demand.

### **Box 4.18: Management of referrals into providers**

The Urban Trust in the Draig area case study was the main tertiary referral centre for Wales, so referrals were accepted from 16 out of the 22 LHBs. Trust staff reported that recently some patients have been refused entry to the Trust prior to first appointment and returned to their local Trust due to limited capacity. These decisions were made by management staff at departmental level in an attempt to achieve Access 2009 targets (the Welsh Assembly Government's initiative to reduce waiting times to acceptable levels by late 2009).

Staff interviewed reported that patients can have a choice of site within Trusts if the relevant consultant runs clinics at more than one site. Staff would normally explain the site/consultant options to the patient before looking for appropriate dates.

Trust interviewees complained that as the efficiency of the system has grown through mechanisms such as improved referral pathways workload has also increased. However the system was not rewarded for higher output, unlike the situation in England under Payment by Results. Several interviewees pointed out that there was no benefit to staff or the Trust in increasing workload beyond the level necessary to meet Access 2009 targets.

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A variety of booking methods were in operation in the case studies. Trusts operated either full or partial booking, both of which were introduced to offer patients choice of date and time of appointment. Interviewees reported that increased resources, administration staff and investment have been needed to achieve fully operational teams. Partial and direct booking were believed by all interviewees to be an attempt to reduce the number of patients who did not attend their appointment and maximise the capacity of the hospital to meet waiting time targets whilst attempting to be responsive to individual patient needs. Partial booking and direct booking offer some degree of choice to patients around the date and time of appointment (See Boxes 4.18 and 4.19).

### **Box 4.19: Partial booking process**

The Trust sends a letter to the patient informing them of a date and time for their appointment, with the opportunity to accept, decline or reschedule. Rescheduling of appointments is undertaken via a telephone conversation and a mutually convenient time and date must be agreed for both the patient and the Trust. In some instances a patient must ring to accept their appointment date, failure to do so means that they are removed from the waiting list.

### **Box 4.20: Direct booking process**

Direct booking was believed to be more patient centred and responsive to patient needs. All appointments are booked through a telephone conversation in which a mutually acceptable date is arranged between the call centre staff and the patient. Patients receive a letter asking them to call a number and book their appointment.

A key element of these new booking systems which offered patients choice of appointment time and dates was the definition of the limits of choice available, within the national definition of reasonableness. In this case the Welsh Assembly Government has defined a reasonable offer as the offer of at least two appointments made 15 days in advance. Various rules were in existence which governed the relationship between choice and waiting time, for instance if a patient chooses a different consultant or hospital from the one initially allocated, the waiting time re-starts.

Other rules within the booking system limited the time patients had to call the provider to make their appointment, for instance if a patient did not respond to the letter within 10 days the Trust sends a letter advising them that they have been removed from the waiting list (see example in Box

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4.21). Whilst the patient can be reinstated for up to 3 months after this if the patient or the GP contact the hospital, this policy was of particular concern to GPs, who believed that patients were being unfairly removed from the outpatient waiting lists to keep referral numbers down, and gave examples of patients who had not understood the appointments letter, or had been discharged whilst they were on holiday.

### Box 4.21: Example of booking process - Porth area case study

Patients are telephoned by call centre staff to arrange an appointment date. Two attempts are made, one during office hours and a second out side of office hours if the patient cannot be reached then a letter is sent to the patient asking them to ring in to arrange an appointment. If not reached within 6 weeks they are removed from the waiting list. When the patient is called the clerk and the patient negotiate a date between them based on the available slots. The later the patient calls the fewer slots will be available to choose from. If a date cannot be agreed, the Trust can remove the patient from the waiting list.

### 4.6.6 Impact of offering choice on service provision

The drive to reduce waiting times for appointments had led to the provision of more out-of-hours clinics, which enable providers to maximise capacity within the service, and also as a by-product resulted in a service which offered more choice of a variety of appointment time to patients.

## 4.7 Shaping choice in Northern Ireland

### 4.7.1 Case study descriptions

In November 2005, the major restructuring of health and social care in Northern Ireland began under the Review of Public Administration (RPA). During the first phase, in April 2007, five new integrated Health and Social Care Trusts were created to replace eighteen previous Trusts. During this study the second and final phase of structural reform took place. Since 1<sup>st</sup> April 2009, the newly formed organisations replace a number of previous Health and Social Care bodies:

**Health and Social Care Board** (HSCB) – The single Health and Social Care Board replaces the previous four Health and Social Services Boards. The HSC Board will focus on commissioning, resource management and performance management and improvement. The HSC Board will identify

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and meet the needs of the local population through five Local Commissioning Groups which were co-terminus with the Trusts.

**Local Commissioning Groups** (LCGs) - LLCGs have been established with the aim of devolving the role of commissioning – with the necessary finance and decision making and a bottom-up approach. The LCGs members include local politicians, GP's, voluntary representatives, public health medicine professionals, the public and council representatives in determining local need.

**Public Health Agency** (PHA) – The PHA will incorporate the work of the Health Promotion Agency but will have wider responsibility for health protection and screening and health improvement.

**Business Services Organisation** (BSO) – The BSO will provide a range of support functions for the whole of the health and social care and will replace the Central Services Agency.

**Patient and Client Council** (PCC) – The single PCC replaces the previous four Health and Social Services Councils with five local offices co-terminus with the Trusts.

### Box 4.22: Park Area - Case Study 1

Park Area includes a Health and Social Care Trust which was formed by the merger of six smaller Trusts on 1st April 2007. The Trust provides services for more than 340,000 people and is one of the largest Trusts in the UK.

### Box 4.23: Borough Area - Case Study 2

Borough Area includes a Health and Social Care Trust which was formed by the merger of three former Trusts on 1st April 2007. The Trust covers five local council areas and provides health and social care services to around 290,000 people across 17 per cent of the Northern Ireland geographic landmass.

### 4.7.2 Definition of choices available during referral

At the organisational level choice was considered to be very limited for patients in Northern Ireland. The common response to questions regarding patient choice was that there was no patient choice policy in Northern

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Ireland and no specific policy documents that related to patient choice. Patient choice policy based on the 'English model' was seen to be irrelevant to the majority of patients in Northern Ireland and a policy favoured by those supportive of a market style health service. This was not to say that patient choice was not considered important by interviewees, who identified a different conception of choice which was relevant to Northern Ireland.

The areas where it was believed patients have real choice was in choosing their GP, giving their consent to treatment and the choice to get a second opinion. Constant reference was made to the issue of waiting time targets during discussions about choice. The frequency with which waiting times emerged during interviews reflects the stringency by which the Department of Health implements the waiting time directive and the significance it holds for health service managers and clinicians. The dramatic reduction in waiting times, in some cases from 4 or 5 years to 9 weeks, dominated all interviews. The reduction of waiting times in Northern Ireland, following the Review of Public Administration, was explicitly associated with giving patients greater choice. The overriding belief was that being on a waiting list for a long time gives no one a choice of anything, and that waiting times had to be reduced before the options available to patients during the referral pathway could be expanded. Any reference to choice of provider was specifically associated with English policy and seen as having little or no relevance in Northern Ireland. Interviewees explained how Northern Ireland was a small region and often there will only be one place to go, particularly if it was for a specialty or serious condition.

Interviewees identified a set of choices which were available to patient such as a choice of GP, being able to consent to treatment, having a choice regarding date and time of appointment and the availability of extended clinic times. The introduction of the 'partial booking' system to outpatient appointments which gave patients choice of date and time of appointment was seen by many as a key way in which patient choice had been introduced to the booking process.

These choices were seen as limited by the Review of Public Administration (RPA), and the reduction in waiting times which was central to its reform programme. The drive to reduce waiting times has resulted in a range of specific policies being introduced to ensure patients were seen as quickly as possible and their waiting time reduced, and in some cases this had limited choices available to patients, such as the choice of being referred to a specific consultant.

Choice of treatment was described as a continuum, happening at different stages along the referral process. Interviewees agreed that in most cases choice of treatment would take the form of a discussion between the patient and the GP with specific treatment choices being discussed at a

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later stage between the consultant and the patient. The belief was that generally patients expected their GP to have expert knowledge and will be guided by their GP.

### 4.7.3 Roles and responsibilities in relation to choice

### **Commissioning organisations**

Interviewees were very aware that offering patient choice must be balanced against other commissioning agendas. Constant reference was made to the government imperative to deliver on the waiting time targets set out in *Priorities for Action 2008-2009* and the importance of meeting these targets. <sup>124</sup> Interviewees from the commissioning organisations believed their responsibility for offering choices was first and foremost a quality issue - to provide support to the Trusts to ensure the delivery of safe, quality services within stipulated waiting times.

### **Primary care**

There was limited data available about GPs perception of their roles and responsibility in delivering choice to patients as only one GP was interviewed for this study. However the following is based on the perception of other interviewees of the role of the GP. The general belief of interviewees was that informal discussions regarding referral options take place between patients and their GP, and the GP will listen to the patient and accommodate the patient wishes if possible and if clinically appropriate. It was noted that the extent and nature of these discussions were very much led by the patient rather than the GP. Most respondents believed that patients put their trust in their GP and want to be guided by them.

It was also noted by interviewees that GPs capacity to offer choices to patients who were being referred had diminished following the introduction of referral pathways (such as mandatory referrals to clinical triage services) and the need to streamline the referral process to meet waiting time targets. Interviewees commented that GPs subsequently had less control over who their patients see and patients cannot ask to be referred to specific consultants.

### Secondary care

Interviewees from the Trusts discussed their responsibility in terms of providing a safe and quality service to patients and ensuring that robust consent procedures were in place. Most, but not all, interviewees were aware of a responsibility to involve patients and their carers in the strategic development of services. However, the overwhelming responsibility was seen as implementing government policy on waiting time targets. The Trust must prove to the Department of Health and the Board that they were meeting these targets and have to apply rigorous patient access policies to

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make sure these targets are met. Specific protocols for the effective management of outpatient, diagnostic and inpatient waiting lists are set out in *Integrated Elective Access Protocol*.<sup>125</sup> This emphasis on waiting times resulted in a lack of flexibility to offer choice. However, the Trusts also aspired to be flexible enough to accommodate a patient who may have a particular problem, for example if a patient had a bad experience with a particular consultant and specifically requested that they see an alternative consultant the request would be met if another consultant was available.

### **Patient representation organisations**

When discussing their role in relation to offering choices, interviewees from patient representative organisations (Health and Social Services Councils) spoke about their responsibility to inform and educate patients about what they should expect from the health service, such as raising public awareness of patient entitlements like the waiting time targets. The Health and Social Services Councils often deal with complaints from patients and they see their role as helping patients assert their right to treatment. According to our interviewees, patient choice needs to be acknowledged but a patient's right to experience choice must be balanced with a responsibility of knowing the limitations of choice. Therefore, the Council see their responsibility for choice as primarily one of ensuring patients have enough information to make an informed choice, this includes information on hospital hygiene.

### 4.7.4 Resources

The main resources which were identified associated with delivering options to patients during the referral process were associated with the system of Partial Booking which had been introduced to offer patients a choice of date and time of their appointment. Partial Booking was reliant on increased administrative procedures and requires greater numbers of clerical and administrative staff to carry it out.

# 4.8 Managing choice in Northern Ireland— the administration of choice for ENT and orthopaedic patients

### 4.8.1 Referral options (Choice of provider)

The general belief was that people accepted that if the service was provided in their locality, then that was where they would go. However, it was noted that it was possible, although unusual, for a patient to request a referral to a specific provider and that the request would be considered and the patient accommodated if possible through an Extra Contractual Referral.

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The main referral option for patients requiring an ENT appointment within secondary care was the local Trust. In addition to referral straight into secondary care, Integrated Clinical Assessment and Treatment Services (ICATS) had recently been introduced. All orthopaedic referrals were sent directly to ICATS for assessment and triage, with the exception of emergency, consultant to consultant referrals and paediatric referrals. The role of ICATS was to triage patients before entry to secondary care to ensure only patients who absolutely need to see a consultant will do so. All interviewees were aware of the ICATS system and all linked the introduction of ICATS with the drive to reduce waiting time lists. This was seen by most people as a mandatory referral option for orthopaedics, and most interviewees agreed that the introduction of ICATs services meant that patients do not have a lot of control over which provider they were referred to and neither does their GP. Whilst Orthopaedics was the only condition that had an ICATS service, an ENT ICATS was in the process of implementation. Two example referral pathways are given below in Figures 8 and 9.

### 4.8.2 Administration of referral options

### **Primary care**

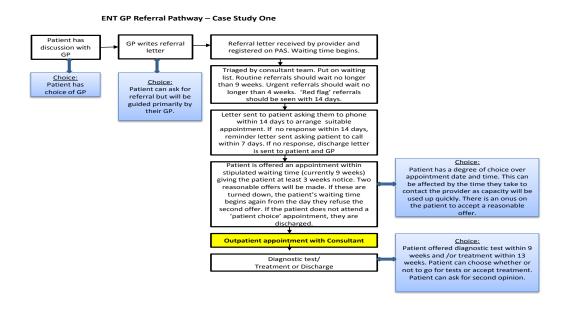
If a decision was made to refer to orthopaedics, the GP would normally make an automatic referral to the closest ICATS service. Whilst this was seen as a mandatory referral pathway by GPs, there was an option for a patient to exercise a degree of choice of provider if they specifically did not want to be seen by ICATS. The ICATs manager highlighted that it was possible for patients and GPs to choose to bypass the ICATs service (see box 4.24 below). However this option was not mentioned by any of the referrers interviewed for this study. Similarly, whilst referral to ICATS was postcode driven, there was an option for a patient to specify which clinic they wished to go to for their initial assessment if they feel strongly about it. GPs also understood that they should not make referrals to specific consultants but instead should refer to services, and the general view was that patients could not make a choice of consultant.

### Box 4.24: Administration of option for bypassing ICATS

There is a 'Strong Preference Not For ICATS' box on the referral letter which the patient can choose if they wish. If this box has been ticked or if the referral is an emergency, the referral will bypass ICATS and go straight to the consultant. If this box is not ticked, it's managed by ICATS. However, this practice is not encouraged and does not appear to be widely known. The only respondent who made reference to this option was an ICATS manager.

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Figure 8. Example of Northern Ireland ENT referral pathway



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Orthopaedic GP Referral Pathway - Case Study One Choice: Patient offered Patient has Hospital Registration Office Diagnostic test/ diagnostic test within 9 weeks and GP writes referral receives referral. Identifies Treatment or Discharge ICATS/non ICATS within 24 hours /or treatment within 13 weeks. Patient Outpatient booking with can choose whether ICATS referral Non ICATS Choice: Choice or not to go for tests Patient has choice to logged onto Patient has or accept treatment Patient can ask for logged onto express a prefere ERMS. choice of GP. PAS. Waiting Choice not for ICATS. Waiting time Has choice to go Patients will be offered an appointment within the second opinion. time begins practice is not stipulated waiting time (9 ncouraged and Referral is picked up by the weeks). Two reasonable offers does not appear to of appointment will be made giving at least 3 weeks notice. appropriate ICATS team, according be widely known to the patient's postcode, for If these are turned down, patient's waiting time is recalculated from date second offer was declined triage outcome Discharge -ICATS Discharge to Diagnostics Return to GP Outpatients appointment other service Choice: Patient is offered appointment within waiting time guarantee. Two reasonable offers of appointment times will be made giving at least 3 weeks notice. If these are refused, waiting time is recalculated from the date the second offer was declined. Patients can choose whether or not to go for tests or to accept treatment. Patient can ask for a second opinion.

Figure 9. Example of Northern Ireland orthopaedic referral pathway

### **Interface services**

If resolved, patient is discharged

ICATS referrals were clinically assessed by the ICATS team. The patient will either be sent for diagnostics or referred to other services, be managed by the ICATS team or discharged to return to their GP with advice. If treatment was required by the ICATS team, the treatment could be provided in a health centre or in the new 'Wellbeing Centres' so a patient has a choice here, although they will routinely be directed to the one closest to home or most appropriate. However, it was noted that as waiting lists have reduced and targets have got even tighter, choice at this micro level was becoming increasingly difficult to offer as the onus was on getting people seen quickly, ICATS cannot afford to have clinics backed up with patients wanting to wait for specific locations. Only those patients that require seeing a consultant will be forwarded on to a consultant outpatient list.

### **Secondary care**

Once a referral has been made to secondary care the administration of referrals involves a number of possible choices for patients. However, some of the existing choices were under pressure as waiting time targets become more rigorous. Mechanisms introduced to bring down waiting time lists such as patient access policy, pooled referrals into a service, and the introduction of ICATS all constrain choice. It was felt that the introduction

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of more stringent waiting time targets had lessened the ability of providers of services to offer options to patients, as queues needed to be managed more carefully, for example GPs can no longer refer to a named consultant and must refer to a service.

The hospital operates a partial booking appointments process, and writes out to the patient advising of expected waiting time, inviting them to phone to arrange a suitable time and date for an appointment. Two reasonable offers of appointment time and date will be offered giving the patient at least 3 weeks' notice. Reasonable was nationally defined by the Department of Health, Social Services and Public Safety as 'an offer of appointment, irrespective of provider, that gives the patient a minimum of three weeks' notice and two appointments'. It was noted that the scope of choice of appointment available to patients was often dependent on when a patient rang the appointment line, with those phoning most quickly after receipt of their appointment letter having the broadest choice of available appointment slots (See Box 4.25)

### Box 4.25: Slot availability -Park area case study

Administrative staff noted that the first one or two hundred patients to phone the appointment line will have a lot of choice but once these slots get filled, availability decreases. Those patients who telephone to make their appointment later will have less appointment dates and times to choose from. The focus then will be on finding an appointment that gives the patient three weeks' notice although this is not always possible. Some patients will be contacted and asked if they will take a cancellation if one becomes available.

Providers outlined a number of rules which were nationally set, which allowed them to reset a patients waiting time if reasonable offers were refused by patients, or if patients cancelled appointments. It was noted that if a patient requests an appointment beyond the waiting time guarantee, the patient will be discharged and told to revisit their GP when they were ready to be seen.

During interviews it emerged that some discretion can be used if short periods of time were involved (see examples in Box 4.26). If a patient rings up to cancel their appointment, they will be given a second opportunity to book an appointment which should be within six weeks of the original appointment date. If a second appointment was cancelled, the patient would not normally be offered a third opportunity and will be referred back

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to their referring clinician. A clinician can ask for a patient to be given a second appointment and that appointment will be booked.

### Box 4.26: Referral and follow up appointments

A respondent in Borough area said a number of consultants had made written complaints about perceived risks to review patients. The belief is that the imperative to maintain waiting time targets for outpatient appointments is impacting negatively on patients who need to be reviewed.

In one appointment centre in the Park case study area, choice of appointment date and time is only offered to new patients. The Trust is trying to get a partial booking system for review cases but they don't have the staff to deal with the number of calls.

### 4.9 Conclusion

This section summarises the findings of the organisational research against the first three objectives outlined in the meso section of the methodology chapter (see p32). A discussion of the impact of the delivery of patient choice on government objectives for choice policy can be found in Chapter 6. The final objective relates to the production of data to allow comparison of the operationalisation and impact of choice policy between case study sites and countries and therefore does not require discussion.

## 4.9.1 Operationalisation of choice at point of referral policy in England, Scotland, Northern Ireland and Wales

As might be expected, organisations and staff in the English NHS articulated a different understanding of patient choice to their counterparts in Scotland, Wales and Northern Ireland, which reflected the policy differences between the countries. However despite the differing policy stances concerning choice, the referral systems which deliver choices to patients share a number of similarities. Whilst the organisational interviews in Scotland, Northern Ireland and Wales generally reflected the hostility to choice of provider policy that existed in policy terms, it was apparent that all systems aspired to offer as many choices as possible to patients, including offering a choice of provider where possible.

All countries identified a standard subset of referral choices apart from choice of provider which were potentially available within the referral pathway. This consisted of choice of treatment, choice of appointment date

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and time, choice of location of appointment and choice of consultant. All countries were unified in adopting formal policies to offer choice of date and time of appointment to patients.

In all countries the availability of options was strongly shaped by the need to ensure that waiting time targets were met. It appeared that the resource cost of providing choice to patients during the referral pathway both in terms of the extra administrative resources required, and the strain put on the fixed resources such as consultant time meant that for many interviewees, even in England where choice was a prominent policy, the offering of choices to patients as they were being referred was simply not an operational priority.

In terms of referral options which were available, England had many more potential choices of providers than Scotland, Northern Ireland and Wales, where choice of provider was mainly limited to automatic referral to the nearest provider. However it is worth noting that there was some scepticism in the English organisations about how meaningful choice of provider was for patients due to the distribution of hard resources (i.e. choice of provider was limited to some extent by the same geographical layout as the other countries although efforts had been made to open up the provision of services to private sector and not for profit providers). Interviewees in Scotland, Wales and England cited the tendency of patients and GPs to 'support your local' as typical referral behaviour. Whilst Scotland, Northern Ireland and Wales distanced themselves from the delivery of choice of provider it was not strictly true that choice of provider did not exist in these countries, and it was noted that a preference would be honoured if it was brought up. The difference therefore was in the way this choice was delivered to patients.

## 4.9.2 Organisational structures and processes supporting choice in England, Scotland, Northern Ireland and Wales

All countries identified various interface services which had been set up to manage referrals before they entered secondary care. These services consisted of both clinical and administrative triage. The driver for the establishment of interface services was in the main the demand management of referrals, to ensure that only those patients who absolutely required secondary care took a secondary care appointment. However in England these services were in some cases associated with the delivery of choice to patients, namely that they had been set up to ensure that orthopaedic choices were offered in the same way to all patients.

Booking systems for secondary care appointments were immensely important in the discussion of choices. All countries had a degree of formalisation around the booking of appointments, and booking systems

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which offered a choice of date and time of appointment were prevalent in Scotland, Wales and Northern Ireland.

However whilst these booking systems offered a degree of parity in the way referrals were made and the way choices were offered to patients, it was also the case that there was often a lack of a consistent approach to offering choices to patients within the booking systems. The administration of each system had an impact on the choices that were offered to patients. For instance it was noted that booking systems which invited patients to phone for an appointment upon receipt of a letter, led to the allocation of appointments on a first come first served basis, with those phoning early having the best choice of appointments. It was often noted that a mixture of booking systems were in operation, and again, this led to potential differences in the choices offered to patients. In the case of England various booking systems meant that there were a number of different advice sources for patients. For instance patients booking over the internet would have a free choice of appointments from the menu available, and those booking over the phone with a provider would be offered one appointment at a time.

In all countries, the choices available to patients often depended on the referrers' understandings of choice availability, and in some case the GPs interviewed expressed confusion about the referral options that were open to them and their patients. In Scotland, Wales and England referrers said they were uncertain about referral options which were available, most commonly whether referral pathways were mandatory or optional. That this confusion existed in England, where the referral options have been formalised into an electronic menu was perhaps surprising, however, the confusion can at least partly be explained by GPs not knowing their way round the system effectively, and not being aware of the options for appointments which were available. Moreover, whilst referral choices, particularly in terms of English choice of provider policy, were often imagined to be located with the GP, our data showed a variety of other points at which referral choices were potentially available to patients, most notably through interface services between primary and secondary care.

A key difference between England and the other countries was the Choose and Book system, which was the high profile 'face' of choice policy in England, which in addition to formalising the choice of provider, also offered the opportunity for patients or their referrers to directly book into the hospital appointment of their choice. However, the use of an electronic booking system was not as alien in other countries as it was assumed, for instance in Scotland reference was made to the SCI Gateway system which allowed electronic booking of appointments.

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## 4.9.3 Impact of patient choice on the organisation and delivery of health care services in each country

Booking systems functioned to offer choices to patients, but also were important in defining the limits of choice and what could reasonably be expected to be offered to patients. In general the priority for those involved in allocating appointments to patients appeared to be the achievement of waiting time targets, and it was commonly felt that this was in tension with the requirement or desire to offer options to patients during the referral process. The booking procedures which delivered referral choices to patients were also used by service providers to control resources. A common feature of the systems which offered choices to patients was that they functioned as mechanisms to define and thereby limit choices in order to allow queues to be effectively managed, whether this was by limiting the options open to patients on the Choose and Book menu, or by restarting patients' outpatient waiting times when patients had rejected a 'reasonable' offer. All systems put the onus on patients to contact the provider to make the appointment rather than automatically allocating appointments. Indeed, many interviewees saw the key benefit of booking systems which offered choice of date and time and the driver for their adoption, to be their effectiveness in reducing the number of patients who did not attend their outpatient appointments rather than the opportunity to offer choice to patients. The view extended to Choose and Book in England which was seen to in some cases to work to reduce the scope of choices for patients. Interestingly the use of defined choice menus within the Choose and Book system had given providers the opportunity, which many of them appeared to take, to only give the option of referring to a specialist team rather than a specific consultant.

In other cases a similar management of choice availability was achieved by only reactively offering choices to those patients who asked for a specific option, or often, in the case of referrals to a named consultant, not honouring the choice that had been made when allocating referrals within the consultant teams.

In general terms patient choice was felt to be an important factor in the shaping of health services. Interviewees from Wales and Scotland felt strongly that this was achieved through the involvement of patients and the public more collectively in the planning and redesign of services. Interviewees in England tended to see patient choice as having a strong cultural impact on their organisations, which had embedded the need to attend to the wishes of patients throughout the business of the organisation.. From the analysis of the interviews which were conducted, and the quantitative data which were made available to us, it appeared there was little evidence that patient flows had changed as a result of choice at referral policy. However the Herfindahl-Hirschmann indices of the

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market position of the organisations provided by Professor Carol Propper of Imperial College, London suggest that in fact all the NHS trusts within our case studies have been subject to more competition over the period 2003/04 to 2007/08.

Therefore whilst organisations did not report experiencing a significant financial or operational impact as a result of choice of provider policy, it may be that they were not sensitised to changes that were taking place.

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Table 16. A comparison of choices and referral systems across the UK

	England	Scotland	Wales	Northern Ireland	
Choices					
Provider	Yes	No (Exception basis only)  No (Exception basis only)		No (Exception basis only)	
Consultant	At providers discretion	At providers discretion	At providers discretion	No	
Time/date	Yes	Yes	Yes	Yes	
Site	At providers discretion	At providers discretion	At providers discretion	At providers discretion	
Referral system	ıs				
Waiting times	18 week referral to treatment target in operation	18 week referral to treatment target to be reached by 2010	26 week referral to treatment target to be reached by 2010	9 week outpatient waiting time target. 13 week target for operations.	
Clinical triage services orthopaedics	Yes	No	Yes	Yes	
Clinical triage services ENT	No	No	No	No	
Administrative triage	Yes (1 case study)	Yes (1 case study)	Yes	No	
Electronic booking systems	Yes	Partial	No	No	

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# 5 Patients' experiences of choice in the context of referrals to specialists

### 5.1 Micro Level

This chapter reports on the 'micro-level' study of how patients understand, experience, exercise and value choice relating to secondary care provision. The methods are described in chapter two. Here, after a brief description of our response rate and sample, we summarise participants' accounts of their referral to specialist health services, focusing especially on options relating to whether, why, where, with whom and for when specialist appointments were made. We present material relating to discussions with general practitioners before material relating to communication with specialist services. We then look at how participants understood - and whether and how they valued - issues relating to choice, including the adequacy of options, attention to their views, and other aspects of involvement in the referral process.

Within each of the four countries, participants reported a range of experiences and evaluations. Since there was a lack of consistency of patient experience within countries and the types of choice-related issue were broadly similar for each, we present our findings as from 'across' the four countries, noting country-specific variations where appropriate.

The chapter contains boxed summaries of the referral stories of 12 patients. We selected these stories to illustrate something of the range of issues relating to choice that participants reported experiencing. We have presented summary versions of 'whole' stories, rather than 'fragments' of data that illustrate particular analytic themes because we think these more helpfully convey the variability of patient experience and the complex reality of issues relating to 'choice'. We have used each story to illustrate several issues, so references from the text may be to boxed summaries several pages away. The names are pseudonyms.

## 5.2 Response rate and sample

Some of the practices that recruited patients were unable to provide accurate records of how many people they sent recruitment packs to. We therefore cannot say what proportion of those invited 'opted in' to be contacted by the research team. Our experience, however, was that recruitment was slow (especially for ENT).

### Table 17. Numbers of participants by country and specialty:

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Country	ENT	Orthopaedics	Total
(number of			
practices)			
England (3)	9	24	33
Northern Ireland (2)	7	12	19
Scotland (2)	9	14	23
Wales (2)	8	16	24
Totals	33	66	99

Participants included 34 men and 65 women, 3 of whom were aged 16-29, 42 aged 30-59 and 54 aged 60 years or older. The sample included people with diverse ear/nose/throat and bone problems. Their index referrals (the referrals that triggered the sending of invitations to participate in this study) had been for diverse complaints, including persistent sore throats, blocked sinuses, hearing loss, ringing in ears, and lumps in the neck for ENT, and bunions, carpal tunnel syndrome, and swelling or pain in various bones and joints for orthopaedics. Participants had had the problems for which they were referred for different lengths of time and their familiarity with their (probable) diagnoses and management options varied.

Almost two thirds (62/99) of participants said they had consulted the referring GP about the problem they were referred for at least once before the consultation in which the referral was made or agreed. About half (45/99) reported having previously consulted other professionals about the problem (including acupuncturists, other GPs, physiotherapists, practice nurses, consultants). In all, 73/99 reported at least one consultation about the problem before the consultation in which the referral was agreed or made.

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# 5.3 The first phase: discussions with general practitioners

### 5.3.1 'Choice' about whether, why and when to be referred

Although the interview guide was designed primarily to explore the implications of policies relating to choices about referrals to secondary care providers that seemed to relate primarily to which providers patients might be referred to and when and where their appointments would be, participants' accounts of their experiences of referral often raised issues relating to (absence or presence of) choice about whether, why and when GPs made referrals. They recognised that GPs controlled access to many specialist services, and knew they could not simply choose to go to any specialist for any problem at any time. Participants' accounts suggested that referrals in practice reflected varying levels of agreement between GPs and patients about whether, why and when they were appropriate.

Most people (75/99) said it had been their GP who first suggested a referral might be appropriate, and 20/99 reported that they had initiated the referral. Some of these, however, commented that they found this question hard to answer, especially if they had considered the possibility of referral over a period of time. Referrals had varied objectives. In some cases, GPs (and/or patients) were confident about the nature of the problem and sought a particular kind of intervention that was only available from specialists (e.g. osteopathy or joint replacement surgery). In others, they sought clarification about the nature and/or extent of the patient's problem (e.g. via an MRI scan, or a comprehensive hearing assessment), and/or a second (specialist) opinion about how a problem should be managed. Patients' reasons for seeking referrals not suggested by GPs included wanting to establish a relationship with a new specialist after moving home (Box 5.1), or to switch treatment to the NHS from the private sector (Box 5.2).

### Box 5.1

Sarah had significant deafness in one ear. After moving home, she asked a GP to make a referral so she could establish a relationship with a local specialist. In the consultation, the GP refused to do this, disputing Sarah's assessment of her deafness. However, Sarah was insistent, and was told subsequently by the practice that the GP had checked her notes and agreed to refer her. When Sarah received a letter offering a specialist appointment, she realised that the hospital she had been referred to was about an hour from home and in the opposite direction from her workplace. (She reflected in her interview that a choice of appointment locations could be useful for people who live and work in different places). She was given a say about the date and time of her appointment.

Sarah did not think the GP involved her adequately in the referral process, but

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noted that there was a sense in which she had been involved anyway because she had initiated and insisted on the referral. Her main suggestion for improving the referral system was that GPs should believe their patients and be sensitive to their needs.

(Wales, age 16-29)

### Box 5.2

John had longstanding back problems. He had been paying privately for osteopathy and went to his GP to try to get NHS treatment. The GP suggested painkillers or physiotherapy, but John declined these and specifically requested a referral to an osteopath. John thought the GP seemed unwilling, but said he did listen to him and did agree to make a referral. The GP suggested the most local osteopath, but when they discussed the likely waiting time, John said he did not mind travelling and asked to be referred to another osteopath with a shorter waiting list. John was subsequently disappointed to discover that the referral only covered five appointments. At the time of interview, he was planning to return to his GP to request a re-referral.

John thought that osteopathy was not advertised as an option on the NHS, and that he had had to push his GP for a referral "because it obviously cost them more money". He suggested that referral systems would be better if GPs were more forthcoming about options such as osteopathy. John felt involved in the referral decision because he asked for what he wanted. (England, age 30-59)

None of the participants who described GPs recommending referrals appeared to have felt pressured into accepting these, and some were positively surprised to have been offered referrals they had not asked for, or to have their requests acceded to so readily. Several people said they had been encouraged or given time to adjust to a GP's suggestion of a referral for surgery, but they commented favourably on this. Some accounts portrayed an emergent consensus between GP and patient that a referral would be needed. For example, it could become clear over time that primary- and self-care efforts were failing to resolve a new and developing health problem. Some people with gradually worsening hearing loss or joint pain, for example, described having agreed with GPs or consultants that they would ask for a referral when they thought specialist intervention (e.g. hearing aid or surgery) was becoming necessary.

Even without a clear prior arrangement, some patients who went to their GP seeking a referral met with quick agreement that this was appropriate (Box 5.3). Others, however, thought a referral was necessary before their GPs agreed (or before the GPs with special interests to whom they were first referred agreed to a further referral to a hospital-based consultant).

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Some of these people felt frustrated but bore with GPs' requests that they wait a bit longer and/or try more tests or potential solutions from the primary care repertoire (Box 5.4). Others reported being more insistent, asking repeatedly, or going to several GPs to secure the referral they wanted (Boxes 5.1; 5.5).

### Box 5.3

Flora had had one hip replaced a few years ago. She went to her GP when her second hip was "starting to go" because she thought there might be a long waiting list for surgery and so wanted "to start the process" in good time. Flora's GP agreed she had a problem and referred her for an X-ray. Flora did not recall discussing where or to whom she would be referred, nor when she would be seen. At the time of her interview, she had had an X-ray at a large local hospital and received a letter saying she had been referred for further assessment at an independent treatment centre about 30 miles away. Flora did not know why she needed further assessment, nor why she was being asked to travel so far. She speculated that the local hospital might be full, but thought the issue should be discussed with her if that were the case. She felt unable to travel to the treatment centre, which was hard to get to by public transport. The letter had not mentioned any alternatives, but Flora had written to explain that at her age (over 80), and given her lack of family and the bad weather, she could not contemplate the journey and would rather be seen at the large local hospital. (Flora told us she was aware of another local NHS hospital where joint replacements were done, but said she had not asked to go there because she feared problems with MRSA). She had not yet received a reply, but she had got a long pre-assessment questionnaire from the treatment centre Flora thought some discussion about options for where people were referred to would be appropriate. She also thought it was feasible to offer some flexibility about appointment dates and times. Flora reported not having needed to be involved in making the decision about her referral (she was probably focusing on the decision about whether or not she should be referred), and said she had left the decision to the GP. However, she felt (appreciatively) that the GP had tried to involve her because he "was interested and wanted what was best for me". (Scotland, age 60+)

### Box 5.4

Bryony had sinus problems and noticed she was losing her voice increasingly often – which was problematic because she was a teacher. She went to see her GP, who referred her to another GP in the practice who had a special interest in ENT. Bryony saw the GP-specialist twice. Although she was convinced the voice problem was connected with her sinuses, the GP-specialist asked her to take medications for reflux to eliminate this as a possible cause of her voice problems

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before he would refer her on.

The medications for reflux did not work, and once a decision to refer was agreed, the GP-specialist showed Bryony a list of hospitals on the computer and said she could choose which to be referred to. He gave her a print-out of the list (which included the two most local hospitals) to take home to make her booking. At home, Bryony found that the hospital clinic she wanted to attend was not bookable online, so she telephoned to arrange an appointment. She was offered several time slots to choose from.

Bryony reported feeling "a bit frustrated" that the process was slow because she had had to work through the medications for reflux first, but said she hadn't wanted "to tell the doctor his job". She thought her views had been adequately attended to once a referral had been agreed, and said she felt able to be more involved and in control once she had a referral to book. (England, aged 30-59)

Participants who initiated requests for referrals for reasons not suggested (and unlikely to be suggested) by GPs also described some (variable) resistance. Our sampling strategy meant we only spoke with people who had been referred, and participants who reported making these requests appeared determined and persistent in their pursuit of "off menu" options. (Boxes 5.1, 5.2).

In response to structured questions, 45/99 participants said that they and the GP had discussed what the referral was for. This proportion seems low when compared with participants' narratives: all were readily willing and able to describe the health concerns behind their referral, and the ways these were discussed with GPs. The discrepancy may be partly explained by the fact that the question focused on discussion in the consultation in which the referral was agreed (some people had discussed the rationale for referral in previous consultations). And possibly some people thought the question referred to discussion about what specialists would *do* (which was often less clear for people with referrals intended to help clarify what their problem was).

All the participants who mentioned it appreciated GPs sharing their understanding of what was or might be wrong with them. They also valued being given information about the recommended course of action, including the referral. But ideas about what information it was reasonable to expect from a GP varied according to the circumstances and reasons for referral: people did not necessarily expect the GP to know in advance of the referral exactly what specialists would do or suggest.

### 5.3.2 'Choice' about to whom (which specialist) to be referred to

Relatively few (26/99) participants reported any discussion with the GP about which (type of) specialist they would be referred to. When asked who

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they had been referred to, some remembered being told the type of department (e.g. ENT, orthopaedics, physiotherapy) or type of health professional (e.g. GP-specialist, sports physiotherapist, orthopaedic consultant). A few remembered GPs naming individuals, but not all could recall this name in interviews.

For the most part, participants had not expected GPs to offer a choice between individual specialists of a particular type, and they often noted that they would not have been well placed to make a selection if they were offered such a choice. Choosing between specialists was not something people were keen to do: most just wanted to be referred to someone with the appropriate expertise and resources to deal with their problem, and trusted their GP to identify someone who met these criteria.

They generally accepted that if GPs did not know specific individual specialists, they would be able to identify appropriate kinds of specialist. (Although some participants from England and Wales in particular were aware that new referral management systems might constrain access to particular kinds of specialist, or require assessment by, for example, a GP with a special interest or a physiotherapist before a referral could be made to a consultant (Boxes 5.4, 5.5, 5.6).

The two main circumstances in which people wanted and/or received some say about which specialist(s) their GPS referred them to were (a) when they had consulted specialists previously for the same or a similar problem and (b) when they requested referrals to the private sector. Most of the participants who had consulted a specialist previously for the same or a similar problem, would have appreciated the continuity offered by a referral back to the same specialist, although not all could remember their specialists' names and it was not necessarily a top priority (Boxes 5.5 p138, 5.7 p139, 5.8 p140). Choice between particular consultants could also be important if consultants varied in terms of their willingness to provide the forms of intervention that patients wanted: one of our participants had asked for a second referral after the first consultant he saw would not give him the surgery he wanted (Box 5.9).

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### Box 5.5

Two women who attended the same general practice in Wales were referred for apparently similar problems with pain and deformity in their feet. Lynn, a retired nurse, was told by her GP that a new referral policy required that she go first to another general practice where a GP or nurse with a special interest would assess what treatment was required. Lynn accepted this and was seen within two weeks by a GP-specialist and physiotherapist who asked her to walk around in front of them, told her that physiotherapy would not help her condition, and "decided not to waste time and made a referral to the hospital". When we interviewed her, Lynn was waiting for her hospital appointment. She said she was happy with the system and very grateful for the NHS. Mary, a retired GP, had been referred to an orthopaedic consultant several years previously but had waited over a year for an appointment and eventually been seen by a podiatrist, whose interventions had resulted in some improvement but not resolved the problem. Mary told us that she knew what her problem was, and that it was obvious that her toes needed straightening and this could only be done mechanically. Mary rejected her GP's suggestion of a referral to a podiatrist because she knew podiatry would not work. She requested a private referral, because she had insurance and was concerned about MRSA infection rates in the local NHS hospitals. She relied on the GP to know and recommend the best consultant locally, then made her own appointment via the consultant's secretary.

(Wales, both age 60+)

### Box 5.6

Camille had one knee replaced several years ago and went to see her GP because she was getting a lot of pain in the other knee. The GP referred her to the musculo-skeletal service and she was seen by a physiotherapist. The physiotherapist asked Camille whether she wanted to see a particular consultant. The consultant who had done Camille's first knee replacement was retiring. Camille asked the physiotherapist which consultant was the best. The physiotherapist was reluctant to answer this question but did say whom he would prefer to see if he needed a knee replacement.

The consultant whom the physiotherapist recommended only operated from a private hospital, where Camille had previously had a bad experience. However, she chose to go there again with NHS funding. She was only offered one appointment time slot, but had no problems with that. Reflecting on the process and her options, Camille commented that she would have preferred to discuss the choice of consultant with her GP than with the physiotherapist, and that being referred via the physiotherapist delayed access to the consultant.

(England, age 60+)

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### Box 5.7

Five months after surgery on her knee, Kay had had no follow-up appointments and was still getting a lot of pain. When she saw her GP about this, he noted that her knee was also still swollen, and referred her back to the hospital. Kay could not remember who had done the original surgery, so although she would have preferred to go back to them, she said she did not mind who she was referred to. Kay was pleased to receive an appointment letter soon after seeing the GP. (She contrasted this favourably with her referral for the original surgery, which was lost twice). The letter offered a specific appointment time and said she could contact the hospital to rearrange the appointment if this was not suitable. Kay told us she "went with the first one as you never know when the next one will be".

When Kay saw the consultant, he told her that the surgery had dealt with quite a large tear, but that her knee was OK. He said, as she had thought, that she should have been referred for physiotherapy after her operation. He made a referral for physiotherapy at that point, and Kay was waiting to hear about this when we spoke to her – hoping that it could be at the local hospital rather than the big city hospital where she had her surgery. Kay had been happy with her recent referral. She felt she had been involved by going to see the GP, and she thought the GP had involved her because he believed she had a problem and referred her back to the hospital (which was what she wanted but had not asked for). Kay thought it would be nice to have some options about where and when appointments were, but commented that "It is difficult to be too demanding as you might put them off and they would delay it even further".

(Scotland, age 30-59)

### **Box 5.8**

Bill had had tinnitus for 16 years. He had always seen the same consultant about it, and although he had not seen her for several years, he went into the local hospital regularly for replacement batteries for his "masker". When he became worried that his condition was deteriorating, he telephoned the consultant to ask if he could come and see her again. She told him that the health system had changed and it was not longer possible for him to just phone up and come in: he would have to ask his GP for a referral.

When Bill asked his GP for a referral to his usual consultant, the GP said he should get an MRI scan first. When the results of this scan came back clear several months later, Bill again asked for the referral and was told it was "all in the process". At the time of his interview (6 months after his initial request to the GP), Bill had not been given an appointment. He had telephoned the GP and hospital three or four times and been told that his referral had been lost due to a computer fault. He thought there should be some better means of finding out what was happening with referrals.

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Bill found questions about the adequacy of the options he had been given difficult to answer. He had not wanted a lot of options: he just wanted to see a consultant (ideally the one he knew and trusted) to check his apparent deterioration and see if any new technologies or treatments were available. Bill did not think his views had been attended to or that he had been involved in the referral decision. He thought the old referral systems had been better than the new.

(Northern Ireland, age 60+)

### Box 5.9

Stephen had ongoing and worsening problems with his knee after damaging it 10 years ago. He had had several arthroscopic examinations/interventions and been through several physiotherapy programmes. At a recent consultation, an orthopaedic surgeon told him he was too old to benefit from a repair of his anterior cruciate ligament. Stephen was unhappy about this. His previous experiences and recent internet searches convinced him that he wanted the procedure, and he went back to his GP who agreed to make another referral. Stephen described sitting with the GP and using Google to identify consultants in their county who did anterior cruciate ligament repairs. They were impressed by the website of one local consultant, and the GP agreed to make a referral to this consultant. Stephen had had his operation by the time we interviewed him. Stephen told us he hadn't needed lots of options, just options that worked. He also said that he was naturally inquisitive, wanted to know about what was going on, and would always ask again if he wasn't getting what he needed. In relation to this latest referral, he felt he had been well involved and his views had been well attended to.

(England, age 30-59)

### 5.3.3 'Choice' about where to be referred to

Despite the fact that only England had a policy of offering patients a free choice of secondary care provider organisations<sup>5</sup>, the proportion of participants who answered 'yes' to a question about whether the GP had discussed where they would be referred to was not strikingly higher in England than in other countries (15/33 compared with 9/19 for Northern Ireland, 7/23 for Scotland and 14/24 for Wales). Possible reasons for this include: our small, non-random samples; variations in what people counted as discussion (when asked to explain WHY they picked this particular response option, some people said they had answered 'yes' because the GP had told them where they would be referred to but others apparently had a higher threshold for an affirmative answer); and the fact that the English practices all belonged to primary care trusts that had established preferred

<sup>&</sup>lt;sup>5</sup> A policy of offering free choice of any secondary care provider was introduced in England from April 2008. All interviews for this study were conducted in 2009.

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referral pathways to local musculo-skeletal services, so orthopaedic referrals from these practices were exempted from the policy of offering a choice of specialist provider.

Although the counts were not strikingly different, it was only English participants (and a few participants from other countries who asked for private sector referrals) who described having been offered a menu of providers to choose from (Boxes 5.4 p136, 5.10 p142).

### Box 5.10

Jean went to see her GP when problems moving her index finger started to interfere with her work. The GP told her there was a problem with one of the bones in her finger, but that she was not sure exactly what it was. Jean asked if the problem could be dealt with in-house, because the practice offered minor surgery, but the GP thought she needed a referral to secondary care. The GP said she would send Jean a letter and a list of providers to choose from because she didn't have their waiting times to hand. When the letter and list arrived, with a password and code to allow her to book an appointment online, Jean noted that the GP had suggested that a particular hospital might be good because it specialised in plastic surgery. Jean went to the NHS Choices and Choose and Book websites. She looked at information about 5 providers and chose the one with the shortest waiting time, which was also the one the GP had suggested. She was offered a good choice of appointment slots within a reasonable time frame, and was pleased to be able to arrange the consultation around her diary. (England, age 30-59)

The nine practices from which participants were recruited varied in terms of the numbers of specialist provider facilities they had within reasonable geographic proximity or travel time. Participants from one practice in Northern Ireland could identify just one hospital as their local. Most participants from other practices were aware of at least two NHS facilities to which people from their area would routinely be referred for specialist care (sometimes a relatively small hospital and a larger teaching hospital). Some participants from all practices mentioned 'assuming' their referral would be to one or either of these local hospitals.

Even those participants from England who recalled being offered a list of providers did not report much discussion about their choice. We did not hear any accounts of GPs encouraging or facilitating comparisons other than on the basis of waiting times and/or travel convenience – although some GPs apparently made recommendations on grounds of specialty interest (Box 5.10 above). Participants who did report considering and choosing between several providers also appeared for the most part to base their choices on one or other of these criteria. (This was also true of people who were given lists of private hospitals to choose from).

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Participants generally did not seem to have expected much discussion about where they might be referred with their GPs, and for the most part were happy to be referred to a local NHS facility, trusting their GPs to refer them to providers who could address their health needs. Those who were aware of a couple of local possibilities said they (would have) appreciated being told which they were being referred to, and some who had a preference (would have) welcomed a choice between them, especially if particular work or travel issues made one much less convenient to get to – although some participants told us they had not mentioned their preferences to their GPs when they might have had the opportunity.

People only mentioned strong preferences to consider options other than a local NHS hospital when they thought there were (or might be) very long waiting times, very high infection rates or other major problems at the local facility, or when they had private health insurance and wanted to be treated in the private sector.

Some people found out after they had been referred that they had been offered appointments in places they had not expected (see section 5.5 below on communication with specialist)

### 5.3.4 'Choice' about when the specialist appointment will be

Two issues relating to the timing of specialist appointments were considered important by participants: the overall length of wait; and the specific date and time of appointments.

Although some participants recognised that problems with very long waits for specialist care on the NHS were (becoming) a thing of the past, there was still a concern that waits could be long. Some people who did not think their problem was particularly urgent suggested that they could and would manage a wait if necessary. Others, however, were very concerned about the implications of long waits for their ability to work or pursue valued leisure interests. Some described investigating (or self-generating) various ways of getting around the problem. We heard examples of people going to the GP 'early' to ask for a referral (Box 5.3), and requesting that referrals were made simultaneously with (rather than after) recommended first-line primary-care treatments (Box 5.11).

Some people were able to incorporate consideration of length of waiting lists into choices between specialist providers - either before their GP made a referral or (in England) when using the Choose and Book system once a referral code had been issued. Those who had not had these options but subsequently learned that they would have or were likely to have a long wait for an appointment with the provider they had been referred to sometimes reported going back to their GP to explore options for being seen more quickly - either less locally on the NHS or privately. In a sense,

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they generated further options when the initial suggestion came to seem unacceptable. In terms of the specific dates and times of appointments, having options or scope to be flexible was important to many participants. However, this was not generally discussed with GPs (unless the English Choose and Book system was used to make a referral within the consultation). We consider it in the context of communication with specialist providers.

### Box 5.11

Lisa twisted her knee and was advised by her GP to do some particular exercises and take anti-inflammatory painkillers. Lisa was concerned to make a quick recovery because she had booked a ski-ing holiday a few months hence. She asked the GP what would happen if the exercises and painkillers were not successful, and was told she would then be referred to the local musculo-skeletal service. Lisa asked the GP to fast-track her by referring her to the service straight away. There was no information about waiting times for the service available at the time, but the GP sent an electronic referral while Lisa was still in the consultation.

Concerned about the possible wait, Lisa used a directory service to identify a sports therapist, and went for 3 private appointments before she received a letter from the musculo-skeletal service. The letter said that her referral had been inappropriate, and had now been passed to a different team, for whom the wait for an appointment would be 8-10 weeks – but Lisa was not sure whether this meant that she had been put on the waiting list. The letter also suggested Lisa contacted the physiotherapist based at her GP practice. She did this, but the physiotherapist was on maternity leave. When we interviewed her, Lisa was planning to contact the musculo-skeletal service to check that she was still on their waiting list for physiotherapy.

Lisa said she had been happy not to have been involved in the referral decision as she assumed the GP would know the best option. However, she subsequently became concerned about the confusion about her referral and reflected that she would have liked to have been informed at an earlier stage about waiting list times and given information about other feasible (i.e. fairly local) options. (England, aged 30-59)

# 5.4 The second phase: communication with specialist providers

Once a GP has made a referral, specialist care providers generally communicated directly with patients about arrangements for their secondary care provision. Depending on the system, there were more or fewer possible permutations at this stage in terms of where, by whom and when particular patients were seen, and more or less opportunity for patients to make choices or otherwise influence this.

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As our meso-level study highlighted, referral options and systems for arranging appointments varied somewhat across case study sites, and there had been several transitions around the time of data collection. These transitions often involved the introduction of local referral management centres and/or the development of referral pathways, both of which were intended to standardise patients' experiences, with implications for the kinds of 'choice' available in referral processes. We found substantial variation in patients' experiences - even between patients referred from the same practices and for similar health problems (Box 5.12)

### Box 5.12

Mark had had joint pains for over ten years, and consulted his GP when these worsened. After listening to Mark's symptoms, the GP was not sure what the problem was. She wrote a referral letter, telling Mark that she was marking it as urgent in part because of his other conditions.

Mark soon received a letter from the local hospital asking him to telephone to arrange an appointment. Mark was pleased that the letter named a consultant whom he had seen previously, and also that the appointment was arranged within 4 weeks. However, he felt let down subsequently because when he got to the hospital he was seen by a registrar who did not seem to take his medical history seriously, and he left the short consultation feeling nothing useful had been achieved.

Mark commented that while the referral system ran very smoothly, that was pointless if the 'end product' was poor. He was concerned that highly publicised reductions in waiting times were being achieved only at the cost of patients' experiences of care.

(Northern Ireland, age 30-59)

### 5.4.1 Initial communication

Patients' initial communication came from either (a) (in England) an appointment booking system used by multiple specialist care providers (Choose and Book); (b) a more localised referral management centre (covering fewer providers, and perhaps involving more 'behind the scenes' triage decisions that could shape/constrain the kind of appointment offered to particular patients; and (c) the particular specialist care provider organisation/clinical team that would deliver care (which might or might not work in more than one facility).

It was striking that even within our relatively small samples at least one patient from each country told us they had not heard anything for so long after their GP agreed their index referral that they became concerned their referral had been 'lost' – and we heard additional accounts of problems with previous referrals (Boxes 5.7p140, 5.12 p145). Most of these patients'

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concerns had been compounded by the fact that they did not know what they should expect in terms of communication, so were unsure whether, when, with whom and how it would be appropriate to try and chase the referral up. Those who contacted their GP practice and/or a specialist provider were variously told that their referral had not been made by the GP who had agreed to make it, or had been 'lost' in the system (perhaps by a computer) either before or after having been received. One Northern Irish participant was told she had been removed from the NHS waiting list because she had obtained a private referral. Some patients, especially in Scotland, told us they had received a letter acknowledging their referral and indicating a time frame in which they should be sent an appointment. Although this could be interpreted as a 'stalling tactic', it did also serve to let people know that their referral was not lost.

### 5.4.2 Choice about which specialists were consulted

A number of participants had been referred initially to GP-specialists or nurse-specialists (or physiotherapists or podiatrists for orthopaedic or foot problems). Some had been told by their GPs that assessment by these professionals was a requirement before appointments could be made with consultants (including for potential surgery). None of our participants had the impression that these first assessments were optional, and none told us they had been offered options in terms of which professionals they saw. Participants did not always find these appointments helpful, and some experienced them as unnecessary hurdles that delayed their access to consultants or surgery (Boxes 5.4, 5.5, 5.6).

Some people were asked within these first specialist appointments whether they had a preference for which consultant they were referred on to – with the professionals who led the appointments taking on the referral and decision-support role more traditionally associated with GPs (Box 5.6)

As mentioned in section 5.3.2, most participants did not think they were in a position to make good choices about which particular consultant they saw. However, several commented that they appreciated being informed in advance (on an appointment letter) which consultant (or members of which consultant's team) they would be seen by. They were not using this information to make choices and none reported doing anything particular with it, but they were pleased to be told. The only downside of being given this information, as Box 5.12 illustrates, was that if arrangements are changed (or if only consultants were named) patients could be disappointed when it was not fulfilled.

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### 5.4.3 'Choice' about where secondary care was provided

For some people whose referrals were made direct to secondary care provision teams at one facility (and not to referral management centres that covered more than one such team, or to teams that operated out of more than one centre without specification of which the person was to be seen at) no choice about where they would be seen would be expected at this stage. People given referral codes to use themselves with the English Choose and Book scheme had more obvious options in terms of where they might be seen, but they also needed to take the initiative and make decisions and appointments. Some were clearly able to do this – and appreciated the control they had over the process. Others were perhaps less confident – about the decision making or the technologies designed to support it. However, only one person from our sample reported talking through his/her options with an adviser from the National Appointments Line.

Some people whose referrals were handled by specialty referral management centres were given no options about where or by whom they were seen for their first assessment appointments (which were usually with GP-specialists, nurse-specialists, or physiotherapists or podiatrists for orthopaedic problems), but were subsequently given options (in or after that appointment) about which hospitals or consultants they would see if the initial assessors deemed such appointments appropriate (Box 5.6).

Issues relating to where they would receive specialist care also arose for some patients as arrangements for specialist consultations, assessments and procedures were communicated to them. For some people, a letter offering them an appointment contained the first information they had had about where they had been referred to. For a few, this information was surprising – and not always in a good way (Boxes 5.2 p135, 5.3 p136)

People also reported being surprised – pleasantly or otherwise – when they were told as they progressed through assessment and treatment pathways that pre-consultant or pre-operative assessments were not always conducted in the same facilities as consultant appointments or surgery – and that post-operative follow up could be somewhere else again.

### 5.4.4 Choice about when care would be provided

Some flexibility about date and time was the aspect of choice that most people thought it reasonable to expect. It was especially important for people who worked shifts or otherwise found it difficult to ensure cover, or people who had holidays booked.

For a number of participants, the first or second communication from specialist providers was a letter suggesting an appointment date and time.

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Some of these patients recalled that the letter said they could request an alternative date and time if possible, and several reported that they had happily availed themselves of this option and changed their appointments with no difficulty. However, several people told us they feared that if they tried to change the date and time they might be penalised and experience long delays (Box 5.8). For them, the formal offer of another option was not experienced as genuine or safe. Participants who received letters asking them to telephone either to confirm *or* to reschedule did not seem to have this problem – if a friendly person on the other end of the telephone asked whether the appointment was OK, a real-time check of options could seem more feasible.

The English Choose and Book system offered more obvious and direct 'choice' of date and time, and some English patients clearly appreciated being able to go online and pick a date and time that suited them – although it did require some active input from patients.

### 5.5 Understanding and valuing aspects of choice

We elicited information about how participants understood and valued issues relating to choice both by using structured questions and by inviting more open reflections on their experiences and suggestions about how referral arrangements could be improved.

The structured questions were less successful than we had anticipated. Some participants clearly struggled with them, and some of their responses seemed inconsistent with what they told us in more open discussions. We have summarised responses to these questions below, but stress that these should be interpreted with caution, and not only because our study involved small, non-random samples of participants. We note the issues that arose for the interpretation of each particular question below.

\*\*\*HERE

### 5.5.1 Perceived adequacy of option sets

Responses to our structured questions about whether participants thought they had had enough options in terms of who and where they were referred to, when and what for, were rather mixed. At face value, they suggest that English participants were more likely than others to perceive they had been offered an adequate option set (Table 18). However, these responses need to be interpreted with caution.

Table 18. Numbers of patients reporting they had been given enough options

E (n=33)	W (n=24)	S (n=23)	NI (n=19)	Total

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					(n=99)
Where	27	6	9	15	57
Who to	23	6	7	7	43
What for	28	5	10	9	52
When	24	10	7	10	51

#### **Issues in interpretation**

We used different interviewers in each country, and although they asked the questions as worded, they asked them in the course of more conversational interviews during which their particular characteristics and approaches might have encouraged certain types of response tendency among participants. After early interviews suggested the questions were difficult and not always meaningful (see Box 5.10), we agreed that interviewers could acknowledge that the questions were perhaps problematic to avoid participants feeling they were not answering them well. It is possible that their different approaches to this may also have influenced responses.

There were several sources of ambiguity in these questions and their responses. People were not always sure which stages of a referral process to focus on, and had sometimes had different experiences across several (see for example Box 5.12: Stephen did not think he had been given adequate options by the first consultant he was referred to, but got what he wanted from the second). The question about options in terms of what a referral was for could relate both to the participant's health problem(s) and/or to particular interventions that might contribute to their resolution. Also, participants who made a choice in one domain, for example to see a particular consultant, could then be constrained in other domains, for example to choose a hospital out of which that consultant operates (Box 5.11). Judgements about how to assess the adequacy of options offered in these contexts could be variously influenced.

We observed that participants varied in terms of their inclination to give yes or no responses to questions about the adequacy of options. For example, when no alternatives of place were offered but they thought the one place they were offered would be fine, or when they had tried all 'conservative' treatments and got to a point where they considered themselves to have no (worthwhile) option other than surgery.

It is also important to note that these questions were asked at the end of the interviews, and people might have been sensitised during the

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interviews to options and issues of choice that they had not previously reflected on or been particularly concerned about.

## **Insights from broader discussions**

In conversation, most people appeared not to have been expecting a major discussion or consideration of various options about where or to whom a referral would be made. With the exception of a few participants from the English sample who were familiar with the ideas behind the Choose and Book policy, and a few from the Welsh sample who were aware that English patients were offered choices and thought they should be similarly entitled, they had not anticipated (and often did not see a need for) a discussion of multiple options about this as such.

Quite a few people also spontaneously offered general comments to the effect that it would be unreasonable to expect to have high degrees of choice about where, who and when they were seen. They accepted a need to ensure some efficiency in the healthcare system and thought some constraints on choice were necessary to avoid healthcare facilities and professionals being very rushed at the most popular times and idle at others, and to avoid people becoming *too* fussy. The private sector was generally thought to offer more flexibility and prompt responsiveness for those who could afford to pay.

A small menu of service providers was generally not seen as problematic (and a bigger set was not desired) as long as people could be confident that they would be referred to facilities and health professionals that could and would address their health problems competently and appropriately, within a reasonable time frame and without exposing them to unacceptable risks. People did want options to be able to look for and choose something other than a default service provider if they perceived the proffered default as seriously substandard or problematic (for example if waiting times were very long or if they had heard a particular hospital had high rates of healthcare acquired infections). They needed to be confident that they could avoid problems, but did not necessarily require a menu of options 'up front' to ensure this. As Boxes 5.8 and 5.9 illustrate, one good enough option would suffice.

Having options in terms of where and when they were seen was often seen as valuable, but what people wanted was sufficient flexibility for reasonable convenience, especially if they had important work or social commitments, or found travel to some locations difficult. They did not necessarily need to be offered a menu of dates and times to perceive they had adequate options. A starter offer with a clearly genuine message that this could be easily and safely renegotiated sufficed for many. And as Box 5 illustrates, people do not value conveniently timed appointments if these come at the cost of thorough care.

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In terms of options for what they were referred for, people clearly did not want treatments to be imposed on them. A few people within our sample who were required – before they could access the treatments they wanted - to 'try' medications to rule out diagnoses they were convinced they didn't have, or to 'work through' exercise and/or medications that they did not think would suffice might have been described as imposed on to some extent). They did, however, want to be able to access treatments that they believe were appropriate and necessary (see Boxes 5.1 and 5.12 in particular). Only one person clearly associated having options and making choices with improvements to the quality of care.

#### 5.5.2 Assessment of attention to views

As Table 19 shows, participants from England and Northern Ireland gave more positive responses to questions about whether adequate attention was paid to their views than participants from Wales and Scotland. Again, however, this finding needs to be interpreted with caution.

Table 19. Numbers of patients reporting views adequately attended to:

	E n=34 (33)	W n=24	S n=23	NI n=19	Total n=99
Where	22	5	10	17	54
Who	24	7	7	14	52
What for	26	9	13	18	66
When	26	7	7	10	50

#### **Issues of interpretation**

Researchers from all four countries reflected that participants often had difficulty with these questions and that they seemed to vary in how they answered them if, for example, they had not had (and hadn't felt they needed to form) strong views, or to have a say, about where, by whom and precisely when they were treated. Again, the researchers may have differed in terms of whether and how they helped people to understand and answer these questions.

#### **Insights from broader discussion**

The more discursive parts of the interviews suggest that the key issue was that people have an opportunity to air and discuss their concerns about their health problems and possible treatments with their GPs (and any specialists to whom they were referred), and that they were listened to when they present their problems and express preferences or concerns. Participants who were offered a referral, given a clear explanation of its

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purpose, encouraged to feel that they had scope to check or disagree with this if they were not immediately convinced of its appropriateness, and offered some kind of a say seemed to appreciate this.

Some participants' comments, however, did remind us of the need to attend to the limitations of questions about patients' perceptions of whether their views were adequately attended to as an indicator of either choice or the 'quality' of healthcare more generally. Some participants had quite particular views about what they wanted (perhaps after actively looking for information about ways of managing their health issues, and perhaps inconsistently with most understandings of what might be appropriate). Some apparently manoeuvred quite actively to ensure they got what they wanted, and some accounts suggested they had almost manipulated GPs into 'capitulating'. Comments about whether their views were adequately attended to could variously reflect their own views and efforts.

## 5.5.3 Judgements about involvement

Responses to questions about whether they wanted to be and were involved in the referral decision were also somewhat mixed, but it was notable that more people reported that they were involved in this than said they wanted to be involved in this (Table 20).

				_	
	England	Wales	Scotland	Northern	Total
	(n=33)	(n=24)	(n=23)	Ireland	(N=99)
				(n=19)	
Wanted to	20	17	10	14	61
be involved?					
Was	25	17	13	16	71
involved?					

Table 20. Patient involvement in referral decision making

#### **Issues of interpretation**

The question about whether they wanted to be involved was asked first, and some of the people who answered it negatively apparently did so on the grounds that they saw no need to be involved because they trusted their GP to make an appropriate referral. There was no indication in our interviews that people who said they had not wanted to be involved but then reported having been involved in the decision were in any way coerced

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into making choices that they did not want to make (or have the responsibility for making).

Some people commented that they had been involved because they had (taken the initiative and) gone to see the GP about their health problem, had requested a referral or otherwise acted to secure what they wanted. Those who had manoeuvred to overcome GPs' resistance to their requests for referrals or other shortcomings in the system were sometimes both disinclined to say they had been involved (because they had felt dismissed or excluded by one or more health professionals) and inclined to say they had been involved because they had taken active steps to make things happen.

Some of those who reported that they had been involved in the decision did not seem to have been given options or engaged in discussions that influenced where or to whom they would be referred, or when their appointment would be. Their explanations suggest they associated 'involvement' with their GP listening to them, giving them explanations that resulted in them feeling confident about the reasons for the referral and what would happen, being explicitly asked what they thought, and feeling they could have intervened to change things if they had not been happy with the referral.

The people who reported *not* having been involved generally commented to the effect that their GPs had disbelieved their accounts of their problems, had not respected their knowledge of their condition, and had not listened to what they wanted. (Their comments were generally consistent with previous reports that patients consider interpersonal relations with health professionals (and not just information about options and decisional influence) as important for involvement. 126,127

#### 5.6 Conclusion

The broad research question to which this component of the project sought to contribute answers was "What are the effects of the different policies on choice on access to care and responsiveness to patients' wishes in each of the four nations?"

Our interviews with patients suggest that, with the obvious exception of the fact that some NHS patients in England were offered a menu of specialist providers and/or a menu of appointment dates and times to choose from, choice policies had not resulted in any obvious systematic differences in patient experience across the four countries. We saw as much diversity of patient experience within as we did between nations, and patients raised similar issues in each of the four countries. The distinctiveness of policy

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rhetoric about choice was not clearly reflected at the patient experience level.

Our interviews also suggest that patients have differently nuanced ideas about choice than policy leaders, and that they may face issues of 'choice' before they get to the kinds of choice about secondary care provision that policy leaders have focused on. For forms of access to specialist care that are mediated by GPs, patients need to secure the agreement of GPs before they have any kind of referral. Some patients in all four countries reported difficulties 'getting past' GPs to forms of specialist care that they wanted. Some of these difficulties probably reflected GPs' attempts to follow standardised care pathways and referral management protocols that have been introduced with the intention of improving the effectiveness and efficiency of healthcare. Patients' 'success' in overcoming them to access the forms of care they wanted seemed to depend in part on their persistence and skills in negotiating with (or shopping around between) GPs. This raises questions about how GPs 'should' juggle their responsibilities to follow recommendations about the management of particular conditions and exhortations to be responsive to the wishes of individual patients.

Once GPs agree to make referrals, policies about choice and referral management may have varying influences. The practices of triage introduced within some referral management systems and by some secondary care provider organisations can sometimes preclude options NOT to go via a certain service or type of specialist. Our study took place during a time of policy transition and the implementation of change – involving the introduction of new, complex and variable (sets of) referral system(s). Some GPs and patients were unfamiliar with the opportunities these presented for individual patients' preferences to influence particular issues relating to referrals to specialist care. We consider here, though, how responsive the systems might be said to be in terms of reflecting and accommodating preferences for 'choice'.

Our data strongly suggests that people did not want options to choose between for the sake of having options to choose between. Rather, they value being able to access good and individually appropriate healthcare, with as many options (or as much flexibility within a broadly standardised system) that will allow them to avoid seriously substandard providers and be treated at places and times that were reasonably convenient for them personally. They valued being involved in referral decisions at least in the sense that they were being listened to and kept informed about the rationale for and progress of their referral. This did not require a system like the English Choose and Book one – and the English Choose and Book system alone could not ensure it.

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Responsiveness to patients' wishes did not seem to require the provision of menus of healthcare provision with multiple options in terms of place, date and time of care. It did seem to be promoted by attentive and caring health professionals who engage in careful discussions about individual needs, explain the system and support people to navigate around it.

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# 6 Discussion: interpreting UK 'choice'

## 6.1 Introduction

This project was undertaken in response to a call for research to examine four questions:

- What is the political and ideological provenance of each of the four national policies on choice?
- What are the essential elements and objectives of the four different policies on choice and how do they relate to other differences in policy between each country?
- What processes do the relevant health care organisations in each country use to implement the choice policies at local level?
- What are the effects of the different policies on choice on access to care, responsiveness to patients' wishes and overall efficiency of the national health system in each of the four countries?

The previous three chapters reported on our key findings from the study. Our aim was to examine policy differences and the relevance of such differences in how choices, if any, were offered to patients. We structured the research in order to examine policy development and policy implementation at national policy (macro) level, local organisational (meso) level and at the patient (micro) level in each of the four UK home countries. In this chapter we draw together the key themes that have emerged from our research.

After commissioning this project the Department of Health funded a study to examine the impact of choice on NHS performance as part of the Health Reform Evaluation Programme. This project was jointly undertaken by the King's Fund, Picker Institute Europe and RAND. Where relevant, we draw comparisons with findings from this project when we discuss our own results. In addition Propper et al developed a competition index to examine whether there was potential and actual competition between health care providers in England. Again data from that study are included where relevant.

As explained in Chapter One, the study did not set out to evaluate the implementation of English patient choice policy or the impact of choice policies across the UK *per se*. The research was undertaken to provide an in-depth analysis of the nature of patient choice policies in each country in the UK and to compare approaches between countries. Rather than just

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examining the nature of policy at the political (macro) level, we undertook to investigate the implementation of policy at organisational (meso) level and also how patients experienced choice (the micro level). The research raised a number of problems in terms of differing language and perceptions of choice across the UK and the policy shifts that occurred during the study period (2007-late 2009). Some issues were of concern across all the countries and, in particular, the length of waiting lists for patients was a common priority for policy makers. This point is made in Chapter 3 and constitutes a key policy driver. However, waiting list issues were also an important factor in the organization of services and in this sense the impact of national policy relating to choice was identified as potentially competing with a stronger imperative to manage waiting times. Perhaps more importantly, this tension had implications for the management of option availability at a patient level, with the offering of choice being utilised as a mechanism by organizations to reduce waiting lists rather than to expand the possibilities offered to patients.

Perception issues about the nature and meaning of choice as well as the way patient choice policy in England was viewed outside of England were more complex to deal with. It was not possible, for example, to explicitly discuss choice in the Welsh and Scottish contexts as interviewees did not interpret their policies in terms of choice and, specifically, saw choice policy as something only relevant to England. Because of this, interviewees were engaged in a discussion about referral pathways and where decisions about treatment, consultant, provider etc are taken. This was more acceptable to participants interviewed for the macro and meso levels of the study. We also used a similar approach with managers within the NHS in England to try and trace patient pathways and identify where, within these pathways, decisions between options were made – as discussed in chapter four.

The impact of policy and organizational changes was evident during the period of data collection. Key policy changes related to the continuing extension of patient choice in England with free choice for elective procedures from April 2008 and the subsequent widening of choice policy to include choices in mental health services and services for people with long term conditions. This study only focused on elective procedures as this was all that choice policy covered at the start of the project in 2007 and most organisational (meso) level interviews were completed in England by the summer of 2008. Patient interviews were conducted after the introduction of free choice policy, promoting an open choice of any provider in England, in England but there is no specific mention of this by our respondents. There were also a number of key organizational changes during the project. These included major reorganization in Northern Ireland and the start of changes to the commissioning and provision structures in Wales. Another key organizational change was the introduction of referral

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management centres and intermediate assessment centres (especially for orthopaedics) in all countries. These organizational changes have been referred to in the report where relevant, and introduce a new context to patient choice within the referral process. Notwithstanding the different emphases between England and the other health systems regarding the promotion of individual patient choice and 'voice' – with policies supporting patient and public engagement, policy in England and Scotland, and to a lesser extent in Northern Ireland and Wales, focused at the point of referral on the GP consultation.

Table 21 provides a summary of the key findings in relation to the research questions. This is followed by a fuller discussion of our findings identifying key themes that emerged from our data analysis and synthesis.

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Table 21. Mapping research findings against research questions

Research questions:	Data collected	Key findings
What are the sources and bases of argument for choice regimes in each home country? How have policies shifted over time and what are the putative mechanisms by which stated policy intents are to be achieved?	Interviews with policy makers – senior NHS managers and civil servants, politicians, political advisors.	In England there has been a gradual shift from seeing choice as an organisational driver to one which directly engages with patients being offered a range of options relating to the timing and location of their appointment.  All countries placed emphasis on responsiveness alongside access issues. In Scotland, Wales and Northern Ireland, however, more emphasis was placed on patient and public involvement to ensure that appropriate services were in place to meet patient wishes. This compared with more emphasis in England on individual patient choice. There was also a greater emphasis on voice as necessary for choice in Wales and Scotland with an emphasis on patient and public involvement (patient focus, public involvement in Scotland). All systems did provide choice of some kind and recognised that at a policy level some aspects of choice in relation to the timing of appointments was important. However, choice was only one of the policy
		mechanisms being employed to meet goals of

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		improved access and responsiveness.
How do the different choice policies, together with the structure of the service, influence the range of choices offered to patients?	Data on changes in organisation and referral systems from interviews with NHS staff, GPs, practice managers, IT and referral centre staff, patients. Examination of documentary evidence (reports, guidelines, committee minutes etc)	choice of provider and booking arrangements.  Policies regarding offering a menu of providers ensured that patients in England were likely to be offered more choices than patients in Northern Ireland, Scotland and Wales.  However, choice is an important aspect of policy in all
In what ways do service providers provide patients with choice? What influences the range of options that GPs offer to patients and	Interviews with NHS managers, referral centre staff, practice managers, GPs.	, , , , , , , , , , , , , , , , , , , ,

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how?		The choice decisions about different options need to be made at a number of points in the referral pathway and do not always occur at the start of the referral process in the GP consultation.
		The increasing use of referral management centres and intermediate assessment services has introduced new points at which options are considered within the patient pathways. Choices also depended on whether choice is proactively sought by patients or whether they respond to choices offered. Choices (in England at least) are also shaped by whether the 'Choose and Book' system is accessed via the telephone or online – the latter providing more choice.
How do patients understand, experience and value choice (of secondary care service provider and of treatment options) and to what extent are they willing to exercise it within current policy-	Interviews with patients	There was no consistent requirement by patients for having a set of options providing them with choices about where to get treatment although patients valued discussions about options.

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formulated choices?			
What is the relationship between choice regimes and how choice is experienced by patients in each country?	Interview data		The main differences were in the range of options available and whether choice decisions for patients were offered proactively or reactively. The existence of the menu system for Choose and Book in England meant that where patients were offered choices the range of providers was greater and they were more likely to be offered the choice proactively. In Northern Ireland, Wales and Scotland the range of choices was generally more limited and choice was less proactive or offered reactively oif the patient expressed a demand for choice. However, despite such differences, for patients, the actual experience of choice and choices available varied little between countries.
			Providers managed patient access to consultants, booking slots and locations in similar ways in all countries. A key driver for all providers was to meet key organisational goals. In the main these were related to waiting list targets and reductions in waiting times.
What impacts does patient choice have on the efficiency of local health services in terms of capacity and	Referral dinterview data providers.	data, with	The findings do show that choice mechanisms are structured to maximise the utilisation of existing capacity but little reference was made to providers actively expanding their capacity or aggressively competing for new patients. Patient choice appeared

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volume of services	to act more as an internal driver within providers to
provided?	ensure that services were responsive to patients.

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## 6.1.1 Politics and policy: choice regimes in the UK

In the macro level study we set out to compare the development of patient choice policy in each of the four countries of the UK. The data were derived from policy documents, interviews and public policy pronouncements. In our analysis we sought to identify the key antecedents of policy and to compare policies between health policy systems. We developed a narrative of policy development using a chronological consideration of policy documents together with interview data. This narrative was presented in chapter three. The narrative 'frame' provided a clear view of the ideological and political roots of choice policies. In particular, in England, policy was developed at the centre of government close to the Secretary of State and the Department of Health rather than being the result of pressure from a coalition of interests and advocates. There appeared to be no identifiable advocacy coalition promoting patient choice policies and policy development in England was characterized by a distinct absence of any real coalition of views or policy network or community involving patient groups, policy advisers, civil servants and politicians. It was clear, however, that in England key policy advisers were important in the development of choice policy, providing ideological support for developing patient choice of provider.

At a national policy level, there were clear political differences in emphasis on patient choice between England and the other countries - referred to in Wales for example as the 'clear red water' and in Scotland as distinguishing Scotland from the approach 'south of the border'. What was less discernable was whether there was, and is, any particular ideological underpinning for these different choice policies. Policy advisers in England were most explicit about patient choice having strong relationships to individual responsiveness and equity as well as being associated with market competition to improve services. The main significant difference between the countries was the contrast between England dominated by the idea of individual choice of provider and the emphasis in Wales and Scotland, and, to a certain extent, Northern Ireland, on public and patient engagement, and the importance of 'voice' - the collective action and engagement of patients or the public - as necessary for ensuring appropriate services meeting patient choices or wishes were provided. For these countries 'patient and public engagement' at a community level was seen as central to improving quality and meeting patients' needs in a more responsive way.

## Continuing policy development

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This study and other research on patient choice suggest that over the three years of the study there were significant changes in policy and impact of patient choice in the health care systems in the UK. In Chapter two we detailed how policy on choice developed in each country. Essentially in England there was an expansion of choice policy from a limited range of elective procedures and providers in 2004 to include all elective referrals and to provide a choice of provider from any accredited provider. However, choice of provider was still structured around choices made at the point of referral supported through Choose and Book. In addition, English choice policy was also extended to provide choices in mental health services and to support ways of developing service choices for people with long term conditions. As a result, the conceptualisation of choice was itself beginning to change. The Department of Health acknowledged that choice for people with LTCs had to be constructed differently from individual choice of provider.82 Thus there was a shift in emphasis to highlight the role of patient groups and representatives and their involvement in shaping the services that people with LTCs would use or, where applicable, from which they would choose services.

In Scotland and Wales there was a consistent commitment to engaging patient groups and the wider community in discussions about service developments and ensuring locally appropriate services which was strongly articulated within health policy. While patient and public involvement was also subject to policy commitments in England these were not linked to developing patient choice - except more recently for people with long term conditions –and were not referred to by respondents in our study when discussing patient choice. However, degrees of choice existed in both countries and, in Scotland in particular, there was an increasing acceptance of the need to provide choices for patients - in terms of when, and where, they were treated. In Wales the 2<sup>nd</sup> Offer scheme provided a limited choice where waiting time limits were likely to be breached and there was a commitment to supporting limited choice of time and date of appointment. In Northern Ireland the introduction of the 2<sup>nd</sup> Offer scheme (modelled on the Welsh system) was coupled with a recognition of the need to be more responsive to patients allowing a degree of choice around when patients were treated.

The findings of this study about patient's awareness of choice demonstrates that a degree of choice existed in each country. While it is not possible to generalise from the patient data due to the approach to sampling and small sample size, our findings were that just over 70% of patients reported that they were involved in decision making about their referral. However, it is important to distinguish between the different ways patient's themselves interpreted what is meant by choice. Of the patients in our study about half felt that they had been given options about where and when they were

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seen although fewer patients were involved in discussions about who they would see. Generally patients in England were more likely to report that they were given options about where and when their appointment would be. Scottish patients were least likely to express this despite Scottish respondents from providers and general practice outlining the widest range of choices for patients. There is no survey on the offer of choice outside England. The responses that patients gave to structured questions in our study are broadly consistent with those from recent surveys of patients in England conducted by Robertson and Dixon (2009) and the Department of Health (who have conducted annual population surveys to gather data on knowledge and experience of patient choice. <sup>63,64,129,130,131</sup> However, as the findings from our qualitative explorations suggest, the interpretation of patient responses to questions about choice needs to be undertaken with caution given that patients interpret choice in different ways (see Chapter 5).

Robertson and Dixon and the annual surveys by the Department of Health show that in England awareness of choice of provider increased year by year.

- The percentage of patients recalling being offered a choice of hospital for their first outpatient appointment was 49% in February 2010, up from 45% in January 2007. 2006).
- 54% of patients were aware before they visited their GP that they had a choice of hospitals for their first appointment, up from 36% in January 2007.
- 63% of patients who were aware of choice recalled being offered choice, whereas only 32% of those not aware of choice recalled being offered it, similar to the January 2007 survey (64% and 34% respectively). Interestingly in our study more patients reported being involved in decisions about the timing and location of their care than thought they would be before their consultation (see Table 20).

While the 2010 Department of Health survey results also show that patients were usually able to go to the hospital they wanted (88% of those offered a choice) there is no indication whether patients chose to go to an alternative provider than the one closest to them. Of those who were offered a choice the single most important factor in choosing a hospital was whether it was close to home or work (by 38% of patients offered choice). This suggests that location and accessibility remain the key determinants of hospital choice in England. The level of awareness of choice of provider is similar to that found in the survey by Dixon et al where 46% of respondents were aware they had a choice before visiting their GP. However, the three main reasons for choosing a hospital were different as these were cleanliness, quality of care, and the standard of facilities. However, in both surveys

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what these actually mean is not clear. In Dixon et al, a bad experience of a local hospital was more likely to make patients choose an alternative provider. They also found that access to a car was more likely to lead to choosing an alternative provider.

## 6.1.2 Comparison of choice policy

There were two common objectives across all four countries that emerged in policy interviews: reduction of waiting times and the improvement of service quality. A central focus on tackling waiting times was evident in all countries and very closely linked to initiatives for reducing waiting times for patients in England, Wales and Northern Ireland. The other common objective was the priority placed on quality of service and in England patient choice of provider was part of a set of policy drivers that was also seen as a way to drive up provider quality while other countries emphasized patient and public engagement as the mechanism for achieving quality improvement. Similarly engagement was seen as more important for choice outside England although the more recent emphasis on choice for long term conditions in England has emphasized participation of local patient groups in developing the 'choice sets' or 'service menus'. These developments also seem to be driven from within the Department of Health.

Despite misgivings and, in some cases, hostility to the English patient choice policy in Wales, Scotland and Northern Ireland, all systems aspired to offer as many choices as possible to patients, including offering a choice of provider where possible. Choice was even embedded in referral management systems. Respondents at all levels of our study and in all countries identified a standard subset of referral choices which were potentially available within the referral pathway including:

- choice of provider
- choice of treatment
- choice of appointment date and time
- choice of location of appointment
- choice of consultant.

The results from our study suggest that the nature of choice is not always clearly defined in policy documents. There are specific references to choice in terms of the English patient choice of provider policy, *Choose and Book*, Welsh and Northern Ireland 2<sup>nd</sup> Offer and choice of appointment, the Scottish National Guarantee, but these are very narrowly drawn definitions of process with clear parameters. Choice is also used more loosely in policy in advocating choice for patients, to enable patients to make more

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decisions about their care etc. Often in these circumstances choice is not well defined. Of particular interest is the extent to which 'choice' is distinct from 'voice'. In Wales and Scotland there was explicit reference to the use of patient and public 'voice' as a mechanism for ensuring choices for individuals. This is partially referred to in policy but clearly stated in political rhetoric. For example, in Wales policies such as Designed for Life explained that the intention was to: '... empower the community to have its voice heard and heeded, rather than simply being given a choice of treatment location'.(14)<sup>44</sup> But Ministers perhaps expressed this more clearly such as Hutt quoting Julian Tudor Hart "Though the market model may give patients a louder voice, this will be the shrill cry of consumer choice, not the sceptical thought and responsible voice of the citizen " 101 This is absent in English policy except in relation to long term conditions. While the lack of policy clarity about the nature and degree of choice and how choice is to be defined creates some ambiguity about policy goals but perhaps provides opportunities for local innovation. However, given similarities in booking systems and the actual choices provided to patients greater policy clarity would provide greater policy transparency.

One question we sought to examine in the study was whether there were clear policy differences between England and the other countries. We did find a clear difference at a policy level – particularly within political rhetoric and talk relating to markets but there were signs of some convergence in terms of the application of choice at the level of service delivery (e.g. booking systems, delivery of the 18- week waiting time target in England), although not around use of markets and market rhetoric. There was thus an increasing use of choice as a service delivery tool across the UK. From our study, however, it was not clear how far this was a result of policy learning between countries, a common political concern about waiting times or a reflection of a broader shift in the nature of public services as explored in John Clarke's work and other studies on consumerism in public services.<sup>1,10,14,78</sup>

In all four countries choice for patients remains a limited concept in that not all possible dimensions of choice were being actively pursued in any of the four countries. Respondents in England focused mainly on the stated policy frame for choice and non-English respondents reflected how their policy differed to England or explored notions of choice through discussion of referrals or simply did not see choice as an element of health policy. Some respondents did however, refer to a broader range of choices and there was a strong sense that choice would become more important as an aspect of health policy and service delivery in the future.

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It is not surprising, therefore that the largest number of choices of provider was available in England and, in the other countries, less emphasis was placed on the proactive routine offering of choices, although, where feasible, patient requests would be accommodated. However, as our study shows English GPs did not always offer choices to patients - a finding echoed in the study by Dixon et al. However, offering choices within the referral pathway was not considered an operational priority. The most important operational concern was the need to manage waiting lists and meet waiting time targets although politicians and political advisers in England mentioned equity as an important consideration, seeing choice as providing improved access for more socioeconomically disadvantaged patients

# **6.1.3** Policy in action: implementation of choice policies in the NHS

In this section we examine how patient choice was implemented focusing on the process of providing choices. In examining how NHS and provider organisations managed choice we sought to explore the following:

- How choices were offered to patients were shaped by purchasing/funding organisations and providers
- How choices affected provider organisations

#### How choice was offered

While patients are offered choices in all four health systems there is a lack of consistent approach to offering choice between and within countries. In chapter four we described how providers offer and manage choices in the eight case study areas. While the distinction between policies on choice at a national level was reflected in the views of staff in NHS organisations we found that the referral systems which deliver choices to patients shared a number of similarities irrespective of case study location or country. For example, there was a standard set of potentially available choices in the referral systems of each country:

- choice of treatment
- choice of appointment date and time
- choice of location of appointment and
- choice of consultant.

Irrespective of the national policy focus all countries were unified in adopting formal policies to offer some choice about the date and time of

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appointment to patients. However, the way in which such choices were offered differed between case studies and countries. More choices were made available to patients in England than in the other countries due to specific policies to promote a range of different providers. Choice in England was potentially more proactive than in the other countries although actual choice was provided in different ways with all providers describing how choices became limited depending on how patients made appointments (through *Choose and Book* in the consultation, by calling appointment centres by telephone, responding to letters).

The choices offered, therefore, depended on the methods by which choices were made available and how these are accessed by the patient or by the GP. Choice decisions are defined by whether bookings are made by telephone or over the internet in the English 'Choose and Book' system, whether choices are made at the point of referral by the GP or at a later point in the referral pathway, and whether choice is proactive (offered to the patient) or reactive (responding to the patient).

## Impact on hospital providers

Interviewees at a policy level in England and providers in all countries did not see choice as a driver for improved performance. Choice was not referred to by providers as a key determinant of either their approach to service quality or for completing for patients and interviewees did not report any substantial changes to referral patterns. In England at the policy level (macro) and organisational level (meso) respondents referred to patient choice as an internal organisational driver making organisations reflect on the potential to improve patient care and service quality based on the premise that they might lose patients to other providers or could attract new patients. These responses were not seemingly related to any notion of what patients might want. In this sense English policy on patient choice of provider was not viewed as specifically related to being responsive to patients themselves. There was some evidence of this in our organisational interviews, but as similar expressions of patient focus and quality also formed part of the findings in other countries, it is not clear how patient choice has driven providers specifically to focus on these issues. In contrast, in Scotland and Wales, our findings suggest that patient and public engagement is seen as the 'choice' mechanism for improving service quality and responsiveness. In England providers seemed to be directing attention at GPs rather than patients, for example through the establishment of GP liaison posts. Dixon et al also found that providers focused promotional activity on GPs, and aimed to attract GP referrals rather than patients. 128

All providers in the study were operating booking practices for booking new appointments in secondary care which were defined as 'best practice' at a

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national level. The booking systems in NI, Scotland and Wales, and to some extent England, were broadly similar and contained within them definitions of reasonable choices of date and time of appointment which should be offered to patients. The booking systems in England were slightly more complex as they also allowed patients in some cases to 'directly' book an appointment of their choice over the internet. However, providers structured the booking and referral process to not just limit the extent of choices but also timeframes. This was specifically driven by waiting time priorities. For example, in Northern Ireland, patients were expected to be 'reasonable' when booking appointments and not to turn down appointments. They were allowed to have up to two options for times and had to pick an appointment within the three week timeframe provided. Similarly Welsh patients had 10 days to confirm or change an offer of appointment or otherwise would be removed from the waiting list. Also in Wales there were both partial and direct booking processes offering different degrees of choice of appointment. In Scotland patient focussed booking provided patients with a limited choice of two reasonable offers of appointment.

Generally, therefore, all four countries provided a limited choice and there was an emphasis on what might be considered reasonable. Central to this was the fact that hospitals were using choice systems to manage supply and demand. The ability of providers to remove named consultants from choice menus (within 'Choose and Book') and allocate slots from which choices are made has been used to manage share consultant workload within clinical teams; i.e. a way for hospitals to make the best use of their current patterns of staffing to help manage elective demand. Providers in all countries placed greater priority on meeting waiting list targets than maximising patient choice, especially of individual specialists and in all countries the availability of options was strongly shaped by the need to ensure that waiting time targets were met. It appeared that the resource cost of providing choice to patients during the referral pathway, both in terms of the extra administrative resources required, and the strain put on the fixed resources such as consultant time, meant that for many interviewees, even in England the offering of choices to patients as they were being referred was simply not an operational priority.

#### **Booking systems**

All countries operated some form of booking system for patient appointments. While centrally designed in each country to offer a degree of parity in the way referrals were made and the way choices were offered to patients, it was often noted that a mixture of booking systems was in operation. This led to potential differences in the choices offered to patients between case study sites.

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How booking systems were accessed, influenced the choices available. For example, in England, patients booking over the internet would have had a free choice of appointments from the menu available, and those booking over the phone with a provider would have been offered one appointment at a time. The 'Choose and Book' system was the high profile 'face' of choice policy in England, which, in addition to formalising the choice of provider, also offered the opportunity for patients or their referrers to directly book the hospital appointment of their choice. Electronic booking was also available in Scotland through the SCI Gateway system which for GPs used in consultation with patients to directly book appointments. In Wales direct booking was possible through a telephone appointment system, although partial booking also operated where patients could request a change of appointment when they received appointment letters.

The use of booking systems provided choices for patients, but also defined the limits of choice and what could reasonably be expected to be offered to patients. Those working in provider and commissioning organizations identified a tension between the achievement of waiting time targets and the requirement or desire to offer options to patients. Of particular interest is the way in which booking mechanisms were used to define and thereby limit choices in order to allow queues to be more effectively managed against available capacity to treat patients. Providers perceived another advantage of the booking system to be a reduction in non-attendance rates. Other aspects of booking systems were the placing of greater onus and responsibility on the patients thereby reducing the number of missed appointments, and also the opportunity (especially in England) for providers to offer choice of a specialist team rather than an individual consultant. This provided the hospital with greater control over the management of patient referrals and waiting times, and represented a local trade-off between a focus on individual patient choice and reducing overall hospital waiting times.

#### Referral systems

The focus of choice was on referral for elective procedures made by the GP – choice at the point of referral. Referrals were made through a range of processes but relied on GPs both understanding the referral systems - where patients can be referred, and how. Referral options were framed by the potential choices offered at the point of referral. GPs in our study expressed confusion about the referral options that were open to them and their patients, in particular relating to which were mandatory (such as triage systems for orthopaedics) or optional. The findings suggest that GPs did not know their way round the referral system effectively, and were often not aware of the options for appointments which were available.

132,133,134 This has implications for the operation of choice given that choice

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of referral constitutes part of the patient consultation and how information is accessed.

Scottish GPs appeared to have wider discretion over referrals than those in Wales and Northern Ireland (and until 2008 England) as they could refer patients to any hospital and the expectation was that GPs would discuss such options with patients. Despite this potential, our study suggested that fewer patients in Scotland felt that they had a choice or were involved in decisions. Similarly, in Wales, GPs could refer to any hospital but generally made their own judgement and tended to follow traditional referral routes. This compares with England where more choice was actually available albeit initially from a specific menu of providers. As Gaynor et al have shown, where choice was exercised it may mainly involve patients choosing to go to nearer hospitals, although not necessarily the closest rather than those further away to which GPs may have traditionally referred them. Our findings appear to suggest that simply having a choice of providers is not sufficient to ensure that choice is provided to patients.

Our findings further suggest that the process of choice is more complex than providing a choice of provider and booking time at the point of referral. Patient pathways include a number of points at which further choices could be made. A key development during the study period was the growth in intermediate services designed to manage patient referral pathways. These services consisted of both clinical and administrative triage, but in England these services were in some cases associated with the delivery of choice to patients. The introduction of referral management centres and intermediate assessment services removed decisions about referral choices of provider away from the practice and patients just when patient choice was also a policy priority and the focus was on choice at the initial point of referral from the GP consultation. Similarly, in Northern Ireland, where choice was less of a policy priority, the ICATS regulated the referral process. While ICATS was technically supposed to be a referral choice for patients, in reality all patients were referred to the ICATS where further referrals were then made.

#### Competition

There was little evidence from our data that specialist providers in England were competing for patients although reference was made to patient choice placing greater emphasis on patient experience. Providers in our study seemed to be unaware of increasing competition and the risk of losing market share. This suggests that choice may not have been the only, or most important factor affecting their decision making Interviews with managers and clinicians highlighted other factors such as waiting time targets. Recent studies also suggest that informal perceptions of performance (hospital reputation, perceptions of service quality etc) are an

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important driver in determining organisational performance.<sup>136</sup> One marker of service improvement is a reduction in waiting times for patients. Nationally, Cooper et al report that mean and median waiting times for hip and knee replacements fell between 2002 and 2007.<sup>37</sup> They argue that this reduction is probably a result of a combination of policy initiatives including a rise in funding, government targets, increased patient choice and provider competition.

Le Grand has argued that performance improvements in the English NHS identified in Cooper's and other studies are primarily a result of patient choice and provider competition. The points to falling waiting lists and productivity increases as being a result of increased competition. The Herfindahl-Hirschmann competition indices (HHI) calculated in the current study do suggest some increase in spatial competition but the indices vary across our case studies (See 4.2.3). Analysis of hospital use data by Gaynor et al suggests that there has been a increasing tendency for patients to choose more local hospitals since the introduction of patient choice in England. The main driver of this is that patients with GPs in PCTs whether patients are referred out of the PCT area are less likely to choose suggestions offered by their GP and choose a hospital that is nearer to them. 135

In contrast to Le Grand's claims, Street has argued that it is not possible to argue that choice and competition have driven productivity improvements as other factors have contributed to shorter waiting times, and increased patient numbers. In fact, Street suggests that choice and competition may have had a negative effect on productivity. Bevan and Wynand have also recently questioned whether market style forces within the English health system have produced any benefits. The findings from our study would tend to support the view that patient choice has not been a key factor in creating competition between providers.

Nevertheless, the findings from this study suggest that patient choice is an important influence on health service providers. In England, patient choice appeared to have had a strong cultural impact on health service organisations embedding the importance of the need to attend to the wishes of patients, while in Wales and Scotland it was strongly felt that this was achieved through the involvement of patients and the public more collectively in the planning and redesign of services, although elements of choice existed within referral systems and were, to some extent articulated within policy. However, from interviews with staff in health service providers we found little evidence that patient flows had changed as a result of the choice at the point of referral policy and provider organisations did not report experiencing a significant financial or operational impact. In contrast, Dixon et al did find small but significant changes in patient flows associated with taking up the offer of choice which could be important for

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providers, especially in future as financial pressures grow. Those offered a choice were more likely to travel out of the area. 128

## Provider performance and quality

It would appear that choice mechanisms are important for the management of resources and ensuring efficient service provision. As highlighted above, providers utilise the structures of offering choice to manage capacity and utilisation through restricting time slots available, and retaining control over allocation between individual consultants and clinic locations within the same provider. Our study did not suggest that providers were changing behaviour in response to patient choice. In fact both policy interviewees and NHS staff in England reflected on the role of patient choice not as a market mechanism that incentivised providers to compete for patients but rather as an internal driver that would encourage organisations to be more responsive.

The effect of patient choice as an internal quality driver is also supported by the findings of Dixon et al who conclude that choice acts on quality indirectly rather than through competition for patients. They conclude that providers are more responsive to patient views, and that retaining patients, rather than competing for additional patients, was the more important factor in focusing on performance and quality. Performance rather than responses to competition are an important driver in determining organisational performance.

#### Patient choice in relation to other policies/targets:

Given the fact that providers in our study seemed to be unaware of increasing competition, it seems likely that choice may not have been the only, or most important factor. Interviews with managers and clinicians highlight other factors such as waiting time targets. Choice policies are not implemented in isolation and it was clear that the focus on reducing waiting lists was closely linked to the development of choice policy but also that waiting list targets were seen as more important by those working within provider and commissioning organisations. Our study suggests that there is a constant tension between the need to manage referrals to maximize the best use of consultant time and provider resources to reduce waiting times, and the pressure to offer individual patients choices which may also drive competition and could, potentially, improve quality (and efficiency).

Providers manipulated choice processes in all countries to ensure they achieved maximum use of resources and to avoid distortions in resource use – whether consultant time or location. Providers in England in our study reported meeting their waiting time targets. Whether this was linked to the exercise of patient choice is difficult to ascertain from our findings. In North

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Goringhamshire PCT area, Newtown FT and Eastingshire FT were operating in an increasingly competitive market based on HHI scores. However, this was not the case in Hamptonshire PCT and all sites, in all four countries, reported a reduction in waiting times. It would appear though, that choice mechanisms are important in this process because providers utilise the structures of offering choice to manage capacity and utilisation through restricting time slots available, retaining control over allocation between individual consultants and clinic locations within the same provider.

# 6.2 Policy impact: patient experiences of choice

Our aim was to follow the policy process from policy development to local operationalisation. Therefore, as well as exploring how health care organizations managed patient choice, we wanted to examine how the offer of choice was experienced by patients. Our key objective was to identify the effects of the different policies of choice on access to care and responsiveness to patients' wishes in the NHS in each of the four nations. As outlined in chapters 2 and 5 patient recruitment was difficult, but we interviewed 99 patients across nine practices. While this cannot be seen as a definitive assessment of the impact of choice policies, there are consistencies in experience which provide valuable insights into how choice policy was experienced.

## 6.2.1 The complexities of choice

Our findings echo recent surveys about knowledge and uptake of choice of provider as in some cases patients were offered choices even though they did not expect to have a choice. 63,64, 128, 131 Our study also supports the view that there is low usage of formal information sources such as the NHS Choices Website and a continuing reliance on GPs to guide referral decisions. Patients made little reference to information on hospitals except that one English patient used the choices website and another English patient found information about a consultant from his website. The lack of use of systematic data is not surprising given that reviews of the use of public performance data show that these sources are little used and do not seem to have a major impact on clinical or referral decisions. This is despite patients placing great value on quality as a reason for making provider choices. 59,63,64

Our findings clearly show that referral decisions about choice or location of provider are intrinsically linked to discussions about the nature of the referral in terms of treatment options, severity of the problem etc. This concurs with other research that shows that patients value being involved in decision making processes and that the relationship with the practitioner is crucial. 126,127

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Apart from the fact that some NHS patients in England were offered a menu of specialist providers and/or a menu of appointment dates and times to choose from, the evidence from this study did not demonstrate any obvious systematic differences in patient experience across the four countries. There was as much diversity of patient experience within countries as between countries, and patients raised similar issues in each of the four countries. The GP, and the GP/patient consultation is still a key focus of both policies on choice and where choice decisions about provider and booking time are made. The patients interviewed in this study raised concerns about how discussions about choices were managed in GP consultations. These concerns relate to access to care and reflect, on the one hand, GPs' attempts to follow standardised care pathways and referral management protocols, and on the other lack of knowledge about available services as well as unfamiliarity with the information sources available.

There was no uniform or consistent approach to offering choices to patients between case studies and there were differences within countries. The role of intermediaries is still important and it is not clear how informed either patients or their intermediaries are – whether these are GPs or other health professionals. Reliance on soft or informal information remains high, reflecting the findings of the 2010 National Patient Choice Survey. Dixon et al identified that there was still a reliance on GPs for information but that family and friends experiences also influenced patient choices.

Patients in our study seemed to value involvement in decision making about whether, why to whom and for what they would be referred rather than just being offered a menu of choices. They appreciated information and an option to have a say in discussions about potential referrals with their GPs. This supports the findings of other studies examining choice. <sup>59,</sup> Our findings provide some important observations for the development of choice policies from a patient perspective:

- Patients did not want options to choose between providers just for the sake of having options to choose between. Similarly being responsive to patients' wishes does not necessarily require the provision of menus of healthcare provision with multiple options in terms of place, date and time of care
- Patients value being able to access good and individually appropriate health care, with as many options (or as much flexibility within a broadly standardised system) as will allow them to avoid providers they have reason to think are seriously sub-standard in some respect (for example because they currently have very long waiting times or high infection rates).
- Patients wish to be treated at places and times that are reasonably convenient for them personally

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- Patients value being involved in referral decisions at least in the sense that they are listened to, given information about the rationale for their referral, and kept informed about how their referral should be progressed and is progressing.
- Rather, responsiveness to patients is promoted by attentive and caring health professionals who engage in careful discussions about individual needs, explain the system and support people to navigate it.

# 6.3 Choice and responsiveness

The findings of this study support the hypothesis that the application of choice policy provides a mechanism for improving some aspects of patient responsiveness. Table 22 summarises these findings in relation to the dimensions of access identified by Pechansky and Thomas. 41 Choice of time and date of appointment provided a limited responsiveness to accommodate patient's circumstances although patients in our study were also often concerned about when providers would contact them regarding their referral. In England some patients appreciated the degree of control Choose and Book provided although others found the system difficult to navigate. Few patients expressed an expectation to have a choice of provider or consultant and most were more concerned with discussions within the GP consultation about whether they would be referred. Patients are more concerned about being offered referrals that are good enough by practitioners who have appropriate attitudes and establish good relationships with them, than about choosing between options per se. As discussed above, the role of intermediaries is still important although it is not clear how informed either patients or their intermediaries are – whether these are GPs or other health professionals. While the findings from patient interviews strongly suggests that patients were less interested in menu driven systems and wanted to discuss options with their GP this was not the way that policies were being developed, especially in England, or the way that hospitals were responding.

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Table 22. Patient choice: access and responsiveness: key questions

Access dimension	Relationship to choice agenda	System and patient impacts/outcomes	Key findings	Evidence supporting finding
Acceptability	How do patients get information about the different services/ treatments in order to base their perceptions of that service regarding quality? Do patients know how to access the service and do they use the service? Is the service socially and culturally acceptable?	Changes in patient satisfaction  Range of different types of services available  Changes in use by traditionally excluded populations  Increased social/cultural acceptance	The findings of this study suggest that both patients and GPs have limited knowledge about the range of available services. Patients still rely substantially on referrers to make choices about appropriate providers.	Interviews with GPs, practice staff and patients (Chapters 4 and 5)
Affordability	Who bears the cost of `Patient Choice'? Does Patient Choice escalate health-care costs?	Cost shift from NHS to patients in terms of direct fees and out of pocket costs.  Changes in commissioner costs	There was little evidence among our sample of patients that cost was an issue. This is not surprising as few patients exercised a choice to travel elsewhere.	Patient interviews (Chapter 5)

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Availability	Is there sufficient spare capacity to offer choice? Do the choices enable all patients to get appropriate services and to be satisfied? Do patients and public have choice in types of services made available? How does the availability of different types of health care service affect choices? What impact will supplierinduced demand have on the choices patients make?	Service utilisation Range of services with capacity Patient/public involvement in service and commissioning decisions Impact on service delivery of increased/decreased volumes of patients	Capacity is managed by providers to maximize use of existing resource. Choices are restricted in terms of ability to choose consultant and where providers have more than one site, patients may not get choices about which site they go to.	Provider interviews (Chapter 4)
Physical accessibility	Can patients get access to the service and can they physically use the service?	Location of services Accessible by public/ private transport	Few patients exercised a choice to travel to a non local provider	Patient interviews (Chapter 5)
Accommodation	What differences exist between services in terms of waiting	Waiting times Quality of care	Waiting times were a key priority for service providers	Interviews with service providers (Chapter 4)

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times, amenities,	and commissioners.
quality of care? How	However, choice
do patients trade off	was utilized as a
these differences	mechanism for
against other	structuring service
dimensions of access?	delivery to help
	meet waiting list
	targets.

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In making choices about where or who to be referred to, most patients reported relying on guidance from their GP except where patients had previous personal experience of particular providers and consultants. Being responsive to patients' views is signalled by more than the use of 'exit' strategies and the patients interviewed in this study highlighted the importance of communication and the importance of discussions in GP consultations that encompass more than just a choice of provider or date of appointment. While 'voice' was seen as a key priority by Welsh, Scottish and Northern Irish respondents in relation to ensuring that local services were appropriate (in terms of having a relevant choice) we did not explore whether the processes of voice in these countries contributed to greater patient responsiveness. The study by Dixon et al does suggest that providers are concerned generally about patients' views for their own sake and not specifically because patients may move between providers. 128 Schlessinger has argued that many choices in health care are in response to previous experiences and this view is reflected in our study. However, he also argues that it is voice, not choice " ... that provides a more reliable marker for problematic patient experiences". 142 His argument is that patients are less likely to simply opt for an 'exit option'. The data from our study suggests that the situation is not as clear cut as this. Previous experiences -whether personal or those known about by patients - did form an important element of the decision process in determining choice of hospital or consultant within the context of the GP consultation. However, how much weight was placed on these factors vis-à-vis the guidance from GPs is not clear. From our data the main finding is that patients value being involved in such discussions.

However, choice policy and the mechanisms developed to support the provision of choice also contribute to providers managing their resources more efficiently. As discussed in chapter four, NHS organisations use choice mechanisms to maximise appropriate resource use within NHS providers. While there is no uniform or consistent approach to offering choices to patients, providers in all the case study sites provided a limited set of choices to patients structured around a set menu of time and date, provider and location. However, these choices were not always evident to patients which may reflect the fact that the extent of choice was always limited in ways to achieve optimal utilisation of provider resources.

This study confirms other research that suggests that While GPs are crucial to the choice process they are both ambivalent about promoting choice and acting as a choice advocate on behalf of patients. In our study, English GPs found *Choose and Book* a constraint in the consultation. The reasons for this are complex. GPs in this study were unsure of their role as advocates of particular services when asked for their opinions, as these were often subjective. Some GPs felt they should remain neutral, yet policy-makers

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see GPs as crucial information givers in the choice process. There was also scepticism amongst GPs that patient choice policy increased choices for patients. As Rosen et al found in 2007, GPs vary in the extent to which they actively support choice. There is some evidence from this study to suggest that GPs have limited knowledge about options for treatment and where patients can go reflecting the findings of earlier studies on GP referrals and knowledge of local services. The Dixon et al and DH surveys suggest that half of patients rely on GP mediation of choices and our data support this. This might suggest that more patient information would be useful although most patients in this study did not report actively seeking additional information outside the context of the GP consultation

## 6.4 Strengths/weaknesses of the study

This study explored only one aspect of patient choice associated with the focus of English health policy, namely choice of provider for elective procedures. In addition we focussed on a specific choice made when a patient was referred to a secondary provider. Some choices are clearly made before patients access their GP and these are not included in this study. We did not explore the range of voice mechanisms that are available in each country to determine their role in structuring patient choice. In England this is not explicitly part of choice policy in relation to people with long-term conditions. Notwithstanding these limitations the study does provide some useful insights into these areas.

As with all comparative studies, drawing general conclusions from case studies data may be problematic. We employed various strategies to try and minimise this including choosing case study areas with different characteristics and analysing data by case study as well as by country and across case studies. Therefore, even though the numbers of practices and patients was small we believe that these findings are sufficiently robust.

However, it is important to acknowledge the following limitations:

- We only examined orthopaedics and ENT and not other elective procedures. This may be of particular relevance in England given the introduction of 'free choice' for these specialities in 2008. We decided to use these two areas as there were distinctly different and generally high volume. Orthopaedics was in fact the first pilot condition for free choice in 2007 so on reflection provided a good tracer condition.
- While we are confident of the study results regarding process issues in provider organisations this was a small study and care needs to be taken not to overstate the findings. Our findings do, however,

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resonate with the findings Dixon et al and, importantly, provides important context to some of their findings in relation to how questions about choice are asked in surveys. For example, when asking about choice patients do not simply equate making choices with choice between providers but also wish to discuss other aspects of their referral.

The lack of data on system efficiency and effectiveness meant that we could not undertake the detailed local analysis of referral changes in local areas. We also intended to examine what impact patient choice had on local health services in terms of capacity and volume of services provided. We developed a detailed quantitative data collection framework (see Appendix 3) but despite protracted discussions with local NHS organisations we were not able to collect comparable and reliable data. We were able to examine processes of choice and the way provider organisations have responded to choice type policies but were not able to present data on changes in referrals and service utilisation. However, the HHI data and the study on choice and performance provide some useful data on competition.<sup>77,135</sup> The interview data also suggest that choice mechanisms are being used to improve efficiency in terms of the use of resources to manage patient referrals and minimise waiting times. We do not have sufficient data from our interviews to categorically say that there have not been changes in referral patterns of any significance. This could be a result of our choice of case studies as there were only two in England and the analysis on competition suggests only one of these saw an increase in the HHI In addition, we were not able to collect referral data to examine this within case studies.

# 6.5 Implications for future research

This research has demonstrated the importance of not just examining national policy rhetoric. Examination of policy needs to include looking at those interpreting policy and putting it into practice, and how policies are operationalisted (e.g. the mechanisms for turning policy intent into services that for users). The study highlights both the difficulty of defining or putting bounds around a policy domain of interest and also the complexity of trying to examine the operationalisation, understanding and impact of policy. The multiple contexts of policy pose methodological challenges to the researcher, policy analyst and policy-maker. While 'case studies' provide an ideal way of examining policy development what encompasses a 'case' in this respect is, in itself, a problem. The policy may have been possible in terms of documented policies relating to patient choice, we found that choice policy emerged or 'unfolded over time' – an issue of particular significance in Scotland for example – and that to understand choice policy involved examining its application (and people's

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understanding) within the NHS as well. This was not an evaluation of choice policy but set out to understand the nature of choice policy. While initially the intention, as in many case studies of policy, was to use multiple lens or frameworks to analyse the policy, we found that choice unfolded as a story and thus we focused on building narratives of policy in different countries and at different levels and in different locations. Through this approach, we were able to discover different interpretations of policy and their application. In particular, the approach provided a way of examining the policy within context – national (macro) policy level and at the organisational and operational levels (meso and micro). The comparative nature of the project also highlighted the importance of thinking about health policy in the context of devolution.

Where policy is less, or even non-specific, narrative approaches to case studies, such as used in this study, have considerable attraction. They provide a way of organising the analysis of policy uncovering its internal context (actors, processes, implementation) and the context within which policy is enacted. The approach within this study was to become involved in redefining the unit of analysis as we drilled down into the different levels. However, each level clearly nested within higher levels (National, PCT, department, practice, GP/patient encounter). Essentially we started from the general level of policy documents and interviews, where we retrospectively examined a variety of policies under the broad banner of choice and how they changed over time. Later, we focused down on specific choices in referral pathways being offered at specific times. Combining multi-level case studies with narrative approaches to policy analysis provide a useful and robust way of examining policies which capture both the ideological or value base of policies and their application in practice. Future studies of health policy need to adopt similar multi-level approaches. In addition this study has demonstrated the relevance of within UK comparative studies as providing important insights into policy development.

#### 6.6 Recommendations

Based on the findings from our study we make the following recommendations:

#### 6.6.1 Practice

1. Professionals should not simply present a menu of choices, but discuss if/how different options might be preferable to their patients in their circumstances; i.e. where appropriate, help to interpret quality information (and its limitations).

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- 2. Providers and commissioners need to be clearer about the range of choices being offered and make these clear to patients and local GPs so that there is a clear understanding of what can be chosen.
- 3. Providers and commissioners need a clearer understanding of the patient referral pathways so that choice points are better understood.
- 4. GPs need clear knowledge of referral options and systems if they are to help guide patients through the referral process.

## **6.6.2** Policy

- 1. Provide resources (to cover time) and training for professionals (GPs, referral centre staff) to discuss options (where appropriate) with patients.
- 2. Develop and maintain a database for comparative analysis of referral policies across nations for purpose of policy learning.
- 3. The type and method of providing information is crucial and simply making information available is not sufficient for supporting patient choices. Attention needs to be placed not just on the type of information but also the context within which patients are provided with such information and which they discuss it. Our study clearly demonstrates that patients value discussing options relating to their referral with their GP rather than just making choices from set menus.

#### 6.6.3 Research

- 1. Investigate relationships between patients' options, decision-making supports and choices and changes in quality of care.
- 2. Further research with patients about their actual experience of the choice process.
- 3. Further studies are needed about the choices or decision points in patient referral pathways given the increasing use of referral management centres, integrated triage systems or GPSi triaging.
- 4. Political devolution has introduced a new dimension to UK health policy studies. Further studies are needed that explore:
  - The inter-relationship between health policies in each country to inform cross country learning between systems and also to help explore different solutions to common problems.
  - How political devolution is shaping specific country health policies.
- 5. Further research is needed on the role of 'voice' as a mechanism of choice. The complexity of choices and the way that choices are structured

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by providers suggests that individual mechanisms of exit are not sufficient alone to provide responsive patient services.

- 6. The research also has shown that policy studies need to examine both policy rhetoric as defined by policy makers and in policy documents but also collect data from those involved in implementing and experiencing policies. This study clearly shows that policy is shaped by the context within which it is implemented. The inter-relationship between policies (in this case between choice and waiting time policies) and the demands of ensuring best use of hospital resources) shaped the way choices were offered and experienced by patients in ways that differed from what may have been envisaged at the macro policy level.
- 7. Further application and exploration of narrative analysis is needed to develop better understanding of how policy develops. This examination of patient choice policy reflects a developing policy approach where ideas about choice and the purpose of policy are not always clearly articulated. In this sense policy here could be described as 'unfolding' rather than following a particular pre-determined path.

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# Appendix 1 Ethics approval

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WC1E 7HT

Dear Mr Peckham

Full title of study: A comparative study of the construction and implementation of patient choice

policies in the UK

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# REC reference number:

#### 07/H0806/65

Thank you for your letter of 25 July 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 23 August 2007. A list of the members who were present at the meeting is attached.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA. There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

#### **Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### **Approved documents**

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The final list of documents reviewed and approved by the Committee is as follows:

Document	Versio n	Date
Application		12 June 2007
Investigator CV	6	07 June 2007
Protocol	6	07 June 2007
Covering Letter		07 June 2007
Letter from Sponsor		12 June 2007
Interview Schedules/Topic Guides	3	25 May 2007
Letter of invitation to participant	1	01 May 2007
Participant Information Sheet: Meso	1	23 April 2007
Participant Information Sheet: Practice Staff	1	23 April 2007
Participant Information Sheet: Patients	2	16 July 2007
Participant Information Sheet: Macro	2	16 July 2007
Participant Consent Form: For NHS Staff Member or Patient/Carer	1	20 April 2007

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Participant Consent Form: For Practice and Patient/Carer	1	20 April 2007
Participant Consent Form: Attributed quotes	1	19 July 2007
Participant Consent Form: Individual	2	16 July 2007
Response to Request for Further Information	1	25 July 2007
Referee's Comments-PR3		07 June 2007
Referee's Comments-PR2		07 June 2007
Referee's Comments-PR1		07 June 2007
Statement of Indemnity Arrangements		27 February 2007
Interview Topic Guide: Policy Informants	2	25 May 2007
Interview Topic Guide: NHS Staff	2	24 May 2007
Letter from Funder		30 August 2006

## **R&D** approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

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Guidance on applying for R&D approval is available from <a href="http://www.rdforum.nhs.uk/rdform.htm">http://www.rdforum.nhs.uk/rdform.htm</a>.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx

We value your views and comments and will use them to inform the operational process and further improve our service.

07/H0806/65	Please quote this number on all
	correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

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# Dr Hervey Wilcox Committee Chair

Email: sheree.manson@stgeorges.nhs.uk

Enclosures: Standard approval conditions

Copy to: Ms Penny Ireland

London School of Hygiene and Tropical Medicine

Health Services Research Unit

Keppel Street

London

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## **London - Surrey Borders Research Ethics Committee**

# Attendance at Sub-Committee of the REC meeting on 23 August 2007

#### **Committee Members:**

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Name	Profession	Pre sen t	Notes	
Canon Christopher Vallins	Head of Pastoral Care	Yes		
Dr Hervey Wilcox	Consultant Chemical Pathologist	Yes		

### Also in attendance:

Name	Position (or reason for attending)	
Mrs Sheree Manson	Committee Co-ordinator	

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# Appendix 2 Policy documents and sources published

## **Policy documents - England**

Authors	Year	Title	Findings
Departm ent of Health	2000	NHS plan: A plan for investment a plan for reform	The NHS Plan outlines a vision of a health service designed around the patient. Of its 10 key commitments, two can be seen as relating to choice: to 'shape services around the needs and preferences of individual patients, their families and their carers' and to 'respond to the different needs of different populations' (p4). Specifically care will be 'shaped around the convenience and concerns of patients' (p15) by providing:
			More information for patients
			•Greater patient choice
			Chapter 10 ('Changes for patients) states that patient choice will be strengthened by:  •Right to choose a GP  •A much wider range of information will be published about each GP practice (eg list size, accessibility, performance against standards in NSFs, numbers of patients removed from list)
			•By 2005 every patient will have choice of convenient date and time for hospital appointments

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			and elective admissions.  •GPs (through PCTs) 'will be able to act on published information about patients' views of hospital services by moving service agreements from one hospital to another'. (p89)
Blair, T	2001	Speech to public sector workers at the British Library in central London. October 16.	'We are backing investment with reform around four key principles:  First, high national standards and full accountability. Second, devolution to the front-line to encourage diversity and local creativity. Third, flexibility of employment so that staff are better able to deliver modern public services. Fourth, the promotion of alternative providers and greater choice.  All four principles have one goal - to put the consumer first. We are making the public services user-led; not producer or bureaucracy led, allowing far greater freedom and incentives for services to develop as users want.'  'Patients, similarly, need an ability to choose their GP, and successful GP practices should be encouraged to expand'  'The point, very simply, is this: the user comes first;If the service they are offered is failing, they
			should be able to change provider; and if partnership with other sectors can improve a service, the public sector should be able to do it'
Departm ent of Health	2001	Extending Choice for Patients	A discussion document following on from the direction of the NHS Plan.
			Reiterates Plan undertaking to give choice of appt by 2005, but also promises that 'patients and their doctors will be able to consider a range of options. This might include local NHS hospitals, NHS hospitals or diagnostic and treatment centres elsewhere, private hospitals, private diagnostic and treatment centres, or even hospitals overseas. They will be able to compare different waiting times at different hospitals and across specialties. GPs and referring

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			consultants will be able to book appointments online, The point is that by then, at the point of referral, the patient will be able to choose the hospital and waiting time that is convenient for them'
			From July 2002 all patients who have been waiting more than 6 months for a heart operation will be offered treatment:
			-At another NHS or private hospital
			-At a hospital in Europe
			-In their current hospital but waiting no more than 12 months
			Patients will be supported in making their choice by a patient care advisor and their GP, and will be helped 'at each stage of the patient journey by their own care co-ordinator'.
			'Too often, choice in health care has meant patients having to choose between waiting for treatment of paying for treatment – no choice at all for many' (p3)
			Reduction in waiting lists in order to create the room to manoeuvre to begin to offer real choices for patients' (p3)
Departm ent of	2002	Delivering the NHS	•From July 2002 patients who have been waiting 6 months for a heart operation will be able to choose from a range of alternative providers (public or private)
Health		plan: next	•The system will be rolled out for other conditions beginning in London later in the year

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		steps on investment, next steps on reform	•Information on waiting times for all major treatments for all providers will be published on the internet and elsewhere
			From 2005 patients and GPs will be able to book appointments that are convenient in terms of time and place, and IT systems will allow waiting time comparison
			Patient choice will be underpinned by:
			1. A financial system where money follows the patient in order to incentivise providers and identify and use spare capacity
			2. Information:
			PCT prospectus containing data on the availability and quality of local services and the choices that are available in primary care (eg female GPs, specialist services)
			CHAI (now healthcare commission) will provide information on outcomes from individual consultant teams eg mortality rates following heart surgery
Brown, G	2003	A modern agenda for prosperity	In this speech Gordon Brown acknowledges limits to markets:
		and reform, speech made to the Social	'in health, not only is the consumer not sovereign, but a free market in health care will not produce the most efficient price for its services or a fair deal for its consumers.'
		Market	'Even in a world where health care is not organised on market principles with consumers paying

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		Foundation, 3/2/03	for their care, it is in the public interest to have devolution from the centre and to champion decentralised means of delivery. This includes contestability between providers on the basis of cost and efficiency.'
Miburn, A.	2003	Choices for All. Speech by Rt Hon Alan Milburn MP, 11/2/03 to NHS	In this speech Alan Milburn argues that the historical approach to providing public services was paternalistic and treated everyone the same ('the era of the one-size-fits-all public services is over). This approach weakened public attachment to public services. Milburn argues that 'expanding choice can strengthen it'.
		Chief Executives	Milburn also argues that 'greater choice can bring greater equity'. It does this in three ways:
			(1) Extending choice from the few to the many
			(2) Driving up the quality of services in poorer areas
			(3) Binding the middle classes to public services.
			'The main argument against more choice has been that it will bring less equity. I want to argue the reverse: that greater choice can mean greater equity.
			We do not start from a position where uniformity of provision in the NHS - with precious little choice for patients - has guaranteed equality of outcomes. In fifty years health inequalities have

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widened not narrowed. Too often even today the poorest services tend to be in the poorest communities. Choice has only ever been available to those with the ability to pay. Those with the money have been able to exercise more choice - and buy faster, if not better, services as a result.

This institutionalised two-tier health care is anothema to those of us who believe care should be based on need and not ability to pay. The real inequity is to force the pensioner with modest savings who has worked hard all their lives and then needs a heart operation to choose between paying for treatment or waiting for treatment. That is a dilemma I want to solve.

We can do so by making choice more widely available on the NHS so that it is extended to the many not just the few. Some say poorer people do not want to exercise choice or are not able to do so. I disagree profoundly. That is patronising nonsense.

When I grew up on a County Durham council estate it didn't much impress me that it was the council, not my family, who chose the colour of my front door. Perhaps unsurprisingly hundreds of thousands of council tenants opted out of council ownership when they had the chance to do so. The old-style, often paternalistic take-it-or-leave-it, like-it-or-lump-it relationship between council housing services and council tenants weakened public attachment to public services. Expanding choice can strengthen it.

And by linking the choices patients make to the resources hospitals receive - alongside the systems of standards, inspection and intervention we have put in place - we can provide real

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incentives to address under-performance in local NHS services. As we know poorer performance is often concentrated in poorer areas. Giving people the power to choose between services will drive standards up. In this way, greater choice can enhance equity, not diminish it.

The world has moved on from the days when Henry Ford said you could have any colour car as long as it was black. The Ford Motor Company is 100 years old this year. Today, Ford produce cars so that you can have any colour - including five different shades of black!

Of course, choice in public services is more complicated than choosing the colour of a new car but unless the NHS offers some choice to patients, more of them - at a time when personal disposable income continues to rise - will simply take their custom elsewhere. More will abandon collectively funded public services for privately paid-for services. In the mid-1950s only half a million people had private cover for health care. Today it is almost 7 million. Ironically, those who rail against choice in public services on the grounds that it is a market-based reform risk ending up strengthening private markets not weakening them.

The trap we must avoid, is that identified by Richard Titmuss four decades ago, of middle class people opting out so that public services become only for the poor and then end up being poor services. By strengthening the appeal of NHS provision across social classes, greater choice can enhance social cohesion not diminish it.'

PbR:

'Over the next four years an increasing proportion of each hospitals income will come as a result

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			of the choice patients make. Choice is not just about making patients feel good about the NHS, It is about giving the patient more power within the NHS.'
Byers, S	2003	Speech to the Social Market	Posits that choice can reduce inequalities by 'binding' the affluent to the public sector:
		Foundation. 28 May	'To deny choice would lead to the break up of public service provision as we know it today. It would create real two-tierism, as those who could afford it would flee to the private sector in order to be able to exercise choice.
			If this were to happen it would put at risk universal provision funded through general taxation. We cannot allow this to happen. Offering choice is one way in which we can bind into the public sector those that can afford to go private'.
Blair, T 2003	Progress and Justice in the 21st	Posits that choice reduces inequality by extending choice to many:	
		century. Fabian	'Those who defend the status quo on public services defend a model that is one of entrenched inequality. I repeat: the system we inherited was not equitable. It was a two-tier system.
		Society Annual Lecture. Fabian Society 17 June.	Our supposedly uniform public services were deeply unequal as league and performance tables in the NHS and schools have graphically exposed. The best schools were either private or in affluent areas; access to the best healthcare could be bought; the highest crime areas were in the lowest income neighbourhoods; and public transport was most deficient in serving the most deprived housing estates. The affluent and well-educated meanwhile had the choice to buy thei way out of failing or inadequate provision - a situation the Tories 'opting out' reforms of the 1980s encouraged. It was choice for the few, not the many.'
Reid, J	2003	Speech to New Health	Undertakes to: - extend choice beyond elective care into services such as chronic conditions, primary care and

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		Network, 16/7/03	maternity service - work with patient groups to develop 'radical proposals' - enable people to contribute to the debate
			Holds that patients should be given individual and collective power. Individual choice where possible, and where this is difficult (e.g emergency care) 'we will empower patients collectively by increasing the accountability of local health services to local communities' for instances through Foundation Trusts.
Departm ent of Health	2003	Choice of hospitals (July)	Guidance for PCTs, NHS Trusts and SHAs on offering patients choice of where they are treated, specifically outlines the actions needed to give choice at 6 months to all patients waiting for elective surgery by summer 2004 and introduces initial guidance for the introduction of choice at referral for electives from December 2005.
			Assumes that 'patients value choices'.
			Proposes that the benefits to patients of choice are:
			•Greater involvement and control over their treatments so that choices reflect the patients' priorities
			•Faster treatment
			•Greater certainty over the time they will be treated
			•Reduced variation in standards of care, as more standardised care pathways are introduced and patients apply pressure for higher standards
			•Greater equality of choice for all patients
			For choice at 6 months PCTs are to be responsible for 'establishing a system of Patient Care

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			Advisors who will support patients in making their choices', and also commissioning 'an appropriate package of transport services'.  Introduction of choice at referral will be accompanied by the roll out of the Electronic Booking Service.
Departm ent of Health	2003	Fair for all personal to you	A consultation pack for the national consultation on choice, responsiveness and equity in health and social care (August – December 2003). Asks what choices people want, information needs, how the system should change to accommodate these choices, and how choice should be made fair.
			'Offering choice is not an end but a means to improving the patient and user experience – a means to empower and enable patients and users and professionals to make shared and sustainable decisions, to enable the NHS and social care to deliver a service that is more responsive and to tackle unfairness'
Departm ent of Health	2003	Building on the best. Choice, responsiven	A strategy paper based on results from the 'Choice, Responsiveness and Equity' consultation led by Harry Cayton, launched in August 2003
		ess and equity in the NHS. (December)	Choice as a means to better and more responsive services. Choice strongly linked to equity of access and efficiency '…responsiveness to patients and the ability to offer them real choices goes hand in hand with better use of capacity' (p5) Choice to be 'widened and deepened' beyond elective surgery (p6) Also proposed as a route to 'equity of excellence: to make the best available to all' (p13)

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Outlines 6 main changes to increase choice and responsiveness:

- Give people a bigger say in how they are treated
- Increase choice of access to a wider range of services in primary care
- Increase choice of where, when and how to get medicines
- Enable people to book appointments at a time that suits them, from a choice of hospitals
- Widen choice of treatment and care, starting with greater choice in maternity services and greater choice over care at the end of life
- Ensure people have the right information to make choices

#### Primary care

•From April 2004 PCTs can encourage a wider range of primary care providers offering a wider range of services

#### Medicines

- •From December 2004 patients can pick up repeat medications from their chosen pharmacy. By December 2007 patients can pick up repeat medications from any pharmacy.
- •Continuing to increase number of medicines available OTC and types of health care professionals who can prescribe

#### Secondary care

- •From August 2004 people waiting more than 6 months for surgery will be offered faster treatment at an alternative hospital
- •From January 2005 choice at point of referral for cataract patients
- •By December 2005 patients requiring surgery will be offered a choice of 4-5 providers at the point of referral

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			•Building capacity to increase choice of treatment options in maternity and palliative care Information to support choice
			Shared decision making - Development of personalised care plans in HealthSpace for inclusion in the NHS care record - Development of Expert Patient Programme
			Increase choice of information channel:
			•NHS direct digital TV service
			•NHS direct online
			•NHS direct self help guide in Thompson Local
			•'Your life' magazine in conjunction with Dr Foster
			•'Your guide to local health services' produced by PCTs and delivered to every household
			•www.nhs.uk
			•NHS Information Partner accreditation scheme
			•'Best treatments' in conjunction with the BMJ
Departm ent of Health	2004	Choose and Book – Patients	Policy framework for choice and booking at point of referral.  - Patients will be 'supported in making their choice by their GP or primary care professional and, where necessary, by a range of practice, PCT and community and voluntary sector based
		choice of	services. PCTs will provide targeted packages of support designed to ensure that all patients,

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		hospital and Booked appointment s	<ul> <li>including heard to reach patients and communities, can benefit from choice.'</li> <li>- Aftercare and rehabilitation to be provided locally following any hospital treatment.</li> <li>- Secondary care services will be responsible for ensuring that bookings are honoured.</li> <li>- All patients can expect their GP to introduce the choices available to them and to discuss any clinical implications of the choice.</li> </ul>
Departm ent of Health	2004	The NHS improvemen t plan: putting people at the heart of public services	This document sets out the priorities for the NHS between 2004 and 2008. Attention moves from increasing investment and capacity in order to achieve improvements in waiting times to ensuring responsive, convenient and personalised services. It states that 'patients' desire for high-quality personalised care will drive the new system'. It reiterates many of the policies set out in 'Building on the best'.  - •Patients will be able to choose from at least 4 or 5 providers for planned hospital care from December 2005  - •By 2008, patients will have the right to choose from any health care provider which meets the Healthcare Commission's standards and which can provide the care within the price that the NHS will pay.  - Certain patients will have transport costs covered by the Hospital Travel Costs scheme.  - Innovative new providers in primary care will be encouraged to provide services in deprived areas and for commuters.  - Where possible patients with long term conditions 'will be able to choose where and when they receive care and will be supported in making these choices'. Specifically patients will be given a choice of making contact via the telephone, digital television or the internet and increasingly GPs with a special interest may be able to provide specialist treatment.  - Emergency/unscheduled care will be provided in a wider range of settings.
Departm ent of Health	2004	Choose and Book	This document sets out the requirements to offer fully booked appointments from a choice of 4-5 providers by December 2005. NHS organisations are expected to increase the level of choice available to patients so that:

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			•From Aug 2004, patients waiting more than 6 months for elective treatment will be offered faster treatment at an alternative hospital.
			•From Jan 2005 patients requiring cataract surgery are offered a choice of hospital at the time they are referred for treatment
			•From April 2005 patients who need a heart operation will be offered a choice of hospital at the time they are referred for treatment
			•By December 2005 patients who require an elective referral will be offered a choice of 4-5 providers and a choice of time and date for their booked appointment, at the time they are referred:
			By 2005 patients can also expect information to be provided locally to inform their choice and
			'to be supported in making their choice by their GP or primary care professional and, where necessary, by a range of practice, PCT and community and voluntary sector based services. PCTs will provide targeted packages of support designed to ensure all patients, including hard to reach patients and communities, can benefit from choice.'
Blair, T	2004	Choice, excellence and equality,	'In reality, I believe people do want choice, in public services as in other services. But anyway choice isn't an end in itself. It is one important mechanism to ensure that citizens can indeed secure good schools and health services in their communities. And choice matters as much within those institutions as between them: better choice of learning options for each pupil within

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		Speech 23/6/04	secondary schools; better choice of access routes into the health service. Choice puts the levers in the hands of parents and patients so that they as citizens and consumers can be a driving force for improvement in their public services. And the choice we support is choice open to all on the basis of their equal status as citizens not on the unequal basis of their wealth'.
Departm ent of Health	2005	Creating a Patient-led NHS	Details of changes required to deliver the commitment of the NHS Improvement Plan to create a patient-led NHS.
			'Choice and diversity are as important in primary care as in hospital services. The NHS needs to have enough capacity so that a patient's existing choice – which practice to join – is not constrained by lists being closed locally. And the NHS needs to develop new choices for patient who want an alternative to traditional models'
			While [choice of provider] are very important to patients, they are just the beginning in terms of making choice a reality across the whole system. There is more work to do to develop thinking on how choice should be available within primary care, emergency and specialist networks, how far providers should offer choices in treatment and ongoing care and how choice at the end of life will work.'
			<ul> <li>PCTs to offer choice of 4/5 providers from 2006</li> <li>By 2008 will be free choice of providers who can meet standards and tariff</li> <li>GPs and PCTs not to direct patients to particular providers</li> </ul>
Departm ent of Health	2005	Health reform in England:	Moving from a 'politician led NHS' (targets and performance management to drive up standards) to a 'patient-led NHS' (improvements become continuous, driven by the NHS always responding to patients' needs and expectations). The aim is a 'self –improving NHS' that is 'free

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		update and	for all and personal to each'.
		next steps	4 connected strands ('inter-related and mutually reinforcing'):
			Demand side reforms – more choice and stronger voice (policies include patient choice and practice-based commissioning).
			Supply side reforms – more diverse providers with more freedom to innovate
			Transactional reforms – money following the patient, rewarding the best and most efficient and giving others incentive to improve
			System management reforms – to support quality, safety, fairness, equity and value for money
Departm ent of Health	2006	Our health, our care, our say	White paper describing how reforms will be applied to primary and community care.
i iodiii		our ouy	Better access to general practice
			Changes to the system of registration to make it easier for patients to register with a general practice of their choice
			PCTs are expected to take steps to improve provision of general practice in underserved areas, for example through encouraging entrants from the independent sector.
			PCTs will be expected to provide information to patients to support choice of primary care services.
			PCTs are charged with encouraging GP practices to become more responsive to patient preferences (eg offering more convenient opening hours).
			In the future the DH will seek to refine GMS and PMS contracts so as to reward practices that attract new patients.

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			Long-term conditions
			The aim for patients with long-term conditions is to provide 'comprehensive, integrated and more effective packages of care'. This will be achieved through extension of PbR:
			'we will explore whether there are refinements to the current tariff that could provide incentivesto support co-operation between commissioners and providers in delivering integrated long-term conditions care.'
			Care closer to home
			<ul> <li>Defining clinically safe pathways within primary care for dermatology, ENT, general surgery, orthopaedics, urology and gynaecology</li> </ul>
			Establishing community hospitals
			Patient choice and Practice-based commissioning 'will be pivotal vehicles for making this happen. Using indicative budgets practices will be able to see clearly how the overall health spend on new patients is being used; they will then have the scope to redesign care pathways to match patients' needs and wishes'.
Departm ent of Health	2006	Choice Matters	Report illustrating ways in which choice has improved patients' experiences. Details timeline for implementation of choice. Future milestones are:
Пеаш			2008 Free choice
			2009 Women given choice over where and how they have their baby and pain relief
			No date given More flexibility in choice of GP
			Reference group to be established, to include clinicians, patient representatives and other

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			experts Information Taskforce to be established, chaired by Bruce Keogh
Departm ent of Health	2006	The NHS in England: the operating framework for 2006/07	Choice to be extended in 06/07 to include any NHS FT, nationally procured ISTC, and any other centrally accredited IS provider.
Departm ent of Health	2007	Choice at Referral – Guidance Framework for 2007/08	Supplementary guidance giving framework for extension of choice. Announces phased implementation of free choice on a specialty by specialty basis, starting with orthopaedic services in July 2007. Gives details of eligibility for national menu (meeting 18 weeks, Choose and Book registered and directly bookable appointments online, Healthcare Commission registered, meet information requirements, appropriate liability cover)
			'GP referral will continue to constitute authority to treat on behalf of the relevant PCT. PCTs may wish, in accordance with practice-based commissioning, to guide their GPs on the affordability of certain treatments that may be available on the national menu in other parts of the country, and what the PCT is prepared to fund must be clear to all parties at the point of referral'
Departm ent of Health	2007	Choice Matters	Report illustrating ways in which choice has improved patients' experiences, including information of latest policy developments concerning the introduction of the Extended Care Network.

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Departm ent of Health	2007	The Operating Framework for the NHS in England 2008/09	Choice characterised as an 'enabling strategy'. Annex D, 'Principles and Rules for Co-opera and Competition', provides a code of practice for providers. The Framework also refers to a 'promotion code' advising providers how they may inform patients of services.  Framework also outlines expectation for PCTs to give more choices to patients with Long Te Conditions.
			Annex D – Principles and Rules for Co-operation and Competition  Rules apply equally to NHS, third sector and independent sector and are effective from April 2008. Principles include allowance of 'appropriate promotional activity'
Brown, G	2007	Speech at Launch of NHS Next Stage Review	Refers to choice in the context of increasing access to GP surgeries at convenient times, ar opening GP-run health centres.
Departm ent of Health	2007	NHS Next Stage Review Interim Report	Patient choice 'should be embedded within the full spectrum of NHS care, going beyond elective surgery into new areas'. Suggests that new GP practices should be invested in, her centres should be established in easily accessible locations, greater flexibility in GP opening hours. Emphasis on providing access to services at the time and place of patients' choice. It information about all GP practices to be made available on NHS Choices from October 200's States that personal care budgets may be possible.
Departm ent of Health	2007	Generic choice model for	Gives best practice generic model for commissioning services for those with long-term conditions to support choice and personalisation of care.

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		long term	
		conditions	'For people with long term conditions, choice means bringing together with their healthcare professional the information about their life, available care and treatment options, and together deciding on a personalised package of treatment and care.
			Choice at two stages, diagnosis and living with condition. Choices are i) where/whether to receive treatment or services; ii) whether to receive single or group services and iii) support for decision making. Envisages shared decision making between individual and care professional. Commissioners have to aggregate the choices of individuals into a range of services to commission. Suggests that commissioners undertake robust market research to understand patient views and experience and segment the population using 'social marketing techniques', design services that respond to the outcomes of market research, create a meaningful menu covering treatment type, individualised support, access to information, options for self-care, supported living and end of life care.
Departm ent of Health	2008	Choice at Referral – Supporting information for 2008/09	Provides support and guidance for commissioners and providers on how the full roll-out of 'free choice' in elective care will operate in 2008/09.
Departm ent of Health	2008	Code of Practice for the promotion of NHS-funded services	Sets out the rules around promotional material issued by providers of NHS service to ensure that:  the information patients receive is not misleading, inaccurate or offensive;  the brand and reputation of the NHS is protected; and  expenditure on promotional activity is not excessive.

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			States that Care Quality Commission is to be established in April 2009 to assess both public and private providers of services to ensure that services meet NHS standards.
Departm ent of Health	2008	Choice Matters – working with	Update on the implementation of patient choice in the NHS focusing on the work that has been done with library staff.
		libraries	

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## **Policy documents -Wales**

Authors	Year	Title	Findings
Secretar y of State for Wales	1998	Better Health Better Wales	This paper stated that "The new focus of NHS Wales will be on collaboration rather than competition." Patient choice is one outcome of a consumer based or competition based healthcare system, thus NHS Wales have suggested that this is not the way they wanted to go.  However it also stated that to improve health and support patients, that they will increasingly demand information about the choice of services available to them.
The National Assembl y for Wales	2001	Improving Health in Wales. A plan for the NHS with its partners.	The primary objective of the plan is to improve health and reduce inequalities in health and access to health services. The plan aims to do this primarily through joined-up working and partnership between the NHS, local government, the independent sector and communities. In so doing the plan aims to address the wider determinants of health such as poverty and deprivation.
			Secondary objectives are to provide better services for patients and to improve waiting times.
			The plan emphasises engaging citizens, participation and democracy.
			Key policies:

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- •Planning provision of health services to achieve political objectives (eg address health service inequalities, use collaborative working to provide more effective care)
- Managed clinical networks
- Integrated packages of care for chronic illness
- Care pathways and protocols

## Choice:

The Plan emphasises 'voice' rather than 'choice'.

Reform of the primary care sector includes policies to increase team working and in so doing increase the range of services for patients. In this way an increase in choice is seen as an element of better, more responsive services (achieved via hierarchical governance rather than markets). Similarly there will be an increase in the number of services that are available 24 hours.

There is a single reference to extending direct payments for long-term care

Like England, Wales seeks to reduce waiting lists but uses targets rather than choice as the mechanism.

Chapter 3 of this paper is entitled 'the people's NHS: public and patient involvement'. This chapter states that a framework for NHS Wales is being developed which is sensitive to patients' needs. It also states that finding out what patient want will underpin the improvement of services. "This will help us to shape services that are

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			sensitive to patient needs and which, whenever practicable, comply with patients' preferences."
			Improvements to the NHS appointments system it states will ensure that it reaches all members of society in Wales, particularly those from under-represented communities. It also states that people need better information to have more control over their own health in order to make the best decisions of the options available to them.
			The paper also states that in 2001, a new Health and Social Care Charter will be published and it will be underpinned by local charters which will provide information about choice and access to local services.
			As the paper continues into the next chapter on partnerships for health it states that "Service users and, where appropriate, their families and carers should feel that they have choices about the services provided for them."
National Assembl y for Wales	2001	Signposts - A practical guide to public and patient involvement in Wales	This document is a guide for NHS organisations to use when developing patient public involvement and mentions the issue of patient choice very little. It suggests that NHS Wales should be responsive to patients needs in its introduction.  In the section on performance management it has a table of values and aspects of performance and under 'responsiveness' states that an aspect of performance is "The
		vvaics	extent to which services: demonstrate patient involvement, good information and choice."  The paper suggests that at the individual level of involvement might mean receiving information about services and so forth and it also states "or getting involved ion choices about care and treatment options." It suggests that this is an influencing dimension to patient involvement and further expands this in a table which links

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			purpose and outcomes that states that influence at the individual and collective involvement will or should lead to patient choice and patient centred care as an outcome.
Welsh Assembl	2002	Informing healthcare	This document sets out a vision for transforming healthcare in Wales through the use if ICT tools.
y Govern ment			The paper states that "In response to growing consumer demand for higher quality service and greater choice, many industries and services have taken advantage of technology in recent years to
			Improve the quality of their service to customers.
			Improve the quality of their products and services.
			Improve the speed and efficiency of their operations."
			The paper suggests that the potential benefits from automated healthcare processes include the electronic resource scheduling and booking systems which can ensure services are patient centres and that activities take place the right way for minimum patient inconvenience.
			Under the heading of patient empowerment the paper suggests that modern care must be based on the beliefs and wishes of patients. It also suggests that complexity of care means that there are often many choices in terms of nature, timing, costs, risks and benefits of treatment. Individual patient wishes it is suggested should be taken into account. An inclusive approach to healthcare therefore means that organisations need access to high quality information to help ensure patients can make decisions, in addition the information from the patient needs to be available to

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			healthcare professionals.  The paper suggest that it will be possible to introduce electronic scheduling across primary and secondary services there will be bookable times convenient to the patient, that they themselves can choose.  The paper suggests that there is evidence to suggest that greater access to information within their own records will help patients make choices regarding complaints about their treatment.
Welsh Assembl y Govern ment	2002	Health and Social Care guide for Wales	This paper is designed to guide patients through health and social care services in Wales, where they can go for treatment, who to contact, services available and so forth. There are a few references to patient choice throughout this paper.
ment			"By 2003 we aim to make sure that most outpatients have a choice of appointments We will continue to make sure that people also\have a choice of inpatient and day case appointment times."
			"Adolescents will be cared for in either a children's, adolescent or adult ward depending on their age, development, the facilities available and their personal choice."
			"Your local social services will: make sure that you have a choice about which care home to move into."
Welsh	2003	Telemedicine	This paper suggests that ehealth can be developed in one of two ways.

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Assembl y Govern ment		and Telecare Programme Deliverable 06: Future of eHealth	<ul><li>1 The "pull" system whereby the change is consumer led and driven by choice – with the possibility in the reduction in equity of access.</li><li>2 The "push" system, an approach based on control, normally when funding is tight, with government playing a major role.</li></ul>
Wanless ,D	2003	The Review of Health and Social Care in Wales - The Report of the Project Team advised by Derek Wanless	In the section on Health and Social Care in Wales in the Future there is a section on choices. The report states that this should not just be in involvement in the decision making process about the shape of service provision and the choices available for that provision.  The report states that as well as involvement in choices about future services, " the public should enjoy choices about the treatment available to them – we must move on from a 'one size fits all' philosophy." It also states that as people become fully engaged in they will want choice in their health and social care. The report also recognises that the expansion of choices implies a recognition that some choices, particularly social care service provision choices will not be paid for by the state.  The section on the role of the state urges the assembly to think about and situate the debate around the role of the state in providing care. Taking into account certain issues including  "That if choices are not provided as part of the publicly funded system, then some will opt out and public provision will be residualised by default."
Perkins, A	2003	Morgan heads for student fees clash	In this interview for the Guardian Rhodri Morgan, first Minister of Wales, sets the Labour government in Wales apart from England:

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			"Clear red water is a useful definition of the difference between London and Cardiff,"
			"We're more interested in community values than con consumerist values," he said.  "Our attitude to the future of the health service is not about how much competition, how much out-sourcing, how much consumer choice."
BBC News	2004	NHS choice 'not relevant to Wales'	Reports on a speech on the public sector given by Rhodri Morgan in Cardiff on 24 June 2004. Rhodri Owen is quoted as saying (in regards to choice):
			"Our geography does not encourage this social model, and I don't think our values encourage this model either".
Audit Commis sion in Wales	2004	The new GMS Contract for GPs and other Healthcare Professionals - Investment for Improvement.	This paper suggests that the new GMS contract provides a real opportunity for LHB it states that it provides LHB's the opportunity to think about how services are provided in their locality. It also states that "By managing their enhances services budget effectively LHBs can: improve patient choice."
Welsh Assembl y Govern	2004	Making the connections: Delivering Better	This paper sets out the Welsh Assembly Governments' vision for public services.  The paper posits that there are two models which aim to extract value from public services

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ment		Services for Wales	The first is based on breaking up large scale organisations into smaller bodies with budgets and freedom as providers, it suggests enhanced efficiency and responsiveness levels emerge through the more competitive and entrepreneurial environment. This model, a competitive model, it is suggested, appear to offer the public service user more choice, it suggests however that it is the management team who are empowered by it. This is not the model that WAG has opted for.  The model that WAG have chosen seeks to optimise efficiency through the scale economies of more effective co-operation and co-ordination between and across the whole of the public sector, including independent, voluntary and private sectors. By
			using co-ordination rather than competition, users and producers of public services are on the same side and the best outcomes are when providers and users work together.
			The paper suggests that services should be more responsive to the needs of users.
			Throughout this paper examples of good practice are suggested and one example from the NHS that is cited is that of the second offer scheme and suggests that this is Welsh public services responding to patients needs. The second offer scheme means that if a patients local hospital doesn't provide treatment within WAG's maximum waiting times, then a second offer will be made for immediate treatment elsewhere. It suggests that co-operation between trusts ensures that the patient receives joined-up working.
			However the patient can choose not to have the treatment and this is basically patient choice.
Bourne,	2004	Wales needs	In this speech Nick Bourne AM criticises the Welsh Assembly for failing to incorporate
N N		choice in	choice in its initiatives. He states that "Our [conservative party] vision of transforming

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		public services - Speech to the South Wales policy forum 6 November	services in Wales is based upon the principle of expanding choice for the many at present enjoyed only by the few who can afford it to pay for it."  He states even Tony Blair has recognised the importance of choice in driving up standards. Bourne states "Rhodri Morgan has dogmatically ruled out choice in Wales' public services. Indeed in a speech recently he criticised more competition or choice in health and education as 'amoral'."
Hutt, J	2004	Nye Bevan Lecture 2004	Jane Hutt in this paper criticises the image of the ill patient as a 'suspicious shopper', demanding " a range of goods from which to make personal choices.' She advocates the reciprocal relationships that can help improve services. She discusses the second offer scheme which highlights the numbers of people being offered their operation at a different hospital.
			She highlights a quote from Julian Tudor Hart which sums up the Welsh Assembly's view of the market model "Though the market model may give patients a louder voice this will be the shrill cry of consumer choice, not the sceptical thought and responsible voice of the citizen."
Welsh Assembl y Govern ment	2004	Health and Social Services Committee minutes 24 March	This committee meeting is focusing on a review of the interface between health and social services with different members representing organisations such as the Welsh Institute for Health and Social Care (WIHSC). The Royal College of Nursing Wales, in response to comments and questions from members presented many points. One of which was "a definition of patient choice was needed."
Wales Audit Office	2005	Press release 14 January. NHS waiting times in	"Partial booking where trusts contact patients around 6 weeks before their appointment has increased the efficiency of outpatient clinics by reducing the number of patients who do not turn up while improving patient choice."

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		Wales. Report by the Auditor General for Wales.	
National Assembl y for Wales.	2005	The Official Record 26 January. The second choice scheme.	The Minister for Health and Social Services asks that the Assembly note the progress made in reducing waiting times thanks to the Second offer scheme. The second offer scheme was first implemented on 1 April 2004, with an 18 month guarantee. It offers anyone who is waiting or likely to wait, longer than the maximum target time for inpatient or day care the opportunity to be treated elsewhere, or in house in their trust. Dr Gibbons states that some however chose not to accept the second offer. David Melding asks Dr Gibbons "We 'have heard you use a particularly ingenious euphemism. Is 'smartening up' a way of saying that competitive pressure, at least in some degree has been brought to bear in the NHS Wales?"  The Minister states that he doesn't think that it is fair to call it 'competitive pressure', he suggests it simply means that trusts will have to focus resources effectively.  Those patients who took up or refused the second offer, exercised patient choice, although, this, as has been stated in the introduction to this paper, is not an aim of the second offer scheme.
National Assembl y for Wales	2005	Audit Committee. NHS Waiting Times in Wales. Questions 1- 129. 3	Janet Davies, the chair  Irene James - Assembly member  Mick Bates – Assembly member  Ann Lloyd – Head of Health and Social Care Department

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		January.	The Committee is looking at the Audit Committee paper on Waiting Times in NHS Wales. Ms Lloyd is asked by Irene James why a quarter of those patients who had waited over 18 months and were subsequently contacted as part of the second offer scheme were actually removed from the list.
			Ms Lloyd states within this answer that patients have also been exercising patient choice, such as in terms of whether or not they still require their operation or treatment. Ms Lloyd continues and suggests that patients cancel because the waiting list slot is not convenient, that is why, she says, they have instituted a partial booking system so that, the number of new out patients who do not attend is reduced. All trusts must do this, and those who have implemented partial booking, which gives patients a choice of when they attend have found that the number of do not attend has gone down 5 or 6 per cent.
			The questions continue and Mick Bates has asked Ms Lloyd questions on patient behaviour affecting efficiency of out patient departments, in terms of failure to attend. Mick asked Ms Lloyd if the number one priority to reduce the 'did not attend' rate was that GP's refer directly. Ms Lloyd states that it would be stating that England, started with partial booking and is now just going to full booking and that is where, she says that Wales wants to go too.
			Ms Lloyd continues and states that partial booking has helped to be much more flexible and it gives patients the choice within six weeks of when they will see someone which appointment suits them and focuses on their needs and lifestyle.
National Assembl	2005	Audit Committee.	Denise Idris Jones – Assembly member  Ms Lloyd –

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y for Wales		NHS Waiting times in Wales. Questions 130-228. 10 February.	Ms Jones is asking about delayed transfers as a key to improving patient throughput and continues by asking what impact the issuing of revised patient choice guidance by WAG has had? Ms Lloyd states that patient choice was a means by which some families or patients decided that they wished to stay in their surroundings and didn't want the alternative. She states that patient choice has to be respected but it isn't good to retain people in hospitals when they could be somewhere else. However if patients choose to stay there, it is very difficult to do anything about it. The new guidance, she says has tightened up the definitions of what choice is about, but also provides alternatives to the service if someone doesn't want to go to nursing home X or their home is not ready for them to be taken back to. So the health service must constructively use the services at its disposal.
The National Assembl y for Wales	2005	Audit Committee. NHS Waiting times in Wales. Questions 229-329. 3 March.	Mark Isherwood – Assembly Member  Leighton Andrews – Assembly Member  Jocelyn Davies - Assembly Member  Bernadine Rees – Chief Executive, Pembrokeshire Local Health Board  Geoff Lang – Chief Executive, Wrexham Local Health Board  Hugh Ross – Chief Executive, Cardiff and Vale NHS Trust  Paul Williams – Chief Executive, Bro Morgannwg NHS Trust.  Mr Isherwood has been questioning Ms Rees about delayed transfer of care, particularly in her area of Pembrokeshire. She states that delayed transfer of care in

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Pembrokeshire are due to patients demonstrating patient choice about where they prefer to go. She continues to suggest that they can work with patients on the issue of choice.

The questioning continues on delayed transfers of care and Mr Isherwood has moved to questioning Mr Lang. Mr Lang is asked why there was an increase in delayed transfer of care for a period between 2003 into 2004. Mr Lang states that they are trying to make it more systematic so that they buy the capacity to allow patients to move through the system but that this has implications for choice. He also states that choice is a big issue. He says that there are several care homes in the Wrexham area that are most popular and waiting for beds in these homes may set patients back in terms of recovery. Mr Lang states that it is a difficult issue to challenge and that the social services policy is outwith NHS control. He states that the local authority's policy on choice is its policy, not the NHS'.

The questioning continues about the cost of residential care homes

Ms Rees states that it is usually the higher priced nursing homes that are the preferred choice and so it comes down to the choice issue.

Ms Davies is asking Mr Lang about whether he has patients that come from England to access care in Wrexham. Mr Lang says that they do have patients from England and that they are for a variety of treatments. He says that sometimes it's down to the proximity of GP practices to particular hospitals but that the issue emerging more and more is that of booking systems because waiting times are so much longer and the choice agenda in England is being heightened. He goes on to state that the GP will

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			offer a choice of options to book for treatment and that the referrals are likely to change, he suggests that this will destabilise hospitals on the Border and that there is a risk from these sorts of changes in referrals possibly to the tune of £1 million.
			Mr Andrews returns to the issue of delayed transfer of care and asks Mr Ross about delayed transfers in Cardiff and the Vale. Mr Ross states that over 10% of beds are occupied by delayed transfers of care and that some 70 patients in general health beds are waiting the nursing home of their choice.
			Mr Williams states that the issues for him around choice are certainly a lot simpler than Cardiff. He does state however that even when numbers are small that the issue of choice with patients and families having a sanction on what is available still causes many difficulties.
Cancer Researc h UK	2005	Wales Against Cancer	The report is based on the 2nd Wales Against Cancer conference which consisted of speakers and breakout sessions. Each group in the breakout sessions made recommendations which it was hoped the Cross Party Group on Cancer in the National Assembly for Wales would take forward.
			One of the groups looked at the issue of Treatment and Patient Care. Issues explored included the ability to meet and support the palliative care needs of patients and offering patients the choice of where they want to die
			"Is patient choice an illusion or reality? In other words, should we focus on ensuring equitable access to basic needs and end of life care or, should we be offering and promoting unlimited patient choice?"

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			Recommendations from this group regarding patient choice were:
			Equitable access to basic core service. Economic constraints demand that patient choice cannot be unlimited; therefore core services should be the priority. This would result in a co-ordinated programme of care that is able to accommodate patient preference about basic end of life care.
Welsh Assembl y Govern ment	2005	Designed for Life: Creating World Class Health and Social Care for Wales in	This document sets out a vision for 2015 in response to the Wanless analysis of health and social care in Wales. This vision will be achieved through a series of strategic frameworks, each covering 3 years. 'Challenging targets will be set in place for each three-year period.' The three design aims are Life-long health; Fast, safe and effective services; and world-class care.
		the 21stcentury.	Under the heading 'Achievements 2001-05':
			'The implementation of the second offer scheme has provided an effective means of reducing waiting lists whilst taking into account patient preferences'.
			And
			'direct payments for users for social services have been extended'.
			Vision 2015 has three design principles
			1. user-centred services
			2. getting the most from resources

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3. Targeting continuous performance improvement.

Under 'user-centred services' the paper agues that 'people will best use services if they help to design them. We will promote the active participation of citizens and communities in service development'. (p13)

'Whenever change is planned, be it a whole hospital, a system for booking appointments, or the design of x-ray gowns, service users and staff will have the strongest voice in identifying what is required. We will work systematically with user groups to define what needs to change. We will aim to empower the community to have its voice heard and heeded rather than simply being given a choice of treatment location.' (p14)

The first strategic framework (2005-08) emphasises service redesign. For example addressing long waiting lists through separation of elective and emergency services and dedicated treatment centres concentrating on short stay surgery.

P19. 'Delivery of care will be based on the model of managed clinical networks'.

P. 23 'The care pathway for these elective conditions will be developed and will ensure there is more information for patients, a wider range of treatment options and greater certainty and reliability. Services from primary care to therapy support, social

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			care and hospitals will be well coordinated to ensure patient/client care is seamless.'
			Financial strategy
			p37 'We must create a financial environment that encourages Health and Social Care to innovate and change without going down the expensive, inequitable and unsustainable route of market mechanisms. In addition, linking to performance management, we need to ensure that poor performance is not rewarded and good performance is.'
			p45 'We will have achieved this by adopting Welsh solutions to meet Welsh challenges'.
Welsh Assembl y Govern ment	2006	Beyond Boundaries. Citizen- Centred Local Services for Wales.	This is a review of local public service delivery in NHS Wales, commissioned by the First Minister, as part of the action plan for implementing WAGs Making the Connections Strategy (2004). This review aimed to be far reaching and open and aimed to identify the improvements in arrangements for local service delivery and examined the existing arrangements for accountability and how they could be used. Chapter 2 of this model examines the Citizen Model advocated in Making the Connections as the driver for public service reform. It states that policy implementation and service delivery have enhanced greatly in the public sector but that there is a changing relationship between services and the public which arises out of the explosion in consumer choice and spending power, or what could be termed the rise in consumerist society.
			It is suggested that public services in Wales must achieve higher efficiency and

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			effectiveness. In England, it suggests that government has responded to these challenges through the adoption of a customer model, which emphasises choice as the means to meet consumer expectations. This model assumes well-informed customers; empowered to express their needs and preferences will drive change through exercising choice. This model is not favoured in Wales, on principal and practicality, including the demography in rural and valley areas, where there is questionability over alternative is suppliers. The model adopted in England, allows people to express choice and dissatisfaction with services by opting for a different provider. This Consumer Model has not been adopted ion Wales where the Citizen Model relies on voice to drive improvement. This citizen models cuts across pathways of all public services and personalisation is at the heart of service delivery. The paper suggests that the citizen model's "great potential merit is that it creates strong challenge to service providers to adapt rapidly to changing demands and circumstances, expressed through consumer choice." It continues "However, it risks relying on a simplistic version of choice between service providers, whereas what citizens may value most is different forms of choice, personalisation and the opportunity to express preferences and influence provision."  The advantages of the citizen model it suggests are that if it rises to the challenge it may be more successful in offering these different forms of choice and voice.
Morgan, R	2006	One public sector for Wales. Speech given by the First Minister at the	•Stresses collaboration at all levels but collaboration beyond rhetoric and that avoids 'an endless cycle of meetings and discussion which takes on a life of its own and does not produce any results.  'The feature of so many o our reforms has been the stress on integration rather than separation.'
		Wales Audit	•Joined up planning and delivery of services. Clinical networks.

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Office conference.	<ul> <li>Participatory citizenship as a means of making service more responsive</li> <li>Emphasises equity and social justice along with improvements in responsiveness, efficiency and effectiveness</li> <li>Draws on a sense of shared identity 'Valuing Wales'</li> </ul>
	<ul> <li>Identifies 'the complex nature of the social, environmental and economic issues' along with rising public expectations and demographic changes as a challenge faced by public services.</li> </ul>
	•Rejects comprehensive reorganisations in favour of making existing structures work more effectively and efficiently
	•A concern for 'the hard to reach and vulnerable who struggle to negotiate their way round the institutional boundaries that still too often dominate public service.

## **Policy documents - Scotland**

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Authors	Year	Title	Findings
NHS Scotland	1997	Designed to care: renewing the National Health Service	This White Paper sets out the programme for replacing the internal market and meeting the manifesto commitment to restore the NHS as a public service working co-operatively for patients, "not a commercial business driven by competition".
		in Scotland	The creation of PCTs will allow GPs and other health professionals to take the lead in combining locally to organise health services in their area; clinicians and service users will be given a bigger say in the management of trusts and there will be scope to respond to local needs and circumstances.
			The paper emphasises that what is envisaged is not 'a disruptive big bang' but instead solutions tailored to the needs of Scotland. The aim is that the service delivers clinically-effective care quickly and reliably in high quality facilities which are available throughout Scotland when patients need them:
			"The Government's vision is a National Health Service for the people of Scotland that offers them the treatment they need, where they want it, and when" (para 1)
			This will be backed by a wider range of information for patients on health, health services and treatment: "Providing patients with more information about their health and about the options for treatment when they are ill." (para 13)

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			The document emphasises that patients should be involved in decisions about their care and suggests that there may be circumstances in which patients can make choices:
			"Central to a designed health care system is involving patients more in decisions about their own care and where possible allowing them to exercise choice, in consultation with their GP or the consultant to whom they have been referred. The desire of patients to become more active participants in decisions about their own care reflects similar developments in many other services, reflecting wider changes in society. In the NHS however, there is a special relationship built on trust between clinicians and their patients at times of anxiety and vulnerability" (paragraph 28)
			This draws a distinction between choice in other services and choices in relation to health services: the model is not one of independent consumers but one of "a special relationship built on trust between clinicians and their patients at times of anxiety and vulnerability". In common with later documents, Designed to Care emphasises the limits of choice ("where possible") and closely links patient choice with guidance from health professionals.
NHS Scotlar	2000 d	Our National Health: a plan for action, a plan for change	The document explicitly links the development of this White Paper with the creation of the Scottish Parliament and emphasises the extent to which it has been informed by public views and opinions through public consultations and one of the largest attitude surveys to date:

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"Devolution... creates many opportunities. We now have the chance to address Scotland's needs with greater focus and determination than ever before, and to do so in a way that is truly open and accountable to the Scottish people." (p.3)

It follows on from Designed to Care which reduced the number of NHS trusts in Scotland and states that it represents 're-wiring' rather than 're-structuring'. It comments that many of the current measures, targets and systems derive from the internal market and are inappropriate for a patient-focused partnership-based NHS:

"The NHS across Scotland should work together to deliver universally high standards of care and it must work in partnership with the NHS across the UK in the interests of patients. The traditional public service ethos and values of the NHS must be put back at its core."

Choice is referred to in this White Paper in relation to maternity services (see Appendix) and in relation to proposals to explore new options for GP employment, including salaried service: "Our aim [in exploring other options for GP employment] is to offer flexibility and choice, both to GPs and to patients" (p.85)

The White Paper comments that what patients want is care provided as close to home as possible, fewer referrals around the system and better information. However, in a theme which continues through later documents, it emphasises the need to balance local and specialised services:

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			"No single NHS Health Board can provide the full range of modern health services. To maintain standards, we will continue to work to develop centres of excellence for specialist and acute care. We will also continue to provide services closer to people's homes where it is possible and safe to do so." (p.25)
Scottish Executiv e	2000	Our National Health: A plan for action a plan for change	Sates that the internal market 'led to fragmentation and division and undermined the public service ethos of the NHS'. Seeks to 'put the NHS back together again and sweep away the behaviours and practices of the internal market' p30.  Emphasises:  Prevention Integration Partnership Patient involvement
			States that patient involvement should take place at the following levels:  1. Involvement at an individual patient (or carer) in their own care  2. Involvement of patients in monitoring and improving the quality of care in an existing service  3. Involvement of patients and the public at an organisational level

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			4. Involvement of patients and the public in planning changes in service provision
			Maternity services
			Our National health makes strong statements about the importance of choice in maternity services:
			'Choice in childbirth should not be the preserve of the privileged - it should be the standard for every woman' p58
			'It [the national Maternity Services framework] will ensure choices for women and their families - while recognising the need for clinical safety - and assist decision-taking on the design of maternity services across Scotland" p58.
			It emphasises that pregnant women must be given information and support so that they can make fully informed choices about their care and that hey must be given the opportunity to choose the birth place.
NHS Scotland	2001	Patient focus and Public Involvement	The document defines a patient-focused NHS as "a service that exists for the patient and which is designed to meet the needs and wishes of the individual receiving care and treatment" (p.2)
			Patient choice is referred to in connection with patient information: "Feedback from the

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			public repeatedly emphasises a need for better information about their health, their treatment, the options for care, and the availability of health services. Without this information it is impractical to expect patients to make informed choices or take more responsibility for their own health." (p.7)
			The importance of services built around patients 'needs and wishes' is reflected in other documents published in this early period before and after devolution. For example, the Ministerial Foreword to the National Health Service in Scotland: Annual Report 1998-99 (1999) states: "We want to create a Health Service where the needs and wishes of patients come first"(p.2) and the Report places meeting patients' needs and wishes as one of the core values of the NHS:
			"The values of the NHS areto identify and seek to meet people's needs and wishes" (p.1)
Scottish Executiv e	2002	Expert Group on Acute Maternity Services:	In this document it is made clear that while choice is very important, maintaining maternity services in their current configurations (however popular) is not an option:
		Reference Report	"Women have the right to be involved in the decision-making process when choosing how and where to give birth. (p 7)
			"There is a consensus of opinion amongst the planners and providers of maternity care throughout Scotland that, given the constraints raised in the previous sections, the present configuration and levels of intrapartum and neonatal care are no longer

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			sustainable in the short, medium and long term It is timely that professionals and consumers have been given the opportunity to review the available evidence and advise on a way forward for intrapartum care" (p10)
Quality Improve ment Scotland	2002	Generic Clinical Standards	the Standard Statement for Standard 1 (Patient Focus) is "All services respond to patients' needs and preferences." and in relation to access the standard stipulates that: "Patients should have access to the services of the healthcare organisation based upon their identified healthcare needs and, as far as possible, their individual preferences." (p.22)
NHS Scotland	2003	Managing waiting times: A good practice guide	States that where there is a particularly high demand for certain services, it may not be possible to offer all patients treatment at the first choice hospital or with the consultant who received the original referral and that consideration should be given to asking the patient at the time of being put on the waiting list if they would be agreeable to receiving treatment from another consultant or at another hospital.
NHS Scotland	2003	NHS National Targets	In relation to targets for waiting times for hospital in-patient and day case treatment and for surgery or angioplasty for coronary heart disease:
			"These targets are firm guarantees. If a patient's host NHS Board is unable to provide treatment within the target time, the patient will be offered treatment elsewhere in the NHS, in the private sector in Scotland, in England, or overseas" (p.4)
NHS Scotland	2003	National Waiting Times Database	This guidance from the Chief Medical Officer regarding the new National Waiting Times Database states:
			'Local pressures and circumstances can, however, mean that clinics become

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			overstretched and that patients may then be told that they face a long wait for a specialist opinion, unaware that this is available elsewhere in Scotland with a shorter waitDetails on 8 selected specialities covering approximately 80% of outpatient consultations in each NHS Board area in Scotland, are displayed on the website at initial launch. Patients will therefore have a choice of an appointment anywhere in Scotland. The intention is that information from the website can be used by the patient and the General Practitioner as they discuss the potential care and treatment of the patient's condition.
NHS Scotland	2003	Partnership for Care	The focus of this White Paper is on addressing the historical splits between primary and secondary care and between health and social care and on creating a single system without barriers. It argues that there are too many separate statutory NHS organisations and that these reinforce institutional, professional and service delivery barriers and inhibit co-operation. It announces plans to dissolve the remaining trusts and to streamline the 50 semi-autonomous organisations that provide a range of support services.
			Partnership for Care echoes the earlier themes of putting the patient at the centre of care and shaping services according to the concerns that patients have raised:
			"Looking at services from a patient's point of view underpins everything that we are seeking to do in the health service. Patients are concerned about the quality of care; treatment at the right time and in the right place; being treated with dignity and respect; having their say in decision-making; having their feedback taken into account; and getting clear explanations at every stage." (p.7)
			This is described as a 'massive culture change' compared to the first 50 years of the

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NHS.

The document refers to patient choice in the context of reducing waiting times. It states that there will be increased national support from the Health Department, including expanding the waiting times database "to ensure that patients and clinicians are given maximum flexibility in deciding how, where and when to access healthcare"(p.26), and refers to the National Guarantee, by which patients have the right to be treated elsewhere (e.g. elsewhere in the NHS, in the private sector or exceptionally elsewhere in Europe) if they are not treated by their local NHS within the National Guarantee.

Like the earlier documents, Partnership for Care returns to the theme that there are limits to patient choice: some services may not be provided locally. The guiding principle is that "If it can be done in primary care, it should be done in primary care" (p.36) as primary care is the right place to influence and promote system-wide seamless care, but it is emphasised that it is not possible to provide emergency and elective care for each condition in every hospital or Board area:

"No single NHS Board can provide the full range of modern health services. We need to strike the right balance between the provision of highly specialised treatment centres and the need to provide services closer to people's homes where it is possible and safe" (p.41)

In acknowledging that the NHS has not always handled public involvement well in the

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			past, Partnership for Care emphasises that public views should be sought at a formative stage of the proposals and that decisions need to be taken in an open, honest and informed way, stating that NHS Scotland needs to work with public, staff and patients to demonstrate that the changes in hospital provision are in order to improve care.
NHS Scotland	2003	Implementing a Framework for Maternity Services in Scotland	Implementing a Framework for Maternity Services in Scotland (2003) makes explicit reference at the beginning of the report to the need to balance choice against safety. The document opens with 'Key Messages from the Expert Group' which include the following statements:
			"NHS Scotland should provide services for childbirth as close to women's homes as is consistent with safe clinical care and informed maternal choice."
			" There is no such thing as 'zero risk' for women who are pregnant or giving birth; an element of risk applies to all pregnancy and childbirth."
			"Women must be informed about risk with unbiased, evidence-based information to help them decide where to give birth. Professionals should balance maternal choice, demand and need against assessment of risks and available services." (pp2-3)
			The first section of Implementing a Framework for Maternity Services in Scotland then reinforces these points and emphasises the limits to women's choice:

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			"The big question for the EGAMS was how NHS resources should be deployed to achieve the best balance between:
			<ul> <li>ensuring choice for women on where, how and by whom their care is provided</li> <li>reducing risk as far as possible to the pregnant woman and her baby</li> <li>ensuring high quality services that offer value for money"</li> </ul>
			"It is not always possible to meet women's first choice in relation to their care at childbirth, particularly in some of Scotland's very remote areas." (p.6)
NHS Scotland	2004	Fair to all, personal to each: the next steps for NHS Scotland	The main focus of this policy document is on waiting times, which it describes as the crucial measure of the delivery of NHS services. It emphasises that the majority of people using the NHS in Scotland do not have to wait at all but states that new definitions and measurements of waiting times will be introduced to make them clearer, more consistent and fairer to patients. These new definitions will balance the responsibility of the NHS with the need for patients to act responsibly in attending for appointments or accepting an offer of hospital admission.
			It states that there will be new patient-focused booking systems to help ensure that patients have the opportunity to choose an outpatient appointment that is convenient for them. It refers also to patients' other immediate concerns: "Where their health services are, and the cleanliness of our hospitals are of critical importance to them" (para 1.10)

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			" Patients should be at the centre of the delivery of responsive care and treatment, with more convenient services delivered more quickly at each stage. Services should be as localised as possible, and as specialised as necessary." (para 1.8)
			Patients will also have more choice in that there will be a wider range of services provided in GP practices (e.g. minor operations).
			Fair to All, Personal to Each reiterates the earlier policy message about the balance between local and specialised services and refers to the forthcoming review led by Professor Kerr on the shape of future services:
			" Communities want to know that services will be available locally wherever possible. Patients requiring highly skilled interventions need to be reassured that services will be as specialised as they need to be to deliver quality care and the best possible clinical outcomes. Clinical teams that often undertake a complex procedure will get better results than clinicians who see and treat such cases infrequently" (para 1.21)
Chishol m, M	2004	Scottish Parliament Health Committee meeting 6 January	Col 527:  "When people ask me why we do not have foundation hospitals in Scotland, I tell them that we have CHPs. We have our own reform agenda, of which CHPs are one of the most exciting parts The most important thing is perhaps that we have a vehicle for integration with social care and specialist services. In contrast with England, our attempt to develop single-system, integrated working is the most distinctive feature of our health reform agenda."

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			Col 546-7:  "The requirement to relate differently to patients and to take on board patients' experiences will impact on every member of the health care team. However, I do not think that every member of the health care team will routinely engage with the wider public as citizens. That activity will be more discrete."
Chishol m, M	2004	Scottish Parliament Health Committee meeting 23 march	"Managed clinical networks are a good example; they are a particularly Scottish model of care and are consistent with the general model of care that we are trying to promote. Our model is different from the English model We are trying to create a more integrated way of working in Scotland – single-system working, with the different parts of the health system working together collaboratively."
			"The fundamental reason why we will not have foundation hospitals in Scotland is that we have our own reform agenda, which is based on the principle of single-system working within a decentralised context. I believe that that is the most patient-centred approach, because patients see one system We want a system in which, rather than compete with each other, health care professionals co-operate and collaborate. In Scotland, I believe that that is best achieved through developments such as the introduction of community health partnerships, rather than by following the English approach, although it might well suit English circumstances. Apart from anything else, England is starting from a different place."

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Chishol m, M	2004	Scottish Parliament health Committee Meeting 21 September	" contrasts are always being made between England and Scotland for different purposes, but it always strikes me that England has 10 times the population – it is probably 11 times now – and 1.66 times the land mass of Scotland one of the reasons we have difficulties in respect of health service issues is that ours is a much more sparsely populated country."
Rumbles , M (Lib dem)	2004	Scottish Parliament Health Committee 23	Col 677:  "To meet the needs of the Scottish people, we must have a different solution from the solution down south [i.e. foundation hospitals] establishing foundation hospitals in competition with each other to serve the population of Grampian would be completely
NHS Scotland	2005	A Guide to Service Improvement	irrelevant For many people in rural Scotland, there is no choice."  Provides guidance to NHS managers and other staff on the implementation of policy initiatives. It includes guidance on Patient Focused Booking (PFB), a mechanism by which patients originally receive a referral acknowledgement letter and then approximately six weeks before they are due to attend receive another letter inviting them to phone to arrange an appointment. When they phone they are offered a choice of dates and times.
			P. 30: 'Patient Focused Booking – also referred to as Partial Booking is a way of managing waiting lists to ensure that when appointments are made there is direct contact with the patient. It is the dialogue with patients which introduces an element of choice about appointment dates and times for patients.'

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NHS	2005	Building a	The document states that it arose out of developments in the summer of 2004 who
Scotland		health service	several NHS boards proposed limited centralisation of services to enable adequate
		fit for the	medical staffing levels and better outcomes to be achieved. The Health Committee
		future: A	the Scottish Parliament commented that many of these decisions failed to understand
		National	what was important to the public about maintaining local facilities and services and
		Framework for	patients (i.e. that long and difficult journeys can affect welfare). In anticipation of a
		Service	debate about these core issues, the Minister commissioned work to develop a Nat
		Change in the NHS in	Framework for Service Change to inform local decisions.
		Scotland	
		Ocotiana	The Framework is intended to be a 20 year plan for the NHS. The Terms of Refer
			for the review (set out in a Ministerial letter in April 2004) stated that it would draw
			set of values underpinning the modernisation of health services;
			-providing services in a consistent and equitable manner across the whole of Scotl
			-ensuring that the patient is at the centre of change, so that they get the treatment require, when and where they need it;
			-removing barriers from the patient's pathway of care, and
			-working in partnership with patients, staff and other stakeholders."
			The report states that patients have lost a certain amount of trust in the NHS as a
			of what is seen as 'unnecessary "creeping" centralisation' (p.8) driven by what is
			convenient rather than by what patients need. However, the report strongly refutes

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idea that the NHS in Scotland is 'in crisis'; instead changes are needed because health care needs are changing.

The report's position on patient choice is somewhat contradictory. The report opens with a statement of guiding principles that, drawing on the public consultations that preceded the report, specifically de-emphasises patient choice in favour of other objectives:

"At risk of seeming overly sentimental, I believe that a more truly Scottish model of healthcare would be to take a collective approach in which we generate strength from integration and transformation through unity of purpose. Patient choice is important, but the people of Scotland sent us a strong message that certainty carries greater weight (bold mine) – if we make a commitment to see or treat a specific patient on a specific date, we must honour this, and ensure the quality of care delivered. ... I believe that Scotland is better suited to health improvement through collaboration and internal cohesion, making us externally competitive" (p.2)

The Framework identifies three inter-related issues that need to shape future health services: ageing population, growth in chronic disease and the rising trend of emergency admissions. It states that there are seven areas that the key concerns of health professionals and the public tend to converge around. There is no explicit reference to choice in this list. Instead the seven areas are: maintaining high quality services locally; improving waiting times; supporting remote and rural areas; empowering clinical staff to meet the challenge of reforming the health service; using new technology to improve standard of care; reducing the health gap between rich and poor; and ensuring value for

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money across the NHS. Under the 'top 10 proposals' listed in the report, patient choice is mentioned only in the context of improving services as a whole: shorter waiting times, more day surgery, more diagnostics in the community, improving management of referrals and speedier access to services. The theme of the balance between local services and more specialised services that appeared in earlier policy documents is repeated: "Patients and the general public told us at our open meetings that they wanted services delivered locally wherever possible; they were willing to travel for highly specialised services but wanted as many 'core' services as possible close to home" (p.8) "They (the public) are looking for health care that is local wherever possible, specialised where it has to be but delivered to national standards, providing a level of certainty about what people can expect" (p.9) "... the principle about delivering care as locally as possible... The overwhelming majority of people's health needs can and should be met locally" (p.22)

original)

"But our approach must be to ask what we can deliver safely and sustainable in the local community and how we can maintain local services to the maximum extent" (p.30, bold in

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Although the opening sections of the document appear to downplay the role of patient choice as a factor shaping service provision, reference is made to Referral Management Centres which will be established to develop new patient pathways, extend referral options (e.g. to GPs with a special interest) and facilitate patient choice, and to the advantages that will result from further development of Managed Clinical Networks which promote integration of services between hospitals and community health centres and increase patient focus through the strong involvement of patients and clinicians.

There is increased emphasis on patient choice when the Framework considers future developments in more detail. Within the 10 "Key questions which define the future" set out in the Framework, choice is subsumed within Question 7 ("How can we give the public and patients a voice in changing how we provide health services?"):

"But it is one thing to enable public engagement in the development of the NHS and quite another to enable patient access to decision making about their own care. We must do both. To inform our thinking on the latter, one of the pieces of work we looked at was [the report by Picker Europe on The Patient of the Future](p. 53)

The report states that the Picker Europe project found that "patients need information... people want more opportunities for choice." The report then provides the broadest definition of choice found in the policy documents reviewed here:

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"Much of the debate about choice in health services focuses on choice in access to elective services. This is an important area where choice can be exercised, with the potential to increase efficiency and reduce waiting times. This is, however, only one area of choice. There is also the possibility for patients and carers, supported by professionals and providers, to make choices across the whole range of health services. These include:

- •Choice over whether, where and when to seek care;
- •Choice of care or treatment offered, and involvement in decisions about their conditions/illness or treatment:
- Choice in appointment date/time;
- Choice of hospital/doctor." (p.54)

The report then recommends that "The Scottish Executive and NHS Boards should establish a clear policy about what patients in Scotland want in the way of choice" (p. 55) and recommends that it does so by developing 'values' (building the service around choice is more likely to meet more what users want and to have higher levels of satisfaction), 'information' (as real choice requires good information) and 'systems' (to ensure that policies and strategies on choice are turned into action and that "services reflect and offer the choices that patients and carers want".)

This recommendation that the Scottish Executive and NHS Boards should establish a

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clear policy about what patients want in relation to choice suggests very early agenda setting. It contrasts with the strong opening statement about the preference of patients in Scotland for certainty over choice and suggests some uncertainty at policy level about the view of patients and the public in relation to choice.

## Maternity services

Uses some of the same wording as Implementing a Framework for Maternity Services in Scotland (2003):

"We recommend that ...Women must be informed about risk with unbiased evidence based information to help them decide where to receive care and give birth.

Professionals should balance maternal choice, demand and need against assessment of risk and the availability of services." (p.208)

It endorses that document's argument that the current configuration of acute maternity services is not sustainable, but does emphasise the broad principle that much of maternity care and neonatal care can be delivered locally:

"Maternity services should continue to be delivered as locally as possible. It is important to note that the majority of antenatal and postnatal care, and intra-partum care for low risk women is available in the local community but sustainable and more specialist services for childbirth may not be as easy to maintain. ...The majority of medical needs of most critically ill newborn babies can be met by the neonatal intensive or high

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			dependency care within most consultant led maternity units."(p.206)
			It also emphasises that user involvement in developing and monitoring maternity services is essential, not least because maternity services impact on the whole family.
NHS Scotland	2005	Drivers for change in Health Care in Scotland	Drivers for Change is one of the documents that supports the National Framework (2005). It pulls together key factors driving change in the health care system in Scotland in the next 20 years, and looks at the inter-dependencies between them. The factors are identified as: the changing population; health inequalities; patient expectations; remoteness and rurality; finance and performance; workforce; clinical standards and quality; medical science; and information and communication technology. In relation to patient expectations, the report refers to the 2004 survey of public attitudes to the NHS in Scotland which aimed to explore attitudes to modernisation (defined as encompassing increased access, choice, public involvement and responsiveness). The report comments that the survey reported high levels of satisfaction with the NHS and that "Importantly there is a clear link between patient satisfaction and some of the key aspects of modernisation especially shortened waiting times and extension of choice."(p.40). The report suggests that these findings from 2004 can be used as a
			Drivers for Change is also important in relation to patient choice in that in the section on workforce issues, it refers to the new General Medical Services contract (in operation since 1 April 2004) and to the opportunities it offers to extend patient choice by encouraging primary care teams to offer new services, expand roles (e.g. GPs with special interests) and offer services in new ways:

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			"The new contract is not simply an administrative change in the remuneration of GPs. It will act as a powerful lever for service redesign, with profound implications for staff working within primary care and the balance of work between primary and secondary care sectors." (p.59)
NHS Scotland	2005	Delivering for Health	"providing care which is quicker, more personal and closer to home"
			Delivering for Health states that it builds on the National Framework for Service Change to provide a template for the future NHS Scotland and sets out in practical terms what action will be taken. The Ministerial Foreword makes clear that the findings of the National Framework will be placed "alongside our existing initiatives and future plans." Delivering for Health does not mention patient choice as such when setting out the main policy objectives:
			"We want to respond to the wishes of the people of Scotland to have more local health care, a more responsive NHS and a greater say in the way their NHS is run" (p vi)
			The key goals identified in Delivering for Health are to improve health, to improve health service productivity and to improve health service quality. These goals are to be achieved through an integrated model of health service delivery but again there is no explicit reference to choice. Similarly when the document sets out the changes that patients will see and when it describes 'the future model of health care', the word choice does not appear, and the emphasis is instead on the services that will be provided (e.g.

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			assistance with self-management of chronic conditions, fewer cancellations).
			Delivering for Health appears to emphasise 'voice' more than choice and states that the Scottish Health Council will hold Boards to account for their performance on patient and public involvement:
			" to ensure that every reasonable effort is made to explain the impact of service changes for both patients and local populations, and to involve patients and the public in the consideration of options for change. We will continue to give patients an influential voice in the future of the health service and in their own individual care." (p.54)
			However, Delivering for Health does refer specifically to patient choice in relation to improvements in the management of hospital admissions. It states that as part of improved referral and diagnostic pathways, patients may be offered their appointment at a choice of locations.
NHS Scotland	2006	Patient Focused Booking Implementatio n Guide	Patient Focused Booking is heavily endorsed as a major and popular advance in providing patient choice and is endorsed by the Chief Executive of NHS Scotland as a model for other parts of the service:
			'NHSScotland has embraced this new way of booking outpatient appointments and patients are now offered real choice. This, coupled with creating more efficient management of waiting lists, has helped drive down waiting times;

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			"The Health Department will continue to support the development and roll out of PFB through future programmes of work, to ensure that similar benefits can be realised in other parts of the NHS". (iv).
NHS Scotland	2006	The NHS and You	The choice offered to patients in this patient leaflet is limited to receiving treatment elsewhere in Scotland:
			"Sometimes, hospital services in your local area might be so busy that it will not be possible for you to get treatment within the national target times. If this is the case, you will be given the opportunity to travel to somewhere else in Scotland to get treatment within the target time." (p13)
			There is no reference here to a patient having the choice to travel elsewhere in the UK (or Europe) for treatment.
NHS Scotland	2006	The Planned Care Improvement Programme: Day Surgery in Scotland	The increase in day surgery rates for appropriate procedures has "the potential to improve the service for patients by achieving shorter waiting times, allowing patient choice and making best use of NHS Scotland capacity."(p1)
NHS Scotland	2007	The Planned Care Improvement	Announces Programme will monitor the introduction of 'intelligent booking process' for outpatients, inpatients, daycase and diagnostics.

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		Programme: Patient Pathway Management	'As the total waiting time for patients reduces, there is a need to move forward and apply the lessons learned into solutions that are appropriate for local circumstances and move towards fully booked service models. PFB methods have made the booking and waiting list management process more open and transparent, and supported the NHs to deliver choice for patients.'
Ormostin , R., Curtice, J.	2007	Different policies, different priorities?	Uses data from the 2005 Scottish Social Attitudes and the 2004 and 2005 British Social Attitudes surveys to compare attitudes to choice of people in Scotland with those in England.
		public attitudes to personal care and patient choice in England and	-63% of people in Scotland think patients should be able to choose which hospital they go to. The level of support for 'patient choice' in the delivery of health care is almost as high as that in England, despite patient choice being lower down the Scottish political agenda.
		Wales	-People on both sides of the border are sceptical about the reality of patient choice (though this scepticism is higher in Scotland).
			-Politicians seeking to improve perceptions of the NHS should note that beliefs about 'patient choice' appear to have relatively little impact on public satisfaction with the NHS. On the other hand, perceptions about outpatient waiting times are strongly associated with levels of satisfaction with the health service in both Scotland and Wales.

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## Policy documents - Northern Ireland

The focus of policy documents has been mainly on issues such as waiting times, the re-structuring of health and social care services (with an emphasis on community-based care) and patient-centred, equitable service provision.

Authors	Year	Title	Findings
DHSS PS	2002	Better Services: Modernisin g Hospitals and Reforming Structures	Focus on prompt access to high quality acute care delivered in people's homes.
DHSS PS	2002	Investing for Health	Overarching Aims:  To improve the health status of all people To reduce inequalities in health  Focus on health promotion and enabling people to make healthy choices, reducing premature death due to social and economic inequalities, and working in partnership (collaboration).

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DHSS PS	2004	Public Health Function Review in Northern Ireland	'Individuals and communities should be fully involved in decision making on matters relating to health'. (p.21)  'HSS Trusts and Primary Care staff will be expected to engage with local communities to identify their needs and produce local solutions for local problems'. (p.27)  'Public health delivery should be grounded in accountability, transparency and participation.' (p.72)
DHSS PS	2005	Independe nt Review of Health & Care and Social Services in NI (Appleby)	Recognised that the scope for improving patient choice more limited in NI than in England, and that a reduction on waiting times for consultation and treatment were regarded as the main priorities. But this 'does not rule out careful expansion of patient choice[F]rom the patient's point of view, a more formalised and embedded process of choice (not just of hospital, but over the myriad of decisions that are taken throughout the system which affect a patient's care) can improve patient satisfaction and service responsiveness. This may be a weaker incentive than that being introduced in England, but the limits to what could realistically be offered by way of choice need to be recognised in what is a relatively small system'. (p.12)
DHSS	2005	Caring for	There is a focus on encouraging people to take more responsibility for their own health

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People Beyond Tomorrow	and wellbeing. The improvement of services is seen as a means of broadening patient choice.
	'Too much reliance is placed on the hospital sector: a more responsive and dynamic primary care sector could provide the necessary care close to home.' Shaun Woodward (Foreword)
	'I want to know that our healthcare systems put patients first – providing urgency and choice in treatment and care.' Shaun Woodward (Foreword)
	'[Clarity of vision and purpose] will also assist people who use and benefit from these services to be aware of both the services available to them and how they can influence the planning of their care and the delivery of services generally.' (p.4)
	'It is likely that by the year 2025 NI will have a population which ismore demanding [seeking a person-centred service operating to the highest standards]' (p.7)
	'Convenience' – 'services in the community offered by means of a 'one-stop shop' where various primary care services are provided under one roof and there is a flow of information across services.' (p.7)
	Beyond

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			'The challenge will be through a combination of improved, better targeted and expanded primary care services allied with more effective self-care programmes, to reduce dependency on general hospital referrals or residential care as well as dependency on health and social care practitioners generally.' (p12)
			'Key attributes of the future system: (p.13)
			<ul> <li>a service focussed on providing comprehensive, person-centred care;</li> <li>a first point of contact that is readily accessible and responsive to meet people's needs day or night;</li> <li>a co-ordinated, integrated service employing a team approach with multi-agency linkages;</li> <li>an emphasis on engagement with people and communities about their care and the way services are designed and delivered; and</li> <li>a focus on prevention, health education and effective self-care'.</li> </ul>
DHSS PS	2005	A Healthier Future: A Twenty Year Strategy for Health and Wellbeing in NI (2005 – 2025)	This document outlines a vision for how the HSS will develop over the next 20 years. There is a focus on:  Reducing waiting times;  Moving treatment away from hospitals and into the community;  Collaboration i.e. the importance of effective working across organisations;  Promoting equality of access to health services for all groups in society;  Recognising that in the future there will be changes to the structure of services and changes to the attitudes of service users;

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- Increasing satisfaction with services in NI.

Patient choice does not feature largely in the document but there are suggestions that in the future the government may have to consider the patient as a consumer. Consumerism is noted as one of the challenges health services will face over the next 20 years. People will expect more and have greater access to information. People who cannot access such information risk greater social exclusion and disaffection. (See p.26)

'As the population becomes more highly educated, people will be more effective at accessing information and more proactive in making decisions regarding their health and social care needs'. (p.28)

'Increasingly the public will not accept the views of health and social care professionals without questioning them. Communities are not prepared to accept decisions about the planning or design of services without being involved in the making of those decisions. More people will become adept in challenging our services to meet their individual needs.' (p 42)

'Over the coming decades, however, we can expect more people to have personal resources to purchase services privately. We can also expect greater demands for choice and immediate access to services. These factors have the potential to lead to an enhanced demand for privately funded health and social care services.' (p.110)

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There is also recognition that new technologies (such as genetic screening) may mean a change in the structure of services. Genetic screening will mean that interventions can be carried out earlier and will increasingly be in the form of health promotion and protection activities. (p.26)

'The spread of new technologies and new medical techniques will provide opportunities to deliver services in different settings and different ways. But again, this will lead to demands for potentially very costly services, some of which have not yet been invented.' (p.27)

The vision of future services is a patient-centred one in which services are increasingly provided in the community.

'Vision for the future

- 1. Greater specialisation in order to promote the quality of some services
- 2. Greater provision of and emphasis on more holistic 'generalist' services provided in communities or on a day-patient or out-patient basis' (p.38).

'Our focus will be on tackling chronic disease and economic disadvantages that give rise to poor health.' (p.38)

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'We will also need to work...to develop services which genuinely respond to need. We will ensure immediate access for community-based and emergency services and people will not wait more than three months for any form of treatment or care.' (p.38)

There is also a focus on increasing 'engagement' so that patients feel a sense of 'ownership' over the services they receive.

'Services will continuously respond to people's individual and collective needs by listening to them and learning. People will be fully involved in decisions and will be provided with meaningful information about every aspect of their care and treatment.' (p.39)

'Working with individuals and communities is the best way of ensuring a truly personcentred service.' (p.42)

Although there is frequent mention of responding to individual needs this is mainly in reference to a vision of a 'person-centred service. Mention of actual individually 'tailored' services are only mentioned in relation to older people and the terminally ill (in terms of *where* they would like to die).

'Our future health and social services will be more responsive to the individual needs of everyone who uses them. Services will be individually tailored to take into account each

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			person's circumstances, preferences and requirements – in other words, more person-centred.' (p.65)
			Older people will have full access to a range of integrated services that promote physical and mental health and wellbeing. Tailored care services will be developed to meet the changing needs of older people.' (p.68)
Wood ward, S	2005	Waiting List Speech	Of the second offer scheme in Wales:  'When the system was about to be introduced, a number of sceptics questioned whether it would work and what the effects would be on the health service and Trusts in Wales. In practice what happened was that so-called 'excess waits' dramatically cleared up and that few Trusts had to reimburse their money because they got patients treated. The threat of such a sanction and the knowledge that it would be implemented was very effective in Wales. I want to borrow that best practice for patients here in Northern Ireland. So, in essence you as a patient will be offered treatment within 12 months It they don't or if they can't, then we –from today – will take the money back for the treatment of that patient. And we will buy, either from another Trust in Northern Ireland, or if we have to, from outside Northern Ireland, the treatment the patient needs and has been kept waiting for'
			From March 2006 will also run a 'second offer scheme', but:  'So to you today, in the interests of everyone else in Northern Ireland we must tell you that if you turn down a reasonable Second Offer, we will take you off the waiting list and

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			refer you back to your GP'
DHSS PS	2007	Priorities for Action 2007/08	Focus on health promotion and increasing service delivery in the community.
		2001/00	Aims:
			Improving health and wellbeing;
			Safer, better quality services;
			Reductions in hospital waiting times;
			Significant improvements in emergency care;
			Fully integrated care and support in the community;
			Improvements in children's services;
			Better mental health and learning disability services;
			Effective financial control and improved efficiency;
			Reforming the workforce (productivity); and
			Infrastructure investment.
DHSS PS	2007	Strategic Resources Framework 07/08	Funding has been allocated to various health related initiatives such as suicide prevention and decreasing teenage birth rates.
		3.755	Funding for general medical services has increased by 5m since last year to allocate monies to the ICATS (Integrated Care) Initiative – 'an approach that seeks to combine

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			and co-ordinate all the services required to meet the assessed needs of an individual. It requires the treatment, care and support to be person-centred and the service response to be needs-led and not limited by organisational practices. It demands collaborative working between agencies and service providers'.
			Waiting times are still very much on the agenda: 'By March 2008, at least 98% of patients diagnosed with cancer should commence treatment within 31 days of the decision to treat and at least 75% of patients urgently referred with a suspected cancer should begin treatment within 62 days (increasing to 95% by March 2009)'.
DHSS PS	2008	Proposals for Health and Social Care Reform	The Review of Public Administration was launched by the NI Executive in 2002 and the following guiding principles were used to assess prospective organisational models:  - The Service must be centred on the needs of patients, clients and carers.
			- Services must be efficient, with fair but challenging savings targets and all unnecessary waste and duplication eliminated Value for money is crucial and therefore the delivery of services and all the supporting activities must be focussed on maximising benefits to patients, clients and carers.
			<ul> <li>Forward looking, innovative health and social care organisations will be encouraged delivering the services that they are commissioned to provide, adhering to priorities, meeting targets and ensuring that performance is always being improved.</li> </ul>
			<ul> <li>Patients, clients and carers must be given the opportunity to voice their concerns and be sure that they are being listened to – dignity, respect, equality and fairness for patients, relatives and staff are at the core of the health and social care system.</li> </ul>

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- Quality and standards will continually be driven up without compromise.

The key elements of this proposal are:

- a streamlined Regional Health and Social Care Board focused on commissioning, performance management and improvement and financial management which both encourages and ensures access to quality services responsive to need;
- dynamic Local Commissioning Groups with the active involvement of GPs; professionals within social work, public health, nursing and Allied Health Professionals; other primary care practitioners; and community representatives;
- a smaller Department more sharply focused on its responsibilities for serving the devolved administration, bringing forward legislation, and determining and periodically reviewing policy, standards, priorities, and targets;
- the establishment of a common services organisation to provide a broader range of support functions for the health and social care service;
- a new Regional Public Health Agency to create better inter-sectoral working to tackle health promotion and inequalities and help realise the shared goal of a better and healthier future for all our people, which would incorporate the functions of the existing Health Promotion Agency;
- action to reinforce the independence of the Health and Social Services Councils and strengthen the regional aspects of patient, client and carer representation while maintaining a strong local focus; and
- increased democratisation through local government representation on key bodies

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			and improved partnership with local government and other stakeholders in the commissioning and delivery of health and social care.
NI Executi ve	2008	Building A Better Future: Draft Programm e for Governme nt 2008 - 2011	Aims: Promote healthy lifestyles; Address causes of poor health and wellbeing; and Achieve measurable reductions in health inequalities and preventable illness.

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## Hansard

Like the policy documents the focus of speeches by NI Assembly members has for the most part been related to the health and social care reforms. Patient choice is mentioned only in relation to future services and the focus is more on re-structuring of services (with an emphasis on community-based care), providing a patient-centred equitable service and reducing waiting times.

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Goggi ns	June 2006	Key note spee ch	'A new future beckons. New structures fit for purpose are being put in place bringing together our community and hospital delivery services into single organisations and allowing us to exploit the potential of our integrated health and social care services. And at the same time providing a better focus for the planning and commissioning of our services, providing for these to be designed around the needs of individual patients.' (p.4)
			'But all this investment will come to nought if it is not accompanied by a major message to you this morning. For too long we have been delivering services in a way which suits our service providers rather than designing them around the needs of individual patients.' (p.6/7)
			Waiting times: 'If you fail to honour your commitment to patients, I'll step in. Where necessary, I'll continue to transfer patients to other providers.' (p.7)
			'What is clear is that the agenda will lead to a much greater need to engage with the population about their health and well-being and about how services are best oriented and designed to meet their emerging needs early.' (p.7)
NIA Mr McGi mpsey	24th July 2007	Priva te Mem bers Busi ness:	'Work is underway to reduce reliance on hospital-based respite for adults and to provide it in more informal, community settings, and new tailor-made services are being designed and introduced by the Eastern Health and Social Services Board associated with the caring break service, which provides individually designed day and evening respite and is complemented by the Southern Health and Social Services Board's "Wraparound" scheme.'

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		Resp ite Provi sion	'Despite Member's reservations about provisions — and I have already acknowledged that there is not enough provision — efforts are being made. It may also be possible to make direct payment to people who need help from social services but who want to arrange and pay for their own care and support services instead of receiving them from a trust. That would be a more flexible way of approaching the problem, and a growing number of people are finding that that option provides the independence and flexibility that they require.'
NIA Mr McGi mpsey	24 <sup>th</sup> Sept 2007	Priva te Mem bers	Speech relating to Alzheimers and Dementia saying that families should be able to access direct payments so as to increase choice and control for those with long-term conditions.
трасу		Busi ness: Worl d Alzh	'That is why we must ensure that sufferers receive the best help available: services must be tailored towards the needs of the individual and must not be based on assumptions made about the disease. Alzheimer's affects each person in an individual way.'
		eime r's Day	'if most carers are to continue to fulfil this function effectively, they will need good-quality, tailor-made services to be delivered to the person being cared for.'
NIA – Mrs	3 <sup>rd</sup> Dec	Priva te	'That funding shortfall will not go awayThere are things we can do. We can encourage people to take responsibility for their own health; we can examine the issue of repeat prescriptions and we

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Hanna	2007	Mem bers Busi ness: Healt h Servi ce Refor m	can educate doctors to save money by prescribing generic drugs and reducing prescriptions'.  'There must be greater efficiency, effectiveness, innovation and value for money in the deployment of health care'.
NIA – Mrs Robin son	3 <sup>rd</sup> Dec 2007	Priva te Mem bers Busi ness: Healt h Servi ce Refor m	'fundamental change to the operation of the province's health service is essentialoverhauling the way in which we commission services is vital. Key to the reforms is the replacement of the four existing health boards with single authority and the establishment of locally based commissioning groups comprising general practitioners and other local health professionals. We must increase productivitya new system of commissioning is needed, with incentives to increase performance'.
NIA – Mr McGi mpsey	3 <sup>rd</sup> Dec 2007	Priva te Mem bers	'In addition to the obvious question of the affordability of such a huge [regional health authority] I wanted to be satisfied that any new structures will deliver my objectives and are robust enough to deal with current demands and future challenges.'

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		Busi ness: Healt h Servi ce Refor m	'There are three key elements of the system that I want to see in place. First, performance management is crucial. The system must ensure the delivery of targets and objectives. Secondly, strong financial management will ensure that we live within our means and get the maximum return on our investment in health and social care. Thirdly, commissioning is crucial. By that I mean the process of planning and resourcing services to ensure value for money. To those functions I have added democratisation – in other words examining ways in which to give local people and councillors a strong voice in the system.'
NIA	10 <sup>th</sup> Dec 2007	Deliv ering Choi ce for the Term inally	Focus on actual choice has been limited to the terminally ill and older people. This debate called for a pilot programme aimed at ensuring that patients who chose to die at home are able to do so.
NIA	15 <sup>th</sup> Jan 2008	Healt h (Misc Provi sions ) Bill: Cons idera tion	Mention of 'Cooperation and Working Together' – an organisation that examines marginalisation in border areas is piloting the use of cross border out of hours GP services.

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		Stag e	
NIA -	4 <sup>th</sup>	Minis	Key elements of the proposal:
McGi	Feb	terial	
mpsey	2008	State ment: : Prop osals for the reorg anisa tion	<ul> <li>A new regional health and social care board to replace the four health and social services boards; five local commissioning groups; a smaller, more sharply focused Department; a common services organisation that will provide a range of support functions for the Health Service; and strengthening the role of health and social services councils with representatives from local government.</li> <li>A new regional HSC board by April 2011 that will focus on prevention and on making services more efficient, accessible and patient-centered. Reduction of staff by nearly 1700 and savings of £53 million by 2011.</li> </ul>
		of the healt h	- Proposes to retain several existing agencies such as NIGALA but restructuring others such as HPANI.
		and socia I care	Future Services:
		syste	'I have considered other models – not only in England, Scotland and Wales but in the Republic of
		m in	Ireland – which have faced similar reform issues. Therefore I am clear on what I want from our
		NI	health and social care system. Value for money is crucial, and the way in which services are delivered must focus on maximising benefits to everyone who uses the service. Our services must

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be efficient, high quality, capable of meeting challenging targets and without unnecessary duplication.'

'I want to develop forward-looking, innovative health and social care organisations that deliver on targets and are constantly striving to improve their performance for the benefit of patients'.

Health in the Community/Local Needs:

'[The new HSS Trusts] will work closely together to be more effective and efficient and promote stronger links between hospital and community services.'

'Perhaps the greatest change that faces our health and social services, however, comprises the demands and expectations of members of a changing population who rightly expect access to services delivered in their own communities and homes and to new life changing drugs and modern technologies that will transform their lives for the better. I want a modern, responsive and forward-looking health service that tackles health inequalities and puts patients at the heart of its thinking.'

'When I took up office in May 2007, I inherited a raft of proposals for reform, which had been drawn up by direct rule ministers...The return of devolution...presents a real opportunity to deliver a local solution that meets our local needs.'

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Patient Centred:
'Patients, clients and carers must be given the opportunity to voice their concerns and be sure that they are being listened to; dignity, respect, equality and fairness for patients, relatives and staff are at the core of everything we do.'
Performance:
'strong performance management and improvement will ensure the achievement of targets, objectives, standards, improved safety and will create and promote a culture of continuous development. There will be renewed emphasis on disease prevention and earlier intervention for individuals and communities to create a healthier population.'

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	41-		
NIA –	18 <sup>th</sup>	Minis	Ministerial Statement re the reform of health and social care services – launch of consultation
Mr	Feb	terial	document.
McGi	2008	State	
mpsey		ment	
		:	Three functions of the new Regional Public Health Agency (health improvement; health protection
		Reor	and the provision of public health support) and three challenges (health inequalities, lifestyle
		ganis	choices, and the prevention and control of infection).
		ation	
		of	
		healt	'We need a coordinated and consistent approach to tackling the key public health challenges. The
		h	new agency, therefore, will build on the work of existing partnerships between health and other
		and	sectors to achieve demonstrable improvement in priority public health measures; for example,
		socia	better mental health, lower rates of suicide, lower levels of obesity, drug and alcohol misuse and,
		I care	ultimately, better life chances for all. The second function is health protection. The agency's third
			function is in the provision of public-health support to commissioning and policy development.
			'The establishment of the regional public health agency, therefore, provides an important new
			centre of public-health expertise, drawing together existing resources to create a focused, co-
			ordinated and sustained effort to tackle the challenges I outlined earlier: health inequalities,
			lifestyle choices, and the prevention and control of infection'.
			'My proposals would therefore enable the new Regional Public Health Agency to drive the health
			improvement agenda by building on the work of existing partnerships between health and other
			sectors to achieve demonstrable improvements in key public health measures such as mental
			sectors to define ve demonstrable improvements in key public fleatur measures such as mental

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health and obesity'.

Ownership and Engagement:

'The Health Service belongs to the people of Northern Ireland. They pay for it, and they have a right for clarity, transparency, openness and accountability. I keep that very much in mind'.

'The engagement of the local population in their health is part of the over-arching strategy. I referred to the report by Dererk Wanless who was commissioned many years ago by the then Prime Minister, Tony Blair, to ascertain whether the country could afford a Health Service that offered free healthcare "from cradle to grave", as envisaged by Aneurin Bevan. The Wanless Report concluded that the country could afford such a Health Service, but that it would depend on three factors. First, investment would have to be made in staff and training and in modern premises and modern equipment rather than in the maintenance of old equipment and old premises. Secondly, there had to be efficiencies in the service with no more duplication or waste. Thirdly — and most importantly — the Wanless Report stated that the local population had to be engaged in a responsibility for their own health. That is covered in my public-health agenda, which is the key part of the proposals that I made this morning'.

'Public health is what we do as a society to improve and protect the health of the population. It is about helping people to take responsibility for their own health, preventing disease and educating the population on the benefits of a healthy lifestyle. It is also too important to be left solely to the health service. All Government Departments and indeed, all of society have a role to play'.

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, , , , , , , , , , , , , , , , , , , ,	NIA – Mr McGi mpsey	19th Feb 2008	Healt h servi ce provi sion in Larn e	'We must have health services that deliver the best treatment and care, both in hospitals, when needed, and, increasingly, in local communities and in people's own homes. The way in which our health services are delivered is changing, and must change, if we are to meet the expectations of the public and the challenges faced by a growing elderly population.'  'To help to deliver my goal of a world-class Health Service, investment in facilities and the construction of modern, state-of-the-art buildings is required. Too many of our hospitals and other facilities are old, rundown and costly to maintain. A capital programme has been implemented to progress the construction and redevelopment of a number of hospitals. We also have a major programme to construct new health and care centres, which will act as one-stop health centre and provide care that is tailored to meet the needs of local communities.'  'However, in light of the need to find 3% efficiency savings and meet challenging targets, the Health Service must become more effective at delivering services, and every penny must be spent wisely. Therefore, it is also important that our health facilities are focused on developing rapid, accessible and tailored care to meet the needs of the communities that they serve'.
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## Newspapers

References to patient choice do not loom large in the NI newspapers – below is a selection of the most common articles related to health. They mostly relate to waiting lists.

Author	Date	Title	Content	

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Belfas t News Letter	July 5, 2005	TRU STS ORD ERE D TO CUT WAI TING TIME S	Health trusts in Northern Ireland must see patients within 12 months or they will have funds withdrawn to pay for the treatment elsewhere, the Government announced yesterday. The Province currently has the worst waiting time figures in the UK. Recent statistics showed 4,000 people were waiting for more than 12 months for treatment, 800 of whom had been waiting more than 18 months.  Speaking at the Royal Victoria Hospital in Belfast, the minister said: "We are going to hold the trusts to account.  "After all, we have an agreement with the trusts in Northern Ireland that they will treat in-patient or day-case patients within 12 months.  "We have paid them to do that. The trusts have the money. Now we will insist that they treat the patients.  "If they do not treat them, or if they can't, then we, from today, will take the money back for the treatment of that patient.  "And we will buy, either from another trust in Northern Ireland or, in exceptional circumstances if we have to, from outside Northern Ireland, the treatment the patient needs and has been kept waiting for."
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Belfas t Telegr aph	May 1, 2007	Flyin g docto rs help	AROUND 600 Ulster patients have been seen by a team of consultants after the Government paid to fly them in from England as part of its drive to slash hospital waiting lists - many of whom were seen on a Sunday.  The Southern Health and Social Care Trust has confirmed to the Belfast Telegraph that the team
		Ulste r's waiti	of neurophysiology consultants from a company called Medinet ran diagnostic clinics at Craigavon Area Hospital during March and April.
		ng lists drop by 600	A spokeswoman for the Trust said: "Facilitated through Medinet, an independent provider of specialist medical services, this initiative is part of the regional drive to reduce waiting times and improve access for patients, particularly in those specialities where a limited resource is available in Northern Ireland.
			SDLP Assemblyman John Dallat, who will be taking a seat on Stormont's new Public Accounts Committee next week, said the efforts were "illustrative of the dire state of the health service".
			"This is very much a quick-fix solution and cannot possibly be sustained in the long-term," said the East Londonderry MLA.
			"And one would even have to ask how much of the problem is it really fixing? There may have been 600 people looked at, but when are these hundreds of people going to get their treatment or cure?
			"This is a fire brigade approach to the problems. But you need to stop the fire starting rather than put it out.
			"Our new Health Minister (Ulster Unionist Michael McGimpsey) must tackle this issue with methods that are sustainable in the long-term."

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Belfas t Telegr aph	April 19, 2007	No- show s to lose waiti ng list place s	NORTHERN Ireland patients who fail to show up for hospital appointments and cost the health service millions of pounds a year were today warned that they face being removed from waiting lists.  Dean Sullivan, Director of Service Delivery at the Department of Health, today predicted "significant" improvements in the situation, as a result of major progress in cutting outpatient waiting lists.  He also stated: "If you commit to coming in to see a hospital consultant on a date and you don't turn up, you will be taken off the waiting list and referred back to your GP.  "There is a two-sided contract being put in place here."  Mr Sullivan stressed that the warning was made in the context of a new "partial booking" system that involves patients in arranging convenient appointment dates and times.
Belfas t Telegr aph	May 4, 2007	Patie nts first in waiti ng list of issue s;	Mr McGimpsey said "fairness and justice" will be uppermost in his mind when dealing with issues.  "I believe in putting patients first and that will be in my mind throughout," he said.  One of his first priorities will be to look at underfunding for mental health, and in particular the implementation of the Bamford Review, which said Northern Ireland needed to double the amount spent on mental health and learning disability services. He hopes to appoint a mental health director as soon as possible.  And he has also promised to look into abolishing prescription charges, after voicing support for the Belfast Telegraph Prescriptions: Free For All campaign.

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Belfas t Telegr aph
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Belfas t Telegr aph	Jan 31, 2008	Tech nolog y warni ng from diabe tes grou p	Diabetes UK in Northern Ireland was responding to a recent announcement by Health Minister Michael McGimpsey that £46m is to be invested to allow up to 5,000 people with chronic conditions - such as heart disease and diabetes - to have their condition managed through the most up-to-date technology by 2011.  Announcing the investment during the 'Developing a Connected Health Economy' conference in Belfast, Mr McGimpsey said: "Within three years there will be around 5,000 patients in Northern Ireland with chronic disease who will have access to a remote monitoring service for their conditions. This will be one of the largest procurements of this nature in Europe.  "The extra monies will also allow us to strengthen our community health and social care services so that they can respond quickly to patients' needs."  The development means patients will be able to monitor various readings and symptoms from home and report them regularly to their doctor's practice via the telephone so they can be monitored.
Belfas t Telegr aph	Feb 14, 2008	Healt h revie w in	That's the advice of Belfast- based consultant Dr Michael Maguire who carried out a wide-ranging investigation into the use of acute beds in hospitals in the Republic.
-1		the Repu blic has impli	But his report also says that simply creating more beds is not the solution. It instead recommends a shift to a less hospital-oriented system with more community-based facilities. "While good practice exists in the Republic, it doesn't provide the best 'patient centred' care.

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catio ns for the North	He said that the report raises questions which could be relevant to Northern Ireland.  The review said that Ireland must reduce over-reliance on acute hospitals that is "out of step with best international practice".  It identified deficiencies in the current Irish system including the fact that no estimated discharge is given to 83% of patients.  There is also a longer length of stay in Irish hospitals than in the UK and only 46% of patients are admitted on the day of their procedure.  Currently, 39% of inpatients could be treated in alternative settings, including at home.
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# Appendix 3 Interview topic guide: policy informants

- Personal information (e.g. name of interviewee, job title, length of time involved with the organisation and role in organisation)
- Have they had any direct involvement in developing national patient choice policy? Prompts including asking about the following:
  - o What was the nature of the involvement?
  - When did the involvement occur? What stage of the policy?
  - In what capacity were they involved individual/organisational/political?
- What are the roots of patient choice policy in the UK as a whole and their own country? How has developed/is developing? Prompts including asking about the following:
  - What was the reason for developing (or not developing) choice policy? What was the policy intention in each country?
  - Who were the key players in relation to the development of patient choice policy?
  - Were there any key events or pieces of information/analysis that contributed to the policy?
  - What do they feel the ideological underpinnings of the policy are?
  - To what extent are all countries influenced by the direction of policy in England? Or how far is English policy influenced by the other countries.
  - What point has policy development reached in relation to patient choice?
  - o What further developments do they expect?

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- What influence did patient organisations, professional groups, or policy/advisory groups have?
- What is their perception of patient choice? Prompts including asking about the following:
  - What degree of choice do they feel patients are offered? What choice is offered?
  - Is choice mainly a rhetorical approach? A way of talking about patients and health care?
  - To what degree do patients have an actual choice? Is it structured by the NHS etc?
  - To what extent do patients/public have choices about the types/range of services/treatments?
  - What issues have arisen in relation to implementing patient choice policy?
- In their view what effect has patient choice policy had on the NHS and delivery of care to patients? Prompts including asking about the following:
  - Was choice intended to achieve change within the NHS. What was the main point of the policy?
  - Has the introduction of patient choice affected decision making by hospitals/practices?
  - How does patient choice relate to other current policy developments?

Date: 25<sup>th</sup> May 2007

Version: 2

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### Appendix 4 Patient Choice Project

# Collection of routine data to assess impact of choice on providers

### Background

In the original proposal for the Patient Choice project it was indicated that an element of the study at the meso level would be the collection of routine data from each site on referrals, waiting lists and activity, to inform discussions with provider and purchaser organisations. The data requirements were also discussed at the May project team meeting where it was agreed that Pauline Allen should lead the exploration of the data requirements and any issues of collection across the four countries, and report back to the project team.

The aim of the research project is to assess the impact of different choice policies on health system performance. An element of this is to look at the possible impact of choice on efficiency of resource use. Policies that aim to increase choice of providers will have impacts on the volume and capacity of services, producing the possibility of unused spare capacity as well as increased volume of service use. In England the emphasis is on the use of choice as a driver for improving quality and efficiency, alongside other supply side developments. The aim of collecting the data is to help assess the impacts patient choice has on the efficiency of local health services in terms of capacity and volume of services provided.

This paper outlines the draft proposals for the collection of this data.

### Issues to consider

There are a number of key aspects to consider when discussing the data requirements.

<u>Purpose of the data</u> - The data is a small element of the meso level research, and is intended primarily to act as an information source during discussion with providers, GPs etc. Therefore it is not intended to function as a data source in its own right.

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In addition, some data is gathered for reasons other than an examination of efficiency, namely in order to facilitate discussion of the operation of the choice system with interviewees.

<u>Comparability</u> – Due to the different focus of choice policies across the UK it is not necessary for the data collected to be comparable across the four countries. Therefore, data collected can differ between countries dependent on what is available and thought to be useful to steer discussions with interviewees.

<u>Data definitions</u> – Each country captures standard data in different ways. As an example, Table 1 is a summary of the differing national data sets for outpatient waits from referral by GP. Whilst the data requirements outlined in Table 3 represent what is thought to be fairly standard data, it is anticipated that project team members will have a view as to how readily available this data will be in their country.

<u>Timescale for data sets</u> – Table 2 outlines the introduction date for various choice policy initiatives. These dates are drawn from policy documents, so it is not clear how far they reflect actual implementation dates. It is proposed to take the date of the introduction of the 'second offer' systems in each country as the trigger date for data collection, and where possible, to start data collection one year before this to gather data prior to the implementation of the system.

Marie Sanderson

Pauline Allen

November 2007

Table 1 Nationally available data - numbers of outpatients waiting for 1<sup>st</sup> appointment

Country	Unit by which data available	Division of wait	Regularity of report	Source
England	Provider	Total waiting by weeks wait. Seen patients and not seen patients	Quarterly	www.performance.doh.gov.uk/wa itingtimes/2007/q1/QMO8s%20W eb.xls

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Scotland	UHB	Total waiting	Monthly from 2005	www.isdscotland.org/isd
Northern Ireland	Specialty/ provider	Total waiting and number waiting over 6 months	Quarterly from 1999	www.dhsspsni.gov.uk/index/stats research/stats-activity_stats- 2/waiting_times/waiting_times- 2.htm#waitinglist
Wales	Specialty/ Trust/ LHM	Up to 13 weeks 13-22 weeks 22-36 weeks	Monthly from December 2003	www.statswales.wales.gov.ik/Tab leViewer/tableView.aspx

Table 2 Commencement date for data collection

Country	Date	Rationale
England	April 2001	Introduction of partial booking (choice of appointment)
	April 2004	Introduction of offer of alternative provider for long waiters – 'choice at 6 months'
	·	Introduction of choice of multiple providers and appointments at referral – 'Choose and Book'
	April 2006	
Scotland	April 2003	Introduction of offer of alternative provider for patients waiting longer than maximum waiting time for elective procedures (12 months @2003) (National Guarantee)
		Introduction of National Waiting Times Database (outpatient waits)
		Introduction of patient focused booking
Northern Ireland	April 2005	Introduction of offer of alternative provider for patients waiting longer than national maximum (12 months @2005) – 'second offer scheme'
Wales	April 2003	Introduction of patient focused booking
	April 2004	Introduction of offer of alternative provider for patients waiting

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	longer than national maximum (18 months@2004) - 'second
	offer scheme'

Italics indicates best practice guidance

All data to be based on Financial Year (April – March)
Referrals to include GP referrals only

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Table 3 – Proposed base-line data for all countries

Data	Source	Timescale	Purpose
Waiting time for first outpatient appointment (broken down by specialty) per provider in case study areas	Providers /commissioners. Information may also be published centrally.	England – 2003 onwards  Scotland – 2002 onwards  N Ireland– 2004 onwards	To act as a partial indicator of efficiency. Reduction in waiting times may indicate an increase in capacity (not efficient) or more efficient use of resources. Any changes can prompt areas for further discussion with providers.
		Wales– 2003 onwards	Irrespective of economic indication, data is useful as a prompt in discussion with GPs to establish the basis for making choices, especially if information about provider waiting times is presented together with information about referral flows to highlights whether or not referrals are made to providers with the shortest wait. It is suggested that data is gathered for all specialities as there may be interesting changes in patterns in areas other than tracer conditions.
Number of referrals (broken down by specialty) from case study GP practices to each provider	GP practice managers PCT/UHB/LHB/HSCB	England – 2003 onwards  Scotland – 2002 onwards  N Ireland– 2004 onwards  Wales– 2003 onwards	For use in discussion with GPs regarding current referral practice as 2) above.
Number of referrals for all specialties (broken down by specialty) to each provider within case study area (per year)	PCT/UHB/LHB/HSCB	England – 2003 onwards  Scotland – 2002 onwards  N Ireland– 2004 onwards  Wales– 2003 onwards	For use in discussion with commissioners rather than as an economic indicator, as a prompt for exploring changes in referral flows within the area.
Number of referrals to provider by	PCT/UHB/LHB/HSCB	England – 2003 onwards	Data useful to show change in referral flows, but also a

originating body (per year)		Scotland – 2002 onwards  N Ireland– 2004 onwards  Wales– 2003 onwards	decrease in referrals may be a prompt in discussion with providers to ask if there is spare capacity, especially if combined with low waiting times.
Performance against Service Level Agreement (or equivalent)	PCT/UHB/LHB/HSCB	England – 2003 onwards Scotland – 2002 onwards N Ireland– 2004 onwards Wales– 2003 onwards	1) Over performance or underperformance against Service Level Agreements is an indicator of changes in referral flows. An underperformance may be a prompt in discussion with providers to ask if there is spare capacity, especially if combined with low waiting times.
Financial baseline information for case study area – over/underspends for purchaser and providers within case study area	PCT/UHB/LHB/HSCB	England – 2003 onwards Scotland – 2002 onwards N Ireland– 2004 onwards Wales– 2003 onwards	Indicates effect of change in volumes on organisations, to be used in discussion with providers and commissioners to further investigate efficient use of resources.

### **Data for England only**

Data	Source	Timescale	Purpose
% Choose and Book referrals of overall referrals for case study practices (per quarter)	PCT	April 2006	To assess % of referrals made under Choice system
% Choose and Book referrals of overall referrals for case study PCTs (per quarter)	PCT	April 2006	To assess % of referrals made under Choice system

### Appendix 5 Meso level interview topic guide

(GPs and practice managers, staff in commissioner organisations, staff in secondary care organisations, patient and public involvement organisations)

Note to interviewer: This topic guide indicates the areas to be covered during the interview. It should be used as a conversational guide, and is not prescriptive in terms of terminology or the order of questions. Interviewers have the freedom to ask any other questions required to capture the specific local context.

### **Example Introduction**

'We are conducting a national study based on the options available to patients when they are referred by their GP to secondary care. We are examining national policy regarding the type of influence patients have over referral options (for example regarding type of treatment and secondary care provider). We are also looking at how referral arrangements work in practice, and whether and how national policies about referral and/or about patients' rights/roles/responsibilities in health care affect organisational arrangements and health service staff's and patients' experiences. We have used ENT and Orthopaedic referrals as example tracer conditions but are generally interested in how choices are offered, discussed etc with all patients and how referrals are managed.'

- 1. Personal information (e.g. name of interviewee, job title, length of time involved with the organisation and role in organisation)
- 2. What degree or type of choice (or scope for patient influence) is available when a referral from primary to secondary care services is being considered within your health board/region /locality?
  - Are there options regarding treatment type and provider, any other options?
  - Are referral options fixed/formalised in any way? If so by whom?
  - What referral options exist for ENT and Orthopaedic secondary care services within your health board/region/locality?
  - Who chooses between referral options when a referral to secondary care is being considered?

- 3. To what extent is policy regarding the degree of patient involvement in referral decisions nationally or locally driven?
  - Is there tension between national policy and the implementation of arrangements in local health systems?
- 4. What do you see as the organisation's responsibilities in terms of the provision of choices/options for patients who need a referral to a specialist in secondary care?
  - Ensuring choices/options are available
  - Providing choices/options
  - Responds to patients' choices/decisions
  - Aiding/supporting patients to make decisions relating to their referral need
- 5. How are these responsibilities fulfilled? Can you describe the processes in place? (Ask general question & specifically in relation to ENT/Orthopaedics)
  - what are the systems in place?
  - how was the system(s) decided?
  - have you (the organisation) needed to put any extra resources in place?
- 6. What is your individual role in relation to the provision of choices/options to patients?
  - how much freedom do they have with regard to decisions about choices offered to patients?
  - what do they do /what do they have to consider?
- 7. What impact (if any) do you think policies relating to offering choices/options to patients have on local service provision and nationally (elsewhere in UK)? (making reference to the data on ENT/Orthopaedic referrals if appropriate)

- What issues have arisen?
- Has anything actually changed as a result of policies? Have there been any changes in nature or location of service or capacity?
- 8. What effect do you think offering choices/options to patients has on the way the organisation works? (making reference to the data on ENT/Orthopaedic referrals if appropriate)
  - Do you do anything differently in the organisation?
  - Do partners discuss the practices response to policies around patient involvement in referral decisions now, compared to before the choice policies were introduced in England? (GPs only)
  - Is central/practice guidance issued to staff members on how choices/options are to be supported/offered?
  - Role of choose and book (England only)
  - Have relationships with other organisations changed?
  - Have relationships with patients changed?
  - Has there been an impact on clinical networks?
  - Has there been an impact on clinical standards?
- 9. Have there been any other effects?
  - Any effects on strategic planning at the level of the local health economy?
  - Effect of competition for patients?
  - Effect on relationships between clinicians?
  - Has it had a financial impact on the organisation?
  - Effect of Payment by Results (England only)
  - Effect of choose and book (England only)
- 10. How do you think patients' influence over decisions about treatment and/or provider will develop within the NHS?
- 11. What is your perception of the scope patients have to influence referrals (e.g. in terms of choice of provider/location and treatment)?

- are the choices/options provided meaningful/helpful?
- what degree of choice/options do they feel patients are offered?

Date: 27/05/08

Version 6

## Appendix 6 Micro level interview topic guide

### **Patients**

### **Interview Guide**

Local researchers might want to modify some aspects of this to suit their preference, but questions in blue should be asked in a reasonably similar way in all interviews, and questions in red should be asked verbatim.

### Pre-amble:

Reminder about study and key points on consent form.

Reminder that the interview is about your experiences of being referred by your GP to a specialist. We'd like to hear how you got to the point of needing a referral, and what's happened since the recommendation for a referral was made.

Reminder that this study is NOT about evaluating your GP.

Signing of consent form

Audiorecorder on

### 1. About pre-referral

Broad opening question aiming to get people to talk us through the story up to the consultation at which the referral was recommended/initiated/made: "We understand that a decision was made for you to see someone else about your [ENT/bones]. Could you talk me through the story of how you got to this point?"

[If they need clarification: "We'd like to know a little bit about what the problem is, and also who you've consulted about it and what if anything has been done about it so far – this might include tests, treatments or therapies, not necessarily from doctors. Basically, what has happened up to the point at which a referral was decided on?"]

Prompt as necessary to check you have the answers to the following questions:

- What were the main symptoms/problems/concerns that this referral is intended to address?
- Had you consulted the GP about this problem before the most recent appointment in which the referral was initiated/made?
- Have you consulted any health care professionals other than the GP about this problem?
- Has the GP told you what s/he thinks the problem is?
- Have you had any tests or tried any treatments other than the [what they've already mentioned] for this?

# 2. About consultation in which referral was recommended/initiated/made

Broad opening question:

"I would like to find out how the decision to refer to a particular specialist was made. Can you talk me through what happened in the consultation during which the GP (or other health care professional) made, or agreed to make, a referral to a specialist"

Prompt as necessary to check you have the answers to the following questions:

- Who first suggested that a referral might be appropriate? (Patient, GP, [other check whom the other person influenced!])
- Did the GP say what kinds of things the specialist/other provider might do?
- Did you and the GP discuss where you might be referred to? [Yes/no] If yes, What was said?
- Did you and the GP discuss who you might be referred to? [Yes/no] If yes, What was said?
- Did you and the GP discuss **what** you might be referred **for** (what the referral letter would say/ask for?) [Yes/no] If yes, What was said?
- Did you and the GP discuss when the referral appointment should or would be? [Yes/no] If yes, What was said?
- Did the GP give you (or suggest you got) any further information (e.g. leaflets, details of websites, talk to a nurse) relating to the referral? [Yes/no]

# 3. About what's happened since the consultation in which referral was recommended/initiated

"OK, so you left the consultation with ... [brief recap of where patient was at in terms of referral. This is country dependent and should reflect back what patient said in phase 2 of interview)]. Could you tell me what's happened about the referral since that consultation?"

Prompts if necessary or check:

- Have [the things that the GP said would happen] happened yet?
- Have you had any further contact with the GP practice about the referral? If yes, what and how did you feel about/respond to that?
- Have you had any communications from /with the place you were referred to or from anyone else about the referral? If yes, what and how did you feel about that?
- Have you thought or done anything else about the referral? (Including talked to anyone about it, checked up on any information, done anything about making/changing or cancelling an appointment)
- (If action has been taken to arrange the appointment) Have you been given a choice or say about the time/place/person you will be seen at/in/by?
- Have you used / looked for any information relating to the referral other than medical information about your condition or proposed tests/treatments?

- Have you used / looked for any information about your condition or proposed tests/treatments?

### 4. Reflections on whole process

"Ok, so you've given me a very helpful account. Looking back, can you tell me what you feel about it all?"

If asked for clarification; "Did the referral process work in the way you would have liked it to work? What was good and what was bad about it?" "Is there anything you would have liked to have been done differently?"

To be asked after the main question has been answered:

Did you want to be involved in making the decision about your referral? Did you feel you were involved in the decision about your referral? In what ways and to what extent did you feel involved?

What roles did you play or what contributions did you make? How in an ideal world would you have liked to have been involved in decisions relating to your referral?

How, if at all, do you think your GP tried to involve you?

Do you think you were given enough options in terms of:

- where you were referred to [Yes/no] If no, what other options would you have liked?
- who you were referred to? [Yes/no] If no, what other options would you have liked?
- what you were referred for? [Yes/no] If no, what other options would you have liked?
- when your referral appointment would take place? [Yes/no] If no, what other options would you have liked?

\_

Were there any other possibilities or options for managing your [ENT or bone] problem that you would have liked to explore with the GP or someone else, but that didn't get explored?

What sorts of choices do you think people should have, and why?

Do you think the GP/referral process paid enough attention to your views in relation to:

- where you were referred to? [yes/no] Can you explain why you think that?
- who you were referred to? [yes/no] Can you explain why you think that?
- what you were referred for? [yes/no] Can you explain why you think that?
- when your referral appointment would be? [yes/no] Can you explain why you think that?

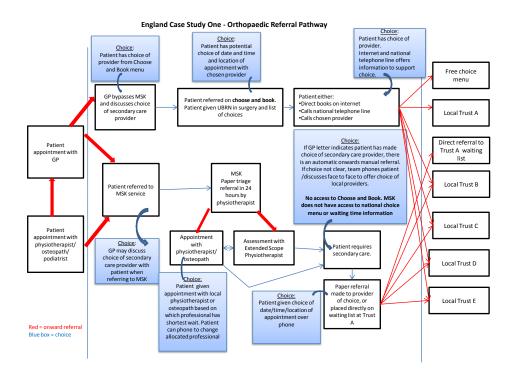
If you could change the referral system, what if anything would you do to improve it?

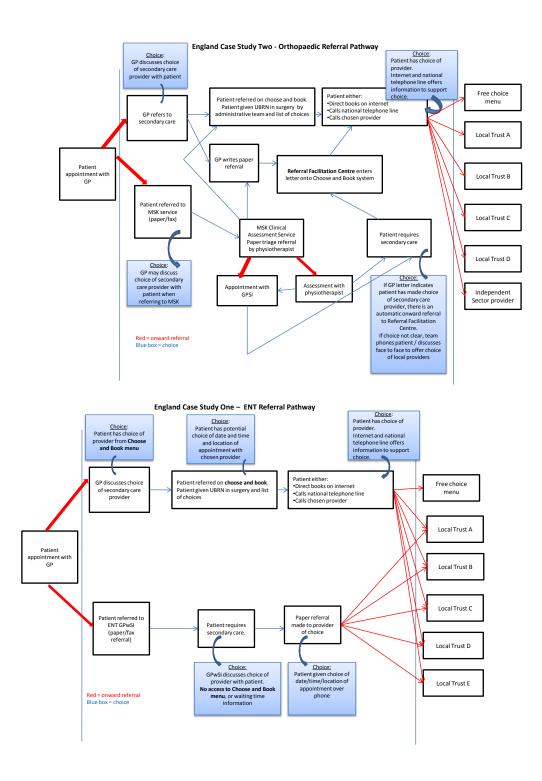
### Closing

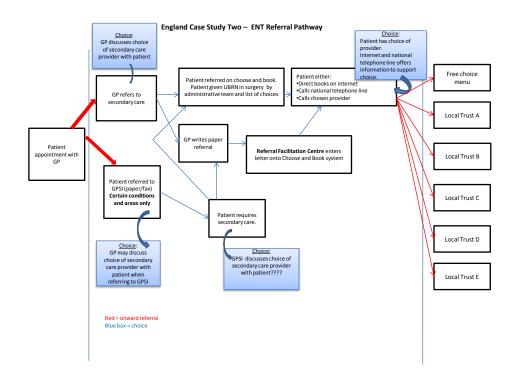
To help us describe the group of people who took part in our study, please could you tell me your:

AGE BAND (16 – 29, 30-59, 60 upwards)
POSTCODE
[Researcher to document gender]
[Researcher to document time elapsed between referral appointment and interview]
THANK YOU

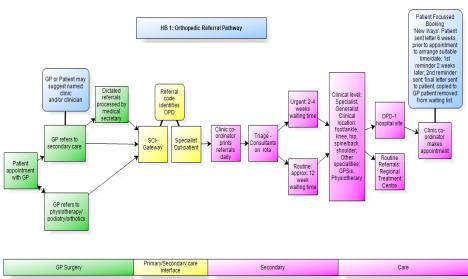
## Appendix 7 Patient referral pathway diagrams



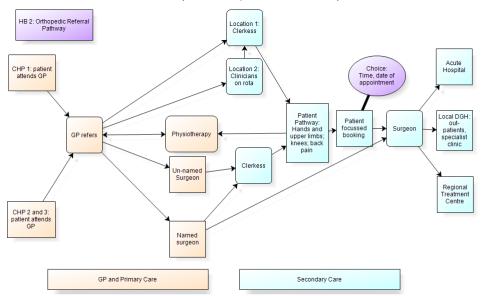




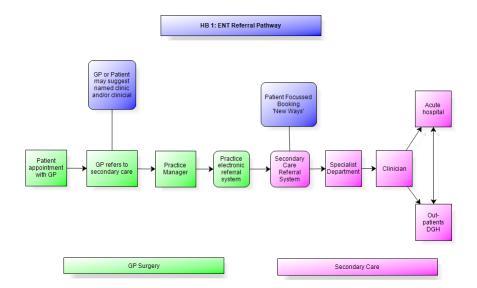
### Scotland Case Study One - Orthopaedic Referral Pathway



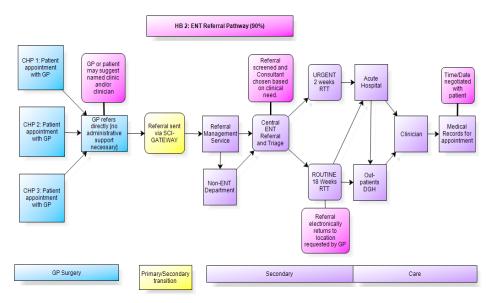
### Scotland Case Study Two - Orthopaedic Referral Pathway



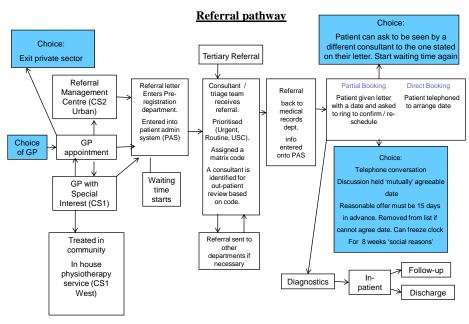
Scotland Case Study One - ENT Referral Pathway



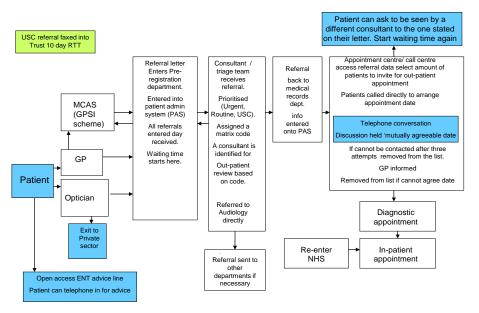
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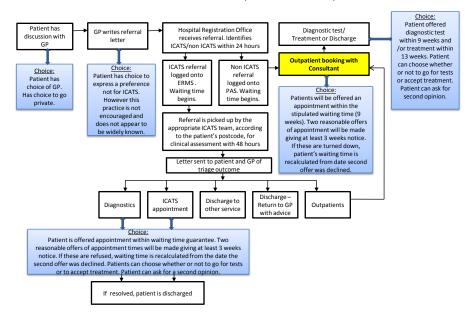
### Wales Case Studies One and Two Orthopedics



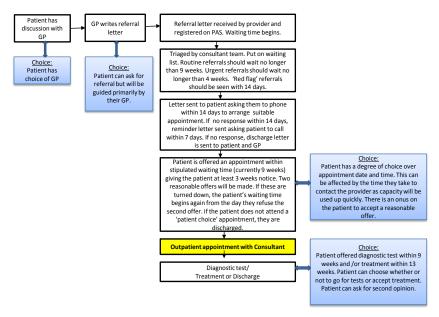
### Referral pathway Case Study 1: NHS Trust (East) ENT



#### Northern Ireland Case Studies One and Two - Orthopaedic GP Referral Pathway



### Northern Ireland ENT GP Referral Pathway – Case Study One and Two



### Addendum

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.

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