Theory and conceptualisation of public trust in the health care system

Three English case studies: care.data, biobanks and 100,000 Genomes Project

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Declaration

I, Felix Gille, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

There is little research into the understanding, protection and recovery of public trust in health care systems, considering the underlying importance of public trust, not only for the effective functioning of health care systems, but also for society in general. There is no robust conceptual framework of public trust. This poses problems for policy making and public trust measurement. Therefore, research is needed to identify what public trust in the health care system means. This research will not only inform health policy making, but should also allow the development of a public trust measure in the future.

Hence, the aim of this research is to gain deeper understanding of what public trust in health care systems at the macro level is, and to close a theory and conceptual gap. Furthermore, this research aims to determine whether public trust is measurable.

To fulfil the research aim, three qualitative case studies of the English NHS were conducted: an analysis of online news with readership comments concerning care.data; a secondary analysis of interviews about participants' experiences and perceptions of biobanks in general; and an analysis of public focus groups about perceptions of the 100.000 Genomes Project in particular. Further, existing measurement instruments and their conceptual frameworks, as well as general trust theory, were reviewed. Based on these elements, public trust theory and a conceptual framework of public trust were developed.

The findings suggest that public trust grows in the public sphere from open public discourse and as a result legitimises the actions of the health care system. Public trust builds on information equally relating to past experiences, present perceptions and future expectations. Public trust is established in anticipation of a net benefit for the public as well as the system. With respect to the measurability of public trust, this research suggests that public trust can be measured.

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Disclaimer

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Abbreviations

BBC	British Broadcasting Corporation
BIO	Biobank participant interview
DH	Department of Health, England
DNA	Deoxyribonucleic acid
EU	European Union
FG	Focus group interview
GP	General Practitioner
HERG	Health Experiences Research Group at University of Oxford
LSHTM	London School of Hygiene & Tropical Medicine
NHS	National Health Service, England
PIRU	Policy Innovation Research Unit at LSHTM
UK	United Kingdom
US	United States of America

Chapter 1: Why public trust in health care systems matters and deserves greater research attention

Key findings

- Public trust is essential for the functioning of the health care system and society
- At present research cannot provide a robust conceptual framework of public trust in the health care system
- Detailed conceptual work with a view on measurement instrument development, and the development of policy guidelines and methods to improve public trust would be beneficial

Overview

There is too little research into the understanding, protection and recovery of public trust in health care systems, considering the underlying importance of public trust, not only for the effective functioning of health care systems, but also for society in general. Several researchers have pointed towards a contemporary crisis of public trust in health care systems and there have been many examples that show the severe effects of mistrust. More research into public trust in health care systems could contribute to improving efficiency while protecting the health of the public.

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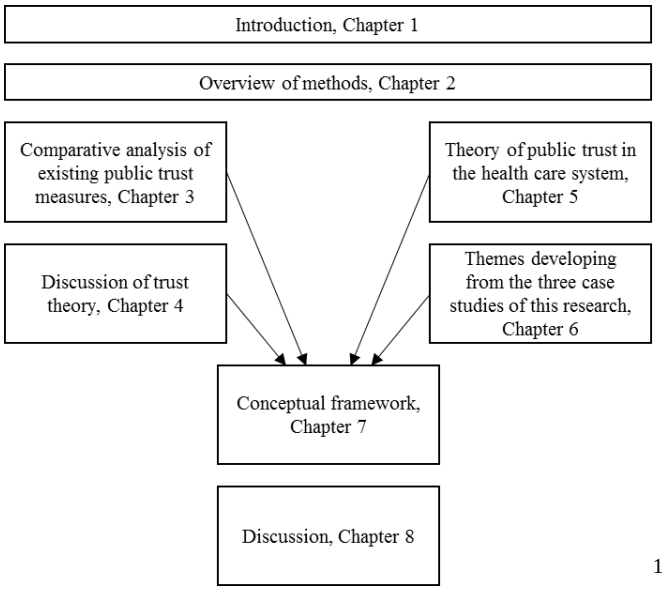

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[1] This figure is presented at the beginning of each chapter to guide the reader.

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Supervisors' contributions to the article	Sarah Smith and Nicholas Mays commented on the draft versions and made suggestions on how to improve the article.

Introduction

There is a clear imbalance between the importance of trust for the functioning of a health care system and the priority given to research on trust. Historically, health care, especially primary care, has enjoyed a high level of trust compared to other sectors in society (O'Hara, 2004). However, scholars are now pointing towards something of a trust crisis in health care systems (Abelson, Miller, & Giacomini, 2009). For example, in the United States of America the crisis is attributed, at least in part, to a decline in trust in the government, repeated scandals across the health sector highlighted in the mass media, rapidly rising costs and the large number of uninsured people (Blendon, 2006). Despite rising concern, there is a paucity of research about the nature and extent of public trust in health care systems, and the implications of its presence or absence. Current political developments, plus the importance of trust in society, call for research and advocacy to understand, protect and restore public trust in health care systems. Researchers should not wait until trust is destroyed to such a degree that mistrust is the common base of interaction. So why is there so little research on public trust in health care systems? Have we not yet recognized the importance of public trust to the effective and efficient functioning of health care systems? Or is it the case that public trust is too complicated to grasp? Or do we need a major system failure to open our eyes to understand that public trust is one of the fundamentals both of a good society and a robust health care system?

Why does trust matter for health care systems?

Trust is paramount to the delivery of health care (Mohseni & Lindstrom, 2007). An obvious example of the value of trust lies in its effect at the level of compliance with therapy (Straten, Friele, & Groenewegen, 2002). Perceiving, enhancing and justifying trust are embedded in law and policy as fundamental ethical goals (Hall, Dugan, Zheng, & Mishra, 2001). The absence of trust might have harmful effects for the health of patients, as it could delay consultation with a doctor by a patient or the withholding of necessary patient information (Ahnquist, Wamala, & Lindstrom, 2010). Paradoxically, as health literacy increases, trust becomes more important, while at the same time becoming harder to win (Brown, 2008). Trust is often taken for granted, leading to neglect in the ways to maintain and build it. In turn, this results in harm to the system (Jones & Barry, 2011). Robust measures of trust could therefore be used as indicators of performance of

health care systems and might show the need for reform at the macro level (Abelson et al., 2009). This is particularly true if trust is considered as a dimension of patient satisfaction (Kelly, Njuki, Lane, & McKinley, 2005). Given that good governance is a key aspect of health care policy, the importance of trust for system stewardship, a key component of good governance, needs to be stressed (Siddiqi et al., 2009).

However, trust in health care systems is difficult to study as there is no agreement as to how it should be conceptualised. Different authors use different terms, such as public trust, interpersonal trust and institutional trust; horizontal and vertical trust; individual trust and system trust; simple trust and established trust. They have also distinguished between cognitive trust, knowledge-based trust and affective/altruistic trust (Abelson et al., 2009; Gilson, 2003; Goudge & Gilson, 2005; Hall et al., 2001; Lindström, 2011). Often these terms are used interchangeably between studies with a similar focus, and are not clearly defined and distinguished. Rolfe et al. (2014) after reviewing 10 intervention studies to increase trust between doctors and patients, found a similar lack of consistent definitions of trust (Rolfe, Cash-Gibson, Car, Sheikh, & McKinstry, 2014). These varied conceptualisations of trust result in diverse approaches to measuring trust in terms of what is measured and how. The diverse range of instruments purporting to measure trust makes comparing or synthesizing evidence from studies difficult (McKnight & Chervany, 2002).

Examples of the importance of public trust in health care systems

The first example provides insight into vertical trust, which is the trust that people place in higher authorities such as experts or governments. It illustrates the widespread effect of parental mistrust of measles-mumps-rubella vaccine which started in the late 1990s, particularly in the United Kingdom. Unproven links between the vaccine and bowel disease and autism were spread by the media and caused low vaccine coverage due to a lack of trust, leading to disease outbreaks. Similar trust dilemmas related to vaccines are found around the world (Larson & Heymann, 2010). Larson et al. (2011) describe the *Vaccine confidence gap* where public confidence in vaccines is associated with low levels of public trust in the wider health care system (Larson, Cooper, Eskola, Katz, & Ratzan, 2011). They argue that public trust in vaccines is highly variable and the building of trust among members of the public depends on factors such as the perceived risk of the vaccine

to cause harm rather than benefit, political and religious beliefs and socioeconomic status. Therefore, research should not only focus on the safety and effectiveness of a vaccine but also on the psychological, social and political factors affecting the public's trust in it.

A second example shows the importance of trust in situations where people face choices, in this case, in the private health insurance market. Here trust plays three roles: In relation to reducing uncertainty about being able to afford treatment on the part of the person insured; in relation to the economic viability of insurers, as trust might be one motivating factor for choosing one insurer over another and in relation to preventing information asymmetry as private information has to be shared between the purchaser of insurance and the insurer. This form of trust might be described as established trust or history-based trust. In the Australian context, Natalier and Willis (2008) conclude that trust in private health insurers is built up during a family's history of insurance. It seems that trust accumulates among loyal insurers (Natalier & Willis, 2008). From the point of purchase of a policy, the purchaser is able to have a positive expectation towards the future, resulting in a reduction of fear and uncertainty. This, in turn, supports trust.

Use of the Internet to identify health-related information is the third example, where the consumer needs to trust a remote, anonymous and often foreign information provider in order to be able to benefit from the information available. This form of trust is probably best described as cognitive or knowledge-based trust. In the US, in the mid-2000s, 80% of adults regularly sought online health advice and in Europe it was 66% (Sillence, Briggs, Harris, & Fishwick, 2007). Misleading information, which if perceived to be trustworthy by the consumer, could have negative health effects and prolong recovery. Though the Internet is increasingly used as a source of information, evidence regarding its usefulness and quality and the ability of the public to understand the information provided, is conflicting. The Internet is said to be the biggest contemporary addition to social capital (Hardin, 2006). In the context of the Internet, trust is most likely influenced by security, identity, privacy and quality. Nevertheless, the apparent quality (accuracy, completeness, readability, design, disclosures and references) of Internet content tends to be assessed as poor (Eysenbach, Powell, Kuss, & Sa, 2002). In the case of cancer risk web sites, of 22 sites reviewed in 2005 by Ekman et al. (2005), only two fulfilled the quality criteria of transparency, authority, privacy and currency as defined by the

European Union. The overall impression of quality and the risk estimates provided were poor (Ekman, Hall, & Litton, 2005). There is an inherent disadvantage in Internet communication since no additional verbal or visual information can be provided unlike face-to-face interaction (Jucks & Bromme, 2007). Perhaps in response to the poor quality and limited trustworthiness of health care web-pages, the European Commission has recently launched a web site called *E-Health*, where so called *trustworthy* e-health web sites are listed (Commission, 2013).

Conclusion and thesis aims and objectives

These three examples show the importance of public trust in health care systems for their effective functioning and the potential harmful consequence of mistrust or low levels of trust in health interventions. Yet there has been little research in this area and a more vibrant exchange of knowledge among researchers and with policy makers and health care managers is needed. Many issues are still to be resolved. In particular, detailed conceptual work and the development of common concepts and methods for public trust measurement would be beneficial. Exploration of the extent to which trust theories from other disciplines can be used creatively in the analysis of health care systems would also help. The long-term aim should be to learn how to earn, build and preserve public trust in health care systems since, if we wait until trust in health care systems is eroded or even broken before giving its analysis sufficient priority, it may be too costly and too late to rebuild it.

Therefore, the first aim of this research is to gain a deeper understanding of what constitutes public trust in health care systems and whether this is a construct that could subsequently be measured on a continuous scale. The second aim is to close an existing theory gap and to refine the terminology of public trust. Last, this research aims to foster deeper discussion within this small research area.

The objectives for this research are:

Objective 1: To map contemporary trust theory developed outside the health care field and to draw out its relevance for trust in healthcare systems.

Objective 1.1: To synthesise a preliminary concept of trust based on theoretical literature.

Objective 2: To elaborate the meaning of public trust.

Objective 3: To further refine the concept of public trust in the health care system through three case studies of public trust in the NHS, England.

Objective 3.1: To study and conceptualise public trust in care.data on the basis of discussion and commentary in public fora.

Objective 3.2: To study and conceptualise trust existing between participants and Biobank research.

Objective 3.3: To study and conceptualise trust existing between the public and the 100.000 Genomes Project.

Objective 3.4: To conceptualise public trust based on objectives 1, 2, and 3.1-3.3, 4.

Objective 4: To develop an approach to measurement of public trust in health care systems.

Objective 4.1: To review classical and modern psychometric theory to determine the principles necessary for effective measurement.

Objective 4.2: To review existing public trust measurement tools applicable for healthcare systems research.

Objective 4.3: To determine whether public trust in the healthcare system is a measurable construct.

The overall research question is: what is public trust in the health care system?

Consistent with this question, and these aims and objectives, this thesis comprises an overview of wider trust theory, an analysis of existing public trust conceptualisations, and an analysis of three case studies from the field of biomedicine and mass data use. In doing so, a conceptual framework of public trust in the health care system is developed which can form the basis of policy making and measurement instrument development. As existing public trust measurement instruments have considerable conceptual deficits and

as established measurement instrument development guidelines have somewhat limited information about the characteristics of a good conceptual framework, the thesis includes a psychometric analysis of existing public trust scales and improves quality criteria for the construction of a robust conceptual framework of public trust.

Chapter 2: Methods overview and research ethics

This short chapter provides an overview of the research methods. Detailed descriptions of the methods are presented in each chapter. Chapter references referring to the methods in the thesis are found in the Table 2.1. It is important to note that this research builds on my Master's Thesis, *A pilot study on measuring public trust in health systems* (2013). The pilot study informed the overall research strategy. In the remainder of this thesis it is indicated when the Master's Thesis had a particular strong influence on this research.

Table 2.1: Methods overview

Objective	***Motivation***	**Method**	***Chapter***
Objective 1: To map contemporary trust theory developed outside the healthcare field and to draw out its relevance for trust in healthcare systems.	*Numerous different trust theories are available, but unfortunately there is no overview of applicable theories found in the literature. Further this theory mapping provides an easier access to the research field.*	Heuristic approach; Narrative literature review; Snowball sampling.	*4*
Objective 1.1: To synthesise a preliminary concept of trust based on theoretical literature.	*An understanding of trust theory is essential to discuss the empirical data. Further it provides first hints of what public trust in health care systems may look like.*	Comparative discussion of trust theories described in the literature.	*4*
Objective 2: To elaborate the meaning of public trust.	*Public trust is a poorly elaborated concept, however commonly used within the research and public sphere.*	Discussion of contemporary theory on public spheres as well as trust theory describing leading to a theory of public trust.	*5*
Objective 3: To further refine the concept of public trust in the healthcare system through three case studies of public trust in the NHS, England.	*To understand what constitutes public trust in the health care system.*	Qualitative analysis of inductive open coded themes evolving from data of three case studies.	*6-7*
Objective 3.1: To study and conceptualise public trust in care.data on the basis of discussion and commentary in public fora.	*Assuming that public trust develops from public discourse, public trust can be conceptualised by analysing public discourse.*	Qualitative analysis of national online newspaper articles (n=58) with readership comments (n=1625).	*6*

Objective	***Motivation***	**Method**	***Chapter***
Objective 3.2: To study and conceptualise trust existing between participants and Biobank research.	*Biobanks are an example of a health care system's programme on macro level which are likely to depend on public trust. Further they are long established compared to the other case studies, i.e. assumingly more trusted and accepted.*	Qualitative secondary analysis of 21 interviews of biobank participants in the UK. Interviews provided by Health Experiences Research Group at University of Oxford.	*6*
Objective 3.3: To study and conceptualise trust existing between the public and the 100.000 Genomes Project.	*A research programme on national level which had the aim to refine future health care and to contribute to the public good. Public trust is understood to influence the success or failure of such a programme.*	Qualitative analysis of two public focus groups conducted to research public perception of the 100.000 Genomes Project.	*6*
Objective 3.4: To conceptualise public trust based on objectives 1, 2, and 3.1-3.3, 4.	*To measure public trust and to provide health policy implications on how to improve public trust, a detailed conceptual framework is necessary.*	Conceptualising public trust based on all sources at hand, i.e. trust theory, empirical data, existing conceptualisations of public trust, and wider literature on public trust.	*7*
Objective 4: To develop an approach to measurement of public trust in health care systems.	*Several public trust measurement instruments exist, often lacking conceptual and theoretical description.*	Reviewing previous used measurement instruments. Analysing the concepts deriving from the previous objectives using modern psychometric approaches.	*3,8*
Objective 4.1: To review classical and modern psychometric theory to determine the principles necessary for effective measurement.	*To understand the methodological background for the psychometric analysis.*	Literature review	*3*
Objective 4.2: To review existing public trust measurement tools applicable for health systems research.	*To examine if public trust has common elements between different instruments and to see if public trust is universal conceptualisable. Further, to examine if existing instruments are robust.*	Psychometric appraisal	*3*
Objective 4.3: To determine whether public trust in the health care system is a measurable construct.	*To elaborate on the measurability of public trust.*	Review and discussion	*8*

Methods orientation

Since the field of trust research (especially theory) is often rather confusing, unspecific and feels at times subjective, I aim to stay as closely as possible at the qualitative data and only carefully abstract or generalise from the data. As a result, I keep the research process as open and neutral as possible. I consider the qualitative data to be the leading source of information to find themes conceptualising public trust. Where the qualitative data is contradicted by either existing social theory or previous measurement instruments, priority is given to the qualitative data since these data are analysed specifically with the development of a conceptualisation of public trust in the health care system in mind. Therefore, all insight gained from trust theory, literature and existing measurement instruments will foremost be used to help understand or sort the qualitative data.

Ethics

No anticipated physical, psychological, social, or legal risks were involved in this study. Ethical approval to use the Biobank data for further secondary analysis had been granted previously (South Central Berkshire NRES Committee Ref 12/SC/0495) and the approval for the secondary analysis of the focus groups was covered in the ethical approval of the Department of Health-funded project on the experience of participation in the 100.000 Genomes Project (University of Oxford Research Ethics Approval: MS-IDREC-C1-2015-175). The data for the care.data case study are publicly accessible. LSHTM ethical approval was granted for the entire PhD project on 31st March 2015, London School of Hygiene & Tropical Medicine Ethics Ref: 8982.

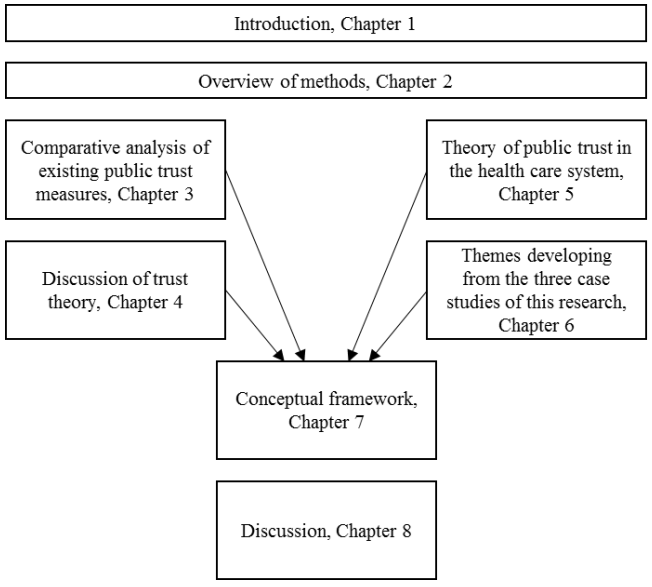
Chapter 3: Review of existing public trust in health care systems measurement instruments

Key messages

- Existing conceptual frameworks of public trust in the health care system as well as the corresponding measurement instruments have psychometric weaknesses
- Existing public trust measurement instruments measure the average of aggregated individual patient trust in selected health care system representatives/institutions
- Established measurement development guidelines are limited in the criteria they provide to develop a robust conceptual framework

Overview

Three existing measurement instruments were identified and reviewed regarding their psychometric properties. All three instruments and respective conceptual frameworks have psychometric weaknesses. A comparative analysis of the conceptual frameworks was conducted to inform the conceptual framework developed in Chapter 7. Furthermore, when reviewing existing measurement development guidelines too little information was identified with respect to the quality criteria necessary to develop a robust conceptual framework. This chapter sets out the necessary research steps to develop a conceptual framework.



Introduction

The following chapter meets the objectives:

- Objective 4.1: To review classical and modern psychometric theory to determine the principles necessary for effective measurement.
- Objective 4.2: To review existing public trust measurement tools applicable for health systems research.

To use public trust in health services research as a measure for example for reform need, transaction costs or state legitimacy or as a measure of health care systems' quality depends on the extent to which public trust can be operationalised into a robust measurement instrument. While a detailed definition and description of public trust is helpful and informative to discussion and debate, to use public trust in these applied contexts necessitates formal quantification, usually via measurement in a questionnaire that is psychometrically scaled to produce a score that represents the construct (i.e. public trust). Measurement in contrast to e.g. counting or checklists as a form of quantification is preferred. Measurement is possibly the only way to understand changing levels of public trust over time. The purpose of measurement *'is to provide a reasonable and consistent way to summarize the responses that people make to express their achievements, attitudes, or personal points of view through instruments …*' (Wilson, 2005, p. 5). Critics of contemporary public trust measurement state that public trust in the health care system is difficult to measure through single opinion polls in contrast to a survey consisting of several questions covering specific branches of the health care system. This is because different sectors in a health care system enjoy different levels of trust among the population so that a single measure would not be meaningful and rather 'abstract' (O'Neill, 2002). The alleged meaninglessness is a result of the different levels of public trust in the many actors that contribute to the concept of public trust. Therefore, the result of such a measure would produce a meaningless average where it is not clear which actors enjoy which level of public trust. Hence, one would be better off measuring public trust in selected branches of the health care system only. This criticism will be considered in Chapter 8, where the measurability of public trust will be discussed.

Nevertheless, in other contexts several sets of well established guidelines document the minimum requirements for questionnaires to be considered as measurement instruments (Lohr, 2002; Reeve et al., 2013; U.S. Department of Health and Human & Administration,

2009). In general, these guidelines suggest that measures should have reliability, validity and responsiveness. Reliability is the extent to which an instrument is free from random error, internally consistent, and yields repeatable and unchanging results. Four types of reliability exist: internal consistency, test–retest reliability, inter-rater reliability and parallel (alternative) forms reliability. Validity is concerned with the question of how far the instrument is measuring what it should be measuring. Content, criterion-related and construct validity are three types of validity. Responsiveness focuses on the ability of the questionnaire to detect meaningful change over time (Smith, Lamping, Banerjee, Harwood, & Foley, 2005, p. 16; Streiner & Norman, 2003, p. 186). Existing guidelines also include the importance of content validity, the extent to which every aspect of a construct is represented by items in the questionnaire. Here guidelines generally stress that the content of a questionnaire should be based on a conceptual framework that is in some way derived from qualitative interviews, a review of existing conceptual literature and compared against existing instruments. Table 3.1 shows a summary of current guidelines on how to develop the content of a conceptual framework and what the needs for validity are.

Table 3.1: Summary of current development guidelines on conceptual framework and validity

Quality criteria	Definition	Source
Conceptual and measurement model	'A ...measure should have documentation defining and describing the concept(s) included and the intended population(s) for use. In addition, there should be documentation of how the concept(s) are organized into a measurement model, including evidence for the dimensionality of the measure, how items relate to each measured concept, and the relationship among concepts included in the ... measure.' (p.1901)	Reeve et al., 2013
Concept measured	'Generally, when it is not obvious, instrument developers initially can hypothesize a conceptual framework to support the measurement of the concept of interest drafting the domains and items to be measured based on literature reviews and expert opinion. Subsequently, patient interviews, focus groups, and qualitative cognitive interviewing ensures understanding and completeness of the concepts contained in the items. ... The conceptual framework of a ... instrument will evolve and be confirmed over the course of instrument development as a sponsor gathers empiric evidence to support item grouping and scores. When used in a clinical trial, the ... instrument's conceptual framework should again be confirmed by the observed relationships among items and domains.' (p.7)	U.S. Department of Health and Human & Administration, 2009

Quality criteria	Definition	Source
Conceptual and measurement model	'The rationale for and description of the concept and the populations that a measure is intended to assess and the relationship between these concepts. Developers should: State what broad concept (or concepts) the instrument is trying to measure ... In addition, if the instrument is designed to assess multiple domains within a broad concept ..., then provide a listing of all domains or dimensions. Describe the conceptual and empirical basis forgenerating the instrument content and for combining multiple items into a single scale score and/or multiple scale scores. State the methods and involvement of the target populations for obtaining the final content of the instrument and for ascertaining the appropriateness of the instrument's content for that population, for example by use of focus groups or pretesting in target population(s). '(p.196)	Lohr, 2002
Content validity	'A ... measure should have evidence supporting its content validity, including evidence that patients and experts consider the content of the ... measure relevant and comprehensive for the concept, population, and aim of the measurement application. This includes documentation of as follows: (1) qualitative and/or quantitative methods used to solicit and confirm attributes (i.e., concepts measured by the items) of the ... relevant to the measurement application; (2) the characteristics of participants included in the evaluation (e.g., race/ethnicity, culture, age, gender, socio-economic status, literacy level) with an emphasis on similarities or differences with respect to the target population; and (3) justification for the recall period for the measurement application.' (p.1901)	Reeve et al., 2014
Content validity	'Evidence that the instrument measures the concept of interest including evidence from qualitative studies that the items and domains of an instrument are appropriate and comprehensive relative to its intended measurement concept, population, and use. Testing other measurement properties will not replace or rectify problems with content validity.' (p.11)	U.S. Department of Health and Human & Administration, 2009
Content validity	'Evidence that the domain of an instrument is appropriate relative to its intended use.' (p.196)	Lohr, 2002
Construct validity	'A … measure should have evidence supporting its construct validity, including documentation of empirical findings that support predefined hypotheses on the expected associations among measures similar or dissimilar to the measured … outcome' (p.1901)	Reeve et al., 2015
Construct validity	'Evidence that relationships among items, domains, and concepts conform to a priori hypotheses concerning logical relationships that should exist with measures of related concepts or scores produced in similar or diverse patient groups' (p.11)	U.S. Department of Health and Human & Administration, 2009
Construct validity	'Evidence that supports a proposed interpretation of scores based on theoretical implications associated with the constructs being measured.' (p.196)	Lohr, 2002
Criterion validity	'Evidence that shows the extent to which scores of the instrument are related to a criterion measure.' (p.196)	Lohr, 2002

The commonalities between the guidelines with respect to conceptual development are that instrument developers need to document and describe the underlying construct as well as present evidence for the items and dimensions used in the instrument. To develop the items, it is suggested that items can be drafted by expert opinion and literature review which should be followed by qualitative research to confirm and improve the items. To assure content, construct and criterion validity, evidence must be provided. This evidence should be based on qualitative research. Unfortunately, none describe in detail what an adequate conceptual framework should look like. The guidelines are superficial with respect to the development process of a conceptual framework, merely stating that one should undertake a literature review, rely on expert opinion and conduct qualitative research with patients (or whoever is the potential repondent) to provide an empirical basis. With respect to content validity, the guidelines suggest that one should have (qualitative/quantitative) evidence at hand to prove how the measure items are linked to the concept of interest. Similarly, evidence is needed to show how items are related to each other to prove construct validity. The major shortcomings are the lack of specificity of the guidelienes and the loose use of the term 'evidence'. The guidelines do not describe in great detail what the contribution of different sources of evidence should be for the development process of a conceptual framework and how the sources should relate to each other; i.e. other empirical literature, qualitative data, quantitative data or theory. Also the guidelines do not elaborate on differences with respect to developing a measure based on an existing measure by re-validation, versus developing a measure from scratch. Last, despite Lohr's (2002; p. 196) very brief mentioning of theory, there is no suggestion of how to make use of any theoretical underpinning. In conclusion one can argue that the guidelines are unspecific and do not stress the benefit of reviewing a wider body of theory. Likely the guidelines lead to a misleading perception of an adquate conceptual framework when used as quality criteria for a psychometric review, as seen further below. It seems that the guidelines acknowledge the importance of a well developed conceptual framework, but focus on the quality criteria of the actual instrument. There seemes to be an imbalance in focus between the qualitative development process of the conceptual framework and the ensuing instrument development process based on the conceptual framework. This imbalance undermines the quality of the measurement instrument.

Importance of a clear conceptual framework underlying a questionnaire instrument

All psychometric measurement requires a clear definition of the underlying conceptual framework from which the measure is developed (Green & Browne, 2005). In its most simple form, this is because a clear understanding of the underlying conceptual framework enables appropriate hypotheses to be set up in order to test the validity of a new instrument. This understanding is emphasised by Perron and Gillespie (2015): '*We must establish clear and concise conceptual definitions of focal constructs by describing what the construct is and what it is not, by specifying and defining all dimensions of the construct, and by ensuring the items that reflect each dimension are unidimensional and cannot be subdivided into more dimensions.'* (Perron & Gillespie, 2015, p. 33). Yet this has often not been achieved. Stenner (2001) wrote: '*There is a simple thought experiment that can inform us regarding how well we understand the construct under study. If presented with an instrument purportedly measuring the construct, can we use our knowledge about the construct-associated (construct theory) specification/calibration equation(s) together with item engineering rules to produce a clone or copy of the instrument - such that the score-to-measure table for the clone is identical to that of the original instrument?'* (Stenner, 2001). This implies that it is essential to present a well-developed conceptual framework so that others can replicate the measure based on the conceptual framework when following the same measurement development rules. In 1983, looking back over 50 years of research, Stenner (1983) stressed that measurement procedures often lack '*persuasive, well-documented construct theories'* (p.1) due to a lack of formal methods. Stenner, Smith, & Burdick (1983) highlight the absolute importance of a robust construct for measurement.

The negative consequences of a poor conceptual framework are manifold: misspecification of the measurement model (i.e. inaccurate calibration of the scale); deficient or contaminated measures (i.e. items being missed out or the wrong items included), and a weak theoretical rationale for validation of the hypotheses, leading to problems of low construct validity, low validity of statistical conclusions and low internal validity (MacKenzie, 2003, p. 324). MacKenzie (2003) states that if a construct is poorly developed, the following discussions of instrument reliability and validity are close to meaningless.

Adding to this issue, there are also more complex ways in which the nature of the conceptual framework has an effect on how it can be measured. Several authors have described the difference between causal indicators and effect indicators, see Figure 3.1 (Streiner & Norman, 2003, p. 75). Effect indicators result from the conceptual framework to be measured and causal indicators influence the conceptual framework to be measured. Whether the dimensions (or items) within the conceptual framework are considered to be a causal or an effect indicator determines the statistical (psychometric) techniques that can be used in evaluation of the measure. In the field of trust research, it is observable that both types of indicators have been used in instruments.

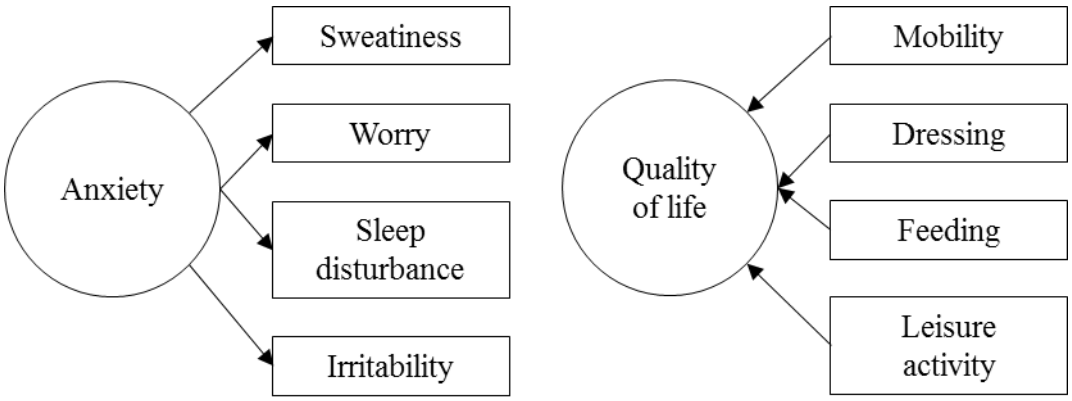


Figure 3.1: A practical representation of effect indicators on the left, and causal indicators on the right

(Source: Streiner & Norman, 2003, p. 75)

The implications of effect indicators for instrument development are: first, all items should correlate with each other to different degrees. Second, in order to measure the construct, the inclusion of every specific item does not really matter. If, for example, one item cannot be used due to wording problems the other items are correlated with the missing item and so in some way compensate for the missing item. Third, when conducting a factor analysis all items load on a strong first item. In contrast, the implications for instruments building on causal indicators are very different: here the items are not strongly related and therefore items cannot be missed. If one item is not covered in the questionnaire, the area the item is representing is missing. (Streiner & Norman, 2003, p. 75). This distinction leads to the understanding that both types of items should not be mixed in the same instrument.

For the conceptualisation of public trust, this distinction is important to consider as trust itself is reciprocal: trust can be the effect of action but also cause action at the same time, as trust legitimises action. For example, a patient trusts a doctor because of her/his personal experience of the doctor. This form of trust can be operationalised, for instance, if the patient formally consents to treatment or if s/he simply allows the doctor to conduct the treatment. Now, by consenting to treatment, the patient hereby legitimises the treatment. Following the differentiation of causal and effect indicators, a conceptual framework must consist of one of the two, but not both. In this particular exercise, to sort items into the two categories, one group of items are of particular interest: items describing an anticipated effect. For example, a person participates in biomedical research as s/he trusts that the participation will lead eventually to a personal health benefit. However, at the point of making the decision to participate, this personal health benefit is not yet certain as it is an anticipated effect (there is always the risk that the anticipated effect of the trusting relationship does not appear for unforeseen reasons). Therefore, anticipated effects can be understood as causal indicators as the effect of the trusting relationship is a result of the relationship itself and can therefore not appear at the point of deciding to trust. This understanding can be challenged in trust relationships where there is an ongoing direct effect as a result of the trust relationship; i.e. where trust and the effect of trust are mutually reinforcing. The difficulty of separating anticipated effect indicators (causal indicators) from effect indicators is increased when the timeframe between the decision to engage in a trusting relationship and the effect of the trusting relationship shrinks. It will be fairly straight forward to separate both in situations where the reason for trust pre-determines a temporal separation; for example, a patient trusting a surgeon and the effect of the surgery which is assessed after the surgery is conducted. On the other hand, it will be very difficult in areas where the effect of trust affects the trusting party as well as the trusted party and where the effect of trust occurs at the same time as the decision to trust. An example could be the trusting relationship of a rally driver and her/his co-driver. Both are sitting in the same car and if the co-driver selects the wrong route, this is a problem for both parties, including the possibility of a crash. Another example could be self-confidence and trust in one's own reasoning and decision making. Here the trusting relationship is taking place in a somewhat closed system as one is trusting oneself and the effect is experienced immediately. Consequently, it is essential to assess the trust relationship under review to determine how far effect indicators or anticipated effect indicators in the form of causal indicators are involved.

Furthermore, modern psychometric theory, such as Rasch measurement theory, suggests that for a construct to be measurable, the construct should consist of a hierarchy of items from low to high along a single continuum of the construct (Wilson, 2005). Rasch analysis itself is described as *'a mathematic modelling technique that converts qualitative (categorical) responses to points on a continuous (unmeasured) latent scale using a logit model and can be conceptualized as 'a statistical approach to the measure of human performance, attitudes and perceptions''* (Young, Yang, Brazier, & Tsuchiya, p. 198). This implies that each item (question) has to have a unique location along the continuum of the construct (Wilson, 2005). It is clear therefore that a good understanding of the construct must be the first building block in developing a robust measurement instrument (Wilson, 2005).

With respect to the design of a construct map, Wilson, (2005) suggests that two necessities need to be fulfilled, a) a coherent and substantive definition of the content of the construct and b) an idea that the construct is composed of an underlying continuum (Wilson, 2005). The construct map will help to focus on the essential feature of what will be measured. Important to the idea is that there is a qualitative order of levels inherent in the construct and underlying that there is a continuum running from more to less (Wilson, 2005). The construct map will picture 'respondents' and 'responses to items' as seen in Figure 3.2 (Wilson, 2005).

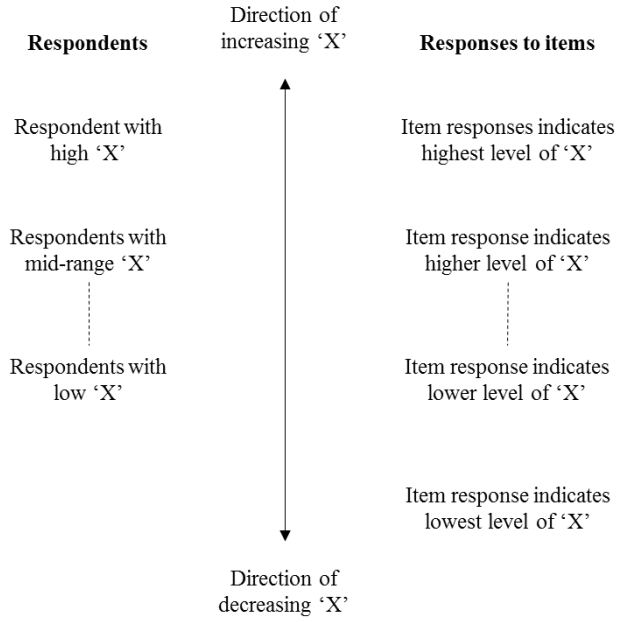


Figure 3.2: A generic construct map

(Source: Wilson, 2005, p.27)

The continuum can be imagined as a continuous ruler without interruptions. All items must be placed on the ruler in a qualitative hierarchy and there is no indifference point (neutral) on the ruler. Hence the ends of the ruler represent the same construct but as a high or low value (Wilson, 2005, p. 26).

Review of existing instruments that measure public trust in the healthcare system

To determine the extent to which questionnaire instruments measuring public trust in the health care system meet the above requirements for "good" measurement (including a good conceptual framework), a critical psychometric and conceptual review of existing instruments was conducted. To review the measurement instruments for their psychometric properties, a methodology was developed based on quality criteria developed by Smith and colleagues, The Scientific Advisory Committee of the Medical Outcomes Trust, and Fitzpatrick and colleagues (Aaronson et al., 2002; Lohr, 2002; Fitzpatrick, Davey, Buxton, & Jones, 1998; Smith et al., 2005). Smith and colleagues (2005) evaluated instruments in the context of the measurement of health-related quality of life in people with dementia. Table 3.2 shows the quality criteria used to evaluate the psychometric properties of the previous instruments. A brief explanation for each quality criteria is provided in the table. Further, the sources for the individual criteria are provided. As mentioned above, it needs to be considered that the quality criteria with respect to the development of a conceptual framework are superficial and therefore the review may give a misleadingly favourable impression of the quality of the conceptual framework.

Table 3.2: Measurement instrument review criteria adapted from Aaronson et al., 2002; Lohr, 2002; Fitzpatrick, Davey, Buxton, & Jones, 1998; Smith et al., 2005.

Attribute	Definition/Test	Criteria for acceptability	Source
1. Conceptual framework	Rationale for and description of the concepts and the populations that the measure is intended to assess and the relationship between those concepts. A definition of (public) trust is provided.	● Development of conceptual model is discussed and evidence for the model is provided. ● New qualitative research is informing the development process of a conceptual model.	Lohr, 2002, U.S. Department of Health and Human & Administration, 2009, Reeve et al., 2013.
2. Item analysis/reduction	Identify items for possible elimination due to weak psychometric performance; assessed on the basis of: 1) unrotated principal component factor analysis to determine whether all items are measuring a single factor; and 2) item analysis for all items.	*Principal component factor analysis:* ● All items should load on the first unrotated factor >0.30. *Item analyses (applied to all items):* ● Missing data <5%. ● No item redundancy (inter-item correlations ≤0.75. ● Item-total correlations >0.25. ● Maximum endorsement frequencies ≤ 80% (i.e. the proportion of respondents who endorse each response category), including floor/ceiling effects≤ 80% (i.e. response categories with high endorsement rates at the bottom/top ends of the scale, respectively). ● aggregate adjacent endorsement frequencies ≥ 10%.	pp. 17-18, Smith et al., 2005.
3. Acceptability	The quality of data; assessed by completeness of data and score distribution.	● Missing data for summary scores <5%. ● Even distribution of endorsement frequencies across response categories. ● Floor/ceiling effects for summary scores <10%.	
4. Reliability	The degree to which the instrument is free from random error.		
4.1 Internal consistency	The extent to which items comprising a scale measure the same construct (e.g. homogeneity of the scale); assessed by Cronbach's alpha and item–total correlations.	● Cronbach's alphas for summary scores ≥0.70. ● Item–total correlations ≥0.20	
4.2 Test-retest reliability	The stability of a measuring instrument; assessed by administering the instrument to respondents on two different occasions and examining the correlation between test and retest scores.	● Test–retest reliability correlations for summary scores ≥0.70.	
4.3 Inter-rater reliability	Agreement between independent raters/observers; assessed by intraclass correlation coefficient.	● Intraclass correlation coefficient ≥0.70.	
4.4 Parallel (alternate) forms reliability	Agreement between two or more parallel/alternative forms or different versions of the same measure (e.g. form A/B, short/long form) that indicates that they can be used interchangeably; assessed on the basis of correlations between parallel/alternative forms of a measure.	● High correlation between parallel/alternative forms of the measure. ● (e.g. between long and short form)	

Attribute	Definition/Test	Criteria for acceptability	Source
5. Validity	The degree to which the instrument measures what it purports to measure.		pp. 17-18, Smith et al., 2005.
5.1 Content validity	The extent to which the content of a scale is representative of the conceptual domain it is intended to cover; assessed qualitatively during the questionnaire development stage through pre-testing with patients, expert opinion and literature review.	● Qualitative evidence from pre-testing with patients, expert opinion and literature review that items in the scale are representative of the construct being measured.	
5.1.1 Within scale analysis	Evidence that a single entity (construct) is being measured and that items can be combined to form a summary score; assessed on the basis of evidence of good internal consistency and correlations between scale scores (which purport to measure related aspects of the construct).	● Internal consistency (Cronbach's alpha) ≥ 0.70. ● Moderate to high correlations between scale scores.	
5.2 Criterion-related validity	Evidence that shows the extent to which scores of the instrument are related to a criterion measure.		
5.2.1 Concurrent validity	Evidence that the scale predicts a gold-standard criterion that is measured at the same time; assessed on the basis of correlations between the scale and the criterion measure.	● High correlation between the scale and the criterion measure.	
5.2.2 Predictive validity	Evidence that the scale predicts a gold-standard criterion that is measured in the future; assessed on the basis of correlations between the scale and the criterion measure.	● High correlation between the scale and the criterion measure.	
5.3 Construct validity	Evidence that supports a proposed interpretation of scores based on theoretical implications associated with the constructs being measured.		
5.3.2.1 Convergent validity	Evidence that the scale is correlated with other measures of the same or similar constructs; assessed on the basis of correlations between the measure and other similar measures.	● Correlations are expected to vary according to the degree of similarity between the constructs that are being measured by each instrument. Specific hypotheses are formulated and predictions tested on the basis of correlations.	
5.3.2.2 Discriminant validity	Evidence that the scale is not correlated with measures of different constructs; assessed on the basis of correlations with measures of different constructs.	● Low correlations between the instrument and measures of different constructs.	
5.3.2.3 Known groups differences	The ability of a scale to differentiate known groups; assessed by comparing scores for subgroups who are expected to differ on the construct being measured.	● Significant differences between known groups or difference of expected magnitude.	
6. Responsiveness	The ability of a scale to detect important change over time; assessed by comparing scores before and after an intervention of known efficacy (on the basis of various methods including t-tests, effect sizes, standardised response means, or responsiveness statistics).	● Significant differences between known groups or difference of expected magnitude.	

Attribute	Definition/Test	Criteria for acceptability	Source
7. Interpretability	The degree to which one can assign easily understood meaning to an instrument's quantitative scores.	● Rationale for selection of external criteria or populations for purposes of comparison and interpretability of data is provided. ● Information regarding the ways in which data from the instrument should be reported and displayed in order to facilitate interpretation. ● Citation of meaningful 'benchmarks, to facilitate interpretation of the scores.	pp.196-197, Aaronson et al., 2002.
8. Burden	The time, effort, and other demands placed on those to whom the instrument is administered, as well as the demands placed on those who administer.		
8.1 Respondent burden	The time, effort, and other demands placed on those to whom the instrument is administered.	● Average time needed to complete the instrument. ● Reading and comprehension level needed for target population. ● Special requirements and requests that might be placed on the respondents. ● Acceptability of the instrument.	
8.2 Administrative burden	The burden placed on those who administer the instrument.	● Average time required to train staff to administer the instrument. ● Level of education or professional expertise and experience required by administrating staff. ● Availability of scoring instructions.	
9. Alternative modes of administration	Different types of administration (self-reported, interviewer administered, trained observer rating etc.) including proxy respondents.	● Evidence on reliability, validity, responsiveness, interpretability and burden for each mode of administration. ● Information on the comparability between different modes of administration.	
10. Cultural and language adaptation or translation	Situations in which the instrument has been fully adapted from original or source instruments for cultures or languages different from the original.	● 1st At least two forward translations that yields a pooled forward translation. 2nd at least one backwards translation that yields in a pooled backwards translation. 3rd a review of the translated version by lay and expert panels. 4th field tests to provide evidence of comparability. ● Methods are described to achieve conceptual equivalence between or among different versions of the same instrument. ● Identification and explanation of any significant differences between the original and translated version. ● Explanation of how inconsistencies are reconciled.	

Measurement instruments of public trust in health care systems

To identify instruments that measure public trust in the health care system the following platforms were reviewed: Business Source Premier, Cochrane Reviews, Economic and Social Data Service, Ovid, PsycINFO, PubMed, ScienceDirect, Sociological Abstracts, SveMed+, Web of Science with Conference Proceedings. This resulted in the final selection of three instruments that fulfil the inclusion criteria of measuring public trust in the health care system (incorporating social trust which is understood as a part of public trust) (Anand & Kutty, 2015; Egede & Ellis, 2008; Straten et al., 2002). Nine instruments were excluded, predominantly on the basis that they engaged with distrust (see Chapter 4, where the difference between trust and distrust/mistrust is discussed) and were not measuring public trust in the system (Armstrong et al., 2008; Katapodi, Pierce, & Facione, 2010; Kelly et al., 2004, 2005; Laveist, Isaac, & Williams, 2009; Rose, Peters, Shea, & Armstrong, 2004; Shea et al., 2008; Shelton et al., 2010; Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004). Instruments measuring trust in specific parts of the health care system only such as health care providers, insurance companies, medical staff, pharmaceutical companies, government, etc. were excluded. Also no trust instruments are included that use synonyms of trust. This decision is motivated by the lack of conceptual clarity that arises, as described in Chapter 4. Even though it is argued that trust itself is culturally dependent, the review was not limited to a cultural region to increase the number of reviewed measures.

The search strategy identified three instruments and Table 3.3 provides an overview. The instrument by Straten, Fiele and Groenewegen, 2002, was used as a basis for the later published instrument used for cross country comparison in Europe and elsewhere (Peters & Youssef, 2014; van der Schee, Braun, Calnan, Schnee, & Groenewegen, 2007).

Table 3.3: Overview of reviewed instruments

Instrument	Author & Year	Description	Response Scale	Administration	Target population	Language	Cultural and/or language adapted or translated versions
Public healthcare system trust scale	Anand and Kutty, 2015	23 items representing five domains covering individual trust (domain: communication, transparency, competency) and institutional trust (domain: quality, reliability).	5-point Likert scale ranging from "Strongly disagree" to "Strongly agree".	Paper based self reported	People living within the area of the public health care system in Kerala, India.	Malayalam/English	N/K
Multidimensional Trust in Health Care System Scale	Egede and Ellis, 2008	17 items capturing trust in health care providers, in health care institutions, and in health payers.	5-point Likert scale ranging from 5 (strongly agree) to 1 (strongly disagree).	Self reported, as a proxy, or in interview administered self-reported	Patients of an academic medical centre of a general internal medicine clinic in the south-eastern United States	US English	N/K
Public trust in Dutch health care	Straten, Friele and Groenewegen, 2002	36 items covering six dimensions of public trust: Patient focus of providers, policies at the macro level will be without consequences for the patient, health care providers' expertise, quality of care, information supply and communication by care providers, quality of cooperation.	4-point Likert scales ranging from 'very low trust' to 'very high trust'. Six items are combined with a 5-point Likert scale. All items have in addition a 'no opinion' response option.	Paper based administration	Dutch general population	Dutch	van der Schee, Braun, Calnan, Schnee, Groenewegen, 2007, Public trust in health care: a comparison of Germany, The Netherlands, and England and Wales. Health Policy. 2007 Apr;81(1):56-67. ●Double forward backward method from Dutch into German and from Dutch into English. Peters, Youssef, 2014, Public trust in the healthcare system in a developing country, Int J Health Plann Mgmt (print online). DOI: 10.1002/hpm.2280 (Trinidad and Tobago) ●Following a review by the authors and an expert in survey design within the local setting, the questionnaire was adapted.

Psychometric review of existing public trust measurement instruments

After reviewing the instruments based on the information provided in the original articles presenting the instruments, Table 3.4 shows the psychometric properties of each instrument (0 = no evidence or not tested; + = some limited evidence; ++ = some good evidence, but some aspects do not meet criteria or some aspects not tested/reported; +++ = good evidence). The evidence was assessed independently by two raters and any discrepancies was discussed to reach a consensus.

Table 3.4: Psychometric characteristics of the reviewed measures

	Public healthcare system trust scale. Anand and Kutty, 2015	**Multidimensional Trust in Health Care System Scale. Egede and Ellis, 2008**	**Public trust in Dutch health care. Straten, Friele, Groenewegen, 2002**
Conceptual framework	+ (Based on a distrust model (p.126). Poses a conceptual problem)	++	++
Item analysis/reduction	++	++	++
Acceptability	0	0	0
Reliability			
Internal consistency	++	++	+
Test-retest reliability	++	0	0
Inter-rater reliability	0	0	0
Parallel (alternate) forms reliability	0	0	0
Validity			
Content validity	+	+	+
Within scale analysis	+++	+++	+++
Criterion-related validity			
Concurrent validity	0	0	0
Predictive validity	0	0	0
Construct validity			
Convergent validity	+++	0	0
Discriminat validity	+++	0	0
Known groups differences	0	0	0
Responsiveness	0	0	0
Interpretability	0	0	0
Burden			
Respondent burden	0	0	0
Administrative burden	0	0	0
Alternative modes of administration	0	0	0
Cultural and language adaptation or translation	++	not applicable	not applicable

This review analysed three public trust in health care system instruments against existing quality (psychometric) criteria. Overall evidence was relatively sparse, but was strongest for the Public Healthcare System Trust Scale (Anand and Kutty, 2015). In terms of reliability, good evidence was provided for two scales for *internal consistency* but only the Public Healthcare System Trust Scale had evidence of both internal consistency and test-retest reliability. In terms of validity, all three scales showed some limited evidence of content validity and all three had evidence of some item analysis. Across all three scales good evidence of *within scale analysis* is provided. However only the Public Healthcare System Trust Scale had any further evidence of validity (convergent and discriminant).

Anand and Kutty (2015) define trust in the healthcare system as *'a combination of trust in the healthcare provider and trust in the healthcare institution*' (Anand & Kutty, 2015, p. 126). Figure 3.3 shows the conceptual model used in their study. By *healthcare provider* they mean a doctor or alike professional. The instrument builds on previous research and integrates the healthcare distrust model by Armstrong and colleagues, despite measuring trust (Armstrong et al., 2006). The initial item pool of 40 items was developed by conducting five in depth interviews with adults who have experienced the health care system, by reviewing literature and by reviewing previous trust instruments: '*Multidimensional Trust in Health Care System Scale, Trust in Primary Care Physician Scale, Trust in Physician Scale and scale measuring trust in a physician, health insurer and the medical profession'* (p.126) (Anderson & Dedrick, 1990; Dugan, Trachtenberg, & Hall, 2005; Egede & Ellis, 2008; Hall et al., 2002). The final item pool consists of 23 items covering five domains relating to institutional as well as individual trust: quality, communication, transparency, reliability and competency.

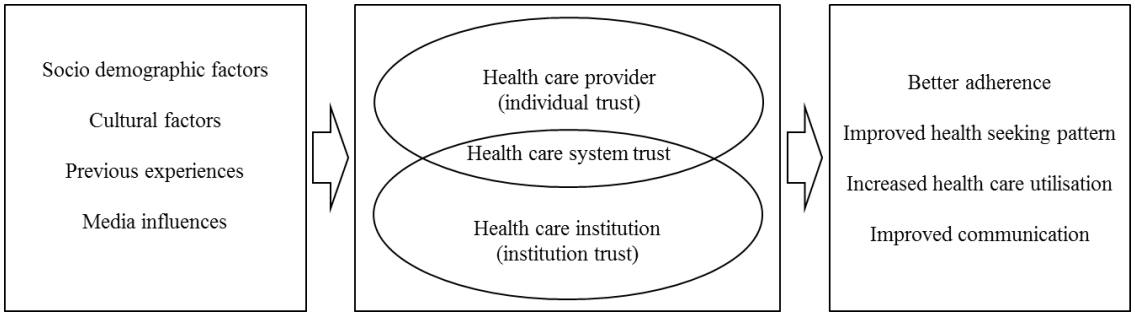


Figure 3.3: Conceptual model of "health care system trust"

(Source: Anand & Kutty, 2015, p. 126).

The *Public Healthcare System Trust Scale* consists of questions partly formulated with the trust synonym, *belief* (Anand & Kutty, 2015, p. 132). Furthermore, the instrument consists of both causal items (items: 1, 2, 3, 4, 5, 9, 10, 11, 13, 14, 15, 17, 18, 19, 20, 22) and effect items (items: 6, 7, 8, 12, 16, 21, 23). The *Public healthcare system trust scale* built upon an item reduction process in three steps: 1st items were reviewed by experts, 2nd an item to total correlation analysis and exploratory factor analysis was performed, and 3rd a maximum likelihood analysis for factor extraction was conducted. Reliability was tested by internal consistency (Cronbach's alpha: 0.86) and test-retest reliability ($r=0.97, p<0.05$). The mean value of the content validity ratios was 0.64. Convergent validity between the public healthcare system trust scale and a general trust scale was ($r=0.48$, $p<0.05$). Discriminant validity was obtained by correlating the score of the Medical Mistrust Index and the public healthcare system trust scale ($r=-0.52$, $p<0.05$). As the Medical Mistrust Index was in Malayalam, the items were translated into English and checked by an independent body (Anand & Kutty, 2015).

Building on Hall and colleagues (2001) Egede and Ellis (2008) defined trust operationally as *'the optimistic acceptance of a vulnerable situation in which the trustee believes the trustor will take care of the trustee's interests'* (p.808) (Egede & Ellis, 2008; Hall et al., 2001). Egede and Ellis (2008) distinguish in their study interpersonal trust as well as social trust (social trust is understood as a comparable construct to public trust) and conclude that there are three main objects of trust in the health care system: health care providers; institutions; and payers (p.808). Previous work has suggested that at least four dimensions are prominent in trust measurement instruments: agency/fidelity; competence; honesty; and confidentiality. The conceptual model developed after a literature review defines *'trust in healthcare systems as comprised of trust in health care providers, health care insurers, and health care institutions. Patient characteristics included in the model were age, gender, marital status, educational level, insurance status, income and having a usual source of care…also …race/ethnicity as an important variable that influences the level of trust patients have in health care systems'* (p.809). The final item pool consists of 17 items organized in 3 subscales covering trust in health care providers, trust in health care payers and trust in health care institutions. The *Multidimensional Trust In Health Care System Scale* was partly formulated with the term 'trust' (Egede & Ellis, 2008, p. 812). Again, the instrument consists of both causal items (items: 1, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17) and effect items (items: 2, 3, 4). An

exploratory factor analysis (principal component analysis with Varimax Rotation) and the Kaiser– Guttman criterion (eigenvalues greater than 1.0) were used to select the final set of items. Reliability was tested by internal consistency (Cronbach's alpha: 0.89). Content validity was indicated to be good, without further explanation. Within-scale analysis was conducted with a principal component analysis and further statistical measures (Item selectivity and Cronbach's alpha without each item).

Straten, Friele and Groenewegen (2002) define public trust in health care as *'being confident that you will be adequately treated when you are in need of health care. This means confidence in the agency relation between patients and health care providers'* (p.227). Straten and colleagues distinguish public trust from interpersonal trust. Public trust is understood as *'a generalized attitude based on personal experience in trust situations, on direct communication of other people's experience and on mass media communication'* (p.227). The final tool consists of 37 items covering six dimensions: patient focus of providers; policies at the macro level will be without negative consequences; health care providers' expertise; quality of care; information supply and communication by care providers; and quality of cooperation of medical specialists (p.231). This instrument was the cornerstone for the study, 'Public trust in health care: a comparison of Germany, The Netherlands, and England and Wales' by van der Shee and colleagues (2007) which provided the background of the initial public trust model presented in this thesis, see Chapter 5. The *Public Trust in Dutch health care* instrument was constructed following an item generation process based on telephone interviews. Following the development of the final set of items, further items were added (not specified further). The scale consists of causal items only. As the scale consists of six subscales, Cronbach's alpha was calculated for each subscale and all Cronbach alphas were above 0.80, except for one scale scoring 0.74. Further eigenvalues were calculated for each scale all scoring above 1.0.

Analysing the conceptual differences between existing instruments measuring public trust in the health care system

The purpose of the following section is to compare the existing instruments. The conclusions drawn here will inform the conceptualisation of public trust developed in Chapter 7. When looking at Tables 3.5 and 3.6, below, and comparing the different conceptualisations, several observations can be made:

1. Previous research understands public trust as a relational concept between the patient and selected parts of the healthcare system: healthcare provider, health care organisation, health care payers and macro level policies. This implies that public trust is only applicable to patients as opposed to the public including healthy individuals.
2. It remains unanswered in how far the previous conceptualisations actually describe public trust. Their content reflects individual patient trust in health care system representatives.
3. Previous research describes the health care system with selected access points only (e.g. Provider, Payer and Institution), neglecting other actors in the health care system and public sphere which influence levels of public trust.
4. Previous research understands public trust as an effect of certain health care system qualities, missing the possibility that public trust also legitimises health care system action.
5. All conceptualisations touch in one form or the other on quality of care, financial costs, information, professional behaviour and professional competences.
6. No item represents intrinsic motivations, implying that all conceptualisations are located in the area of calculated conscious decision-making. As no intrinsic motivations are represented, the conceptual model might be at risk of failure, see Chapter 4 for a detailed discussion about the implication of calculated decision making on conceptual frameworks of public trust.

Table 3.5: Overview of key themes or key focus of existing conceptualisations of public trust in the health care system

Instrument	**Public healthcare system trust scale**	**Multidimensional Trust in Health Care System Scale**	**Public trust in Dutch health care**
Author & Year	**Anand and Kutty, 2015**	**Egede and Ellis, 2008**	**Straten, Friele, Groenewegen, 2002**
Domains / Key focus	Healthcare provider trust (individual trust)	Trust in health care providers	Patient focus of providers
		Trust in health care payers	Policies at the macro level will be without consequences for the patient
	Healthcare institution trust (institutional trust)	Trust in health care institutions	Health care providers' expertise
			Quality of care
			Information supply and communication by care providers
			Quality of cooperation

Table 3.6: Overview of themes of existing conceptualisations of public trust in the health care system as formulated in respective measurement tools

Summary categories developed for this research	Public healthcare system trust scale Anand and Kutty, 2015		Multidimensional Trust in Health Care System Scale Egede and Ellis, 2008		Public trust in Dutch health care Straten, Friele, Groenewegen, 2002	
	ID	Questions	ID	Questions	ID	Questions
Quality of care	19	My healthcare institution provides me quality care.	9	My health care provider offers me the highest quality in medical care.	19	The right dosage will be given.
			16	Healthcare institutions provide the highest quality in medical care.	20	Doctors won't prescribe medicines too late.
					21	Patients receive the correct medication.
					22	Doctors won't prescribe medicines too quickly.
					23	Doctors will always treat the patients' confidential data with great care.
					24	Doctors won't do too few tests.
					25	Doctors won't do too many tests.
					26	Doctors will give the patients the best treatment.
					27	Doctors will make the right diagnosis.
Reasonable costs	18	The treatment expenses in my healthcare institution are reasonable.	12	When needed, health care payers will pay for you to see any specialist.	7	Cost-cutting will not be to the disadvantage of patients
	4	My healthcare provider understands my economic and social conditions.	14	Health care payers will pay for everything they are supposed to, including treatment that is expensive.	8	Patients will be able to meet their own financial contribution requirement
			15	Health care institutions only care about keeping medical costs down, and not what is needed for my health.	10	Patients will not be the victim of the rising costs of health care.
			17	When treating my medical problems, health care institutions put my medical needs above all other considerations, including costs.		

Summary categories developed for this research	Public healthcare system trust scale Anand and Kutty, 2015		Multidimensional Trust in Health Care System Scale Egede and Ellis, 2008		Public trust in Dutch health care Straten, Friele, Groenewegen, 2002	
Efficient use of resources	5	I believe my healthcare provider is efficient in terms of using the resources available.				
	20	I believe my healthcare institution has enough employees for providing health services.				
Information	2	My healthcare provider will give all the information available on the diagnosis and treatment of my illness.	1	My health care provider is usually considerate of my needs and puts them first.	3	Doctors will listen to their patients.
	10	I believe that the health promotional messages given by my healthcare provider are valid or logical.	3	I trust my health care provider so much that whatever he/she tells me, it must be true.	28	Patients will get sufficient information about the effects of the treatment.
	11	My healthcare provider listens to me patiently about my health problems.	13	When questioned about what treatments are covered, health care payers are honest with their answers.	30	Patients will be given information that they can understand.
	12	I think I can tell my healthcare provider everything, so that he/she can understand my condition better.			31	Patients will get sufficient information about the cause of their problem.
					32	Doctors will discuss things thoroughly with their patients.
					33	Doctors will make use of the patients' own understanding and insights.
Decision making	14	My healthcare provider will involve me in the decision-making process regarding my treatment.	8	I can trust my health care provider's decisions on which medical treatments are best for me.		

Summary categories developed for this research	Public healthcare system trust scale Anand and Kutty, 2015		Multidimensional Trust in Health Care System Scale Egede and Ellis, 2008		Public trust in Dutch health care Straten, Friele, Groenewegen, 2002	
Competence	1	I believe my healthcare provider is technically competent.	5	I can trust my health care providers judgments concerning my medical care.	6	Doctors will understand their patients' problems.
	3	I believe that my healthcare provider will give me the right treatment.	7	Because my health care provider is an expert, he is able to treat medical problems like mine.	16	Dutch doctors are very well trained.
	8	Even if my healthcare provider makes a mistake, I believe in him/her.	11	Health care payers are good at what they do.	18	Doctors are always looking for the right answer.
Development of profession	17	My healthcare institution has all the latest facilities for treatment and diagnosis.			13	Nowadays doctors can do a lot more than they used to be able to do.
					15	New discoveries are always being made and put into practice in the health care system.
					17	It is amazing the sort of operation surgeons carry out nowadays.
Cooperation between professionals					34	Medical specialists always cooperate with one another.
					35	Doctors won't give conflicting information.
					36	The tendency towards a high degree of specialization does not cause problems.

Summary categories developed for this research	Public healthcare system trust scale Anand and Kutty, 2015		Multidimensional Trust in Health Care System Scale Egede and Ellis, 2008		Public trust in Dutch health care Straten, Friele, Groenewegen, 2002	
Professional behaviour	9	My healthcare provider gives value to my time also during consultation.	6	My health care provider will do whatever it takes to give me the medical care that I need.	4	Doctors spend enough time on their patients.
	13	My healthcare provider considers every patient equal.			5	Doctors will always stick up for their patients.
	14	My healthcare provider will involve me in the decision-making process regarding my treatment				
Seeking a 2nd opinion	7	I have never taken a second opinion from health workers about my health problem.	4	Sometimes, I do not trust my health care provider's opinion and therefore I feel I need a second one.		
Following advice	6	I often try to follow the instructions my healthcare provider gives me.	2	I have so much trust in my health care provider that I always try to follow his/her advice.		
Other	16	I respect my healthcare provider for his/her activities.	10	All things considered, I completely trust my health care provider.		
	21	I recommend my healthcare institution to my friends.				
	22	My healthcare institution is a dependable one.				
	23	I believe that I can approach my healthcare institution for any medical problem.				

Conclusion

Following the review of measurement instrument development guidelines as well as literature on this topic, it can be concluded that the existing guidelines do not sufficiently outline the criteria defining what an adequate conceptual framework should look like. This chapter proposes a set of additional criteria with which to evaluate the conceptual frameworks of instruments claiming to measure trust in the healthcare system. The discussion above suggests that the 1st attribute focusing on the conceptual framework in table 3.2, above, can be expanded as shown in table 3.7 below.

Table 3.7: Expansion of review criteria

Attribute	Definition/Test	Criteria for acceptability	Source
1. Conceptual framework	Rationale for and description of the concepts and the populations that the measure is intended to assess and the relationship between those concepts. A definition of (public) trust is provided.	● Development of conceptual model is discussed (literature review/theory/empirical work). ● Empirical research is informing the development process of a conceptual model.	Lohr, 2002, U.S. Department of Health and Human & Administration, 2009, Reeve et al., 2013.
		● Comparison with other similar conceptual models is provided. ● A review of applicable theory from within and outside of the research field is conducted. ● The construct of interest is defined and distinguished from similar constructs and/or synonyms.. ● The construct is defined and discussed in relation to its opposite. ● Reasoning for the measured construct is provided. ● The word describing the construct itself or synonyms do not appear in the questionnaire.	This thesis
1.1. Causal or effect indicators	The items in the scale must either be causal indicators or effect indicators. Whether the construct is considered to be a causal or an effect indicator determines the statistical (psychometric) techniques that can be used in evaluation of the measure.	● The scale consists of either causal or effect indicators but not both. ● Items are ordered along a single continuum.	Wilson, 2005

An application of these criteria to existing instruments suggests that the conceptual underpinning of existing instruments is not adequate. Foremost, the conceptual frameworks are not well developed and seem to focus on patient trust in a range of health care system representatives. The notion of public trust is missing in the conceptual frameworks. Further, the psychometric properties of these instruments are weak.

To improve the measurement instrument development process and to incorporate the suggested criteria, it will be essential to understand that the development process of the conceptual framework is as important as the development process of the measurement instrument itself. It is important to understand that a conceptual framework is the first building block of a measurement instrument. If it is not clear what the instrument is measuring, the instrument will have minimal applicability and usefulness.

Hereafter, the conceptual framework of public trust in the healthcare system evolving from this research, is developed with the expanded development criteria in mind.

With respect to the content of the existing public trust measurement instruments, it can be concluded that the instruments cover themes in the following categories:

Table 3.8: Categories of themes conceptualising public trust in health care systems

Competence	Information
Cooperation between professionals	Other
Decision making	Professional behaviour
Development of profession	Quality of care
Efficient use of resources	Reasonable costs
Following advice	Seeking a 2nd opinion

The list of categories will be used to inform the conceptualisation of public trust as developed in Chapter 7.

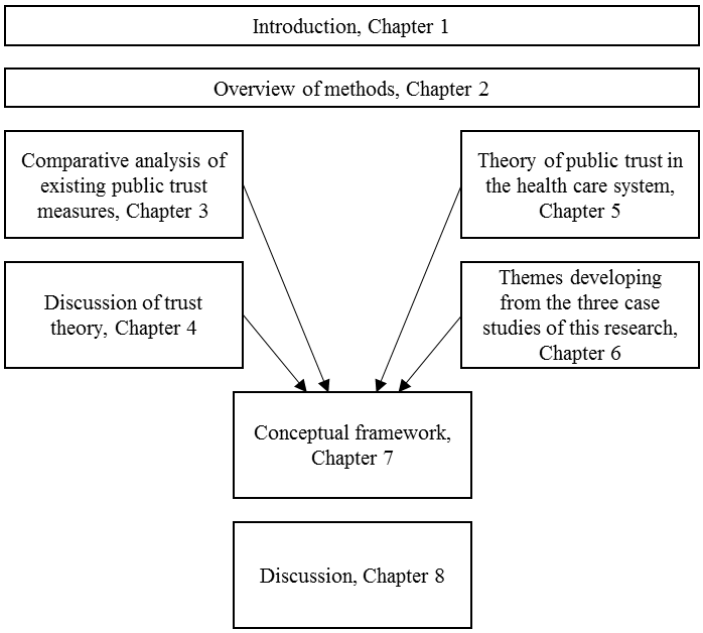
Chapter 4: Contemporary trust theory

Key findings

- There are many contemporary trust theories which explain trust in different ways
- Trust theories use the term ‘trust’ and similar terms in different ways
- Niklas Luhmann is the most influential theorist for the contemporary understanding of trust

Overview

Since there are a number of different theories relating to the social determinants of trust and its role in society, it is difficult to come to a theory based conclusion of what trust is. Despite the differences between theories, a discussion of major contemporary theories reveals that trust can be described as a relational concept, developing from information relating to the past, present and anticipated future, which enables the trusted party to act autonomously to reduce future complexity for the trusting party. This complexity arises from the lack of full information about the actions of others and/or lack of resources, knowledge and power to cope with the complexity alone.



Introduction

The following chapter meets the objectives:

- Objective 1: To map contemporary trust theory developed outside the healthcare field and to draw out its relevance for trust in health care systems.
- Objective 1.1: To synthesise a preliminary concept of trust based on theoretical literature.

It is agreed across the social sciences that trust has a distinct role in the functioning of society (Seligman, 1997, p. 75). Since the 18th century the scope of trust relationships has developed alongside the secularisation of society. Trusting a doctor is one of the earliest examples in encyclopaedias describing trusting relationships between humans as distinct from faith in God (Frevert, 2013, p. 30; Seligman, 1997, pp. 22, 45). The boundaries of what can be trusted expanded from solely placing faith in God via trusting family members in the private sphere to being able not only to trust within the private sphere but also to trust other individuals with whom one is connected by technology and abstract systems in the public sphere (Frevert, 2013, pp. 28–43; Misztal, 1996, p. 2; Sztompka, 1999, pp. 41, 51). A physical example of trust boundaries between the private and public sphere are door keys. Keys draw a boundary between the trusted realms and the not trusted. Only trusted individuals get access to a private and somewhat protected sphere (Papakostas, 2012, Chapter 2). This development of the scope of trust is fuelled by the emergence of modernity (Giddens, 1990). Giddens observes distinctive attributes in relation to modernity, which cause discontinuities separating modern institutions from the former social order. Pace of change, scope of change and the nature of modern institutions distinguish modern society from previous societies and, as a result, the understanding of trust has changed (Giddens, 1990, p. 6). As the individual is living in a highly complex environment with increasing technological development and increasing human freedom to act which influence the environment itself and the future, Luhmann argues that trust and the increasing need to trust is a way to reduce complexity and to strengthen tolerance for ambiguity (Luhmann, 2009, pp. 19, 48). The complexity develops from the endless number of possible future outcomes of present interaction (social as well as environmental) which overstrains the human capacity to envision which future will become real. Alongside the development of trust theories from an individual and local focus to a public and global focus, the change of scope of trust theories can also be described by a shift from a focus on the act of trusting as motivated by an intrinsic

somewhat heartfelt wish (probably more a gut feeling) to an understanding of trusting based on a conscious choice (Hartmann, 1994, p. 472; Reemstma, 2008, p. 31). Therefore, most contemporary trust theories can be mapped on to the grid in right-hand side quadrants in Figure 4.1. The vertical axis describes the development of trust theory from individual to public focus and the horizontal axis describes the shift from trust theories developed based on intrinsic motivations to understanding trust as based on a conscious choice.

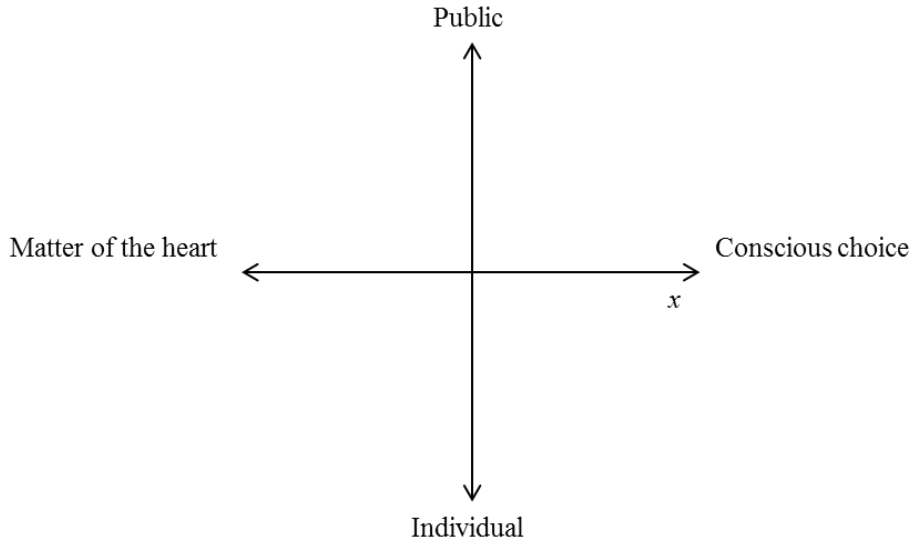


Figure 4.1: Trust theory grid describing the focus (individual to public) and underlying roots of modern trust theory (trust developing as a matter of the heart to trust developing based on conscious choice)

To provide an overview of contemporary trust theory and the use of the term trust in colloquial speech and research, the following Chapter will engage with the major theorists of trust to provide an understanding of the differences and commonalities between their theories. Subsequently an understanding of what a theory-based conceptualisation of trust might entail will be developed.

It would be dangerous to generalise on trust theory on such a scale like public trust in health care systems. This is the case as several different forms of trust occur in the health care system at the same time (Haddow & Cunningham-Burley, 2008; Pilgrim, Tomasini, & Vassilev, 2011). But when researching public trust it is necessary to explain and develop a definition of trust as a working definition in this context. Otherwise it will not be possible to compare the outcome of the thesis and it would equally not be possible for

the reader to understand how trust is understood in this research. Further, it is necessary to drill down to the essence of trust theory to understand what the core of trust is which is identifiable in every conceptual framework of trust in whatever context. Only if we understand what the common core conceptualising trust is, we can identify the differences between other conceptualisations of trust as for example public trust compared to institutional trust, compared to individual trust and so forth. Therefore the following will pursue this attempt to define trust based on contemporary trust theory and to discuss the essence of different trust theories.

A full historical approach to trust theory was not taken, as today's health care systems are relatively recent developments in Europe by historical standards, considering, for example, the National Health Service in England and the social insurance system of Germany (Dean, 1998; Freeman & Schmid, 2008; Kamke, 1998; Tavanxhi, Burazeri, & Laaser, 2008). Hence, the discussion starts with Erik H. Erikson publication from 1950 on *Childhood and Society*. Also contemporary trust theory builds largely on the past. Furthermore, a Western societal perspective was taken. This is motivated by the assumption that trust is highly influenced by culture and a global view would even more complicate the theory, if not make it impossible to theorise trust (Fukuyama, 1995; Igarashi et al., 2008). It is recognised that the understanding of the welfare state and the health care system is different between Western countries. Nevertheless, the application and the transfer process of theories from one cultural realm to the other within Western societies seems applicable due to similar underlying societal values and norms. The literature search was conducted in the British Library, the Senate House Library and LSHTM library as well as the Library of the Westfälische-Wilhelms Universität, Münster, Germany. Search terms used were: 'Trust', 'faith', 'confidence' as well as 'Vertrauen'. Further, the search was guided by references from my Master's Thesis. Snowballing, by following references to other theories in literature already identified, was continued until saturation was reached and the 'new' theories identified were not necessarily leading to new insights. Snowball sampling is a qualitative research method where new subjects are sampled by recommendation of previous sampled subjects. The strength of this method is to get access to hidden populations or in the case of this research to less well known material (Atkinson & Flint, 2001). The focus of the discussed literature is on literature engaging with the trusting relationship between individuals, public and a system, e.g. health care system or other political systems. Initially Niklas Luhmann, Anthony Giddens, and Francis Fukuyama were read (Fukuyama, 1995; Giddens, 1990;

Luhmann, 2009). It was anticipated that relevant literature in this area would mostly be available in English, however sources in German were also included. This has the added advantage that original sources are used where possible.

Mapping contemporary trust theory

Theoretical literature on trust has grown considerably since 1989 when Niklas Luhmann noted the meagre professional literature on trust. By 2001, Martin Hartmann was writing about a '*publication wave'* (Reemstma, 2008, p. 30). The search described above generated a set of trust theories from outside the field of health policy and system research to inform the understanding of trust, set out in Table 4.1.

Table 4.1: Major contemporary trust theories from outside the field of health policy and system research

Author	Country	Title	Year
Erik H. Erikson	Germany/US	Childhood and Society	1950
Niklas Luhmann	Germany	*Original:* 'Vertrauen: ein Mechanismus der Reduktion sozialer Komplexität'. *Translation:* 'Trust and Power'	*Original:* 1st Edit. 1968 (4th edition 2000) *Translation:* 1979
Niklas Luhmann in Diego Gambetta (editor)	Germany	'Familiarity, Confidence, Trust: Problems and Alternatives' in 'Trust – making and braking cooperative relations'	1988
Anthony Giddens	UK	The Consequences of Modernity'	1990
Martin Hartmann	Germany	Die Praxis des Vertrauens (The practice of trust)	1994
Francis Fukuyama	US	Trust : the social virtues and the creation of prosperity	1995
Barbara Misztal	UK	Trust in Modern Societies: The Search for the Bases of Social Order	1996
Adam Seligman	US	The problem of trust	1997

Author	Author's Country	Book Title	Year
Melissa S. Williams	US	Voice, trust and memory: Marginalized groups and the failings of liberal representation	1998
Piotr Sztompka	Poland	Trust-a sociological theory	1999
Onora O'Neill	UK	A Question of Trust: The BBC Reith Lectures 2002'	2002
Onora O'Neill	UK	Autonomy and Trust in Bioethics	2002
Russell Hardin	US	Trust & Trustworthiness	2002
Gabriella R. Montinola in Russell Hardin (editor)	US	'Corruption, Distrust and the Deterioration of the Rule of Law' in 'Distrust'	2004
Russell Hardin	US	Trust	2006
Jan P. Reemtsma	Germany	Original: 'Vertrauen und Gewalt' (Trust and Violence)	*Original:* 2008 *Translation:* 2012
Apostolis Papakostas	Sweden	Civilizing the public sphere: Distrust, trust and corruption	2012
Ute Frevert	Germany	Vertrauensfragen - Eine Obsession der Moderne (Questions of Trust - An Obsession of Modernity)	2013 *only available in German*

The publication timeline of the literature list is framed by Erik Erikson, (1950), and Ute Frevert, (2013). The literature touches on a wide range of disciplines, mostly on economics, history, politics, psychology and sociology. This implies that the domain of reference of the literature reviewed in this chapter is far beyond the health care system and engages with trust relationships in a variety of settings of social life. This implies that the findings of this chapter are likely to be generalizable across different societal systems and do not apply to the health care system only. Next to the single or co-authored books, edited books are included in the list as they provide additional insight into the topic. Also it needs to be noted, there is a large body of journal articles which find their way into this thesis in other chapters but which do not contribute additional theoretical insights, so are not discussed here.

When reading the books and seeing how they refer to each other, it is evident that Luhmann was the most influential author in the field and that the theories build on each other as seen in Table 4.2. Exceptions are Erikson (1950), Fukuyama (1995), Williams

(1998) and the chapter by Montinola (2004). Erikson's book was written before Luhmann and therefore does not cite any of the other books. It is not clear why Fukuyama, Williams and Montinola do not engage with the other theories. Further, Table 4.2 shows that some disciplines have had a continuing interest in this topic (for example especially sociology) while others have been less involved and are much less intellectually grounded in previous theory from other disciplines.

Table 4.2: Cross-referencing in trust theory

Author:	Title:	Year	Erik H. Erikson	Niklas Luhmann	Niklas Luhmann in Diego Gambetta (editor)	Anthony Giddens	Martin Hartmann	Francis Fukuyama	Barbara Misztal	Adam Seligman	Melissa S. Williams	Piotr Sztompka	Onora O'Neill	Onora O'Neill	Russell Hardin	Gabriella R. Montinola in Russell Hardin (editor)	Russell Hardin	Jan P. Reemtsma	Apostolis Papakostas	Ute Frevert
	Referencing:																			
			1950	*1968*	*1988*	*1990*	*1994*	*1995*	*1996*	*1997*	*1998*	*1999*	*2002*	*2002*	*2002*	*2004*	*2006*	*2008*	*2012*	*2013*
Erik H. Erikson	Childhood and Society	*1950*																		
Niklas Luhmann	Original: 'Vertrauen: ein Mechanismus der Reduktion sozialer Komplexität'. Translation: 'Trust and Power'.	*1968*																		
Niklas Luhmann in Diego Gambetta (editor)	Trust: Making and breaking cooperative relations.	*1988*		•																
Anthony Giddens	The Consequences of Modernity'.	*1990*		•	•															
Martin Hartmann	Die Praxis des Vertrauens (The practice of trust).	*1994*		•		•														
Francis Fukuyama	Trust : the social virtues and the creation of prosperity.	*1995*																		
Barbara Misztal	Trust in Modern Societies: The Search for the Bases of Social Order.	*1996*		•	•	•														
Adam Seligman	The problem of trust.	*1997*		•	•	•		•												
Melissa S. Williams	Voice, trust and memory: Marginalized groups and the failings of liberal representation.	*1998*																		
Piotr Sztompka	Trust-a sociological theory	*1999*		•	•	•		•	•	•										
Onora O'Neill (BBC)	A Question of Trust: The BBC Reith Lectures 2002'.	*2002*		•																
Onora O'Neill	Autonomy and Trust in Bioethics.	*2002*										•								
Russell Hardin	Trust & Trustworthiness.	*2002*		•	•			•		•		•								
Gabriella R. Montinola in Russell Hardin (editor)	Corruption, Distrust and the Deterioration of the Rule of Law.	*2004*																		
Russell Hardin	Trust.	*2006*		•	•			•				•			•	•				
Jan P. Reemtsma	Original: 'Vertrauen und Gewalt' *English Translation:* Trust and Violence.	*2008*		•		•														
Apostolis Papakostas	Civilizing the public sphere: Distrust, trust and corruption.	*2012*		•				•				•				•	•			
Ute Frevert	Vertrauensfragen - Eine Obsession der Moderne (Questions of Trust - An Obsession of Modernity).	*2013*		•					•				•							

The theories are predominantly 'middle-range' social scientific theories. However, they partly engage with 'grand theory'(Jaccard & Jacoby, 2010). Middle range theories do not attempt to be far-reaching and holistic, whereas grand theory makes an all-embracing attempt to explain. It appears that Germany and the United States have generated a substantial amount of the theory on trust. It needs to be noted that the more recent approaches to trust theory are also influenced by much earlier English and Scottish theories of trust by Thomas Hobbes (1588 – 1679), John Locke (1632-1704), David Hume (1711-1776) and John Stuart Mill (1806-1873) (Hobbes & Mayer, 1936; Hume, 1817; Locke, Shapiro, Dunn, & Grant, 2003; Mill, 2008).

Development of trust terminology

Many different concepts are used as if they are synonyms to describe trust. For example, when looking at the conceptual differences between faith, trust and confidence, evidently theorists do not agree what the differences are. One way to distinguish faith and trust is suggested by Seligman (1997), who concluded that one places trust in man and faith in God. Giddens argues for a different understanding, where trust is the link between faith and confidence, and, thus, a particular type of confidence (Giddens, 1996, pp. 32-33). According to Niklas Luhmann the difference is that *'trust remains vital for interpersonal relations, but participation in functional systems like the economy or politics is no longer a matter of personal relations. It requires confidence, but not trust'* (Luhmann, 1988, p.102). Luhmann discusses further the difference between hope and trust, where the possibility of choice is a pre-condition to place trust, otherwise when no choice is offered, there can only be hope and no trust. Consequently, trust only works in a context where a critical alternative is offered and where the damage occurring when trust is breached is larger compared to the advantage gained from the trusting relationship (Luhmann, 2000, p.28).

Understanding choice to be a pre-requisite for trusting, is one of the fundamental understandings when developing a trust theory in the realm of conscious choice (de Jonge, 2011, p. 8). Here trust is described as risky choice (see below), which is in line with rational choice theory, where a choice made with incomplete information is automatically a risky choice (de Jonge, 2011, pp. 21–23). From a childhood-development perspective on basic trust, Erikson assigns a higher degree of naiveté and mutuality to trust compared

to confidence (Erikson, 1995, p. 222). Sztompka, 1999, distinguishes hope (the opposite of resignation) from confidence (the opposite of doubt) and trust (the opposite of distrust) (Sztompka, 1999, p. 24,26). When looking at the roots of the English term trust, Hardin, (2002, 2006), shows in a linguistic analysis that the present term trust came into use in the Medieval era originating from the Middle English noun *tryst*. *Tryst* had a role in hunting, where according to Hardin, huntsmen were chasing game through a wood and on the other side of the wood other huntsmen would stand *tryst*, i.e. ready to kill the game as it emerged (Hardin, 2006, p. 2). In the following centuries, the term split into the present terms *trust* and *tryst* ,where two 'lovers' in a private romantic rendezvous need to trust each other and might misuse the trust of spouses respectively (Hardin, 2006, p.3).

Confidence developed from the Latin noun *confidentia* and *faith* developed from the Latin noun *fides*. *Confidentia* can be translated as: 'a firm trust in a thing, confidence' (Lewis, 1980, p. 413). *Fides* can be translated as: 'trust in a person or thing, confidence in a person, trustworthiness, faithfulness, conscientiousness, credibility, honesty' (Lewis, 1980). As indicated by the translation of *fides*, Hartmann, (1994) highlights that *fides* was used in Latin with a double meaning. The translation of *fides* as trust, confidence or faith focuses on the modern understanding of the term as used in *'I trust you'*. However, *fides* was also used when describing the characteristics of the person who is trustworthy, namely as: trustworthy, credible or loyal. Both meanings are related in so far as the trustworthiness of a trusted person can only be judged by the person who is trusting. Following this logic, Hartmann concludes that someone can only be trustworthy who is perceived as trustworthy by others. This implies further that a person can only be trustworthy, if s/he is doing what s/he has promised or announced to do (Hartmann, 1994, pp. 376–380).

As one of the most important contributions to trust theory was written in German by Niklas Luhmann, it is worth considering that in the German language, there is only one word for trust and confidence: *Vertrauen*. Faith is translated in the context of faith in God as *Glaube*. In the rarer context of faith in humans, it is translated as *Vertrauen*. The German noun *Glaube* can be back-translated into English as faith, but also (less commonly) as belief. The ambiguity of the concept of trust becomes evident, when looking at the linguistic history of *Vertrauen* in the German language. *Vertrauen* was known as '*sih fertruen*' in Old High German (around 750 – 1050 AD). Here *Vertrauen* (as well as the English word trust) stems from the Indo-European word family of '*deru* –

Oak, Tree' with the meaning of being *strong, solid, hard, like a tree.* In addition, historical analyses of *Vertrauen* prove that the semantic of *Vertrauen* is rooted in: hope, obligation, consolation and grace (Bruckner, 2016, p. 7; MacLeod, 2011, p. 23).

This brief historical overview of the roots of *trust* and *Vertrauen* demonstrates the complexity of the research field, and the distinctions between colloquial speech and the use of the terms in research. In colloquial speech, the terms and other synonyms of trust such as belief, hope or even love can be used interchangeably and motivated by the context they are used in, as well as individual habit (the quotes defining trust below show the diverse use of the terms). Compare here the use of the term confidence in 'self-confidence' as distinct from confidence in systems or the use of 'confidence-man' in book titles such as Herman Melville (1857) *The Confidence-Man: His Masquerade* or Thomas Mann (1955) *Confessions of Felix Krull, Confidence Man* (Frevert, 2013, p.8). With respect to the distinction between faith in God and trust in humans, compare here the Brewers' Hall motto engraved into the wall facing the street called London Wall in London, UK: *IN GOD IS ALL OUR TRUST*. In the context of German to English translations of trust, it is worth keeping in mind when reading Niklas Luhmann's chapter *Familiarity, Confidence, Trust: Problems and Alternatives* that, in German, Luhmann uses for *trust* - *Vertrauen* and for *confidence- System Vertrauen* (system trust) (Gambetta, 1988, Chapter 6). Thus there seems to be inconsistency between trust theory and colloquial speech when it comes to the use of the term trust and its synonyms. Pilgrim et al (2011) observed the same inconsistency in the context of health care research, and highlight the different use of trust in colloquial speech and academic debate (Pilgrim et al., 2011, Chapter 1). This inconsistency is important to highlight, as a conceptual framework should incorporate theory and qualitative work where the text generated might include more colloquial terms.

A preliminary concept of trust based on the theoretical literature

Trust is defined by different authors in different ways. This is very much in line with other findings stressing the same *'confusing potpourri'* of definitions (D. Harrison McKnight & Chervany, 2001, p. 28). When focusing on descriptions of trust, some authors present their own understanding, others build much more on previous work and

start their discussion from there. The following quotes provide an overview of how trust is mostly understood in the social science literature outside health care research:

Niklas Luhmann: *'The complexity of the future world will be reduced by the act of trusting'* (Luhmann, 2009).

Anthony Giddens: *'Trust may be defined as confidence in the reliability of a person or system, regarding a given set of outcomes or events, where that confidence expresses a faith in the probity or love of another, or in the correctness of abstract principles (technical knowledge)'* (Giddens, 1990, p. 34).

Piotr Sztompka: *'Trust is a bet about the future contingent actions of others'* (Sztompka, 1999, p. 25).

Francis Fukuyama: *'Trust is the expectation that arises within a community of regular, honest, and cooperative behaviour, based on commonly shared norms, on the part of other members of that community. Those norms can be about deep 'value' questions like the nature of God or justice, but they also encompass secular norms like professional standards and codes of behaviour.'* (Fukuyama, 1995, p. 26).

Russell Hardin: *'To say we trust you means we believe you have the right intentions towards us and that you are competent to do what we trust you to do'* (Hardin, 2006, p. 17).

Melissa S. Williams: *'... a politics of representation must draw on a fund of popular trust in the government's fairness in protecting and advancing citizen's interests. The concept of fairness, whether in institutions of political representation or in other political institutions, provides the standard for evaluating whether popular trust is justified in any particular instance. The conformity of political institutions to principles of fairness is what makes government worthy of popular trust'* (M. S. Williams, 1998, p. 30).

When looking at the definitions/descriptions of trust as discussed by different authors it is visible that many different themes are associated with trust. To build a conceptual

framework of trust based on the combined theories is difficult. This is so as the theories are developing from different backgrounds. However, there are moderate similarities across the literature. These can be condensed so that trust develops from experience, information, and an expected outcome based on the trusting relationship. Trust usually carries a degree of uncertainty as we do not know what the outcome of a trusting relationship is going to be. As a result, trust is inherently risky or associated with risk, as trust can be betrayed. To further develop a deeper theory-based understanding of trust, the following statements about trust are common to the discussed literature.

Trust arises between a minimum of two individuals

It is commonly understood among scholars that trust is a three-part relational concept between a minimum of two individuals: *A trusts B to do (or not to do) X* (Hardin, 2002, p. 9; Luhmann, 2009, Chapter 9; Sztompka, 1999, Chapter 2). Before focusing on this relationship in greater detail, it is worth discussing briefly the role of basic trust and self-confidence for this relationship. Erik Erikson has influenced the present understanding of when and how humans learn social trust during childhood in the form of basic trust (Erikson, 1995, pp. 222–225). Developing from the quality of the maternal relationship, an infant learns to trust. '*Mothers create a sense of trust in their children … which in its quality combines sensitive care of the baby's individual needs and firm sense of personal trustworthiness within the trusted framework of their culture's life style. This forms the basis in the child for a sense of identity which will later combine a sense of being 'all right', of being oneself and of becoming what other people trust one will become.*' (Erikson, 1995, p.224). This basic trust learned in early childhood and further developed during adolescence has a huge impact on the willingness to trust in later life as well as on trust in oneself, i.e. self-confidence (Hardin, 2002, pp. 116–119; Luhmann, 2009, p. 107; Misztal, 1996, p. 164). In the context of health care, the implications of childhood problems for trust are associated with mental health problems, pathological expressions of the personality, as well as how patients cooperate with their doctors as well as follow advice. On the professional side, this deficit expresses itself by egocentricity and dysfunctional interaction with patients (Pilgrim et al., 2011, p. 48). Similarly, Luhmann, 2009, claims that self-confidence has a distinct role in trust relationships. Self-confidence is understood to be the basis of interpersonal trust as self-confidence allows individuals to cope better with trust disappointment. Furthermore, Luhmann states that self-confident

humans as well as social systems are more willingly trusting (Luhmann, 2009, pp. 102–105).

Returning to the relationship of *A trusts B to do (or not to do) X*, this relationship can be configured in a number of ways. Starting from an individual point of view where *A* equals one individual, *B* can range from one individual to groups, such as family members, friends, colleagues, experts, media, organisations, institutions, technologies or even systems such as the health care system (Giddens, 1990, p. 102; Luhmann, 2009, pp. 47–82). As distinct from this use of trust, trusting relationships are also described between groups (*A*=group and *B*=group) of people or organisations and companies (Cook, 2001, Chapters 9–13). This leads to describing the nature of the trust relationship between the public and the healthcare system (Gille, Smith, & Mays, 2017; Misztal, 1996; Sztompka, 1999).

Last, trust relationships can develop as either one-way relationships, mutual trust relationships, or what Hardin (2002) describes as '*thick relationships'* (Hardin, 2002, pp. 14–23). One-way relationships are considered as relationships where the parties are not equal or not in symmetric roles, e.g. children trusting their parents, or the classic understanding of a layperson trusting an expert. Mutual trust relationships are considered to be more stable, as '*a reciprocal trusting relationship is mutually reinforcing for each truster, because each person then has a built-in incentive to be trustworthy*' (Hardin, 2002, p17 citing Coleman, 1990, p.77). In health care, a good example of a two-way trust relationship is that involved in 'co-production' of health between, say, a general practitioner and a patient where the patient trusts the general practitioner to provide good advice and the general practitioner trusts the patient to provide truthful information (Fledderus, Brandsen, & Honingh, 2014; Wilde, 2013). Fukuyama argues in the context of prosperity that mutual trust based on prior moral consensus and shared ethical values has the capacity to replace contracts and extensive legal regulations between organisations (Fukuyama, 1995, p. 26). Fukuyama stresses the importance for a healthy and dynamic society of being able to depend on people's habits, customs and ethics for the vitality of liberal political and economic institutions (Fukuyama, 1995, p. 4-5). He concludes that the level of trust inherent in a society is the single most important pre-condition for a nation's well-being and ability to compete. To make trusting relationships between members of a society possible, the rules and habits of the society are crucial (Fukuyama, 1995, p. 9). Trust as 'thick' relationships is developed in small communities

and consists of dense overlapping social ties which generate a high level of knowledge of each other among societal members. This knowledge supports the trusting relationship and provides incentives to trust others (Hardin, 2002, p.21). Examples of 'thick' relationships are families or teams which are grown together (Fukuyama, 1995, Part 3).

Trust can only develop by communication and truthful information

Communication needs to be understood in a wide range of ways from body language, passive and active communication, verbal, written or visual communication to largely one way communication such as media communication. As trust is relational, the two parties *A* and *B* need to communicate with each other. If no information is exchanged, trust cannot be established. This implies that trust depends on truthful information (Luhmann, 2009). Fukuyama makes a distinction between the trustworthiness of the information itself and the trustworthiness of the people providing and using the information (Fukuyama, 1995, p.25). Especially in health care, and following the idea that trust is built by conscious choices, to make an informed decision, for example, in the patient consent process, truthful information is essential to build trust.

Next to the understanding of information being communicated to, or obtained by, the trusting party, information to decide to trust can equally develop from personal experience. Personal experience is an important contributor to most newly formed trust relationships. However, previous personal information is not a compelling necessity in situations where the trusting party is able to access the experience of others from trusted sources of information. This could be information about a dentist which is trusted by a trusted family member who previously experienced the dentist's care in a positive way. Though, personal experience or the experience of others is an essential source of information.

Trust develops in a free society and is voluntary

Trust can neither be expected nor forced. This means for the relationship *A trusts B to do (or not to do) X*, that *B* cannot force or expect *A* to trust *B*. Misztal (1996) argues that trust can only develop in a free society based on free will. Also on a personal level, within a free society, it is difficult to imagine how trust can be forced or expected, especially when,

following Hartmann (1994) as discussed above, the trustworthiness of a person can only be judged by others and not by oneself. An expectation to be trusted might develop from arrogance, hubris or thoughtlessness or from a long exercised routine leading to a normative expectation. Nevertheless, this expected trust is not trust, it is purely an exercise of power developing from a power difference between the trusting and the trusted party or a misused dependency (e.g. where A has no choice but to trust B.) Furthermore, obedience could also be misinterpreted as trust. However, these concepts are distinct from trust.

Trust and trustworthiness are not the same

Following from the previous point and Hartmann's (1994) description of trustworthiness, the difference between trust and trustworthiness is important to note and widely discussed (Hardin, 2002; Luhmann, 2009). Both concepts are important for the relationship *A trusts B to do (or not to do) X*. The difference is, that trustworthiness describes an attribute of *B*, but trust describes the relationship between *A* and *B* including the effect of the relationship. This implies that trustworthiness has a more limited scope and does not necessitates a relationship. Just because *B* shows a behaviour or other characteristics that are considered as trustworthy, there is no compelling necessity for *A* to build trust in *B*. Doubtless, if trust is established, one would generally reason that *A* established trust in *B*, because *B* is trustworthy.

Trust is established for a reason

A trusts B to do (or not to do) X for a reason (Luhmann, 2009, p. 29; Sztompka, 1999, Chapter 4). If there is neither a relationship nor a motive to trust, trust would not be established. For example, a study participant trusts the research programme s/he is participating in, because s/he is participating in the programme. If the person chose not to participate in the study and the study had no indirect effect on her/him there would be no need to trust. An example of an indirect effect is a student who does not pay income tax. Despite this, s/he might still trust the government to spend income tax revenue appropriately as the student lives in an environment where the income tax is used (e.g. on cycle paths which the student uses to cycle to university).

Trust exists in the present, but is future-oriented

With the understanding that life is future-oriented, i.e. the effect of our own actions appear in the future, trust is future-oriented in the sense that the person trusting in the present trusts that something will happen or not happen in the future once the trusting relationship is established. According to Luhmann (2009) a theory of time is a prerequisite for a theory of trust since a person who trusts inevitably anticipates the future. S/he acts as if s/he has a tolerable level of certainty as to what will happen in the future (Luhmann 2009, chap. 2). Sztompka (1999) defines trust as *'a bet about the future contingent actions of others'*, p.25 (Sztompka, 1999, p.25). For example, even if one would trust a structural engineer to design a building so that it will not collapse, the effect of this trust placed in the structural engineer and his/her calculations (done in the past) is in the future. For that reason, one can trust the action of persons or objects in the past, but the effect of this trust on the trusting person happens in the future.

Trust is a risky 'advanced payment'

The literature often associates trust with risk. Trust is understood to be a risky choice in the sense of an advance payment according to Luhmann (1980, 2009, p. 27-38). This is the case when *A* chooses to trust *B*, but *A* does not know how *B* will act. There is always a risk that *B* will not act in the anticipated (trusted) way, leading to the erosion of trust. Luhmann, (1988) argues therefore that risk is always a part of decision and action. Information in the form of evidence and experience about *B* minimises the risk, but will never eliminate the risk (Luhmann, 2009, p.40). Giddens reasons slightly differently. For Giddens, trust is bound up with contingency and not with risk (Giddens, 1990, p. 33), as reliability is usually associated with trust in contingent situations and choosing to trust is based on a conscious calculation of the likely risk (Giddens, 1990, p.35). When understanding trust theory in light of conscious choice, one could claim that placing trust is inevitably a risky choice due to the fact that the choice is made based on inevitably incomplete information. As discussed earlier, in the absence of choice one cannot trust, one can only hope. Nevertheless, one could hypothesize a situation where no choice is offered, but still situational trust can be placed, detached from a conscious choice. In other circumstances, it is possible that trust could be mediated by trusted persons or organisations. For example, one could think of trust in emergency rooms as trust constructed on the basis of the previous experience of other members of the patient's

family (Kelly et al., 2005). Here one would trust the emergency room, because one had built trust based on information about the emergency room from trusted family members.

Trust enables action as well as grants autonomy for action

Looking at the relationship, *A trusts B to do (or not to do) X*, it can be concluded that trust enables action or inaction. By *A* placing trust in *B*, *A* is enabling *B* to act in line with *A's* initial intentions motivating him/her to trust *B*. Here the literature describes a (normative) expectation expressed with trust, as seen in the quotes above. In the context of health care, the consent process is an example where trust in the physician or system enables action with trust expressed by the signature on the consent form as critically discussed by O'Neill (2002b, p.19). It is important to note, that alongside with granting *B* the ability to act, *B* is also given the freedom to decide how the action is to be carried out (scope of action). This freedom is framed by the common norms and values of *A* and *B*. On the basis of these common norms and values, *B* can choose how to act to achieve the result *B* is trusted to achieve (Hartmann, 1994, p. 21). Hartmann, describes this as temporary autonomy (Hartmann, 1994, p. 17). For example, a private investor (*A*) trusts a fund manager (*B*) to invest and work with the investor's money to achieve a profit *X*. If both the investor and manager share the understanding (values and norms) that they do not want to invest money in weapons, alcohol and tobacco industries, then the fund will not invest in those industries, but the fund manager can invest in any other industries (scope of action) to achieve the profit *X*. By trusting the fund manager, the investor grants this freedom. In terms of the relationship between citizens and their government, it is commonly understood that trust legitimises representative governance, i.e. public trust enables (legitimises) governmental action (Williams, 1998, Chapter 1.1). It is important to recognise that the power exercised by the government is not for its own benefit, but for the benefit of the people who trust the government. This implies that representation creates a two-sided relationship of trust and obligation. The trusted are obliged to advocate policies which are in the common interest and the trusting are obliged to obey the laws until the government ceases to act in *'good faith'* (Williams, 1998).

Trust reduces complexity

Despite some scholars arguing against Luhmann's concept of the function of trust as a mechanism to reduce complexity, this conception is widely cited and recognised in the field of trust research (Luhmann, 2009). Critics argue that trust itself is inherently highly complex and therefore cannot reduce complexity. Here it is argued on the one hand that the act of trusting always develops new complexity and on the other hand that trust itself is foremost complex in the areas of rationality, normativity and social application (Hartmann, 1994, Chapter 0). However, by reducing the complexity of the world and of future uncertainty, trust enables human action. This understanding is relevant to trust in healthcare systems since they are highly complex.

Trust and distrust can exist at the same time

Distrust is described by many as the opposite of trust or as the mirror image (Hardin, 2009; Sztompka, 1999, p. 26). Luhmann describes distrust to be not only the opposite of trust but also a functional equivalent (Luhmann, 2009, p. 92). Like trust, distrust has the function of reducing complexity. For that reason, someone who distrusts has to use functionally equivalent coping strategies to reduce the complexity of life. In comparison to trust, those strategies are emotionally tiring, desperate and exhausting, such as fight strategies, financial liquidity strategies (where one would keep money at home or spread savings across different places) or abstention strategies. The crux is that a distrusting person needs more information to cope with life but trusts much less information sources. Thus, paradoxically the distrusting person is much more vulnerable to others, as the distrusting behaviour makes it easier for others to deceive the distrusting person (Luhmann, 2009, p. 93). This is the case as the limited amount of information remaining to be considered as trustworthy is much easier to manipulate. For example, when a person is only trusting one information source, it is much easier to manipulate this person via manipulating the one information source, as the person is not engaging with other information sources which would counterbalance the manipulated information source.

Adding to the problematics of distrust, Hardin describes distrust (as well as trust) as a cognitive assessment which can be mistaken. Trust and distrust can be susceptible to false negative and false positive assessments (Hardin, 2009, p. 9). Beside the fact that distrust can have in extreme forms a dramatic outcome for all parties affected, it is commonly agreed among theorists that distrust and trust can co-exist (Haddow & Cunningham-

Burley, 2008; Hardin, 2009; Luhmann, 2009). However, co-existing distrust and trust are purpose-specific (Hardin, 2009, p. 3). It is not possible to trust and distrust the same person for the same matter at the same time in the same context (Ullmann-Margalit, 2009). For example, one might trust a person to buy groceries, but distrust the same person to drive the car to the grocery store.

Theorists describe what lies between trust and distrust, differently. For example, Sztompka (1999) describes distrust as the mirror image of trust. In between both is mistrust as a neutral state. *'Mistrust is either a former trust destroyed, or former distrust healed'* (Sztompka, 1999, pp. 26–27). Ullmann-Margalit (2009) describes a no-man's land of trust agnosticism between trust and distrust; a place with neither trust nor distrust.

Agreeing that trust and distrust can exist next to each other, a slightly adapted understanding of the relationship between trust and distrust is proposed here. This adaptation is based predominantly on three thoughts. First, if distrust were the mirror image of trust, this would require assuming that distrust is the negative image of trust. This would further imply that distrust and trust are diametrical opposites. Such an understanding is challengeable, as the relationship between trust and distrust is asymmetrical (Ullmann-Margalit, 2009). This is most clearly expressed by the widely shared insight that trust is easy to destroy, but difficult to repair. This difficulty is explained in the context of restoring trust in multinational companies such as Siemens or Toyota following different types of scandals such as Siemens bribing to win contracts or a Toyota Lexus car killing everybody in the car by accelerating out of control (Dietz and Gillespie, 2012). The fragility of trust is described by several metaphors and common sense. Also the conceptualisation of trust and distrust is different. The difference relates to the different motivation required to overcome distrust. Overcoming distrust requires overcoming sorrow, envy or frustration. In certain cases, it will never be possible to heal distrust. Second, assuming a neutral point in the middle between trust and distrust which could tip in either direction might make sense from a mathematical point of view where trust might be described with 1 and distrust with -1 resulting in 0 as the neutral point in between. However, the continuum between trust and distrust does not necessarily pass through a neutral state. Further, following Luhmann, trust and distrust are dichotomous choices that have to be made, a neutral position is not logical (Luhmann, 2009, p. 92). Third, it is possible for a person simply not to care or not to have an opinion on trust. Making a cognitive assessment not to care about trust or distrust is distinct from deciding

if something should be trusted or distrusted. If a person is not vulnerable to a situation or is not affected by a certain action where others would need to trust, the person can indeed not care or decide that trust does not matter. If the possibility of not caring is not included in the understanding of trust theory, this would force trust on each individual and would deprive people of the freedom to not care about trust.

Based on the above, it seems to be reasonable to propose the following understanding of the relationship between trust and distrust. Here trust and distrust are two distinct concepts which range from high to low. Both include the possibility of coping strategies to overcome the lower level of trust or higher level of distrust. However, trust is likely to be more fragile and to overcome distrust, if at all possible, is requires considerable effort. This asymmetry is important to recognize, as it fundamentally argues against the idea of distrust being a mirror image of trust. Further, by separating trust from distrust, there is room for not caring about trust or distrust and any neutral position between trust and distrust is eliminated.

Trust is generally important for life, but its importance can vary depending on the situation

Niklas Luhmann writes, '*without any trust, he [human] could not get out of his bed. He would be affected by undefined fears and paralysing horror.'* p.1 (Luhmann, 2009, p. 1). But can we conclude from such a statement that trust is as elementary for human life as the air we breathe? Probably, the answer is *yes* and *no*. As trust is a personal motivation, the arguments in favour and against the generalisability of trust for all situations depend on one's personal point of view. The answer will depend on the trust scenario as well as individual, social and environmental factors. The following points could tend towards an answer in the negative:

- One could simply not care or be indifferent about a situation where others trust. But, indifference does not equal inaction. One can still take part in certain practices without trust, for example, if the outcome of the practice does not involve any personal vulnerability (Hartmann, 1994, p. 58).

- From Luhmann's understanding of trust as a mechanism to reduce complexity one could conclude that in a simple environment without any complexity trust inevitably plays a minor role.
- In a scenario where trust is taken for granted, people might not recognise the role of trust at all.
- Different types of trust might 'overlap' others. For example, if people have confidence in governmental guarantees, regulation and structures, they do not need to trust a research programme under the umbrella of the government, as they trust that the governmental structures will guarantee the trustworthiness of the research programme. Also, faith in God could overlap trust in humans or systems, if one would understand that all actions on earth follow God's plan. Faith could even go so far as to predetermine if one 'is allowed' following one's interpretation of a religion to engage in a situation where trust might be needed. Faith can play a superior role compared to trust.
- In a situation where one has all the information needed to control the outcome of an action in the future, one might not need to trust. Similarly, if one has the resources, power and knowledge to cope with a breach of trust, one might not need to trust. If all activities are visible and processes known, one would not need to trust (Giddens, 1991, p. 33).
- Different people might understand the need for trust differently in the same situation. For example, one person has the knowledge to do something by him/herself while another person needs someone with that specific knowledge to do something on their behalf in a trusting relationship.
- Another scenario could be that for different people different concepts close to trust replace trust. A relationship which one person might describe with trust another person could describe with love.
- People might understand contracts as substituting for trust to a certain degree by replacing a firm handshake among partners. This might be short-sighted as trust reduces transaction costs such as the legal costs of contracts, and economies grow better in a high trust environment. On the other hand if one does not place trust in the business partner, one needs subsequently to trust that the judge and legal system will interpret the contracts as one intended (Fukuyama, 1995; Luhmann, 2009).

- Also different views on political systems might influence the understanding of the need for trust. For example, in a democracy one understands public trust to legitimise governance. Legitimacy theories are often focusing on trust. Here political action is legitimised by public trust in the government. This trust could be understood as a stock of political credit (Misztal, 1996, p. 261). Furthermore, it is assumed that this results in a certain level of quality of compliance and social cooperation (Misztal, 1996, p. 245). Legitimisation of political power is facilitated in democratic societies by elections and so legitimacy is closely linked to democratic principles and procedures (Misztal, 1996, p. 255). Here accountability comes into play, in so far as mediators (representatives) of institutional power need to be the elected 'faces' of power. However other political systems might legitimise governance by inheritance in which case public trust might be far less important to legitimise governance.
- As an alternative to trust, one might impose protocols, monitoring, transparency and supervisory control mechanisms thereby reducing the autonomy of an actor. The aim of such measures is to counteract human error and intended betrayal or fraud. But equally those measures can damage trust by supporting 'self-censorship', dishonesty, and might reveal sensitive information in the process of being transparent. Evidently, in many countries governmental efforts to encourage transparency in recent past have tended to undermine a feeling of trust (O'Neill, 2002a, Chapter 4).

In favour of answering *Yes* to the universal importance of the role of trust one can argue:

- That self-confidence and basic trust play an elementary role in the functioning of humans in society as well as for their personal wellbeing. Deficits in one or the other type of trust can result in extreme pathological behaviour (Erikson, 1995, Chapter 7; Hartmann, 1994, p. 58; Pilgrim et al., 2011, Chapter 3).
- That societies incorporate formal structures and mechanisms as well as common norms and values which to a certain degree guarantee trust. Thus, a trustworthy environment surrounds the individual. As trust is closely linked to freedom, autonomy and hereby to democratic principles, one might go as far as to argue that trust is to a large degree institutionalised. Law, rules and regulation as well as certain mistrust points support and shape trust in the way a society has developed its legal and political structures in first place. For example, since groceries need to show expiry dates, a consumer does not need to check further

the quality of the food and will not need to fear getting food poisoning. Another example is deliberately placed mistrust to foster overall trust, for example, quality checks in a production line (Luhmann, 2009).

- In situations where a lack of information exists, trust is a coping mechanism to overcome this lack of information (Giddens, 1991, p. 33). Most likely, it is not possible to have all the information needed, therefore there is always space for trust.

As seen above it is possible that the importance of trust varies considerably. Trust in its basic forms is axiomatic for human life, but in certain situations, different forms of trust can play a secondary role. However, trust must not be taken for granted. If one would do so, one would risk damaging trust as trust is a relational construct which needs constant reinforcement (Luhmann, 2009).

Conclusion

For the field of health systems and policy research as well as the wider social sciences, trust theory can only be further developed by vibrant discourse amongst researchers about new empirical research while adapting the theory to contemporary societal issues and understanding. Due to the highly subjective nature of trust as well as its tendency to be context-specific, there will inevitably always be different understandings about trust. However, the proposed common features of trust discussed in this chapter, can provide a starting point for further theoretical debate about the commonalities between different conceptual frameworks. If the commonalities between theories and comparability of these theories is not elaborated, it will not be possible to compare trust studies or develop policy targeting trust across different settings. This debate should illuminate how far trust is generally applicable to human life, where the conceptual boundaries between trust and its synonyms are and foremost what constitutes trust. Possibly one can formulate a generally valid and universal definition of trust as well as to describe the function of trust applicable across disciplines and settings. Unfortunately, this causes the dilemma that such a formulation will be too abstract to be directly applicable. Nevertheless, such an abstract definition can serve very well as a guiding construct for context-specific conceptual framework. If the disciplines would agree on such an abstraction, it would be much easier for researchers and others to understand where the context-specific conceptual

frameworks are anchored. Further, this way it will be possible to compare different studies across different settings as the different conceptual frameworks are rooted in the same abstract definition. The challenge will be to find a conceptual framework of trust that balances the level of abstraction to be generally applicable with the accuracy to be as precise as possible.

Building on the theories and discussions above, such a definition of trust could be that: trust is a relational concept, developing from past and present information and future anticipation, which enables the trusted party to act autonomously to reduce future complexity for the trusting party. This complexity arises from the lack of full information about the actions of others and/or lack of resources, knowledge and power to cope with the complexity alone.

To inform the development of the conceptualisation of public trust in Chapter 7, Table 4.3 summarises the points discussed above.

Table 4.3: Summary of the common denominators of trust theory

Trust arises between a minimum of two individuals	Trust enables action as well as grants autonomy for action
Trust can only develop by communication and truthful information	Trust reduces complexity
Trust develops in a free society and is voluntary	Trust and distrust can exist at the same time
Trust is established for a reason	Trust is generally important for life, but its importance can vary depending on the situation
Trust exists in the present, but is future-oriented	Trust and trustworthiness are not the same
Trust is a risky 'advanced payment'	

Chapter 5: Towards a broader model of public trust in the health care system

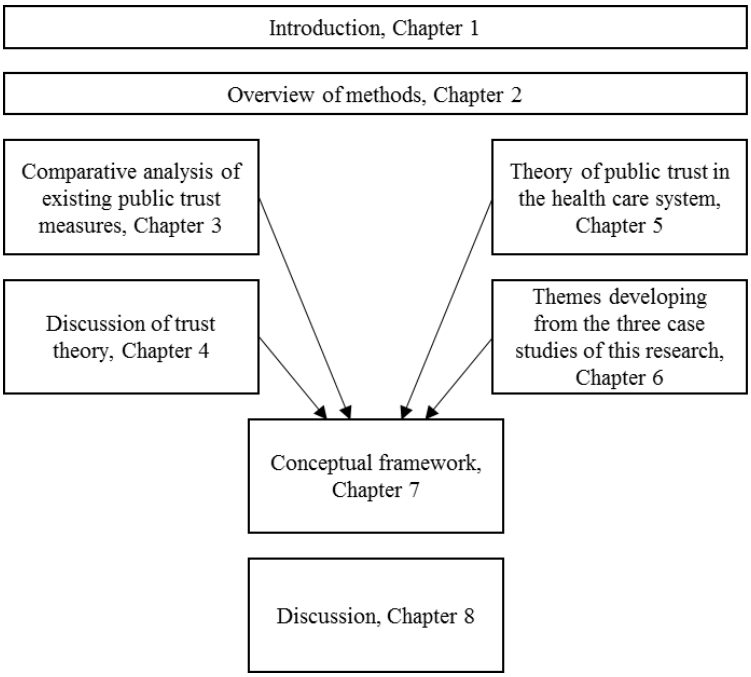
Key findings

- Public trust develops from public discourse in the public sphere
- Public trust can be influenced by actors outside the health care system
- Public trust legitimises the actions of the health care system

Overview

Public trust lacks a precise, theoretically grounded and empirically tested definition. The mass media as well as the scientific community use the term public trust as if there is a common understanding of its meaning. As this is evidently not the case, this chapter proposes a broadening of an existing model of public trust for use in health care system and policy research drawing on wider theories on trust from outside health care discussed in the previous Chapter. In the proposed model, the origin of public trust is understood to be in the public sphere, which is situated between the individual, the health care system, the state and other societal institutions. Public trust in the health care system is influenced not only by the health care system itself, individuals' experiences of it and its media image but also by discourse in the public sphere about individuals' experiences and the system as a whole.

An adapted version of this chapter has been published: see next two pages.



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Principal Supervisor	Nicholas Mays & Sarah Smith
Thesis Title	Theory and conceptualisation of public trust in the health care system

If the Research Paper has previously been published please complete Section B, if not please move to Section C

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Supervisors' contributions to the article	Sarah Smith and Nicholas Mays commented on the draft versions and made suggestions on how to improve the content and text.

Introduction

The following chapter meets the objective:

- Objective 2: To elaborate the meaning of public trust.

As discussed in Chapter 1, examples of health care system activities where public trust matters most obviously are vaccination coverage, health care provider choice, the use of the internet to identify health related information, or participation in biomedical research (Green, 2004; Haddow and Cunningham-Burley, 2008). As described by Brown (2008), the increased interest in public trust among health care researchers can partly be explained by a sequence of scandals covered in the media and the government responses that followed designed to act against the perceived betrayal of public trust. Prominent examples in the English National Health Service are the cases of retention of organs without consent at Alder Hey children's hospital, unacceptably poor quality paediatric cardiac surgery in Bristol in the 1990s, the Beverly Allitt affair where children were deliberately harmed and murdered on a ward in the early 1990s, the homicidal general practitioner, Harold Shipman, in the early 2000s and the quality failure at Mid-Staffordshire hospital in the late 2000s (Bristol Royal Infirmary Inquiry, 2001; Brykczynska, 1994; Francis, 2010; Redfern *et al*, 2001; The Stationery Office, 2005). These scandals led to changes in the health care system in the attempt to regain trust and prevent future scandals. The changes focused on increasing the level of monitoring of performance and the quality of care with the aim of increasing transparency and accountability (Brown, 2008). However, in contrast to these examples, where experience of individual harm led to a public debate about trust, the recent public debate on 'care.data' in the English NHS provides an example where ahead of any individual harm, the public has strongly expressed low trust in a prospective NHS project. 'Care.data' was introduced to the general public early in January 2014 via a leaflet, 'Better information means better care', delivered to all households in the country. 'Care.data' aimed to collect and share information about individuals' care to improve the quality of care for all. Yet the initiative, which would link hospital and general practice patient data anonymously at the individual level, has struggled to win public acceptance in the face of concerns about the trustworthiness of the programme to keep sensitive information secure and the potential for commercial gain to be made from patients' personal data (Carter *et al,* 2015; NHS 2014; Pollock and Roderick 2014). Due to worries expressed in the media by the

public as well as scientific bodies, the programme was first postponed and finally closed on 6th July 2016 (Department of Health & Freeman, 2016).

Cases like these have led to an increase in research about the role of trust in health care systems or parts of health care systems as distinct from the large body of earlier research into trust at the level of the personal encounters between individual patients and health care professionals (Blendon *et al*, 2014; Calnan, 2004; Jovell *et al*, 2007; Larson and Heymann, 2010; Ozawa and Stack, 2013; Platt and Kardia, 2015; van der Schee *et al*, 2007). In this research, a number of terms are used interchangeably to describe trust other than at the inter-personal level, see Chapter 1. The term most widely used in the mass media and scholarly writing as it is in this research is 'public trust'. In the mass media, the term public trust is widely used in relation to many different societal issues. In addition to the health care system, these include lately discussion of the financial crisis, scandals around governments' security service surveillance or leaks of private information from governments and private companies. At present, it appears that the term public trust primarily appears in association with negative headlines. It generally hints at the need for the public openly to discuss public trust because it is perceived to be threatened. However, such use of the term 'public trust' assumes a common understanding of the term which is evidently not the case.

Social theory on trust

To ground any refinement in understanding of what public trust means in the context of the health care system, it is necessary to look at social theory on trust. One obvious starting point is Niklas Luhmann's definition of trust as a property inherent in relationships that reduces the complexity associated with future uncertainty (Luhmann, 2009, p. 18). Niklas Luhmann has been influential for the understanding of trust through his essay on trust (Luhmann, 2009), and his book chapter on familiarity, confidence and trust (Luhmann, 1988, Chapter 6). His work has been extensively discussed by a number of recent authors (Holmström, 2007; Jalava, 2003; Meyer, Ward, Coveney, & Rogers, 2008). Nevertheless, Luhmann does not explicitly articulate the way in which the public through social interaction contributes to 'public trust'. This aspect is more central to the work of scholars such as Barbara Misztal, who discusses trust as a social construct (Misztal, 1996). Misztal (1996) shows how the understanding of trust has changed as modern societies have developed as well as the increasing difficulty such societies face

to attain trust (Misztal, 1996, p.1,9). For Misztal, *''Trust' is not seen as a regulatory mechanism but rather as a public good'* (Misztal, 1996, pp.2, 12). As Misztal develops her definition of trust as essentially a social phenomenon based on communication, she incorporates Jürgen Habermas' Theory of Communicative Action. According to Habermas, communication is built on mutual trust between the communicating actors. In turn, communication itself coordinates social and political interaction (Misztal, 1996, p.13). Referring to Putnam and de Tocqueville, trust is described as a public good as well as being part of social capital. Trust here is sustained by social interaction and by the actions of an active citizenry. Understanding trust equally as a property of social systems as well as an emerging attribute of individual interaction overcomes the conceptual distinction between trust as a personal property and trust as a systemic property (Misztal, 1996, p.14).

As a result of reviewing the 'functions of trust', Misztal proposes a synthetic approach to understanding trust as a phenomenon consisting of three types of order. First, there is trust as habitus (producing stable order) translated into practice as habit, reputation and memory. The stable order of trust is a mechanism to cope with uncertainty, as shown for instance in daily routines based on 'stable reputations and tacit memories' (Misztal, 1996, p.102). Second, there is trust as passion (producing cohesive order) translated into practice as family, friends and society. The cohesive order of trust changed under the impact of modernity from roots of trust in the family to mutual trust in society based on communication (Misztal, 1996, p. 157, 206). Third, there is trust as policy (producing collaborative order) translated into practice as solidarity, toleration and democratic legitimacy (Misztal, 1996, p.101). Central to Misztal's discussion of collaborative order is the concept of civil society as the basis for democratic legitimacy in the modern world (Misztal, 1996, p.212). Since the separation of the 'public' and 'private' spheres has become extreme in Western societies due to fragmentation of society and individualisation of modern social structure, institutional designs of modern democracies must be based on solidarity and trust to counteract the ongoing separation between the individual and society (Misztal, 1996, p.217). She proposes a strategy to support solidarity by a policy of trust designed to satisfy economic interests, embed the cultural view of the relationship between self and state, and facilitate freedoms of association, speech and religion. This strategy should provide reason and trigger people to get involved with each other in the public sphere (Misztal, 1996, p. 219).

Discussing public trust with respect to active citizenship, democracy and solidarity, and stressing its importance for social life in the public sphere are also themes taken up by other theorists of trust such as O'Neill (2002), Fukuyama (1995), Sztompka (1999), Seligman (1997) and Papakostas (2012). O'Neill discusses critically the process of democratic legitimisation in bioethics which can, if well facilitated, increase public trust (O'Neill, 2002b, pp. 169–174). Here two ways to increase public trust are discussed both concerned with engaging active citizens in deliberation: small-scale citizen's juries; and large scale citizen's fora and consensus conferences. Similarly, Fukuyama (1995) sees trust as *'the expectation that arises within a community of regular, honest and cooperative behaviour, based on commonly shared norms, on the part of other members of the community'* (Fukuyama, 1995, p. 26). With this community-focused understanding of trust, he identifies social capital as arising from the prevalence of trust, which requires that individuals in society have norms in common so that they can build public trust. In line with Fukuyama, Sztompka also describes trust as an inherently social phenomenon, and as an important dimension of civic culture and society. He further identifies a strong correlation between quality of life and the presence of generalized trust in a society (Sztompka, 1999, pp. 14–17). Following a line of argument similar to Fukuyama's, Seligman identifies as the two main elements of associational life (which is the basis of social solidarity) confidence in the political system and a shared identity (Seligman, 1997, p. 78). As a last example of this school of thought, Papakostas sees trust as an essential element for the development of the public sphere (Papakostas, 2012). While referring to the scholars above, Papakostas concludes that individual trust, social capital and social networks are central to the production of trust within societies. These scholars all understand 'public trust' to be a distinct social phenomenon that co-exists with individual trust. For them, in general, public trust is based on shared norms and identity, and developed by communication and the activities of an active citizenry or public, contributing, in turn, to the development of social capital.

Existing model of public trust in health care systems

When reviewing both the theoretical and the empirical literature on public trust in a range of areas, including health care system and policy research, it becomes evident that, unlike the theorists summarised above, there is little clear definition of public trust. One of the rare exceptions is the analysis by Van der Schee *et al* (2007) who present a model of

'public trust in health care' in the context of a cross-country comparison of public trust in the health care systems of Germany, the Netherlands, England and Wales, see Figure 5.1.

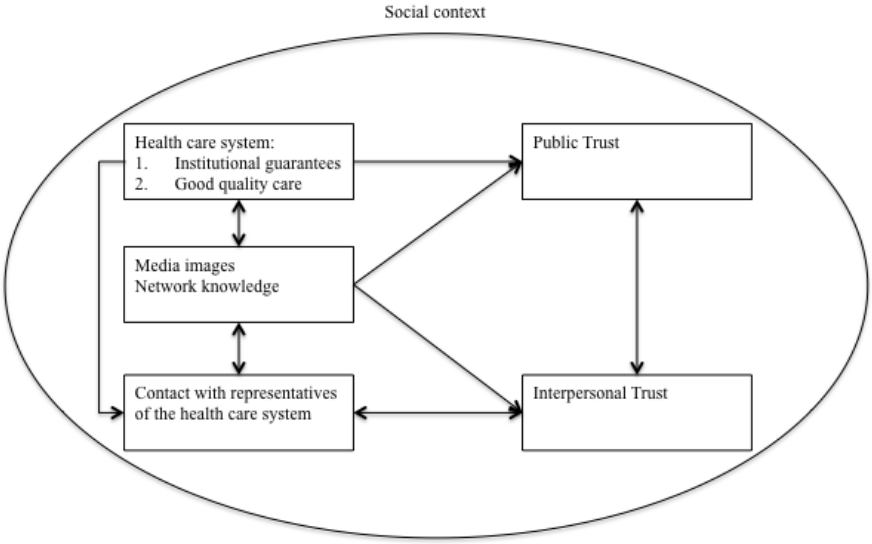


Figure 5.1: Model of 'public trust in health care'

(Source: van der Schee et al, 2007, p. 57).

In their model, public trust in the health care system is seen as shaped by: a) the interpersonal trust between the patient and health care professionals (the underlying level of trust that prevails at this micro level); b) the mass media's image of the health care system and its knowledge network, where activities such as the reporting of crises and scandals may have a strong influence on 'public trust'; and, c) '*institutional guarantees and the actual availability of good quality care.*' (Van der Schee et al, 2007, p.57). Van der Schee et al (2007) argue that all of these factors, as well as the relationship between the actors in the health care system, need to be set in their social context (van der Schee et al, 2007, p. 57). This implies that the construct is likely to change its precise shape in different social and cultural settings. Five years earlier, public trust in the health care system had been defined slightly differently by one of the same authors as: *'... a generalized attitude based on personal experience in trust situations, on direct communication of other people's experience and on mass media communication.*' (Straten et al., 2002, p. 223). It is argued by another of the same group of authors that one of the common features of definitions of public trust in the health care system is that: '*all embody the notion of expectations: expectations by the public that healthcare providers will demonstrate knowledge, skill and competence; further*

expectations too that they will behave as true agents (that is, in the patient's best interest) and with beneficence, fairness and integrity. It is these collective expectations that form the basis of trust' (Calnan and Sanford, 2004, p. 32).

Van der Schee et al's (2007) model of 'public trust in health care' provides a good starting point for public trust research from a health care system perspective, but has some limitations. It builds entirely on the triangular relationship between the individual, health care system representatives (i.e. all types of staff) and media coverage that generates interpersonal trust and then public trust. This model starts at the individual level and develops a notion of public trust from this level upwards, shaped by the nature of the health care system's interaction with the individual, and the broader media image and representation of the health care system. The model omits other social sectors and industries, which have recognizable impacts on the health care system, such as the national and multi-national private sector (e.g. pharmaceutical companies, consulting companies, insurance companies or IT companies), health care advocates (e.g. non-governmental organisations), or religious organisations. The strong influence of pharmaceutical companies on the health care system and the public has been increasingly critically discussed in recent years (Abraham, 2010). The so called socio-technical '*pharmaceuticalization'* of society provides opportunities for pharma industries to shape both their market and health care systems (Williams *et al*, 2011). With the increasing technological development of society, as well as of the health care system, the health care system itself has been opened up to new phenomena such as the Internet, e-health, data sharing, foreign health care industries and, simultaneously, its complexity has increased.

Furthermore, the model omits, to a large extent, the influencing dynamics of the public itself on public trust. The public, as discussed below, is the main driver of public trust, as individuals, forming the public, discuss and exchange their experiences and perceptions of trust in the health care system, and their perceptions of what forms public trust. Further, changing levels of public trust in the health care system may change patients' behaviour, for example by influencing their health care choices rather than causality always running in the opposite direction from the individual to the public. Thus Van der Schee *et al*'s, 2007, model can be expanded and developed to take into account the greater complexity and openness of the health care system, and the increase in publicity given to the nature and level of public trust.

The model thus seems to be too much focused on the relationship between the health care system and the individual, which is a limitation when the focus is a phenomenon that exists at the level of the public. For example, Arendt's (1958) definition of that which is 'public' points to something other than what is described in van der Schee *et al*'s (2007) model. Whatever is 'public' appears in public and can be seen and heard, in principle, by everybody, has the widest possible publicity, is common to all and is distinguished from the private (i.e. personal) realm (Arendt, 1958, pp. 50-58). What is 'public' becomes manifest, for example, in public goods, of which public trust can be understood to be one (Misztal, 1996,pp. 12-32; Seligman, 1997, pp. 97–99). This would not apply to individuals' interactions with the health care system since these are largely private encounters, despite the fact that public trust also develops indirectly and partly from these interactions, as argued below.

Both Habermas' and Arendt's work on the public and the public sphere have significantly influenced today's understanding of the term 'public' and need to be brought into any definition of 'public trust' (Calhoun, 1992; Crossley and Roberts, 2004; Seligman, 1997; White, 1990). The ideal process of discourse in the public sphere was described by Habermas in his account of the so called 'ideal speech situation' which he defined as based on foundations of communicative ethics (White, 1990, Chapter 3). Two propositions are crucial in Habermas' view of communicative ethics: first, that 'normative validity claims have cognitive sense' and therefore can be considered as true claims; second, that the validation process requires dialogue and cannot be conducted as an abstract monologue (White, 1990, p. 48). According to Habermas, it is essential for the development of a consensus that the rules for the 'ideal speech situation' are adhered to, as follows:

1. Each subject who is capable of speech and action is allowed to participate in discourse.
2. a) Each is allowed to call into question any proposal.
   b) Each is allowed to introduce any proposal into the discourse.
   c) Each is allowed to express his attitudes, wishes, and needs.
3. No speaker ought to be hindered by compulsion – whether arising inside the discourse or outside it –from making use of the rights secured under 1 and 2. (White, 1990, p. 56)

Further, the arguments brought forward in the discourse need to fulfil four criteria of validity, namely, that they are comprehensible, true, authentic and morally right, as well as appropriate (Cukier et al, 2004; Denzin and Lincoln, 2005; Habermas, 1995). If the rules of the 'ideal speech situation' as well as the validity claims are met, the discourse has the best chance to lead to a consensus. In turn, this discourse has the potential to legitimise public trust. Habermas' work has been successfully applied to the context of the health care system and is proven to be valuable for discussions on the role of the 'public' in health care systems (Chaudhary et al, 2013; Scambler, 1998; Stevenson and Scambler, 2005). All these strands of thinking have contributed to the model set out below.

Building on van der Schee et al's, (2007) model and understanding of public trust in health care systems, influenced by Arendt's and Habermas' work on the nature of the public sphere, as well as Habermas' work on discourse, and Luhmann's and others' work on trust discussed earlier, and taking a Western view of health care systems (e.g. inspired by reflecting on the British NHS and German health care system), the following presents a more elaborated model for discussion and eventual empirical testing (Arendt, 1958; Habermas, 1990, 1991, 2014; Jakowatz and Habermas 2008; Luhmann, 2009).

A revised model of public trust in the health care system

The proposed model of public trust (Figure 5.2) attempts to describe public trust in health care systems by giving due recognition to its origins in the public sphere. While the model has yet to be used to guide empirical work, there are a number of pieces of research that shed light on different segments of the proposed model. These include research on trust relationships between patient and doctor, trust in health care programmes such as vaccination, trust in health information systems such as biobanks, trust in government institutions and trust in the mass media including the communication of health-related news (Ahern & Hendryx, 2003; Coleman et al , 2009; Feudtner, 2004; Goold et al 2006; Hall et al, 2001; Kelly et al, 2005; Ozawa and Stack, 2013; Picard and Yeo, 2011; Tutton et al, 2004; van der Schee et al, 2012). In Figure 5.2, public trust in the health care system is understood to be trust developed in the public sphere as a consequence of discourse in public about people's experiences and perceptions of the health care system, as well as a broader discourse shaping trust, grounded in the common health values and health norms

of a society. In turn, the public sphere is defined as situated between the individual sphere, the health care system, the state, and other market and non-market institutions.

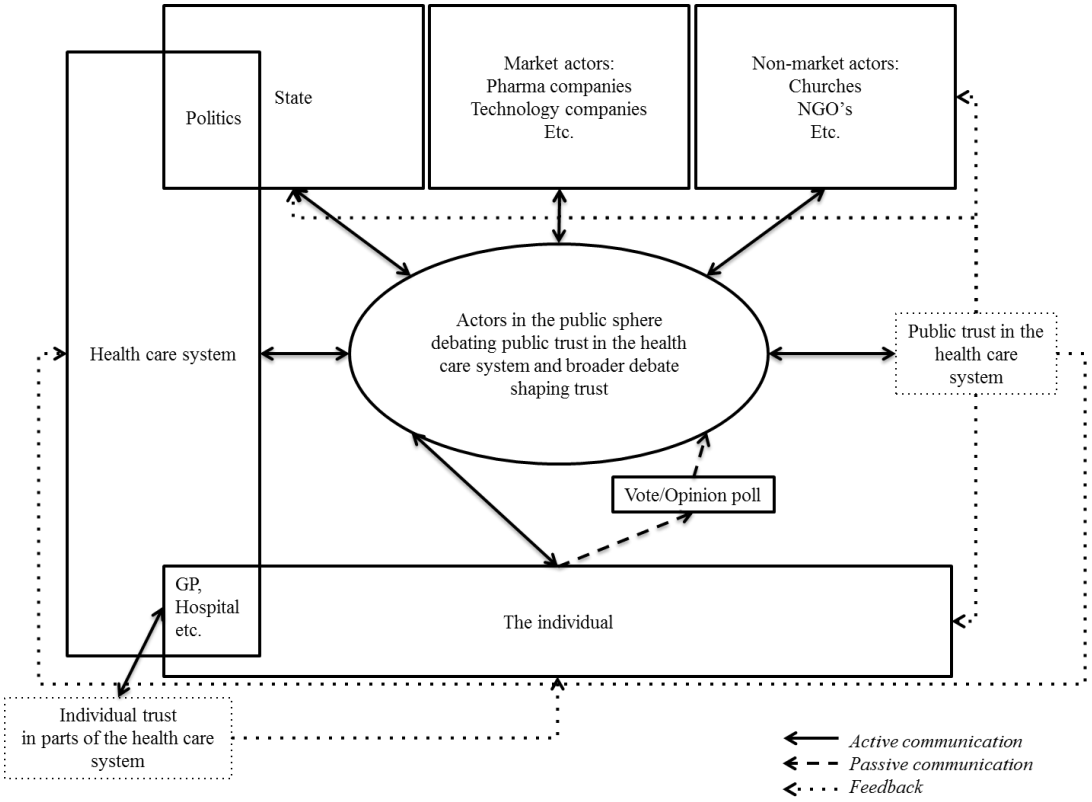


Figure 5.2: Revised model of public trust in the health care system

Communication, indicated by the solid and broken arrows in Figure 5.2, in all forms is essential for the functioning of society and the development of trust, and hereby for reducing uncertainty and thence complexity. Communication in the public sphere can be understood as either active dialogue, face-to-face and in web-based fora, or more passive one-way communication, as in the consumption of information and periodic public participation via opinion polls or elections. The media play the biggest role in channelling, filtering and directing information within and outside the public sphere. As a result, the media have a big influence on public trust in all the institutions of society, including shaping public trust in the health care system. To take an obvious example, the media can be influential in shaping public trust in vaccine programmes by amplifying concerns about vaccine damage and polarizing the ensuing debates (Larson et al, 2011; Larson and Heymann, 2010). In the US, during the late 1990s, organized parent groups spread misinformation about scientifically unproven links between autism and Thiomersal, a compound containing ethylmercury used in infant vaccine, leading to wide public

‘mistrust’ in infant vaccines. In turn, this affected trust in the wider health care system, which, subsequently, led to further falls in childhood vaccine coverage. (Larson et al, 2011, pp. 527–530).

However, depending on the information-consuming behaviour of the individual, the mass media are only one of many routes, in addition to social media, blogs, tweets, newsletters, informal networks, etc. by which the individual receives information in relation to public trust and information that influences his/her individual trust and his/her understanding of public trust. The media and communication are interpreted in Figure 5.2 as a mediator, a connector and an observer to enable and keep discourse in the public sphere alive. Nevertheless, it needs to be recognized that the role of the media in information dissemination can be controversial. For example, Habermas discussed media power in the public sphere and concluded that, if used for opinion manipulation, the public sphere develops into an arena of power where topic selection and the coverage of topics are fought over (Calhoun 1992: 437). While Habermas’ model of the public sphere may seem rather abstract and idealised, an adapted understanding of the public sphere does still exist today (Calhoun, 1992; Crossley and Roberts, 2004). It is in the nature of the public sphere that it changes as society and the environment develop rather than disappearing. The clubs, coffeehouses or salons of the 18th century contributed to the classic understanding of how the public sphere manifests itself, as described by Habermas, (Habermas, 1990, pp. 90-107). Perhaps the epitome of this concept of the public sphere is Speakers’ Corner in Hyde Park, London, where members of the public come together specifically to discuss openly with one another in public. Nowadays, this is exceptional in that the public sphere is far more likely to be represented by an online discussion forum facilitated by communication networks that do not require the participants in public dialogue to be physically present in the same place (Bohman, 2004). Thus the way that members of society engage in public debate to form the public sphere has changed, as well as the ability and skillset required to conduct discourse. This does not mean that the public sphere has disappeared. It is more that the public sphere has become more dynamic and less physically bounded. The topic-related public sphere seems to develop on demand, customised to the needs of participants and the characteristics of the issue triggering the discussion before vanishing again into a more general public sphere of communication when its raison d’être disappears.

The constant features that drive different constructs of the public sphere are the underlying communication networks and technologies, as well as the desire of members

of society to discuss issues of mutual importance likely to have a large impact on themselves and society itself. For example, the discussion around the English NHS's care.data initiative, mentioned above, was facilitated in the public sphere and was conducted in different, but connected, communication fora simultaneously. These fora were the press, press readers' comments, television, radio, Twitter, public newsletters, the Internet, Facebook and other platforms. The composition of the public sphere in this case was constantly adapting to the discussion of the topic and the needs/wants of the participants. Important to the contemporary understanding of the public sphere is its perceived democratic character; i.e. that it is and should be open and accessible to all, and allow free speech, as outlined in Habermas' definition of the ideal speech situation and communicative ethics, above. The current ideal appears to be the notion that everyone should have the same chance to be able to participate in some form of discourse in the public sphere.

Turning back to Figure 5.2, from an individual perspective, the model of public trust starts with *'Individual trust in parts of the health care system' where trusting relationships are understood to be a 'complex 'web of interactions''* bridging the individual and institutional levels (Meyer *et al,* 2008, p. 182). This initial focus on individual trust is important, as individuals form the public, and therefore individuals' trust experiences and perceptions, in turn, fuel but by no means entirely define, public trust. Individual trust and public trust are linked via individuals' perceptions and experiences of each other as well as their participation in the 'public sphere'. 'Individual trust' in the health care system develops particularly when individuals engage with branches of the health care system, such as their general practitioner or the local hospital, and can be built or undermined in the largely private environment of the clinical encounter in the health care system from personal experience. However, an individual does not necessarily need to have had any personal experience of the health care system to reach a judgement about her/his trust in the system. This is because individuals, whether experienced or not, engage with others in discussion of experiences (their own or those they are aware of, for instance, among family and friends as well as cases of strangers or celebrities reported in the media) and of wider perceptions of the health care system, where this exchange has an influence on their perceived trust in the system as a whole. These trust experiences are further raised in other discussions in the public sphere through active or passive participation in public debates concerning the health care system. From an individual's point of view, two forms of participation in the public sphere are possible, either as an

active participant in different physical fora (e.g. as an elected member of a city council) and online fora (e.g. Twitter), thereby directly influencing the discussion, or as a passive participant through opinion polls or by voting in elections, while also reading and consuming the opinions of others. The example of the social media discussion of care.data once more supports the argument for the existence of public discourse that is distinct from personal experience (Hays and Daker-White, 2015).

As the number and range of participants in this discourse widens and becomes public, the concept of the public sphere which exists between the 'individual sphere', the health care system, the state (authorities, politics) and other societal and economic institutions (e.g. non-governmental organisations, religious bodies, business, etc.) becomes central to the model (Chaudhary *et al*, 2013; Habermas, 1990). Within the public sphere, actors with different roles in society (e.g. individuals, health care organisations, third sector groups, politicians, business people, advocates or lobbyists, opinion leaders, etc.) come together to reflect upon their experience and perception of the health care system, from which emerges an understanding of public trust in the health care system. Fotaki describes this trust building consensus discourse at the smaller scale of health care teams or individual provider organisations. Here trust in relation to the values of a team or organisation can be built by consensus (Fotaki, 2014). Similarly, O'Neill describes the process of democratic legitimisation in the field of bioethics operating through deliberations that take place in citizens' fora and consensus conferences, as outlined above (O'Neill, 2002, pp. 169-174). Fotaki's observation hints at the possibility that the individual's perception of trust can be influenced, in particular, by explicit consensus building processes as well as their own perceptions of what individuals consume from the internet, social media, the press, etc.. This observation is important as it links consensus building processes with the development of trust which indicates the possibility of the same processes occurring on a greater scale in the public sphere. Therefore, in Figure 5.2, public trust is defined as the form of trust that is generated in the public sphere. In other words, public trust is distinct from individual trust as it is generated not from the individual's perception of, and experience within, the health care system but rather is generated within the public sphere itself through public discourse about the individual's own and other people's experiences and perceptions of the health care system, including evidence from research and analysis. This discourse, in so far as it builds a consensus about the health care system, also signifies that public trust can be understood as a public good and is legitimised by the public itself.

Public trust is also built through the politics associated with health care system governance and political debate influencing the functioning of the health care system. Further, from the state's perspective, public trust in the health care system is influenced by the state's active communication with the public, and by its selection of policies and how they are presented and justified. Last, as the health care system is an open system, other societal and economic institutions, such as third sector organisations, or the business community, have a substantial impact. Their influence on the shaping of public trust in the public sphere needs to be considered. Examples of influence could be industrial lobby groups and third sector organisations' advocacy activities.

The two 'outputs' of the model in Figure 5.2, namely, public trust emerging from the public sphere, and individual trust emerging from the interactions between the individual and his/her health care providers, both include feedback loops (indicated by the dotted lines). Public trust in the health care system feeds back into all public sphere-associated sectors, and influences the actions and behaviour of affected and participating parties. Individual trust predominantly affects the individual's behaviour, influencing the nature of the future relationship between the individual and his/her health care providers. However, as the individual is potentially an actor in the public sphere, individual trust is not completely separated from public trust. Both forms of trust are linked by individuals' perception of both and therefore are influenced by these perceptions. Nevertheless, the information concerning topical issues shaping public trust and information on public trust, are communicated from the public sphere to individuals. This implies, that individuals depend on an authentic and objective information chain as well as personal experience for their level of public trust.

The distinctiveness of the nature of public trust in the health care system compared with public trust in other sectors of society such as the civil service, the benefits system, or the economy lies in the particularities of the underlying norms and values of society with respect to health and health care. These norms and values shape and guide the arguments about health care and the health care system that take place in the public sphere. They also determine which arguments put forward in the debate about whether the health care system can be trusted are regarded as valid by discourse participants. However, this also implies that the model structure is likely to be generalizable to other health care systems as well as other political systems.

The proposed model in Figure 5.2 adds to previous models of public trust in the health care system in that it recognizes the public sphere as the cradle of public trust in the health care system while showing how individual trust indirectly influences but does not simply determine the development of public trust. It recognizes that public trust in the health care system is not simply the average of individual trust as if it could be assessed simply by aggregating individual views about the health care system in a large opinion poll. The model allows that public trust is a construct originating from the public sphere, which is, in turn, influenced from all sides of society, by the individual, by the health care system, by the state, by the media and by other actors (e.g. religious bodies, business and the third sector). Previous approaches to estimating the level of public trust in the health care system have typically used opinion polls and large-scale surveys to quantify levels of trust. However, this does not necessarily identify public trust. Rather it describes the average level of reported trust of survey participants. Even though it might be that the public debate around public trust has indeed influenced someone's individual trust, it is not clear when examining the results of such surveys, how far the debate has shaped the trust expressed in the survey as against the person's perceptions irrespective of that debate. Public trust is more than the aggregation of private experiences and perceptions of trust in health care. Public trust is a consequence of the on-going public discourse on issues influencing the level of public trust. Simply expressed, public trust has two main ingredients: individual members of the public's personal, family and friends' experience of the health care system; and the discourse, debate and commentary on the health care system that exists distinct from any one individual's experiences. Furthermore, the model allows understanding of the health care system as an open system where not only do individual experiences of trust contribute to the development of public trust, but also the state's and other actors' experiences and perceptions and their practices of communication.

Conclusion

To understand and research public trust in the health care system, a more holistic model of public trust is needed, that goes beyond a narrow focus on trust solely in terms of individuals' experiences of the health care system. In this model, the origin of public trust is understood to be in the public sphere, which is situated between the individual, the health care system, the state and other societal institutions. Public trust in the health care system is influenced not only by the health care system itself, individuals' experiences of it and its media image but also by discourse in the public sphere about individuals' experiences and the system as a whole.

Empirical work is needed to further develop the model advanced in this chapter, especially since the theories and perspectives informing the development of the model come from far outside the health care system. For example, research needs to be conducted to describe the dynamics within the public sphere with respect to health care systems. Further, public trust building (and reducing) discourse relating to the health care system needs to be identified and analysed, including examples discussed earlier such as citizen's juries, consensus development processes, or public consultations. Additionally, it will be necessary to research the boundaries of the model in greater detail to understand how public trust in the health care system is influenced by public trust in other political system. To understand the interaction would enhance the generalisability of the model itself. Also, solutions need to be developed, if possible, to begin to measure public trust in the health care system. To enable mutual understanding and transferability of research results, the goal of such work would be to provide the research community as well as patients, professionals and the public, with a theoretically robust and empirically grounded construct (see following chapters) as well as a way of rigorously measuring the level of public trust in the health care system.

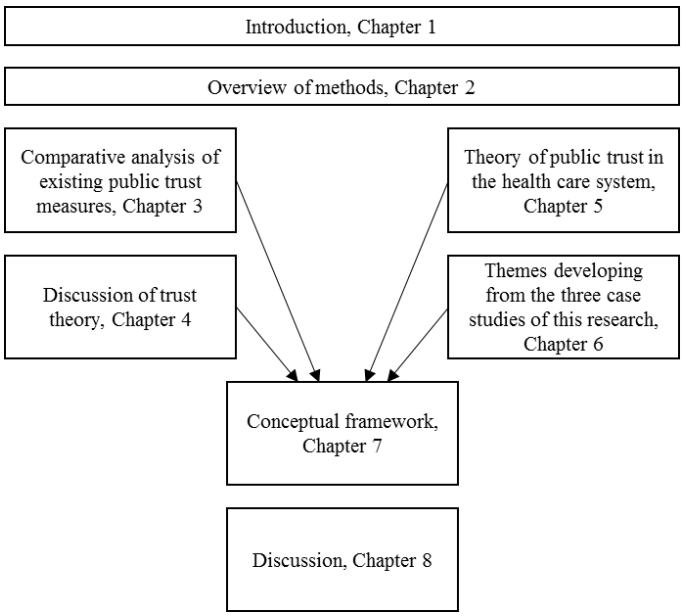
Chapter 6: Qualitative analysis of three UK case studies to develop themes conceptualising public trust in the health care system: care.data, biobanking and the 100.000 Genomes Project

Key findings

- The issue of public trust is widely discussed by those involved in the three case studies
- An considerable overlap of themes conceptualising public trust between the case studies exists
- A wide range of actors inside and outside the health care system influence public trust in the health care system

Overview

Qualitative data from each case study was analysed to generate a set of themes conceptualising public trust, framing public trust and describing the effects of public trust. Further, a large group of actors within and outside the health care system was identified to be influential in terms of public trust. These themes are used as the basis for the conceptual framework describing of public trust in the health care system in Chapter 7.



Introduction

This chapter meets the following objectives:

- **Objective 3.1:** To study and conceptualise public trust in care.data on the basis of discussion and commentary in various public fora.
- **Objective 3.2:** To study and conceptualise the nature of trust existing between participants and Biobank research.
- **Objective 3.3:** To study and conceptualise trust existing between the public and the 100.000 Genomes Project.

The purpose of this chapter is to present new qualitative data on public trust in the health care system. This chapter is divided in two parts:

The first part focuses on the results of the three case studies only. By conducting an inductive thematic analysis of the three case studies individually, themes can be developed which conceptualise public trust. The following will provide a rationale for the case studies, provide an overview of methods and present the results of each case study. As the themes developing from the three case studies separately are not the main results of this research, they will be presented in table format only. Verbatim quotes to support the themes are provided in Appendix 1.

The second part, at the end of this chapter, synthesises and integrates the results of the three case studies and discusses the meaning of each theme contributing to the final set of themes. The methods leading to the final set of themes conceptualising public trust are explained. This sets the stage for the following chapter where the full conceptual framework of public trust in health care systems will be presented.

Part 1: Rationale for the choice of case studies

The choice of case studies was informed by my Master's Thesis, Gille (2013), and motivated by the following considerations:

1. The patient-doctor relationship is often characterised by a relatively big power and knowledge difference between the expert and the layperson. Despite recent

attempts to increase patients' ability to choose and increase their health literacy, as well as establishing mechanisms such as 'co-production', there is still a certain degree of dependency inherent in this relationship (Boye, 2012; Fledderus et al., 2014; Hyde & Davies, 2004; Wilde, 2013). This is particularly so in situations of emergency care and emergency room settings (Kelly et al., 2005; Naghavi, Shabestari, Roudsari, & Harrison, 2012). As an established body of research describing the trust relationship between patients and doctors exists, this research should focus on situations where there is to a lesser degree such a dependency and where the public interacts with the health care system on more equal terms in the public sphere (Calnan, 2004; Dugan et al., 2005; Hall, Forman, Montgomery, Rainey, & Daly, 2015; Hall et al., 2001; Harrison, Innes, & van Zwanenberg, 2003; Illingworth, 2002; Jucks & Bromme, 2007; Mechanic & Meyer, 2000; Ipsos MORI, 2008; Pagan, Balasubramanian, & Pauly, 2007; Rolfe et al., 2014).

2. As public trust in the health care system relates to the entire health care system, the case studies should take place across the entire country and have wide public relevance.

3. Some trust theory emphasises the importance of choice for trust (Calnan, 2002; Luhmann, 2009). The argument is that you would need a critical alternative to public trust; otherwise you would be left only with hope (see Chapter 4 for more detail). Hence, the case studies should offer a choice to take part in a health care programme or not.

4. Asking interviewees directly about the nature and level of their trust might undermine their trust. The underlying bias might develop from the participants' impression that if a researcher asks, for example, about trust in a biobank, there might be something wrong with the biobank. And so, the data of the case studies should not have been collected/developed primarily with the purpose of investigating people's perceptions and expectations towards trust. This is considered to be a strength of this research, as trust is a very fragile concept, and with this approach the themes conceptualising public trust develop more naturally.

5. Considering the suspected generalisability of the data that develops from the case studies, the case studies should cover a topic of public interest as well as be relevant to the functioning of the entire health care system. Case studies, which focus on a specific setting or would only encapsulate a specific form of the healthcare system are not useful for the development of a public trust framework. Further, the content of the case studies needs to show parallels to other areas of public life that are outside of the health care system. This is important to understand if public trust in other political/social systems affects public trust in the health care system.

Considering these reflections, this research examined three different cases of trusting relationships relating to the NHS in England. All three case studies deal with the exchange of personal information, such as medical records, DNA, blood or tissue. Exchange of personal information is a health care system activity that is likely to depend particularly strongly on trust. The three case studies focus on parts of the health care system where sharing of this information is essential for the functioning of the particular branch and the wider health care system. Here, public trust is linked to collection, storage, access and use of personal information nationally. Furthermore, all three case studies apply nationally and potentially have an effect on the entire society. In recent years, it appears from the media discussions in the UK and abroad that the protection, ethical use and safe use of personal information is of increased concern not only for the health care system but also for society in general. Therefore, the first case study focuses on the public debate about the implementation of the care.data programme, the second case study is concerned with the experiences and perceptions of biobanking participants in different biobanks across the UK, and the third case study focuses on public perceptions of the 100,000 Genomes Project. To choose three case studies was a decision motivated by the attempt to balance feasibility against the aims of the research. More case studies would not have been feasible given the resources available as well as the timeframe available.

Overview of the three case studies

Case Study I: care.data – Online news readership comments on care.data.

According to NHS England's web site: http://www.england.nhs.uk/ourwork/tsd/care-data/ (accessed 17th May, 2014), the aim of the care.data programme was to link patient-related information collected by different health care providers to deliver a more complete picture of patient care; for example to link NHS hospital data (Hospital Episode Statistics) with NHS primary care data from general practices. This was intended to clarify the paths patients take through the NHS, and allow analyses of the overall quality and costs of care provided. The information was intended to be used by the NHS, researchers and other approved organisations. Due to concerns expressed in the media by the public as well as scientific bodies, the programme was first postponed and finally cancelled on 6th July 2016 (Department of Health & Freeman, 2016).

The aim of this case study is to conceptualise public trust within the public sphere in England; i.e. to conceptualise trust through an analysis of data from public debate in 58 newspaper articles and 1625 direct commentaries on these articles from readers. Smith and colleagues (2017) recently reported the general value of online fora for qualitative health services research in the context of mental health (Smith, Bartlett, Buck, & Honeyman, 2017). This provides support for this approach taken for this case study.

Alternative public spheres could have been television, radio, magazines, social networks, Twitter, blogs and web-pages (Bohman, 2004; Bowman, 2017). An example of a study focusing on the Twitter discourse around care.data is: *The care.data consensus? A qualitative analysis of opinions expressed on Twitter* by Hays and Daker-White (2015). However, these were not considered as practical for this research given the available resources.

Case Study II: Biobanking in the UK– Interviews on experiences and perceptions of biobank participants conducted by the Health Experiences Research Group, University of Oxford

Several biobanks across the UK exist today, usually associated with universities, research institutions and the NHS. The best-known biobank is the UK Biobank established by the

Wellcome Trust, Department of Health, Medical Research Council and Scottish Government. Biobanks usually collect blood, urine, saliva and/or tissue samples for present and future research. The samples are stored in repositories. Alongside the physical samples, detailed information about the participant is collected. Participants are usually recruited via media campaigns or approached by medical staff during a hospital or doctor visit (UK Biobank, 2014).

Twenty one in-depth interviews (semi-structured, largely inductive and purposively sampled) were conducted across the UK in participants' homes in 2011 (Locock & Boylan, 2015). The participants were involved in different biobanks in the UK. The Oxford Biomedical Research Centre and the National Institute for Health Research supported the work (Coyne, 1997; Healthtalkonline, 2014; Tesch, 1990; Ziebland & McPherson, 2006). A secondary analysis of the 21 interviews was undertaken to conceptualise trust in biobanks.

Case Study III: 100,000 Genomes Project – Focus group interviews on public perceptions of the 100,000 Genomes Project conducted by the Policy Innovation Research Unit, London School of Hygiene & Tropical Medicine in collaboration with the Health Experiences Research Group, University of Oxford

Genomics England was incorporated on 17th April 2013 as a not-for-profit company owned by the Department of Health (Genomics England, 2017). The declared aims are:

- '*to bring benefit to patients*
- *to create an ethical and transparent programme based on consent*
- *to enable new scientific discovery and medical insights*
- *to kickstart the development of a UK genomics industry'* (Genomics England, 2016).

Its ambitious goal is to collect by 2017, 100,000 Genome samples within England which can be used for high-tech DNA mapping to identify cancers, rare non-communicable diseases and rare infectious diseases.

The research for this case study was embedded in a collaborative research project between PIRU and HERG: *Understanding experiences of recruiting for and participating in the 100,000 Genomes Project.* The purpose of this research project is to develop an

understanding of why patients and/or staff agree or refuse to take part in this research, as well as how people experience their journey through the research process. Last, the project asks members of the public and participants about their how they perceive issues related to data sharing, governance and confidentiality. (Mays, Rees, Locock, Ryan, & Carrasqueiro, 2014). For this case study, an analysis of two public focus group interviews was undertaken to conceptualise public trust in the 100.000 Genomes Project.

Methods

Figure 6.1 shows a schematic overview of the methods used leading to the results presented below. As Figure 6.1 shows, the methods for the three case studies were the same from when the data were downloaded (see, shaded box in Figure 6.1) into the qualitative data analysis software programme, NVivo 10/11. Therefore, the methods are presented in detail for the first case study (care.data) and the methods' descriptions for the remaining case studies only highlight how they differ from the care.data case study. Due to the nature of the case studies and their type of data, the three case studies vary in the data collection methods. For example, the care.data case study data were collected from the Internet, whereas the biobanking and 100,000 Genomes Project case studies were based on different types of interviews. The case studies and their results are presented in the order they were undertaken.

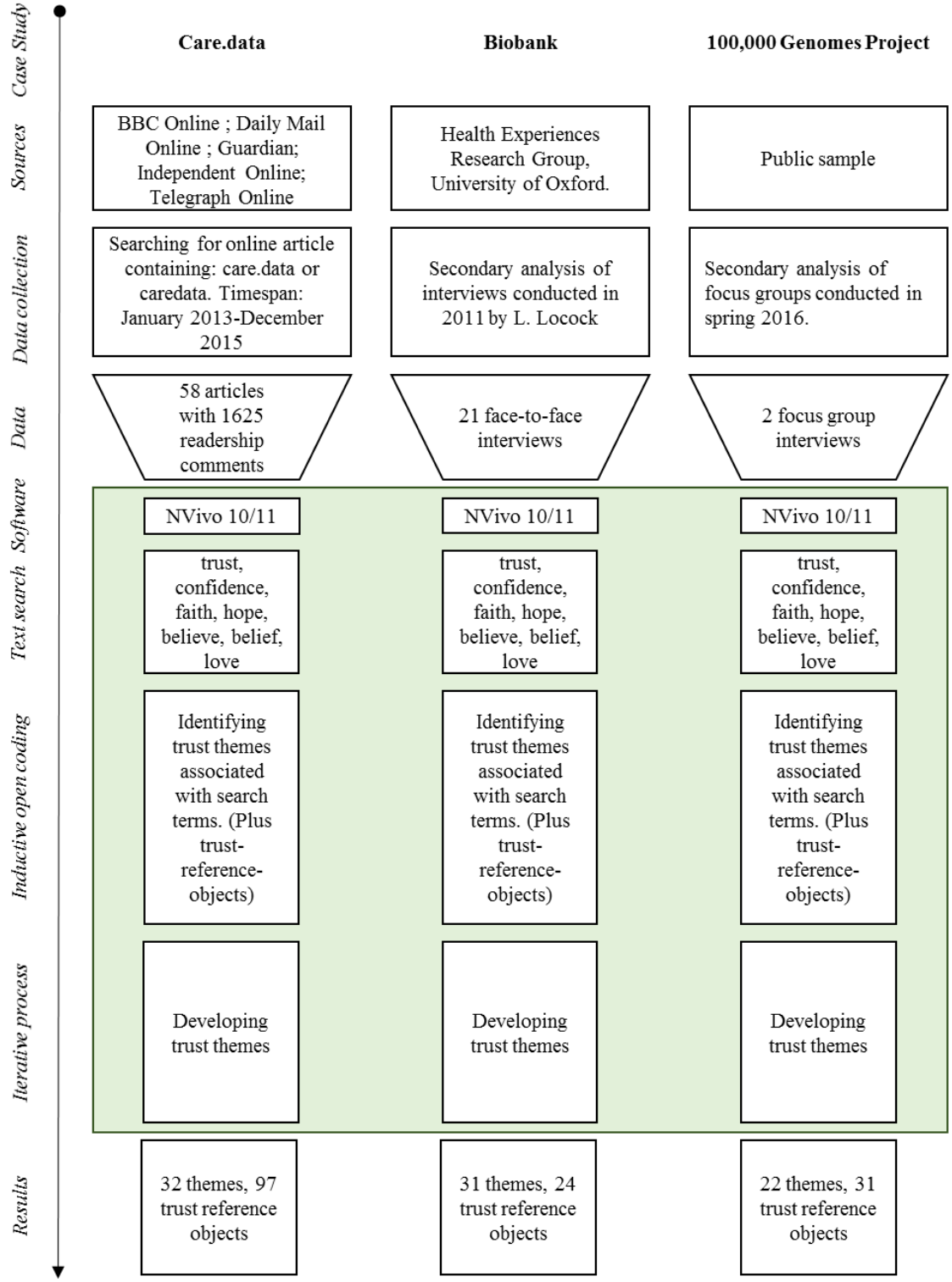


Figure 6.1: Overview of methods used to conceptualise public trust in the case studies

Case study: care.data

care.data methods

Data collection specific to the care.data case study:

National newspapers online with readership fora were purposively sampled satisfying the criterion of free and easy accessibility to make sure that the fora were open to any member of the public. In practice only national newspapers were included which allow free access to their archives. The National Readership Survey was used as an initial guide to the most read newspapers in England (National Readership Survey, 2016). Only national news platforms were considered as care.data was supposed to be rolled out nationally. To search for relevant newspaper articles, depending on the newspaper web site, internal search engines or the search engine *google.com* were used. Google Inc. appeared to be the most practical search engine and was also suggested by the Guardian's news reader service to be the most useful search tool for their own web site (Guardian News & Media Ltd, 2015). Search terms used were *care.data* and *caredata* to obtain the widest possible variation of articles. Narrower search terms might have hindered the search and e.g. *trust* is not a useful search term as too many false results show up since trust can also be a legal arrangement as, for example, in NHS Trust or Wellcome Trust, etc. The timeframe for the news articles and comments included was 1st January 2013 to 31st December 2015. Care.data was introduced to the public in January 2014. The initial search for articles and related comments was conducted in April 2015 and updated in December 2015. All articles found on the webpages were first copied into Microsoft Word 2013 and stored on the London School of Hygiene & Tropical Medicine Servers. Only articles with readership comments were included in the analysis.

Methods applicable to all case studies:

Data were downloaded into NVivo 10/11 for an inductive thematic analysis following open coding. According to Elo and Kyngäs (2008) an inductive analysis is suitable when *'there is not enough former knowledge about the phenomenon or if this knowledge is fragmented'* (Elo & Kyngäs, 2008, p. 109). The inductive analysis followed the overall structure suggested by Elo and Kyngäs (2008): 1st Open coding, 2nd using coding sheets,

3rd grouping the codes, 4th categorising the codes, 5th abstracting from the categories and 6th conceptualising, in this case, public trust.

To narrow the focus for the coding, the imported files were searched for the stemmed words of: *trust, confidence, hope, believe, belief, faith, and love.* This range of similar terms to trust was purposely developed during the theory review and informed by Gille (2013). Further, this selection was discussed with my advisory committee and supervisors. When comparing trust theories, it is evident that these terms are largely discussed in relation to trust or used to describe trust (see Chapter 4). Unfortunately, theorists do not agree on the conceptual boundaries between each term. Using this wide range of terms allowed for the detection of a wider range of themes conceptualising public trust as compared to using the search term *trust* only. But, *trust* as a legal agreement or organisational form (e.g. a financial vehicle or an NHS hospital trust) was dismissed from the analysis, unless a trust was understood as a trust-reference-object. Trust-reference-object is a generic term chosen for actors or objects which are considered to influence trust, such as a doctor or Google Inc. might influence trust.

Guided by the search terms, the words in the surrounding argument were openly coded in an inductive process for each search term separately. The coding was independently repeated by a second researcher (PhD student colleague) for random text samples to compare the emerging codes and to ensure the quality of the coding process. The comparative coding was reviewed and the codes were adapted accordingly.

The evolving themes were developed in an iterative process with repeated discussion cycles with my supervisors. The themes evolving from the case study were sorted into three categories drawing: effect themes; framing themes; and conceptual themes. Naming of these separate types of themes, draws from the discussion of conceptual requirements for good measurement in Chapter 3. The allocation of individual themes to one of these three types of themes was guided initially by the data, the knowledge of wider trust theory, and discussions with my supervisors and other research degree students. Conceptual themes describe the characteristics comprising public trust and are essentially causal indicators (as described in Chapter 3) (Wilson, 2005, Chapter 1). Despite various understandings in the social sciences of what framing themes are, generally *'framing refers to the process by which people develop a particular conceptualisation of an issue or reorient their thinking of an issue'* (Chong & Druckman, 2007, p. 104; Druckman,

2001). Effect themes, in this case, describe an effect as a result of the trusting relationship between the public and the health care system.

To explain in an easily understandable way the meaning of the themes, *if, then statements* were formulated and discussed with my supervisors. For example such a sentence could be: *If health system actors enable people to maintain autonomy, then people trust more*. The wording of the themes and the *if, then statements* was also discussed with other research degree students. Further, feedback received after presenting preliminary results at a health services research conference was considered when finalising the *if, then statements*. To formulate the if, then statements the raw data where the theme developed from was revisited e.g. in the case of *autonomy*:

Both doctors and governments are getting far too much control over our lives. I keep away from doctors. I lost faith and trust in them a long time ago. (Comment on article by Martin Beckford, ‘'Big Brother' database will grab children's health records but parents are being kept in the dark’, Sunday Mail Online, 9 February 2014).

Now, the *if, then statement* was formulated following the logic of the data. This means in the case of autonomy, that more autonomy leads to more public trust. As this research is about public trust and not public distrust, all themes developed were formulated in a neutral or positive (i.e. more trusting) way (see Chapter 4 on the difference between trust and distrust). The drawback of formulating the *if, then statements* with a positive orientation is that they will not express the lower end of the public trust continuum or no public trust at all. However, when understanding that the construct of public trust stretches over a continuum from low to high levels of public trust, it should be possible to reverse the if, then statements as well. This would reflect a low level of public trust. Last, the *if, then statements* should be useful for future public trust measurement instrument development. In other words, the *if, then statements* needed to be phrased in such a way as to serve as the basis for item formulations.

Last, a *trust network* was identified by coding the trust-reference-objects associated with the search terms of this analysis. Then, the identified trust-reference-objects were sorted into different categories. The categories emerged from the data themselves and are

informed by the new model that describes how public trust develops in the public sphere, as presented in Chapter 5. Additionally, the initial sorting was discussed at an early stage with my advisory committee. The data were analysed to assess whether the sorted trust-reference-objects did indeed represent the trust-reference-objects or if they referred to the office or position the trust-reference-object was representing. For example, if Barack Obama (44th US President) was mentioned, a judgement was made as to whether this was a reference to Barack Obama in person or the office of the US president.

As the readership fora are generally impersonal as participants largely use fictitious names and no descriptive data are provided besides posting time and pseudonym, no descriptive data were collected in this case study. However, frequencies of trust and similar terms to trust were obtained. Further, it needs to be kept in mind that readership fora are moderated. In practice, moderation means that inappropriate comments are deleted and usually a 'friendly reminder' replaces the comment, reminding the readership to use appropriate language. The moderation process of BBC Online is described as *'User generated content is checked by a team of trained moderators to make the community a safe and enjoyable place to be, and ensure that they meet the House Rules, the BBC's Editorial Guidelines and the laws of the United Kingdom. Moderators do not post their own comments.'* (BBC, 2017). Similar formulations are found for the other news platforms. Given the resources provided, it was not possible to assess how far Internet bots (software programmes that autonomously generate comments) wrote comments in a systematic way. To cope with this potential bias, the comments were assessed if they seem to be written by a human. It appears that this type of bias has not so far been a focus of attention among researchers conducting online discourse analysis as no publications where found which could provide methodological guidance on how to distinguish content written by software programmes from comments from human readers.

care.data case study results

Five British news platforms were selected to access online news articles with readership comments: BBC Online, Daily Mail Online, the Guardian online, the Independent online and the Telegraph online (BBC Online, 2016, Daily Mail Online, 2016, the Guardian online, 2016, the Independent online, 2016, Telegraph online, 2016). The search resulted

in a total of 96 news articles including 58 news articles with readership comments (BBC n=2; Daily Mail n=16; Guardian n=14; Independent n=15; Telegraph n=11). 1625 related readership comments were included in the analysis with the accompanying articles. The peak number of publications per month was February 2014 (n=38) and the number of news articles reduced until August 2014. From August 2014 to March 2015, eight news articles were published. A summary reference list of the news articles can be found in Appendix 1.

Table 6.1 on the next page shows the frequency of trust and similar terms in the readership comments.

Table 6.1: Frequency of trust and synonyms in the care.data case study

Search term	Frequency
Trust	362
Believe	165
Hope	73
Confidence	53
Love	37
Faith	25
Belief	8

Identifying a *trust network*, Table 6.2 shows the trust-reference-objects associated and referred to by the readership as being influential for trust in care.data. The 97 trust-reference-objects were sorted into nine categories representing different realms in society: personal, public, personal encounter with the health system, health system, national government, state, national actors which are not related to the government or state structures, international actors from outside of the UK, and other. Trust-reference-objects in the *other* category were contextually different or not sortable to one of the categories based on the missing specificity of the text passage they developed from. Table 6.2 shows the nine categories.

Table 6.2: Trust reference objects in the care.data case study

Personal	Public	Personal encounter health system	Health system	National government	State	National	International	Other
Family	Campaigners	Doctor	Academics	Advocates	Authority	Bank	ATOS	Expert
Friends	Class	General practitioner	Audit Staff	Data commissioner's office	Council	Boots	European Union	History
People we love	Dr Paul Hodgkin	Health care providers	Dr Geriant Lewis	David Camron	Data protection Act	British Television	Foreign security agency	Internet
Smart card	Edward Snowden	Information leaflet	Dr Mark Davis	Ed Miliband	Department of Health	Country	Foreigner	No one
	Journalists	Medical staff	Health and Social Care Information Centre	Elite	Institution	Private company	Google	Nobody in power
	Media	Patient	Health system	European Union membership	Regulator		Humankind	They
	News print media		Hospital episodes statistics	George Osborne	State		Pharma	Third party
	NHS spokesperson		IT company	Government	State system		Phorm	Whoever
	Patient organisation		Jane Ellison	Information commissioner			Professor Sir Brian Jarman	World
	People		Jeremy Hunt	Labour				
	Public		Lawyers	Left wing				
	Public sector		National Health Service	LibLabCon				
	Sir Nick Partridge		Researcher	Margaret Thatcher				
	Someone with money		Tim Kelsey	Minister				
	Stranger			Member of Parliament				
				National security agency				
				Nigal Farage				

Personal	Public	Personal encounter health system	Health system	National government	State	National	International	Other
				Official guarantee				
				Officials				
				Political Party				
				Politician				
				Senior civil servants				
				Tax				
				Tony Blair				
				Tory				
				Whitehall				

To conceptualise public trust in care.data, 25 themes were identified, set out in Table 6.3 on the next page. Trust in care.data is framed by seven themes, set out in Table 6.4, and one effect theme is identified in Table 6.5 (the themes are sorted according to the number of codes supporting the theme).

Table 6.3: Conceptualising themes of trust expressed in the care.data case study

	Conceptualising themes	Explanation
1	Financial benefit to the NHS	If data is used for NHS's financial benefit and not for private companies' profit making, then people trust more.
2	Public benefit	If data is used for public benefit, then people trust more.
3	Medical research	If data is used for legitimate medical research, then people trust more.
4	Unlawful data access	If personal information is protected from being stolen, then people trust more.
5	Confidentiality in GP-patient relationship	If personal information is only used for medical consultation, then people trust more.
6	IT competence	If personal data is not managed in a government or GP related IT system, then people trust more.
7	Regulation	If regulatory mechanisms are in place, then people trust more.
8	Local storage	If the data is stored locally, then people trust more.
9	Anonymity of data	If data is anonymised, then people trust more.
10	Personal control	If people have personal control over their data, then people trust more.
11	Data sharing	If people can decide whom their data is shared with, then people trust more.
12	Privacy	If privacy is not compromised, then people trust more.
13	Representative governance	If the government is perceived not to be dictating to the people, but governing in a representative way, then people trust more.
14	Responsible management	If personal data is managed responsibly, then people trust more.
15	Personal benefit	If people can see how they might personally benefit, then people trust more.
16	System integrity	If the health care system is perceived to be telling the truth, then people trust more.
17	Government explaining care.data	If the government explains what care.data is, then people trust more.
18	Altruism	If altruism is not undermined, then people trust more.
19	Data accuracy	If the data used are accurate, then people trust more.
20	Improved quality of healthcare	If data lead to improved quality of healthcare, then people trust more.
21	Certainty about future use of data	If there is more certainty about future use of the data by the government, then people trust more.
22	Fear of negative consequences	If people are less fearful about the consequences of care.data, then people trust more.
23	Political honesty	If politicians appear to be honest, then people trust more.
24	Choice	If people have choice of being part of it, then people trust more.
25	Protection in numbers	If millions of records are stored in one databank, then people trust more.

Table 6.4: Framing themes expressed in the care.data case study

	Framing themes	Explanation
1	Use of participants' medical data	Data use is the reason why the discussion around levels of trust takes place and is understood as the facilitating action / basic condition of the trust relationship. If data would not be used there would be no need to discuss or express trust.
2	Societal context and mood	An alleged erosion of public trust is observed in other sectors of society. This mood of mistrust spills over into the context of health care systems.
3	Communication	Communication is the basis of social interaction. Communication enables a trust discourse. Therefore it is a basic prerequisite for trust.
4	Risk	Risk results from individual as well as environmental action. If there is no action provoked by care.data, there is no risk.
5	People's world view	People's world view, as e.g. expressed by axioms or proverbs, shapes their wider understanding of trust in care.data.
6	General expectations of government	Normative expectation that the government should be trusted by the public.

Table 6.5: Effect theme of trust expressed in the care.data case study

	Effect theme	Explanation
1	Consenting to care.data	Participants consent based on their trust. Therefore consent is understood as an effect of the level of public trust.

Case study: Biobanking

Biobanking specific methods

This case study is based on a secondary analysis of 21 semi-structured face-to-face interviews with biobank participants from the UK undertaken in 2011 by the Health Experiences Research Group (HERG). The interviews were conducted in the participants' own homes (Locock & Boylan, 2015). The purpose of the interviews was to understand perceptions and experiences of biobank participants. The methodology followed by HERG is to allow participants to talk as freely as possible about their views. A video example of the interviews can be found on the web page of Health Talk Online: *http://www.healthtalk.org/peoples-experiences/medical-research/biobanking/topics* (accessed on 2nd of May 2017).

Following a data sharing agreement between the University of Oxford and London School of Hygiene & Tropical Medicine, the interview transcripts were stored on London School of Hygiene & Tropical Medicine servers and downloaded into NVivo 10 for analysis. With the transcripts, a descriptive table of the sample was obtained which is presented in the results. From this point onwards, the same methodology was followed as discussed in the methods section of the care.data case study, above. At the final stage, the themes were discussed with the researcher from the University of Oxford who conducted the original interviews to ensure the quality of the coding of themes.

Biobanking case study results

The sample consisted of healthy volunteers and participants with medical conditions. Eleven of the participants were female and all but one participant was white British or English and one participant was Anglo-Irish. The age range is 37-66 years of age. The participants took part in different types of biobanks, as for example a cancer and population biobank, a diabetes biobank, or a stroke study as family member control and population biobank.

Table 6.6 shows the frequency of the trust synonyms in the biobank interview data.

Table 6.6: Frequency of trust and similar terms in the biobank case study

Search term	Frequency
Trust	54
Hope	54
Believe	50
Love	37
Confidence	21
Faith	6
Belief	2

Identifying a trust network, Table 6.7 shows the trust-reference-objects associated and referred to by the interviewees as being influential for trust in biobanks. The 24 trust-reference-objects were sorted in nine categories (column) representing different realms in society ranging from the personal sphere to international trust-reference-points, plus others. Trust-reference-points in the *other* category were not matching the other categories. The nine categories are: personal, public, personal encounter with the health system, health system, national government, state, national actors which are not associated with the government, international actors, other.

Table 6.7: Trust reference objects in the biobank case study

Personal	**Public**	**Personal encounter health system**	**Health system**	**National government**	**State**	**National**	**International**	**Other**
Carers	British public	Biobank	Health service	Government	Policeman	Media	Internet	Hackers
Family	Nobody	General Practitioner	Liver specialist				Pharmaceutical company	Iggy Pop concert
Friends	People	Professionals	Medical profession					
		Research staff	Medical research					
		Somebody	National Health Service					
		University						

To conceptualise trust in biobanking, 24 themes were identified summarised in Table 6.8. Themes relating to professional behaviour, personal relationship with medical staff and personal condition were discussed the most, followed by altruistic motivations in relation to trust. Trust in biobanking is framed by seven themes. Table 6.9 shows these themes. No effect themes were identified.

Table 6.8: Conceptualising themes of trust expressed in the biobank case study

	Conceptualising theme	Explanation
1	Advance in science	If donated samples lead to a breakthrough in research, then people trust more.
2	Altruism	If altruistic donated samples are used in research for the public good, then people trust more.
3	Anonymity	If anonymity is respected, then people trust more.
4	Arrogance	If professionals are not arrogant, then people trust more.
5	Corroboration	If two or three sources online cover the same information, then people start to trust the information provided.
6	Control systems	If participants (decide) to think that control systems are in place, then people trust more.
7	Data kept in good condition	If data are kept in good condition, then people trust more.
8	Data security	If participants (decide) to think that the study is secure, then people trust more.
9	Clear information	If the consent process contains clear information and participants can discuss the research with somebody who knows about the study, then people trust more.
10	Doing the best possible	If people (officials, researchers, etc.) do the best they can do to foresee risk in the future, then people trust more.
11	Public funding	If research funding is mostly related to the NHS, then people trust more.
12	Honesty	If results are interpreted correctly and researchers are honest with data, then people trust more.
13	Importance of research	If research answers (important) questions and is reasoned, then people trust more.
14	Knowledgeable professionals	If professionals know about the research project, then people trust more.
15	Perception of safety	If people feel safe with professionals, then people trust more.
16	Personal benefit	If participation leads to personal benefit, then people trust more.
17	Privacy	If data are not get to the wrong hands and participants' privacy is breached, then people trust more.
18	Professional reputation	If professionals do not compromise their reputation, then people trust more.
19	Professionals' ability to keep up with new knowledge	If professionals keep up-to-date in their field of expertise, then people trust more.
20	Protection in numbers	If participants' data is stored in a massive data bank, then people trust more.
21	Providing time for medical research	If research is not conducted in a rush, then people trust more.
22	Regulations	If research is regulated, people trust more.
23	Respect for participants	If participants are treated by doctors with respect leading to mutual respect, then people trust more.
24	Self-confident professionals	If professional have a (self) confident behaviour based on their education, then people trust more.

Table 6.9: Framing themes expressed in the biobank case study

	Framing theme	Explanation
1	Communication	Communication is the basis of social interaction. Communication enables a trust discourse. Therefore it is a basic prerequisite for trust and not influencing trust.
2	Data use	Data use is why the discussion around levels of trust takes place and is understood as the facilitating action / basic condition of the trust relationship. If data would not be used there would be no need to discuss or express trust.
3	Fear	To fear is a human characteristic.
4	Human error	Trust needs to accommodate human error as human error is inevitable.
5	People's world view	Personal attitude towards life as personal norm.
6	Religion and afterlife	Religion is influencing the decision to take part in biomedical research. Here faith is dominating trust.
7	Societal context and mood	Concerns about increasing surveillance society and observation cameras coverage.

Case study: 100,000 Genomes Project

100,000 Genomes Project specific methods

This case study is based on an analysis of two focus groups conducted with members of the public. The interview guide is attached in Appendix 1. The interview guide intended to explore the public's perceptions of the 100,000 Genomes Project. The interview guide was developed by the wider research team from the University of Oxford and the London School of Hygiene & Tropical Medicine. The development process was informed by a rapid analysis of the biobank interviews (unrelated to the analysis of public trust in this research). The two focus groups were sampled from the public. In principle the focus group sample size depends on numerous factors, such as quality, scope, feasibility, accessibility (Baker & Edwards, 2012). The targeted sample size in this study was eight participants per focus group.

The topic guide for the focus groups did not cover any questions directly addressing trust. If trust or similar terms were used by participants, the interviewer asked the participants at the end of the interview to clarify what they understood by the terms. The focus group interview data were discussed with the wider research team.

The focus groups took place in the Midlands (FG1), and in the North-West of England (FG2). To recruit participants, information flyers were used which were developed and designed by the research team. A copy of the information material is attached in Appendix 1. As the recruitment process was very difficult, the research team decided to use internal networks to recruit the focus groups. The difficulty to recruit participants seems to arise from the topic itself. Genomics research seems not to be a publicly discussed topic yet. It was recognisable during the focus groups that participants tended to talk about biobank or medical research and not about genomics research. Despite the interviewer coming back to genomics research throughout the interview, participants talked about medical research in general. Hence, both interviews were not just ordinary members of the public, as in both focus groups some people had experience with biobank research or the 100.000 Genomes Project. This was due to the recruitment process as in one focus group participants had been interviewed previously for another purpose as part of the larger research project by the Policy Innovation Research Unit at the London School of Hygiene & Tropical Medicine/ Health Experiences Research Group at the University of Oxford

and their network was used to form the focus group. In the other focus group, one person had taken part in biobank research several years ago and another participant used to work in the medical field.

Each participant was asked to sign a consent form and received a 25 GBP shopping voucher, a copy of the consent form is attached in Appendix 1. All interviews were audio recorded and transcribed at the HERG office at the University of Oxford.

Following a data sharing agreement between University of Oxford and London School of Hygiene & Tropical Medicine, the interview transcripts were stored on secure London School of Hygiene & Tropical Medicine servers and downloaded into NVivo 10 for analysis.

Field notes taken during the focus groups also informed the analysis.

No descriptive data were collected at the focus groups on the characteristics of the participants.

100,000 Genomes Project case study results

Table 6.10 shows the frequency of trust and similar terms in the focus group data.

Table 6.10: Frequency of trust and similar terms in the 100.000 Genomes Project case study

Search term	Frequency
Trust	25
Hope	12
Faith	6
Believe	5
Confidence	2
Love	2
Belief	0

Identifying a trust network, Table 6.11 shows the trust-reference-objects associated with trust, and referred to, by the interviewees as being influential for trust in the 100.000

Genomes Project. The 31 trust-reference-objects were sorted into seven categories representing different realms in society ranging from the public sphere to international trust-reference-objects. The seven categories are: Public, personal encounter health system, research project, health system, government, national actors which are not associated with the government and international actors.

Table 6.11: Trust reference objects in the 100.000 Genomes Project case study

Public	Personal encounter health system	Research project	Health system	Government	National	International
Everybody	Centre of excellence	Big Initiative	Data centre	Central government	England	Commercial companies
Patient	Consultant	Commercial arm	Hospital	Government	Post	European countries
Public	Doctor	Current project	Insurance companies	Local government	Private initiative	Other countries
	Genomics lady		Medical research		Smaller companies	Pharmaceutical companies
	Medics		NHS			
	NHS healthcare professional		Scientist people as leaders			
	Specialists like Cambridge					
	Specialist unit					

To conceptualise public trust in the 100.000 Genomes Project, 18 themes were identified (see Table 6.12). Trust in 100.000 Genomes Project is framed by three themes (see Table 6.13) and one theme was identified as an effect of trust (see Table 6.14).

Table 6.12: Conceptualising themes of trust expressed in the 100.000 Genomes Project case study

	Conceptualising theme	Explanation
1	Availability of help	If people find (professional) help, then people trust more.
2	Central objective how to work with commercial companies	If there is a central objective how to integrate and work with commercial companies, then people trust more.
3	Denial of access to data by insurance companies	If insurance companies do not get hold of data, then people trust more.
4	Experience of a local research facility	If local research facilities are involved, then people trust more.
5	Feedback and results	If feedback which a participant has consented to receive are provided to the participant in a sensitive way, then people trust more.
6	Future benefit	If the research is perceived to lead to a future benefit, then people trust more.
7	Giving participants time to consider if they want to receive results	If participants have time to consider which results they want to get, then people trust more.
8	Good feeling	If people have a good feeling, then people trust more.
9	Government response to breach of data security	If the government 'sacks' people who breach data security, then people trust more.
10	Opportunity for reinvestment in medical research	If the financial gain of research is reinvested in medical research, then people trust more.
11	Personal experience	If people have personal experience with medical staff, then people trust more.
12	Public benefit	If research is leading to a public benefit, people trust more.
13	Relationship with medical staff	If people have a relationship with medical staff, then people trust more.
14	Reputation	If medical staff/facility has a good reputation, then people trust more.
15	Research by public institutions	If a big research initiative is led by a public institution, then people trust more.
16	Safe data handling	If data is not lost, then people trust more.
17	Sensitive data handling	If data is handled in a sensitive way, then people trust more.
18	Structured project	If the project is structured, then people trust more.

Table 6.13: Framing themes of trust expressed in the 100.000 Genomes Project case study

	Framing theme	Explanation
1	Human error	Trust needs to compensate for human error.
2	People's world view	People's worldview, as e.g. expressed by axioms or proverbs, shapes their wider understanding of trust in the 100.000 Genome Project.
3	Risk	Risk results from individual as well as environmental action. If there is no action provoked by the 100.000 Genome Project, there is no risk.

Table 6.14: Effect theme of trust expressed in the 100.000 Genomes Project case study

	Effect theme	Explanation
1	Comfortable with providing personal data.	Being comfortable to provide personal data is an effect of trust.

Part 2: Methods used to integrate conceptual, framing and effect themes respectively from the three case studies altogether

This section of the chapter will bring together the themes from all three case studies, as seen in Figure 6.2.

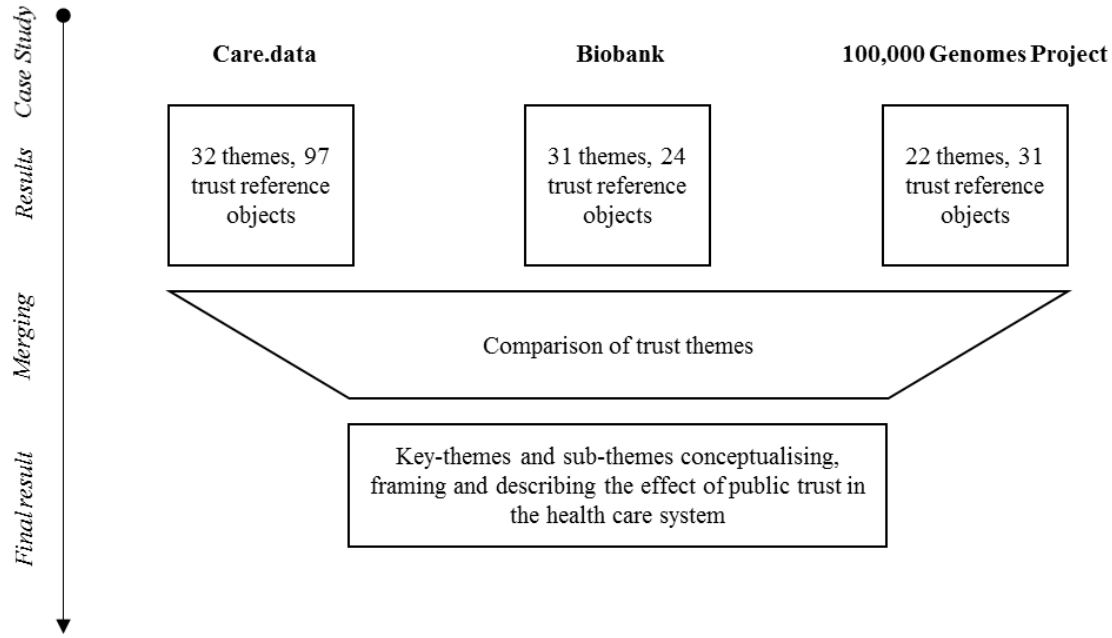


Figure 6.2: Overview of methods used to integrate the themes of the case studies

In an iterative process, the conceptual, framing and effect themes were synthesised from the three case studies altogether. This iterative process was guided by Elo and Kyngäs (2007), as discussed above. As the themes developed from the data and are relatively 'close' to the data, repeated rounds of careful abstraction were needed to be able to group the themes across the case studies. The themes were grouped in discussion with my supervisors. For conceptualising themes this resulted in a separation of key themes and sub-themes. The final set of themes is located at a level of abstraction where each key theme is at the same level and does not overlap in content with other key themes; i.e. each key theme is unique.

The framing themes were grouped according to their potential place in the theory-based model of public trust (see Chapter 5, p.163). The four groups are: basic level, individual level, public level and governmental level. Basic level refers to themes essential for the conceptualisation of public trust; individual level refers to themes developed at the

individual level; public level refers to themes developed in the public sphere; and governmental level refers to themes related to the government. To categorise the themes into different levels allows a better connection of the themes to the theory-based model of public trust in health care systems.

The two effect themes were not further categorised.

The following will first present and discuss the themes in more detail. This discussion will not only engage with verbatim quotes but also with the trust literature. Last, the trust-reference-objects will be discussed.

Conceptualising themes of public trust in the health care system derived from the three case studies

Overall the conceptualisation of public trust across the three case-studies of comprises 15 key themes (see Table 6.15).

Table 6.15: Conceptualising themes of public trust in the health care system as developing from the three case studies

Key-theme	Sub-theme	Explanation
Active regulatory systems		
	Denial of access to data by private companies	If private companies do not get hold of data, people trust more.
	Government response to breach of data security	If the government 'sacks' people who breach data security, people trust more.
	Regulation	If regulatory mechanisms are in place, people trust more.
Autonomy		
	Choice	If people have the choice to be part of something, people trust more.
	Personal control	If people have personal control over their data, people trust more.
Anonymity		
	Anonymity	If data are anonymised, people trust more.
Benefit to others		
	Altruism	If altruism leads to public benefit, people trust more.
	Future benefit	If research is perceived to lead to a future benefit, people trust more.
	Public benefit	If research leads to public benefit, people trust more.
Certainty about the future		
	Certainty about future	If researchers and officials do the best they can do to foresee risk in the future, people trust more.
Familiarity		
	Confidentiality in the GP-patient relationship	If personal information is only used for medical consultations, people trust more.
	Personal experience	If people have personal experience of medical staff, they trust more.

Key-theme	Sub-theme	Explanation
General perception of security		
	Existence of security measures	If participants think that a variety of security measures are in place, people trust more.
	IT competence	If IT systems are not administered by the government or GP, people trust more.
	Local storage	If the data is stored locally, people trust more.
	Perception of safety	If people feel safe with professionals, people trust more.
	Protection in numbers	If participants' data is stored in a massive data bank, people trust more.
	Safe data handling	If data are not lost, people trust more.
	Unlawful data access	If personal information is protected from being hacked, people trust more.
Health system benefit		
	Advance in science	If donated samples lead to a breakthrough in research, people trust more.
	Improved quality of healthcare	If data lead to improved quality of healthcare, people trust more.
Information quality		
	Clear information	If the consent process contains clear information and participants can discuss the research with a knowledgeable professional, people trust more.
	Corroborated information	If two or three sources online say the same information, people start to trust the information provided.
	Explanatory information	If the government explains what its intentions are, people trust more.
	Honest information	If politicians appear to be honest, people trust more.
	Reliable source	If messages are sent from a national source, people trust more.
	Truthful information	If the health care system is perceived to tell the truth, people trust more.
Personal benefit		
	Availability of help	If people find professional help, people trust more.
	Fear of negative consequences	If people are less fearful about the consequences of actions taken by the health system, people trust more.
	Personal benefit	If participation leads to personal benefit, people trust more.
	Reassurance	If professional reassurance leads to a good feeling, people trust more.

Key-theme	Sub-theme	Explanation
Privacy		
	Privacy	If privacy is not compromised, people trust more.
Public financial benefit		
	Financial benefit to the health system	If data are used for the financial benefit of the health system and not for private companies' profit making, people trust more.
	Opportunity for reinvestment in medical research	If the financial gain of research is reinvested in medical research, people trust more.
	Public funding	If research funding is mostly related to the public health system, people trust more.
Recognised potential of the health care system		
	Government integrating private companies for a clear public purpose	If the government has a clear overall aim for involving and working with commercial companies, people trust more.
	Professionals' ability to keep up with new knowledge	If professionals keep up-to-date in their field of expertise, people trust more.
	Representative governance	If the government is perceived not to be dictating to the people, but governing in a representative way, people trust more.
	Research by public institutions	If a big research initiative is led by a public institution, people trust more.
	Self-confident professionals	If professionals behave self-confidently based on their training, people trust more.
	Structured project	If projects are well organised, people trust more.
	Valid research	If research is perceived as working on valid questions and is justified, people trust more.
Respect		
	Data accuracy	If the data used are accurate, people trust more.
	Data kept in good condition	If data are kept in good condition, people trust more.
	Sensitive feedback	If feedback which a participant has consented to receive is provided to the participant in a sensitive way, people trust more.
	Professional reputation	If professionals do not compromise their reputation, people trust more.
	Respect for participants	If participants are treated by doctors with respect leading to mutual respect, people trust more.
	Responsible management	If personal data are managed responsibly, people trust more.

Key-theme	Sub-theme	Explanation
Time		
	Giving participants time to consider if they want to receive results	If participants have time to consider which results they want to get, people trust more.
	Providing time for medical research	If research is not conducted in a rush, people trust more.

A number of observations can be made on Table 6.15.

First, four key themes refer to different types of benefit deriving from trust: *Benefit to others*, *Health system benefit*, *Personal benefit*, and *Public financial benefit*. To group all these themes under one key theme of 'benefit' would not work conceptually as content would be lost, but it is useful to note the similarity. These themes are partly linked to altruism. Hence, this might look like a consequence of the choice of case studies. Donation of samples and the linked altruistic motivation is indeed closely linked to the case studies as well as the expectation that the altruistically donated samples should lead to public benefit. Nevertheless, the understanding that a health care system should serve the public as it is largely funded by public tax money is not a unique characteristic of the case studies, but more so a cultural and institutionalised understanding of the NHS itself (Ipsos MORI, 2015). Moreover, most Western country health care systems are mostly funded from what can be considered 'public' sources since both tax and social health insurance health systems require similar risk pooling and regulation by government. Thus *Benefit to others*, *Health system benefit* and *Public financial benefit* are themes which are at the core of the public interest and probably the distinctive themes of public trust as they refer to a net benefit for society and the system as a whole deriving from public trust.

Second, some themes refer to a personal relationship and relate to a certain actor (e.g. *sensitive feedback* or *respect for participants*; professional in *professional reputation*). Other themes refer to a higher level in the health care system and are abstract as they do not relate to a certain actor (e.g. *public funding* or *local storage*; *privacy*). This hints at the presence of individual trust in health care system representatives as well as trust in health care system structures. This diversity of themes with respect to their specificity in relating to a certain actor developed due to the different characteristics of the data, ranging from a more personal and known context (e.g. a biobank) to a more abstract, less familiar and prospective context (care.data). Here the data suggest that in a more abstract and somewhat diffuse context, comparisons are made to known trust relationships, such as trust in the police or banking sector.

Third, several themes relate to an entire range of actors despite ostensibly addressing one actor specifically. This is the case when the themes refer to a chain of actions in the health care system. For example, *active regulatory system*: the active regulatory system is partly understood to be established and controlled by government; however, one effect of

regulation should be that insurance companies cannot get hold of personal data without permission and that regulatory mechanisms are in place. Those regulatory mechanisms might be based on national or international jurisdiction but are applied in a local research facility and are carried out by local professionals. Therefore, many different actors involved in a chain of action need to perform in a trustworthy manner for the system as whole to be trusted.

Fourth, themes differ in the time periods to which they refer: past (e.g. familiarity); present (e.g. active regulatory system); and future (e.g. future benefit). This implies that the information feeding public trust draws from a wide time span. The information develops from lived experience and present experience, as well as an anticipated future. It remains unresolved in this research how far a conceptualisation of public trust can be developed based only on information from one or two of the three different time periods. From an individual point of view and in the context of the consequences of torture or post-traumatic stress disorder for the ability to trust, the phenomenological study of a *sense of foreshortened future*[2] by Ratcliffe, Ruddell and Smith (2014) can provide some guidance. In brief, it is argued that victims of torture[3] suffer from a foreshortened sense of the future and are not able to anticipate the future as the future is not meaningful, lacks structure and traumatised persons no longer have the feeling of moving forward in life, which is expressed by personal judgments such as 'I will die young' or 'I will not have a family'. As a result of this lack of positive anticipation of future events (despite remaining able to distinguish, past, present and future), '*a loss of personal trust is central to this form of experience*' (Ratcliffe, Ruddell, & Smith, 2014, p. 8). This observation implies that the ability to anticipate the future in a positive way is central to the ability to build trust. In turn, if, for instance, a policy maker does not provide any information on the anticipated effect of a policy, it will not be possible to build trust in this policy. Equally, a novel policy needs to tie in with known experiences to some extent, otherwise it will be

[2] '*A foreshortened future is a matter of what is anticipated, a negative evaluation of what the future offers…*' (Ratcliffe et al., 2014, p. 1).

[3] *'The torturer attempts to destroy a victim's sense of being grounded in a family and society as a human being with dreams, hopes and aspirations for the future. By dehumanizing and breaking the will of their victims, torturers set horrific examples for those who later come in contact with the victim. In this way, torture can break or damage the will and coherence of entire communities. In addition, torture can profoundly damage intimate relationships between spouses, parents, children, other family members and relationships between the victims and their communities.'* (Ratcliffe et al., 2014; United Nations, 1999, p. 43).

equally difficult to establish trust in the policy. For that reason, it can be argued that the information needed to trust must be connected to the past, present and future.

Fifth, most themes are in line with general research touching on issues of trust as discussed in more detail later in this Chapter: *Active regulatory systems*, *Anonymity*, *Autonomy*, *Familiarity*, *General perception of security*, *Information quality*, *Privacy*, *Recognised potential*, and *Respect*. This implies that public trust is linked to other forms of trust.

Sixth, time (different aspect as compared to the discussion above about time periods) is a somewhat eye-catching key theme. It includes two themes referring to time allocated for deciding whether to trust and time for trusted research to be produced. This shows two important characteristics of public trust: First, decisions and processes leading to public trust need time and second, time should be given to the trusted to conduct the action s/he is trusted to undertake.

Seventh, as discussed in Chapter 4, nowadays the general consensus among trust researchers is that trusting is a conscious decision. Hence, most conceptualisations of trust understand the decision process to trust as a conscious choice process. The themes contributing to the conceptualisation of public trust in this research are not based on trust as an intrinsic motivation such as gut feeling, instinct or intuition. However, considering the wider trust literature and research, it is worth recognising that intrinsic motivations can have an effect on where trust is placed (Bonabeau, 2003; Dane, Rockmann, & Pratt, 2012; Frevert, 2013; Ma-Kellams & Lerner, 2016). In the social sciences and behavioural economics, irrationality and irrational choice are widely recognised phenomena (Boudon, 2003; de Jonge, 2011; Howard, Bennett, Bryant, & Bradley, 1993; Zafirovski, 2013). This implies that it may be necessary to expand the conceptualisation developed in this research to account for a theme representing this group of intrinsic themes. Otherwise, the conceptualisation is at risk of failing.

The following will discuss and explain in detail the key themes conceptualising public trust as presented in Table 7.16. The key themes are discussed in alphabetical order, as there is no weight, value or other form of ranking assigned to the themes.

Active regulatory systems

- *Denial of access to data by private companies* - If private companies do not get hold of data, people trust more.
- *Government response to breach of data security* - If the government 'sacks' people who breach data security, people trust more.
- *Regulation* - If regulatory mechanisms are in place, people trust more.

The role of legislation and regulators to foster public trust in professions as well as professional systems is generally accepted across the social and political sciences (Bouwman, Bomhoff, de Jong, Robben, & Friele, 2015; the Wellcome Trust, 2015). For example, Patricia Hewitt, former Secretary of State for Health, wrote in 2007 *'Public trust in the professions needs to be sustained and enhanced by ensuring that the regulators provide effective and objective scrutiny of practitioners from the perspective of reasonable patient expectations, free from any doubt that the regulators are overly sympathetic to lapses in conduct or competence through a sense of professional loyalty.'* (Hewitt, 2007, p. 17).

In the case studies, people suspected that if private companies such as insurance companies got hold of medical records, they could unfairly increase premiums or not insure specific people on the basis of their medical data. Several controversies discussed in the media where insurance companies got hold of medical data in different ways fuelled a public debate covering this issue (Donnelly, 2014; Lythe, 2014; Ramesh, 2014). The other main concern is that private companies should not use medical records for their own profit (discussed below). Here a responsibility is seen on the side of the data storing organisation to regulate the use and access of medical records. The government must follow up the breach of data security and responsible people should be disciplined. Unfortunately, the findings of the current study suggest that there is an expectation among parts of the public that the government is already selling medical data anyway.

I work for a research company and we currently "extract" data from primary care - the hoops we have to go through to do this are extensive - but I believe they are useful to maintain privacy and limit "mess ups".
The problem with the system being proposed is that there is greater scope for mistakes, less safeguards, and more data, meaning both the Risk and Impact of "leaks" are higher. (Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

Until these "stiff penalties" are believable, I think I'll be opting out. (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 February 2014).

Why would they do that because the government is going to sell it to the company anyway? You know, they're going to sell it and make it available. So I have no problem with the trust side of it or anything because they are just doing a job. The ones, people get sacked for breaching security in all different things so I don't really have any issues with them taking the data …. (FG2).

Transparent action by the government in response to a breach of the law is understood to foster trust. Last, regulation in the form of rules and control mechanisms is seen as an instrument to secure trust. As discussed in Chapter 4, trust is to a certain degree institutionalised in society in the form of rules and regulations which themselves should foster trust or behaviour which is trusted.

Anonymity

- *Anonymity* – If data are anonymised, people trust more.

Other researchers found similar opinions on anonymity to those expressed in the case studies. Green and colleagues (2015) discussed concerns of privacy and confidentiality of data sets when shared, especially the problem of possible re-identification. Here de-identification of data sets is essential to maintain anonymity (Green et al., 2015). Hunter (2016) stressed the importance of anonymity in the context of 'big data' capitalised by private companies such as Google or Pfizer. He argued for better legal frameworks to

protect this anonymity and *'Just like security, anonymization or pseudonymization requires constant updates to ensure that health data sets are robust against attempts to re-identify the individuals who provided them.'* (Hunter, 2016, p. 1104). In the context of genomics research, anonymity and how to maintain anonymity is partly contrarily discussed. The problem is that genomics research produces much more detailed information on the individual so that ordinary data anonymising processes are limited as the complexity of information increases (Kaye, 2012). Kaye (2012) concludes that full anonymity will not be possible and attempts to do so will carry a risk of breach, therefore, alternative consent processes are needed and a different approach is needed to engage with participants. On a European level, McConigle and Shomron (2014) reported from the European Molecular Biology Organization, that anonymity alongside privacy and trust are essential for the research field (McGonigle & Shomron, 2016, p. 2). Here anonymity is understood as a mechanism to guarantee privacy of the sample donor. Researchers agree that the problem for privacy in genomics research is the linking of genetic data to phenotype data. To address the problem, a multi-disciplinary approach is needed (McGonigle & Shomron, 2016). The fact that full anonymity cannot be guaranteed is also stated in the context of the 100.000 Genomes Project (Savage, 2016). Savage (2016) argues that anonymity is not the solution to privacy concerns as full anonymity is impossible. Accordingly, it would be sensible to discuss and explain openly the benefits and risks concerning identification in the consent process. Perceived risks are expressed regarding the access of insurance and marketing companies to medical data. To counteract the intentional re-identification of anonymised data by professionals, the UK government is planning to introduce penalties (Perrin, 2016). Research bodies in the UK agreed to recommend penalties up to £500,000 (Wise, 2014). The Wellcome Trust (2015) adds to this discussion that there is currently no legal definition of what 'anonymised' means, leading to organisations interpreting anonymity in different ways. Also, the general public does not understand different degrees of anonymisation (Wellcome Trust, 2015).

With the previous points in mind and focusing on the conceptualisation of public trust, anonymity can be understood as linked to privacy. The link is established by the understanding that anonymity is a mechanism to achieve privacy. A proportion of people are aware of the limits of anonymity. The case studies show that some people realise that full anonymity is not possible. However, others stress that full anonymity is the key:

And I suppose in terms of how it's used, I presume the tissue samples are most useful if they also have some personal history details attached to them. And although maybe anonymised, there are various bits of information that [um] would be necessarily attached to that in some studies. And [um] I would hope that -and I am confident really - that this will be respected. (BIO1).

I think my [er] personal data and medical information getting into the wrong hands is a general worry, mainly because of confidentiality issues. … [Um] But yes, I do think the [um] the security of the data, privacy, anonymity - where that's appropriate in a study - I think they're, they're very important. (BIO15).

Faith in anonymisation is key. (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

Likely, the way forward in the current debate is a mixed approach including open discussion with the public about their concerns regarding anonymity, explaining where present limits of anonymity are. Also it is essential to implement a legal and professional behaviour framework that mirrors public concerns as well as strengthens the lawful use of data as well as the use of data in line with what is morally right. Presumably, the overriding principle will have to relate in some way to not doing anything that would be against the individual or family interests of the people who have provided samples. Further, the actors in the public sphere need to demonstrate how to cope with the lack of full anonymity, how to guarantee privacy, how breach of privacy will be prevented as well as how breached privacy will be penalised. When considering that full anonymity is not possible, one needs to discuss the possibility that anonymity might in fact not be necessary for the conceptualisation of public trust. This however would require that the entire public understands and knows what the limits of anonymity are. Parts of the public who think that full anonymity is possible, build their trust on a false understanding of anonymity.

Autonomy

Autonomy comprises of two items:

- *Choice* - If people have the choice to be part of something, people trust more.
- *Personal control* - If people have personal control over their data, people trust more.

In the context of bioethics, O'Neill, (2002) has extensively discussed the relationship of autonomy to trust (Nys, 2016; O'Neill, 2002b). She observes that autonomy is the basis of genuine trust in a more equal doctor-patient relationship in comparison with a relationship marked by power and knowledge asymmetry (p.18,19). This autonomy is granted in the informed consent process as a 'ritual of trust'. However, one might think that autonomy and trust contradict each other, as autonomy demands space and trust is a relational concept (O'Neill, 2002b). But in a relational setting, autonomy refers to the freedom to act and to choose. As choice is in Luhmann's understanding a pre-requisite for trust, this freedom to choose is granted, on the one side, by the offered choice, and, on the other side, by the autonomy an individual has to make the choice (Luhmann, 2009). Therefore, autonomy and choice go hand in hand as they reinforce each other (Dan-Cohen, 1992). On the individual level, Lee and Lin (2009) discuss the influence of autonomy on the positive influence of trust on health outcomes. They claim that higher degrees of autonomy foster this positive relationship (Lee & Lin, 2009). However, as Burchardt and colleagues (2015) have discussed, making an active choice in an autonomous way is complex. Further, current UK social policy does not always support this choice despite governmental efforts to offer more choice to the public. The complexity arises from the multidimensionality of choosing. In brief, obstacles to active choosing and to autonomy are often related to: lack of time to decide; or lack of full information. Also the options to choose from are not always of equal quality, inhibiting real choice. Last, the most severe obstacles are, '*poverty, ill health and geographical inequality*' (Burchardt, Evans, & Holder, 2015, p. 63). Burchardt and colleagues (2015) show that making a choice is not always easy and people can feel overwhelmed by the pressure to make a choice. Here autonomy has several constrains such as: '*Conditioned expectations; false consciousness; passivity; pressure from others; coercion; structural constraints; lack of resources; lack of information, advice and support*' (Burchardt et al., 2015, p. 49). In the case studies, this lack of personal control and choice was expressed as:

Both doctors and governments are getting far too much control over our lives. I keep away from doctors. I lost faith and trust in them a long time ago. (Comment on article by Martin Beckford, ‘'Big Brother' database will grab children's health records but parents are being kept in the dark’, Sunday Mail Online, 9 February 2014).

Give us a more useful choice. As well as "all in" or "all out", allow us to opt out of commercial/private/third party use but still allow our data to be used for academic and other public sector, non-profit research.

Whether you trust that choice to be upheld and not ignored either wilfully or through negligence, is another matter of course... (Comment on article by Nick Triggle, ‘Health by Care.data: How did it go so wrong?’, BBC News, 19 February 2014).

These observations imply that autonomy is linked to the themes *time* and *information quality*, and that actors in the public sphere need to shape policy so that the previous obstacles are confronted and removed. Otherwise, autonomy and choice cannot be fully realised, which would severely curtail trust, given that choice is a prerequisite for trust following Luhmann (2009).

Benefit to others

- *Altruism* - If altruism leads to public benefit, people trust more.
- *Future benefit* - If research is perceived to lead to a future benefit, people trust more.
- *Public benefit* - If research leads to public benefit, people trust more.

Based on the previous observation that several different types of benefits emerged as themes from the data, public trust in the health care system is closely linked to an anticipated net benefit resulting from the trusting relationship. Here *benefit to others* is composed of three items: *altruism*, *future benefit* and *public benefit*. The items are linked, as altruistically motivated action should usually lead to public benefit. The term future in *Future benefit* should be understood as referring to a more distant future compared to adirect immediate, personal benefit (see below for discussion of the future orientation of public trust and what this implies for the trusting relationship between the public and the

health care system). This understanding is shown by quotes referring to future generations or children and grandchildren.

And I suspect that there is a large part of altruism on the part of these patients, that in participating in some trials they're looking rather than for hope for themselves to give hope to other people, and to find some purpose in what is [um] very trying times. (BIO3)

You might hopefully be helping somebody else in society. It might be 30 years away from now, [um] but it would be nice to look back and think that, you know, maybe for your children, your grandchildren, to say, "My grandma helped me, you know. I've now got something wrong, but it wasn't for her efforts there may not be a cure." (BIO7).

It is all about trust. If I believed that my medical records were being used for the greater good, then I would have no problem with it. (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 February 2014).

Altruism in the health care context of donation and research participation is widely discussed. In trust research, altruism is sometimes associated with the term *generalized trust* and linked to the collective spirit present in a society (Le Grand, 1997; Platt & Kardia, 2015; Stolle, 2002). The collective spirit in a society is important in understanding public trust, as public trust is closely linked to social cohesion (Fukuyama, 1995; Papakostas, 2012). As public trust is described as the glue of society, altruism plays an important role in this glue (Social Analysis and Reporting Division, 2001).

Certainty about the future

- *Certainty about the future* - If researchers and officials do the best they can do to foresee risk in the future, people trust more.

As trust can be understood as a risky advance payment, a higher degree of certainty about the future outcome should foster greater trust. However, there will never be a 100% guarantee about the future, especially when considering the framing themes, *human error* and *risk* which cannot be eliminated. In the care.data case study, the uncertainty about

future use of personal data motivated people to opt out of the programme. The role of uncertainty for a trusting relationship is discussed in detail in Chapter 5. In contrast to the framing theme *risk*, see below, this conceptualising themes focuses not on the unavoidable presence of risk, but about how to possibly deal with risks.

I really don't trust this idea, we don't know that promises made now will be kept by future governments, or private companies. … There may be some benefits, but history tells me that these people cannot be trusted, when profits/cost savings can be made. (Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

No one really knows this is happening, … I think this will make people more reluctant to confide in their doctor over sensitive issues for fear of this information being given to other parties in the future so this could have a detrimental effect on peoples health. (Comment on article by Martin Beckford, ''Big Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

Familiarity

- *Personal experience* - If people have personal experience of medical staff, they trust more.
- *Confidentiality in the GP-patient relationship* - If personal information is only used for medical consultations, people trust more.

Personal experience, including a relationship with a medical practitioner where personal information is only used for consultations as opposed to passing on the information to third parties, fosters trust. Personal experience is crucial to build trust. Here, personal experience with system representatives encourages the transfer of the trust in these representatives to trust in the wider health care system (Giddens, 1990). Familiarity is discussed in relation to individual trust on a personal level as a building block of trust (Sztompka, 1999, p. 124). This is because familiarity provides the trusting party with in-depth information about the trusted party, and the trusted party also has incentives to be trusted (Hardin, 2006, p. 39). Luhmann (1988) writes that trust can only develop in a

familiar environment (Luhmann, 1988). A limited number of studies have investigated the role of familiarity and trust in health care settings. However, the importance of familiarity to build trust in care settings was stressed (Salazar, 2015).

R: Yeah I would not have trusted them.
R: That's down to your personal experience. (FG2).

The doctor-patient relationship is and must be sacrosanct. Unbreakable confidentiality, nothing less. Destroy our faith and trust in that and there will be no return. (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

General perception of security

- *Existence of security measures* - If participants think that a variety of security measures are in place, people trust more.
- *IT competence* - If IT systems are not administered by the government or GP, people trust more.
- *Local storage* - If the data is stored locally, people trust more.
- *Perception of safety* - If people feel safe with professionals, people trust more.
- *Protection in numbers* - If participants' data is stored in a massive data bank, people trust more.
- *Safe data handling* - If data are not lost, people trust more.
- *Unlawful data access* - If personal information is protected from being hacked, people trust more.

General perception of security is developed based on seven themes touching on different areas of security and safety in the health care system. This key theme is particularly interesting as it shows the wide scope of actions which lead to a general perception of security and the internal contradictions within the seven themes. The themes refer to different mechanisms and actions which are spread throughout the health care system implying that a range of health care system actors need to act together to support this perception of security. Security is a widely accepted theme in trust research in the context of healthcare (Calnan & Rowe, 2008; Harrison et al., 2003; Pilgrim et al., 2011; Shore,

2006). *Existence of security measures* refers to a range of security measures which protect medical data against unlawful data access and hereby privacy.

> *Well, I think that for me that was the biggest thing I had to really think about with the Biobank, because [er] my concern isn't so much about what I'm giving, but being sure that it's being treated with respect. And that means, you know, confidentiality and [um] ensuring that it's safe and secure. And, you know, you do hear of data being lost, and hackers hacking into databases, and all these sorts of things. So it is something that I considered. [um] But at some point, and I know things like the [um] research regulations, research governance is sort of tightening things up, and we've got the Human Tissue Act which, you know, I know that there are licenses for storage and inspections and new regulations. So that does give me a little reassurance there. [um] And at some point you have to decide on the balance, don't you, the good against potential for problems. I mean there's always something that can go wrong. But at the end of the day it's a leap of faith. And the balance for me was that this was a really important thing to be involved in, and [um] I was happy to go through it and [um] give, well, tissue samples and also huge amounts of personal information. [laughs]* (BIO1).

IT competence refers to the expressed scepticism in the competences of the government or general practice to run an IT system. The data suggested that there are two types of people, one type who trust the government and not general practice and the other type who trust general practice but not the government.

> *…as an IT professional I have zero confidence that there is any way to effectively secure this data, particularly if a Government-initiated IT project is involved.* (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 Februrary 2014.)

> *Never mind ATOS's lousy record in other matters (which makes ATOS management unable to be trusted), but why a French company rather than a UK company? And it would not surprise me to find that the IT servers will be remotely managed from India or elsewhere.* (Comment on article by Charlie Cooper, 'Hospital records used to 'target ads on Twitter and Facebook' say privacy campaigners, in latest NHS data concerns', Independent, 03 March 2014).

Linked to IT competence, several people seem to trust a *Local storage* place over a data storage place not known to them. This sense of trust in local settings was also found in other studies, and might be linked to a sense of pride in local areas over remote areas (Haddow & Cunningham-Burley, 2008).

> *Why do we need a centralised healthcare database? I cannot see how it can do very much to improve care, but can see plenty of risks with it. And the attempt to build one was the largest and most costly IT project in the history of the World, and failed. Limited authorised extracts from locally held trusted databases is far more sensible.* (Comment on article by Polly Toynbee, 'It's right to worry about security, but sometimes data trawls can be useful', Guardian, 23 August 2013).

Further, a *Perception of safety* leads to trust. This perception of safety can stem from various sources. Unfortunately the data are not informative enough to list such sources. These sources can be assumed to be a range of actors in the health system. In the qualitative data, the perception of safety was associated with a feeling of being comfortable with providing data.

> *I think that's personal choice. I think you've got to just make your own decision, and if you're comfortable, again, if you're comfortable with it, and you trust the people you're with, and you feel safe with them, do it.* (BIO5).

A feeling of security with respect to unlawful data access seems to be provided by a so called *Protection in numbers* which refers to the idea that the odds are very low in a large data set that 'my' medical record will be accessed.

> *Why would you believe that out of millions of records someone would be bothered to identify you and for what purpose?* (Comment on article by Claire Carter, 'NHS medical records database could help prevent disease, senior doctors say', Telegraph, 24 February 2014).

> *And biobanks, the actual biobank that does all the studies must be massive, and I can't believe there's that many people out there that are interested in something of mine, you know – "Miss S" sort of thing, you know, from whatever town, I don't know they're that bothered [um].* (BIO7).

Next, *Safe data handling* refers to the handling of data and that professionals (or the system) should not lose medical data.

> *You'd hope so. But that would be my worry, that - you know - something might get lost in that. Am I sounding very sceptical?* (FG2).

Unlawful data access refers to the perceived threat of hacking. Therefore, data sets need to be safeguarded against hacking. Different government agencies have issued a series of guidelines on cyber security to protect not only medical data sets, but also electronic medical devices. Particularly in the last few years, cyber security in relation to trust is widely discussed and recognized (McKnight & Chervany, 2001).

> *Given the record for government departments "losing confidential information", on laptops, cd's/dvd's and paper copies does not instil confidence whatsoever. Plus the added risk of being accessed by GCHQ, NSA and hackers, I do not believe the system will ever be secure.* (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

Health system benefit

- *Advance in science* - If donated samples lead to a breakthrough in research, people trust more.
- *Improved quality of healthcare* - If data lead to improved quality of healthcare, people trust more.

As part of the group of key themes about benefits, *health system benefit* consists of two themes. *Advance in science*, is closely linked to the content of the case studies, as an advance in science should follow donation of samples.

Yeah, well, I absolutely [um] trust, and I'm a hundred per cent confident that [um] all my, [er] our little collections for MND research will [um] eventually help towards that breakthrough. (BIO12).

Improved quality of health care is the only theme which refers to a quality aspect of health care and the importance of quality for trust or even the importance of trust for quality. Here, donated data should lead to improved quality of care in the health care system if people are to trust the system to which they have donated their data.

It is hoped that the resulting increase in preventative treatments, coupled with improvements in health management, will save billions and improve the quality of healthcare. The sticking point is patient confidentiality. (Comment on article by Mike Hodgkinso, 'The number crunch: Will Big Data transform your life - or make it a misery?', Independent, 19 January 2014).

Quality of care is linked to trust by many different trust studies and is a well-recognised theme conceptualising trust in any healthcare setting (Ahern & Hendryx, 2003; Calnan & Rowe, 2008; Calnan, 2004; Harrison et al., 2003; Hawkins & O'Doherty, 2010; Sachiko Ozawa & Walker, 2011; Pagan et al., 2007; Pilgrim et al., 2011; Shore, 2006; Straten et al., 2002).

Information quality

- *Clear information* - If the consent process contains clear information and participants can discuss the research with a knowledgeable professional, people trust more.
- *Corroborated information* - If two or three sources online say the same information, people start to trust the information provided.
- *Explanatory information* - If the government explains what its intentions are, people trust more.
- *Honest information* - If politicians appear to be honest, people trust more.
- *Reliable source* - If messages are sent from a national source, people are inclined to trust more.
- *Truthful information* - If the health care system is perceived to tell the truth, people trust more.

As discussed in Chapter 4, communication is central to building trust. Hence, the communicated information is equally central to trust (Larson, 2016). Likewise, to the lived experience which informs the decision to trust (as well as the anticipated future outcome of the trusting relationship), the information about the trusted party is of major importance. The range of themes in this study with respect to information quality are not different from other studies and are congruent with the general perception of the qualities necessary to build trust based on information about others (Fukuyama, 1995, Chapter 5). In this study, information quality refers to the quality of information communicated between the trusting parties. The themes address different parts of the information process, the actual information and the source providing the information. These distinctions could imply that people might trust the source providing the information, but are not able to trust the information itself, as, for instance, they do not understand the information provided. This assumption needs further validation as the data are not informative enough. However, there seems to be an underlying logic identifiable, in so far as, despite considering a source honest and truthful and therefore trustworthy, if the source does not express the information in a clear way, one might not to trust the information. The data suggest that the communicated information should be *clear*, *explanatory*, *honest* and *truthful*, compare here also Chapter 4 on the role of truth for trust in general:

'I think the consent procedures are very important. It's good to have clear information and plenty of links to people who you might be able to ask questions of if you have questions.' (BIO1).

"We believe the government must focus on educating the public on how their data will be treated and what security measures will be taken before its second attempt to launch the programme." (By Laura Donnelly, 'Britons 'trust banks more than government' to protect their data.' Telegraph, 21 May 2014).

Believe it or not politicians are not the most honest of all professions and the other candidates might try to leak a story about her being transgender etc. Career over because as much as we all think that is okay, it tends to be a turn off for lots of voters. (Comment on article by Claire Carter, 'NHS medical records database could help prevent disease, senior doctors say', Telegraph, 24 February 2014).

Thin end of the wedge ... I have no trust in politicians or NHS to tell the truth. (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

Furthermore, if the information is provided by a *reliable source*, people trust more.

I think the fact that it (Invitation to a study) *came from the NHS [um] made us inclined to trust it, and the other [um] more involved studies that we've taken part in, because they were based in our local hospital [um] that also made us very inclined to trust the participants. They came with the pedigree of their employing organisations.* (BIO15).

If the same information is provided by several sources (*corroboration*), people trust more. Corroboration can probably also be understood as seeking a second opinion, despite the fact that the data in this study are from online web pages. To use multiple sources to make a decision to trust is considered as a conceptualising theme by other trust studies (Hall et al., 2002). Generally the use of internet sources by patients to make informed choices is widely researched and recognised. The central and recurring problem is that the quality of information provided online is often low and often contradictory, as discussed in the introduction of this thesis (Ek, Eriksson-Backa, & Niemela, 2013; Ekman et al., 2005; Eysenbach et al., 2002; Sillence et al., 2007; Zulman, Kirch, Zheng, & An, 2011)

But you know, more and more people – dare I say it - I won't say they trust the web, but they'll use the web to get information, because they know if they can get the same information from different sources - and I'm a bit like that, if I can get the same information from two or three sources then I start to believe it. (BIO11).

Personal benefit

- *Availability of help* - If people find professional help, people trust more.
- *Fear of negative consequences* - If people are less fearful about the consequences of actions taken by the health system, people trust more.
- *Personal benefit* - If participation leads to personal benefit, people trust more.
- *Reassurance* - If professional reassurance leads to a good feeling, people trust more.

The link between public trust and an anticipated personal benefit resulting from the trusting relationship develops because the public also consists of individuals. Here, the anticipated personal benefit is the anticipated effect of a trusting relationship. Personal benefit develops from four themes. *Availability of help* refers to the general availability of help from the health care system. This could be research staff able to be contacted at any point in time to clarify questions or help a participant in any other way. Also availability of help could be the presence of medical facilities in close proximity.

And that is again, to hope to try and find and help xxx is an issue. And are we to do it personally, because if we are then going to have a child with someone who is also a carrier, you know, potential of having a child with albinism. So it's a two-way situation, you know xxx. So I think that would help in that instance, if you know. (FG1).

Further, the actions of the health care system should not be perceived as likely to lead to negative consequences. So, if a *fear of negative consequences* is mitigated by the health system's actions, people trust more. As a trusting party trusts in anticipation of a positive effect of a trusting relationship, a fear of a negative consequence blights the attempt to build trust. Fear itself is understood as a framing theme, however, the specificity of negative consequences is considered as a conceptualising theme for public trust.

I think this will make people more reluctant to confide in their doctor over sensitive issues for fear of this information being given to other parties in the future so this could have a detrimental effect on peoples health. . (Comment on article by Martin Beckford, ''Big

Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

As a third theme, *personal benefit* refers to individual benefit from research participation. Possibly, this understanding of an expected personal benefit can be expanded to the entire health care system, when being treated by the health care system, or when being part of the health care system in a different way. For instance, one would expect personal benefit from private health insurance.

"They were supposed to believe it was all for their own good." (Antonia Molloy 'NHS boss apologises for tweeting Hitler video mocking Government health database scheme', Independent, 28 February 2014).

There seems to be a touching faith that gathering all this data will improve patient outcomes. (Comment on editorial (no author), 'NHS data: take more care', Guardian, 25 February 2014).

Professional *reassurance* leads to a good feeling and therefore people trust more. The data do not clarify whether reassurance leads first to a good feeling which itself leads to trust, or whether reassurance itself can directly lead to trust. Maybe both are the case, but this causality needs further research.

And so we started off with the puncture, and he and the trainee doctors all had a chinwag about [um] what the weather was like that day or whatever, forgetting me, the patient, and [er] I started getting a bit panicky, I was [um] - and in the end I shouted out to one of them, or shouted out to them, "I'm the patient here. I'd like a little bit of confidence-building, please," [um] and then I got, well, one of them started talking to me, which is all I wanted, just reassurance and comfort, comforting. (BIO13).

But at some point, and I know things like the [um] research regulations, research governance is sort of tightening things up, and we've got the Human Tissue Act which, you know, I know that there are licenses for storage and inspections and new regulations. So that does give me a little reassurance there. (BIO1).

Privacy

- *Privacy* - If privacy is not compromised, people trust more.

Privacy, also linked to security, as security protects privacy as well as anonymity, is a frequently discussed theme in the context of health care and trust, as well as private data and trust (Damschroder et al., 2007; Frost, Vermeulen, & Beekers, 2014; Hagger-Johnson et al., 2014; Platt & Kardia, 2015; Tsoukalas & Siozos, 2011). Research shows that concerns about privacy affect the willingness of patients to provide personal information (Walker, Johnson, Ford, & Huerta, 2017). In this research, privacy refers to the protection of sensitive and private information which should not be revealed in public. When considering the difficulties with respect to anonymity and genomics research, privacy is likely to suffer similar problems to anonymity, given the link between the two (McGonigle & Shomron, 2016).

I think my [er] personal data and medical information getting into the wrong hands is a general worry, mainly because of confidentiality issues. I'm not entirely sure if anybody would be able to use that data [er] to harm me, other than to invade my privacy. [Um] But yes, I do think the [um] the security of the data, privacy, anonymity - where that's appropriate in a study - I think they're, they're very important. (BIO15).

The Government nor its departments can be trusted with private information they are useless and incompetent. (Comment on article by Jason Groves, 'Now our tax data could be sold to businesses: Government planning change in law to allow release of 'anonymised' data to third parties', Mail Online, 19 April 2014).

Public financial benefit

- *Financial benefit to the health system* - If data are used for the financial benefit of the health system and not for private companies' profit making, people trust more.
- *Opportunity for reinvestment in medical research* - If the financial gain of research is reinvested in medical research, people trust more.
- *Public funding* - If research funding is mostly related to the public health care system, people trust more.

This key theme belongs to a series of themes about a net benefit. The key theme *Public financial benefit* is about the financial benefit to the public health care system as well as medical research, in contrast to private companies' profit making. It was frequently discussed that altruistically donated data should be used for the benefit of the public sector and public itself. With a similar understanding, research funding should be related to the public health system and not the private sector. People seem to wish that there should be a separation of public and private profit making. Research funding and financial gain from the research should be related to the public sector. In a Spanish national survey, it was found similarly that people who have a positive perception of science tend to support public funding for science (Muñoz, Moreno, & Luján, 2012).

They'll see if they can commercialise the, the actual and package it, the whole process and sell, sell that to other countries that, that's going to be a massive income boost which will then hopefully [ah] be reinvested into other medical research or expansions to the current project and that sort of thing because I know they are doing. (FG2).

And I would hope that most of the funding is related to the NHS. I got the impression that it's NHS-funded research we're talking about. (BIO11).

I do not trust the NHS to keep the information safe and secure and I have grave fears it beirng sold on to private companies. (Comment on article by Sophie Borland, 'NHS delays plan to harvest your details: Victory for the Mail as database is shelved for six months', Mail Online,18 February 2014).

Recognised potential of the health care system

- *Government integrating private companies for a clear public purpose* - If the government has a clear overall aim for involving and working with commercial companies, people trust more.
- *Professionals' ability to keep up with new knowledge* - If professionals keep up-to-date in their field of expertise, people trust more.
- *Representative governance* - If the government is perceived not to be dictating to the people, but governing in a representative way, people trust more.
- *Research by public institutions* - If a big research initiative is led by a public institution, people trust more.
- *Self-confident professionals* - If professionals behave self-confidently based on their training, people trust more.
- *Structured project* - If projects are well organised, people trust more.
- *Valid research* - If research is perceived as working on valid questions and is justified, people trust more.

Recognised potential of the health care system is derived from seven themes describing various characteristics of different actors in the health care system which lead potentially to a future benefit that can be trusted by the public. The *Government integrating private companies for a clear public purpose* refers to a scheme by the government that integrates the interests of private companies in the health care system transparently. This is in line with the understanding as discussed in Chapter 4, that a reason is needed for the establishment of trust. In other words, public authorities need to show that they have control over private companies and can prevent private companies form working in the health care system solely for their own benefit and not for the benefit of others, as is expected of a public initiative.

> *R6: You can only go off your own experience and I, and I've worked in central government and local government and, you know, I know they are not perfect and things but I do know they are under major scrutiny all the time. And if they are choosing to spend this money at the moment on such a big initiative they are going to have to be qualifying that and they are going to have to be squeaky clean and if they are not then it is going to be a big problem. So I sort of, I think that does*

give you comfort but I wouldn't trust a private initiative to do it because I think they'd be doing it. They only do something for themselves.
R5: Saving money
R: Saving money or to
R6: Yeah
R: Commercial. I mean I know that in a way this is also doing that XXX
R6: But you would hope that there would be some integration and central sort of objective around it. (FG2).

A *structured project* is trusted over an unstructured project.

Rf: Where I like do have more faith in, in the project that's going on there's a lot more trust if your with me.

R: Yeah there's going to be the element of human error but it, I think it's going to be a much more structured [you're laughing at] (FG2).

Professionals' ability to keep up with new knowledge describes the ability of professionals to continue their education and update their knowledge continuously. However, it is also believed that professionals cannot, in fact, keep up with the pace of research output.

And of course the rate of research as well, new stuff on what's been done, every fortnight. I believe even professionals within their own specialism can't often keep up with it. (BIO20).

Representative governance is a theme developed from several comments in the care.data case study about a 'reptile ruling elite' and the feeling of the 'little man' being powerless against the governing class. It also relates to an understanding that one should not believe that there is no link between class and fraud.

The reptilian ruling elite believe they own the human bodies they created on this physical level (but not the consciousness occupying the body) and so also own the all the medical information to do with as they please. (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned:

But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

Research projects on a large scale should be run by a public institution and not a private institution as a private institution is probably linked much more to profit making for its own purposes, as described by other themes in the conceptualisation. This understanding is represented by the theme: *Research by public institution.*

> *You can only go off your own experience and I, and I've worked in central government and local government and, you know, I know they are not perfect and things but I do know they are under major scrutiny all the time. And if they are choosing to spend this money at the moment on such a big initiative they are going to have to be qualifying that and they are going to have to be squeaky clean and if they are not then it is going to be a big problem. So I sort of, I think that does give you comfort but I wouldn't trust a private initiative to do it because I think they'd be doing it. They only do something for themselves.* (FG2).

With respect to professional behaviour, *Self-confident professionals* are trusted more. Self-confidence is understood to develop from good professional training. The data suggest that one would not trust a professional without self-confidence, which is in line with wider trust theory as discussed in Chapter 5.

> *You - I don't know how well somebody without that confidence, without that –you kind of can't have one without the other. Because if you haven't got the education, the confidence, you can't do the confidence bit because you actually don't know what you're talking about…* (BIO18).

Last, research questions raised by a research project should be valid. Hence, research which is perceived as *valid research* is trusted.

> *Certainly I would hope that the grand cock-up that has been made by care.data over the opt-out issue is not the work of legitimate researchers: from the legitimate research perspective they have gone a long way to ensuring their own demise.*

(Comment on article by Oliver Wright, 'Inside Whitehall: Care.data will help prolong our lives and those of our children', Independent, 25 February 2014).

Respect

- *Data accuracy* - If the data used are accurate, people trust more.
- *Data kept in good condition* - If data are kept in good condition, people trust more.
- *Sensitive feedback* - If feedback, which a participant has consented to receive, is provided to the participant in a sensitive way, people trust more.
- *Professional reputation* - If professionals do not compromise their reputation, people trust more.
- *Respect for participants* - If participants are treated by doctors with respect leading to mutual respect, people trust more.
- *Responsible management* - If personal data are managed responsibly, people trust more.

Respectful interaction between the trusting party and the trusted party, respectful action of the trusted party and the respect of the trusted party all increase trust. Respect as a general theme is often found when conceptualising trust in health care (Calnan & Rowe, 2008; Harrison et al., 2003; O'Neill, 2002b; Pilgrim et al., 2011). Respect consists of six themes.

Data accuracy requires that data must be accurately entered into the system:

> *I have no fears about my medical data being held by the NHS and shared: but I do entirely understand your point about accuracy - when I was last in hospital, my discharge notes were a mixture of my details and another patient's who had been admitted at the same time, with a similar condition but different cause. I hope that's been corrected, otherwise anyone accessing my notes will believe I've suffered from a duodenal ulcer in the past....* (Comment on article by Charlie Cooper, 'Your life in their hands: is the care.data NHS database a healthy step or a gross invasion of patient privacy?', Independent, 06 January 2014).

Data kept in good condition refers to the careful handling of donated data.

> *Well, it has, yes. You think, "Oh, I hope they're all kept in good condition."* (BIO1).

Sensitive feedback describes the need to provide feedback in a sensitive way as well as to provide only feedback which a participant has consented to.

> *RF:I think it, it would be something that people need to consider. And I would hope in the study that people are given that time to consider what if we xxx something else that you didn't already know.*
>
> *I: So if they did tell you something? Say you had xxx do you want to know in the future you might be susceptible to x, y, z. So when they did tell you the results, would you believe them? Would you have - you were mentioning that something might get lost in the system? Is that kind of - is that like distrust in the system, or?*
>
> *RF: No, not really. I think it's, I think it's just more about making sure that all of that kind of thing is handled really sensitively, and in partnership with the consultants that the patients are under. Because I think - you know - patients tend to be very, very trusting of their consultants when they are in a situation where they've got incurable cancer, for example.* (FG1).

Respected professionals should not compromise their *Professional reputation* to be trusted.

> *I don't believe that they would compromise their integrity or the reputation of the unit and the quality of the care that they provide by associating themselves with something that wouldn't [um] reflect their service standards and their ethical standards, I think.* (BIO17).

Respect for participants describes the respectful interaction of professionals with participants leading to mutual respect.

> *I'm allowed to and privileged to call my doctor by his first name, [um] and so we are friends and doctor and patient, and [um] all in one. And I think that's [um] a lovely place to be. They respect how I am giving as much as I can of my time and my love. And equally, I respect how they are giving their time and their love.* (BIO12).

On a bigger scale, and linked to the theme of data kept in good condition, *Responsible management* refers to the management of an entire programme in the health care system.

> *I have no problem with sharing medical records as part of an abstracted set of data, but I just wouldn't trust the present NHS to respect the confidence and manage it responsibly.* (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

Time

- *Giving participants time to consider if they want to receive results* - If participants have time to consider which results they want to get, people trust more.
- *Providing time for medical research* - If research is not conducted in a rush, people trust more.

Time refers to the time needed and not to be rushed (likely due to time pressure as, for example, developing from research project timelines) when deciding to trust as well as when acting as a trusted person or object. *Giving participants time to consider if they want to receive results* refers to the question of which information people would like to receive when taking part in research or being treated. *Providing time for medical research* refers to the understanding that medical research needs time. Both should not be rushed. Time generally plays an important role for trusting relationships, as trust cannot be rushed or forced. The role of time for patients' decision making has been stressed in other research as an important part of a trusting patient-doctor relationship (Anand & Kutty, 2015; Keating, Gandhi, Orav, Bates, & Ayanian, 2004; Levine, 2004, p. 930; Straten et

al., 2002). For example, '*Complete trust was significantly increased when the consultant (1) listened, (2) gave as much information as the patient wanted, (3) told the patient what to do if things worsened, (4) gave the patient as much time as he or she wanted, and (5) involved the patient in decision making.*' (p.930, Levine, 2004).

And if we don't allow the medical profession to make this research and undertake experiments on us as, you know, human beings, we're never going to find out, are we? So I'm, I'm a great believer that we give them as much time as possible. (BIO16).

RM: It's a little xxx because a lot of these things xxx don't do tests unless you're prepared to do something about it. And you're potentially being in the situation where you've been given results to tests you wouldn't think you were having. So yeah, I think xxx

RF: Yeah. It's just - yeah.

RM: Mmm, yeah.

RF: I think it, it would be something that people need to consider. And I would hope in the study that people are given that time to consider what if we xxx something else that you didn't already know. (FG1).

Framing themes of public trust in the health care system emerging from the three case studies

The public trust framing themes in Table 6.16 influence the function of public trust in general, as well as the public understanding of the conceptualising and the effect themes. Some of the themes fall into the category which others have described as ‘social context’ (van der Schee, Braun, Calnan, Schnee, & Groenewegen, 2007). Framing themes at the individual and public level (first column in Table 6.16) are likely to be closely related to culture, norms and values, as they engage with belief systems, religion and political systems.

Table 6.16: Framing themes of public trust in the health care system

	Level	Framing themes	Explanation
1	Basic	Communication	Communication is the basis of social interaction. Communication enables a trust discourse. Therefore it is a basic prerequisite for trust and not influencing trust.
2		Reason for the need of public trust	In the case studies data use is why the discussion around levels of trust takes place and is understood as the reason for the trust relationship. If there would be no reason or aim for data use there would be no need to discuss or express trust.
3		Risk	Risk results from individual as well as environmental action.
4	Individual	Fear	To fear is a human characteristic.
5		Human error	Human error is an unavoidable risk.
6		People's world view	People's world view, as e.g. expressed by axioms or proverbs, shapes the wider understanding of trust.
7		Religion and Afterlife	Religion is influencing the decision to trust.
8	Public	Public mood	An alleged erosion of public trust is observed in other sectors of society. This mood of mistrust spills over into the context of health care systems.
9	Government	General expectations of government to be trusted	Normative expectation of the government that the government should be trusted by the public.

Basic level framing themes

These themes are, by the nature of the case studies and dynamics of society, basic requirements for the conceptualisation of public trust; i.e. without these themes, the conceptualisation of public trust would not function.

Communication is understood in the most general sense to relate to all the different types of communication present in the health care system (e.g. one-way communication via leaflet distribution, two-way communication between participants and research staff, media communication and readership discourses in public fora, or communicating via opinion polls or votes). The importance of communication as a framing theme develops from its role in social interaction and thence for the establishment of trust. If there is no communication, and thus no information exchange, it is not possible to build trust.

Different types of communication were addressed in the case studies where the communicated information appeared to lead to low levels of trust, as, for example, expressed in the following quotes:

I never received anything through the post about the introduction of this scheme, if they can't even send out letters properly I've no faith that they look after my details securely. (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

The information provided to households I believe is intentionally very carefully worded so as to be economical with the truth. It represents the thin end of a very large wedge. (Comment on article by Martin Beckford, ''Big Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

Risk (e.g. human error, threats, dangers or hazards occurring in the future) is inevitably inherent in health care. Despite trying to minimize or foresee the risk (e.g. with risk assessments, protocols and professional training) caused by the action of involved trust-reference-objects (e.g. humans, technologies, institutional structures, etc.) or the living

environment (e.g. extreme temperature fluctuations, flooding or earthquakes), a certain element of risk is unavoidable. In trust theory, the relationship of trust and risk is widely discussed, mainly in two ways. First, it is understood that modern society with the development of technologies and globalisation is increasingly risky as well as increasingly uncertain and, therefore, trust will become inevitably more important to counteract uncertainty and tame risk (Sztompka, 1999, p. 40). Second, since trusting is '*making bets about the future uncertain and uncontrollable actions of others, [it] is always accompanied by risk*', p.31 (Sztompka, 1999, p. 31). Luhmann (2009) describes trust as a problem of making a risky advance payment (Luhmann, 2009, p. 27). As trust itself can be understood as a mechanism to cope with risks, risk cannot contribute to the conceptualisation of public trust, only a theme describing a possible mechanism to cope with risk can conceptualise trust, for example the conceptualising theme *Certainty about the future*. He further stresses that trust is a solution for problems of risk (Luhmann, 1988).

Risk was expressed in quotes such as:

Meanwhile, a risk assessment by NHS England, …, raises concerns about the initiative. … The extraction of personal confidential data from providers without consent carries the risk that patients may lose trust in the confidential nature of the health service. (By Jane Kirby and Ella Pickover, 'Doctors raise fears over sharing NHS patient medical records', Independent, 17 February 2014).

They tend to say to their consultant, you know, "I trust, I trust you'll do the right thing." But actually, you know, sometimes all those risks are given and actually people aren't able to consider them all, I suppose, that's what I mean. (FG1).

The last theme is the **reason to trust,** which describes why public trust needs to be established in the particular situation. In the simplest sense, if there was no aim to use personal data in the three case studies, trust would not be needed to legitimise the data use. Public trust is conceptualised as a result of how and by whom participants' data are to be used and for what purpose, but not by the use itself. An aim for a trusting relationship will always be necessary. If the aim is not there, one does not need to trust. In the care.data case study, data use was discussed in the following quote where a reader feared a misuse of her/his data:

Trust in government is at an all-time low and the fear that this data will be used by private companies for profit is very real. (Comment on article by Polly Toynbee, 'It's right to worry about security, but sometimes data trawls can be useful', Guardian, 23 August 2013)

Individual level framing themes

These themes are related to the individual through deep-rooted traits, belief systems or human action in general: *human error*, *fear*, *religion and afterlife, and people's worldview.*

Closely linked to risk, **human error** is an unavoidable and unintentional characteristic of human action. Despite all measures to counteract human error, it will not be possible to eliminate human error. For this reason, trust needs to accommodate human error. Otherwise, a trusting relationship carries an additional uncontrollable risk as a result of human error. An expectation by the trusting that the trusted is free from human error would threaten the relationship as this expectation cannot be fulfilled. Trust is conceptualised by actions to counteract human error, but not by human error itself. Human error was mentioned in quotes as:

Hence the reason I have the view now about sort of, you know, people making mistakes. Everybody makes mistakes. I don't believe anybody in any job sets out in the morning to say, "When I go into work today I'm going to do that wrong. I'm going to really cause an issue today." (BIO7).

R: You fill out an online questionnaire [laughs] And you don't even know anything about their authenticity or their ethics or

R: Or how they're sort of secure in storing that XXX

R1: That's where you're likely to get a mix up with somebody else's

…

R: Yeah there's going to be the element of human error but it, I think it's going to be a much more structured [you're laughing at]. (FG2).

Next, **fear** is described as a generalised characteristic of humans; i.e. all humans fear. However, specific fears were expressed as well. These specified fears contribute to the conceptualisation of trust. According to O'Neill (2002a) in extreme situations such as terrorism, '*fear and intimidation corrode and undermine our ability to place trust*' p.25 (O'Neill, 2002a, p. 25). In the context of health care, unrecorded fear and anxiety was described as challenging the ability to trust hospital care (Pilgrim et al., 2011, p. 145). Fear was expressed in several case studies:

I believe all of us have fear. There is no one immune to it. (BIO12).

I do not trust the NHS to keep the information safe and secure and I have grave fears it being sold on to private companies. (Comment on article by Sophie Borland, 'NHS delays plan to harvest your details: Victory for the Mail as database is shelved for six months', Mail Online, 18 February 2014).

Religion and afterlife mediates trust. It is argued by some researchers that faith in God and trust in humans are distinct concepts (Seligman, 1997). The data suggest that faith influences a trusting relationship. As the quotes below suggest, faith in God or afterlife can play a role in the decision process of taking part in medical research. Both interviewee have no faith in God or afterlife respectively, hence they took part in medical research. Faith seems to frame trust as it pre-determines whether a person is likely to trust a certain programme, to the extent that the programme is in line with the person's own beliefs.

It's God's will, isn't it? Well, it might be God's will. I don't believe in him, anyway. So whatever happens, when I die, whether I go to the maker or not, as long as I can help somebody I'll be happy. (BIO8).

I think the, the point at which I carried a card was really [er] not being precious about my own body organs, for instance, and not believing in an afterlife, or that my organs would affect it even if I did. (BIO3).

With a similar effect, **people's world view** expressed by axioms, proverbs and what people think is 'natural' pre-determines their basic attitude towards trust. Such convictions might have an equal influence on trust as religion. This was expressed in quotes like:

But he did not believe in all of this 'doctor stuff' as he called it xxx took your blood, and xxx research, because he believed it was not natural.Wasn't natural at all. And of course with this belief he taught his children that, and this was xxx that no, it's evil, you don't do that. You don't mess about with what xxx etc. (FG1).

I tend to believe in the axiom "What can be done, will be done" (Comment on article by Claire Carter, 'NHS medical records database could help prevent disease, senior doctors say', Telegraph, 24 February 2014).

Public level framing themes

The public level theme develops in the public sphere.

Public mood influences public trust in health care systems as people compare health care systems to other systems. Suspicion of the government, fuelled by the financial crisis, terrorism, surveillance etc. can transfer to the health care system context. As the government is associated with different 'crises', people compare trust between different systems. Montinola (2004) has researched the context of distrust and corruption, and has described the spill-over effect of distrust from one agency to another (Montinola, 2004). Earlier, in 2002, O'Neill described public suspicion of governments and the resulting threat this posed to public trust (O'Neill, 2002a). This mood resonates throughout the care.data case study. On the one hand, it was pointed out that the word *crisis* seems to be fashionable in the media. On the other hand, comparisons were frequently made between the financial sector and health care system as well as distinctions between 'us' and 'them', including between elites and 'ordinary people'. Powerlessness of the 'little man' against the government resonated in the data, especially considering the following theme: *general expectations of the government to be trusted.* Readership comments were often cynical. The theme of public mood was developed from quotes such as:

With so many CRISES going on throughout the land. You would why people get out of BED?? We have his CRISIS of confidence, we have the Cost of living CRISIS, we have the flooding CRISIS, The cost of Housing CRISIS and so it goes on. CRISIS is obviously the Journalist word of the moment. (Comment on article by Sophie Borland, 'GPs warn

of crisis in public confidence over NHS database: Royal College warns health service of failing to inform patients about data sharing', Mail Online, 13 February 2014).

The reptilian ruling elite believe they own the human bodies they created on this physical level (but not the consciousness occupying the body) and so also own the all the medical information to do with as they please. (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

In the wider context of recent British politics, including the 2015 general election and the 2016 European Union referendum, the care.data readership comments were particularly interesting. Despite the discussion focusing on health care issues, the debate in the fora developed far beyond this issue. It seems that a huge gap exists between some readers and the government. The anonymity of the fora might have supported particularly harsh comments, however, maybe equally, very personal and honest opinions (Ong & Weiss, 2000; Speed, Davison, & Gunnell, 2016). The three quotes below only focus on trust. However, considering the number of readership comments (*n=1624*) it would be worth following up this particular issue in a future study. These comments vividly illustrate that the health care system is not protected against political influences and debate from outside its boundaries.

I believe we can but it's got to start with a Big Bubbly Curvy corporation. And it will mean installing a working man's government to get this kind of job done. And I believe Farage can not only do this but get us out of the EU at the same time. (Comment on article by Martin Beckford, ''Big Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

Here you see the great libertarian and enemy of the right defending the nascent police state. She cites, as most do if you have done no wrong you have nothing to fear (I am living proof that is a crock). But I think her final sentence is classic, 'EVERY FEAR HAS TO BE WEIGHED AGAINST THE PROBABLE GENERAL GOOD" - really? I believe that it was Benjamin Franklin, an individual far wiser than dear Polly, who said "those who are prepared to sacrifice some freedom for security deserve neither" he might as well have said get neither for that is where we are headed, Hitler and Stalin would be so very proud! (Comment on article by Sophie Borland, 'GPs warn of crisis in public

confidence over NHS database: Royal College warns health service of failing to inform patients about data sharing', Mail Online, 13 February 2014).

Since Bernard Ingham emerged from the shadows, we have known that national politics has been controlled by spin doctors. Blair turned it into a black-art form, Cameron (a PR man himself!) has tried and failed to out-Blair, Blair and frequently just looks incompetent. But the end result is that we trust nobody in power and in regard to Care.Data and many other important things, that is a tragedy! (Comment on article by Steven Swinford, 'NHS legally barred from selling patient data for commercial use', Telegraph, 28 February 2014).

Governmental level framing theme

The government level framing theme is the seemingly *general expectation that the government should be trusted* by the public. This expectation might have a normative character and threatens public trust. Imposing trust logically cannot work. A trusting relationship can only be established freely (Misztal, 1996, p. 29). To maintain a trusting relationship needs constant effort from both parties and trust needs to develop freely (Luhmann, 2009). Consequently, trust cannot be forced upon a trusting party. As discussed in Chapter 4, trust is voluntary. The perception that *the* government should be trusted might develop from a government becoming authoritarian and dictatorial leaving the public without any perceived choice. In the context of a default opt-in to care.data imposed by the government on the public, this scenario describes a perceived power distance as well as lack of choice which appears to have contributed to the feeling of being expected to trust. Nevertheless, it might be that the government designed and proposed the system based on a presumed opt-in, presumably mostly on the basis that the public would trust such a system because it was undertaken as part of and on behalf of the NHS (a trusted public service). Perhaps it was no more than an error of judgement since they may have confused the high level of public trust in the NHS with the level of public trust in the government more widely. This assumption needs further validation as the data are not informative enough. This expectation was expressed in quotes such as:

The finance industry is also very heavily regulated. All data has to be masked and anonymised. Yet another leakage and your financial data is again all over the web. Yet the Government expect us to trust a quango to do better with our very personal and private communications and records with our doctors. (Comment on article by Steven Swinford, 'NHS legally barred from selling patient data for commercial use', Telegraph, 28 February 2014).

You (politicians) *cannot rely on blind trust when it comes to sharing private medical records, so explain that you'll be coming back soon with a clear story.* (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 February 201

Effect themes of public trust in the health care system derived from the three case studies

Effect themes (in contrast to causal themes as defined in Chapter 3) are themes which describe the direct effect of a more or less trusting relationship between the public and the health care system. Underlying these themes is the general effect of trust as enabling action. Trust as a relational construct has the effect of legitimising action. For example, if the public trusts a programme embedded in the health care system (e.g. care.data, biobanks or the 100,000 Genomes Project), it will consent to take part in the programme. This consent enables the programme to use participants' information for research. Another effect of public trust is that people feel comfortable to provide personal data to a programme. *Participation* and *Legitimisation* developed from the themes *comfortable with providing data* and *consenting to care.data*. It might be hypothesised that both effects of the case studies are linked and consent results from a feeling of being comfortable: *public trust* causes people to be *comfortable with providing data* and this effect, in turn, causes them to *consent to care.data*. Abstracting from these themes and in line with wider trust theory, one can argue that public trust legitimises the actions of the health care system. The effect themes are shown in Table 6.17.

Table 6.17: Effect themes of public trust in the health care system

	Effect Themes	Explanation
1	Participation	Participation is an effect of trust.
2	Legitimisation	Participants legitimise based on their trust. Therefore, consent is understood as an effect of the level of public trust.

Comfortable with providing personal data was expressed in the focus groups as:

R6: It's trust. It's what you know.

R: You're not going to be completely

R6: There's not many options to go with that you don't know is there really that you would trust outside of a

R: About how comfortable you are trusting them with your data and obviously ultimately your money. [laugh] That your going to. (FG1)

Consenting to care.data is understood as an effect of trust. As described in the previous Chapter, the highly critical public discussion of care.data set up as a programme where all patients opted in by default led to expressed low trust. Consequently, people began to opt out:

I'm afraid I don't trust them to do things properly. Nor do I want any information related to me shared with Big Pharma, so I'm opting out. (Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

Gain their trust (i.e. their opt-in). (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 February 2014.)

The care.data set-up of opting in by default was one of the most discussed issues in the readership comments of the care.data case study. The word 'opt' was the ninth most used word in the readership comments. Considering the pivotal role of consent in relation to trust in health care and thus the success of research programmes, it is worth exploring this issue further with a short detour.

Comparing the *effect themes* of this research to other studies on consent and trust, the relationship of consent processes and public trust in health information sharing in the US context was researched by Platt and Kerdia (Platt and Kardia 2015). They investigated the characteristics of the so called 'trust fabric' between stakeholders, including the general public and researchers in relation to consent processes in an expanding health information system. The underlying problem, as discussed by the authors, is '*The idea that data and samples are collected for unknown future research projects strains current informed consent and data sharing models…in short, consent and data sharing operate on a one/form one/study model, while biobanking seeks to obtain consent and permission for data sharing for future research and/or for multiple projects*' (p.4). Following a questionnaire survey of 447 participants representative of the general public in 2013, they concluded that knowledge of health information sharing and concerns about privacy were the two key factors predicting low levels of trust (p. 15). In contrast, 'having a positive view on data sharing' was 'one of the strongest predictors of system trust'. This is supported by stakeholder engagement. They argue that '*durable consent will require trusting relationships and implementation of policies and procedures that increase transparency, assure the protection of privacy, and demonstrate trustworthiness by stating how data sharing improves health and quality of health care'* (p.16) (Platt and Kardia 2015). Focusing on the consent process itself in the context of research participation, Leach and colleagues (2016) discussed an alternative to the conventional prospective consent process in the form of the recently often discussed 'dynamic consent' model. The 'dynamic consent' model is a new approach to online prospective consent which might have potential to overcome the problem that a high level of trust is generally required to support a conventional consent process. By contrast, in a 'dynamic consent' process, online participants can adapt their consent in real-time and on an ongoing basis (Thiel et al. 2015; Leach et al. 2016).

A public opinion study of Australian adults about protecting the privacy of their health information in statistical databases concluded that respondents were primarily concerned about privacy of health information in medical research. The study was conducted in 2006 with 23 focus group participants and 700 national survey participants. Findings show that participants would like to know the research organisation and details of the research before consenting. However, privacy concerns decreased when extra security measures were put in place. Further, it was discovered that privacy concerns were not necessarily related to the nature of the consent process. Such concerns were more related to individual

circumstances and participants' level of knowledge about analytical methods, particularly the technical ability to link anonymous data back to individuals (King, Brankovic, and Gillard 2012).

Investigating similar questions, a telephone survey with 1,230 adults conducted in 2005 across Canada elaborated alternatives to project-specific consent for use of personal information for health research. The study asked: 'Does public trust vary across different types of research institutions?' (Willison et al.,707). The results were similar to previous findings in that public support for personal information use for medical research depended on the intended use and users of data as well as the safeguards in place. Additionally, when answering the question, 'How much trust do you place in the following institutions to keep any health information they have about you confidential?', government, drug companies and insurance companies were least trusted in comparison to disease-based foundations, hospitals and university researchers (Willison et al., 710). Willison et al suggested the following policy implications: 1. the need for legal recognition of the legitimacy of a broad authorization for future uses of personal information for research purposes; 2. an appropriate repository to track consent choices throughout the health care system; 3. safeguards and governance structures that would ensure that the consent choices of individuals are honoured; and 4. an appropriate method of eliciting those consent choices and keeping them up to date. (Willison et al., 711)

Haddow and Cunningham-Burley (2008) conducted 17 in depth interviews and ten focus groups investigating the meaning of trust among the Scottish public in 2003/2004 towards Generation Scotland, a program aiming to create a family and population-based infrastructure to identify the genetic basis of common complex diseases (Haddow and Cunningham-Burley 2008, 154,157). First, public engagement by Generation Scotland itself to increase public trust, identified as topical issues: open consent, data security and future use (p.155). Haddow and Cunningham Burley found that there is trust in the scientific process linked to *'normative expectations about the role of medical science'* (p.158). In contrast to trust in the future benefit of the project, future use was identified as an area which might undermine trust. Seemingly, future use was associated with human behaviour which was more critically looked at in comparison to the project benefit to society. Next to trust in the scientific process, so called 'home grown trust' was identified, referring to trust linked to Scottish ownership of the data. Here local experience and national pride played a role (p.160). Last, Haddow and Cunningham-Burley suggested

that ‘participation and donation of DNA can be conceptualized as a token of trust’ (p.160). By contrast, the lack of trust was found to be explained by examples where trust had been breached (especially by large organisations), unaccountable science and abuse of science, use and abuse of personal data, commercial access for health-related research and breaches of privacy (pp161-166). To generate trust, the study suggested that research bodies should use education and serious media, being transparent and providing feedback to participants, and finally to ensure ethical governance, regulation and public ownership of the data (pp 167-169).

Trust-reference-objects of public trust in the health care system

When looking once more at Tables 6.2, 6.8 and 6.12, presented above, showing the associated trust-reference-objects in the three case studies, it is notable that public trust in the health care system is not a bi-relational construct as described by *A trusts B to do (or not to do) X*. Trust-reference-objects can be sorted into several categories such as: Personal, Public, Personal encounter health system, Health system, National government, State, National level, International level and Other. The tables show that the trust-reference-objects are not exclusively anchored in the realm of a health care system. This observation confirms the model of public trust as developed in Chapter 5, where it was argued that public trust is shaped by many different actors in the public sphere. Also the trust-reference-objects have very different characteristics such as named persons, institutions, personal memories, unspecified, entire systems, or objects. The tables suggest that potentially public trust is formed by trust relationships between all the actors in the public sphere. Meyer and colleagues (2008) argued from an individual point of view that ‘*trust relationships can be understood as a complex web of interaction*’ (p.182) in which interpersonal and systemic sources of trust are both in play and cannot be seen as strictly separate domains (Meyer et al. 2008). This is equally true for public trust. The inherent complexity of the relationship cannot be reduced to a simple two-way relationship. This observation has implications for the parties in the trusting relationship.

To better understand the tables and provide some guidance, it is worth to consider a theory-supported example by asking: *Whom could a member of the public trust when consenting to future use of private data?* Bearing in mind that the case studies were based

largely on public trust in the use of data, this question focuses on that matter and incorporates the future orientation of trust. To support the exercise with a theoretical frame as well as providing theory-based guidance for the wider understanding of the tables of trust-reference-objects, the following engages with trust theory by Niklas Luhmann and Anthony Giddens, as well as Samantha Meyer's and colleagues' integration of their theories (Giddens 1990; Meyer et al. 2008; Luhmann 2009). These theories are deliberately chosen as they partly work in opposite directions, as described below.

Guiding the discussion, Figure 6.3 shows a simplified model of trust-reference-objects against a timeline. The reference-objects are: research professionals, the research institution, the health care system and the public. This timeline should illustrate the durability of the different trust-reference-objects where at point A (the present) the participant could trust the professional, the institution, the system or the public and in the very long term might be left simply having to trust the public as a whole, as the professionals may have died, the institutions might have changed or disappeared, and the health care system might have changed in such a way that it is not comparable with the prevailing health care system. Also the 'future public' will have changed. The assumption in this model would be that the public itself is the longest lasting trust-reference-point compared to the other three.

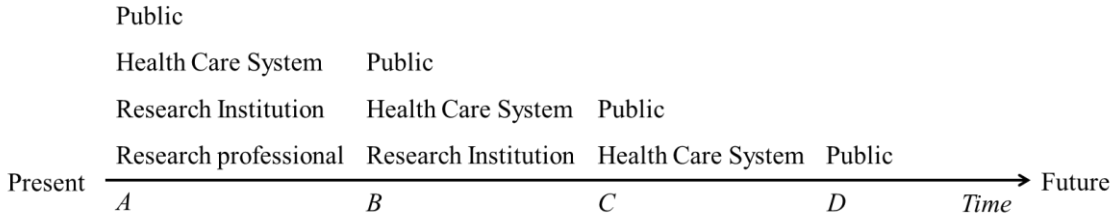


Figure 6.3: Hypothetical trust reference points over time

Three forms of trust come into play: first, interpersonal trust between the participant and the research professional; second, trust in systems where an individual trusts abstract (expert) systems, i.e. the research and health care systems in this case; and third, individual trust in the public (i.e. other people). Luhmann and Giddens differ when answering the question, *Which comes first – personal experience or wider trust?* Following Luhmann, I trust the research professional because I have confidence in the

health care system which is built on common social norms and values and follows legal, clinical and quality guidelines. Following Giddens, I trust the health care system because I have a trustful personal experience of professionals and they enable me to access the health care system (Giddens 1990; Luhmann 1988, 2009). From Luhmann's viewpoint, the participant trusts the health professional as s/he has confidence in the wider profession or the health care system as a system of laws, rules and regulations (Meyer et al. 2008). This allows the participant to trust a professional that s/he has never met previously. Giddens, on the other hand, views trust as arising through personal experience of trustworthy experts who have behaved with integrity in the past and who act as de facto flesh and blood representatives of the wider system (Giddens 1990). Giddens argues that interpersonal trust is required before system trust can grow and Luhmann argues, by contrast, that confidence in the system precedes interpersonal trust (Meyer et al. 2008). Meyer and colleagues (2008) expand both theories and argue that *'trust relationships can be understood as a complex web of interaction'* (p.182) in which interpersonal and systemic sources of trust are both in play and cannot be seen as strictly separate domains (Meyer et al. 2008). Causality can run in both directions, positively and negatively, and iteratively over time.

In light of the theory presented above, it can be postulated that certainly at point A, Luhmann's, Giddens' and Meyer et al's trust theories are valid. This is the case as all trust reference points are available for a research participant to trust. However, when moving towards the future at points B and C on the timeline, Giddens' theory is less applicable and trust is sustained more by Luhmann's understanding of individuals' level of confidence in systems. In this sense, Luhmann's trust theory has a more robust future-oriented perspective, as it does not so much build on inter-personal encounters, as on longer lasting professional rules and regulations which should guarantee stability, continuity and complexity reduction over a longer period. Also, even if an individual's initial access to, and experience of, the system is in the form of a personal encounter in Giddens' sense, future trust will be linked to how the system behaves more generally. For example, a research participant signs the consent form as s/he trusts that rules and regulations will be in place in the future that continue to reflect his/her view at the point of consent. Moving to point D, where the health care system might have changed to such a degree that it is not recognisable any more from the present viewpoint, the question arises, *To what or whom can a participant trust their data in the far distant future?* Even

apparently very stable institutions and legislation change and adapt over time. Therefore, one could argue that a research participant might consider that they are, in fact, making a decision to trust the public (which changes more slowly than individual institutions) over the specific researchers or research institutions present at the time of consent.

In conclusion, members of the public will have a trusting relationship with several trust-reference-objects. This implies that all engaged trust-reference-objects must acknowledge their role in the process of building trust and their contribution to the overall trustworthiness of the system. When looking at the future of a process, these present responsibilities will be equally true. However, it will most likely be the public itself who will need to contribute to the trustworthiness of a process or programme in the health care system in the long run. This is due to the understanding that the public forms the norms and values for future generations of professionals who will be responsible for shaping and maintaining a trusted programme. Further, the public will be responsible for legitimising future governments by elections which hold the power to form the health care system in accordance with the public's views. Last, the public itself and its active citizenship, including a public trust-building discourse, will wield the power which maintains the trustworthiness of an entire health care system. Thus the public ensures that the justification for the original act of trusting remains in place into the future. This implies that the public should build trust amongst its members (social cohesion) as well as trust in trust-reference-objects in the health care system. The health care system must recognise that it should be a common effort of all parties in the system to maintain public trust.

Conclusion

This chapter has presented and discussed the qualitative results evolving from the three case studies. Following the presentation and discussion of the conceptualising, framing and effect themes as well as the discussion of the wide range of trust-reference-objects, it can be concluded that:

- Themes carrying a social and public motivation referring to a net benefit for the public and system as a whole are distinctive themes of public trust as compared to other forms of trust.
- Themes address different levels of abstraction in the health care system, which means that some themes specifically address certain situations, and other themes are more unspecified and/or general.
- Despite themes relating to a certain actor, multiple actors (inside and outside the health care system) in the public sphere are related to the themes as part of a certain process or chain of actions.
- Information feeding into the conceptualisation of public trust develops from past experiences and present perceptions as well as anticipation of the future.
- The conceptual framework of public trust developed in this research consists of several known themes commonly associated with other forms of trust.
- As several themes are not unique to public trust, public trust has elements in common with other forms of trust.
- Trust cannot be rushed and trusted action should not be rushed.
- The conceptual themes reflect an understanding that public trust is largely a conscious choice.

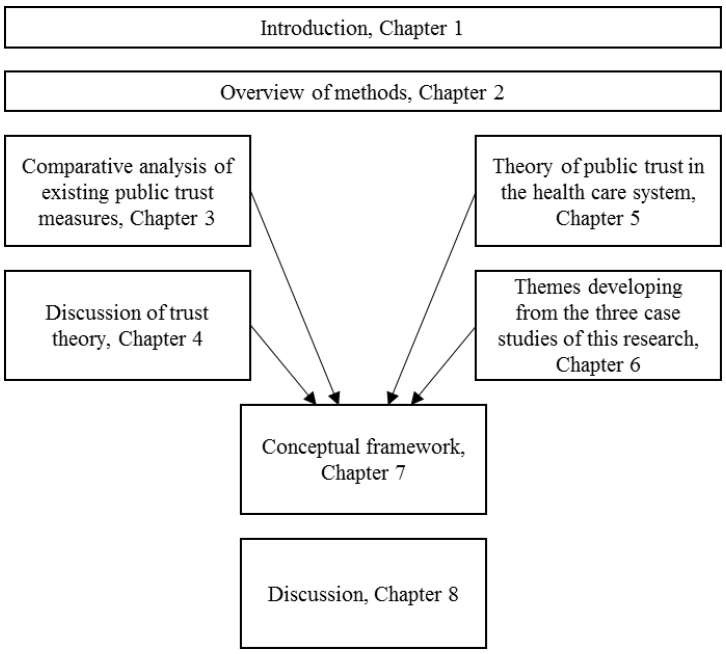
Chapter 7: A new conceptual framework of public trust in the health care system

Key findings

- Themes carrying a social and public motivation referring to a net benefit for the public and system as a whole are distinctive themes of public trust as compared to other forms of trust
- Information feeding into the conceptualisation of public trust develops from past experiences and present perceptions as well as anticipation of the future
- Despite the fact that qualitative data suggest that the public consciously decides to trust, a theme reflecting 'gut feeling' is included in the conceptual framework

Overview

A new conceptual framework of public trust in the health care system is developed in this Chapter by drawing new qualitative data and being informed by the findings of the previous chapters. In its simplest form, public trust can be summarised as a construct which builds on information relating equally to the past, present and future. As public trust is formed in the public sphere, public trust legitimises the actions taken in the healthcare system leading to an anticipated net benefit for the public and the health care system.



Introduction

This Chapter meets the objective:

- Objective 3.4: To conceptualise public trust based on objectives 1, 2, and 3.1-3.3, 4.

As shown in Figure 7.1, this Chapter presents a new conceptual framework of public trust in the healthcare system that is synthesised from the insights gained in the previous chapters. The leading sources are the themes developing from the qualitative case studies in the previous Chapter. This conceptual framework fills important gaps and is more detailed than those on which existing instruments to measure public trust have been based.

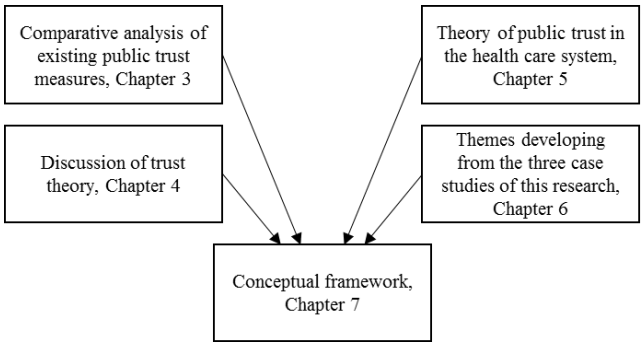


Figure 7.1: Sources used to conceptualise public trust in the health care system

To present and synthesise the conceptual framework, this chapter is structured as follows:

1. Description of how the previous chapters influence the method to synthesise the new conceptual framework of public trust in the health care system
2. Presentation of the full conceptual framework of public trust in the health care system

How previous chapters influenced the method to synthesise the new conceptual framework of public trust in the health care system

All previous chapters of this thesis informed the synthesis leading to the new conceptual framework of public trust in the health care system. The goal was to engage with all the information provided and to use the insights gained from the comparison of existing conceptual frameworks, the discussion of wider trust theory and the model describing the origin of public trust in the public sphere to inform, discuss and structure the qualitative results from the three case studies. This overall approach follows the guidelines described in Chapter 3 and ensures that empirical data have a central role (Aaronson et al., 2002; U.S. Department of Health and Human & Administration, 2009). In this work, the central role for empirical data was particularly important as theory and existing literature were either too abstract or limited and therefore not informative enough to conceptualise public trust in the health care system based on these sources only. The development process of the conceptual framework lasted over several cycles and over several months. To ensure the quality of the conceptual framework, the development process and preliminary versions of the conceptual framework were discussed in detail with my supervisors and PhD colleagues. Furthermore, parts of a preliminary version were presented at a national health services research conference as well as London School of Hygiene & Tropical Medicine internal work in progress meetings.

To describe in more detail how the previous chapters influenced the development process, the following will present a summary table (Table 7.1) showing the insight gained in the chapters above. When looking at Table 7.1 it is visible that across the different chapters some themes or aspects of (public) trust are dominant: autonomy, communication, the need for a reason to establish trust, time, and (truthful/quality of) information. Based on this observation one can argue that themes of the new conceptual framework of public trust covering these areas are important for the establishment of public trust, as discussed below. Hereafter, each chapter's contribution is described in detail to make better sense of the methods and thinking used, leading to the new conceptual framework of public trust in the health care system.

Table 7.1: Summary of insights gained from the previous chapters leading to the conceptual framework of public trust in this research

Chapter 3 **The comparative analysis of exiting public trust measures revealed the following conceptualising themes:**	**Chapter 4** **The discussion of trust theory revealed:**	**Chapter 5** **The development of a theory of public trust in the health care system revealed the following insights:**	**Chapter 6** **The qualitative analysis of three case studies revealed the following types of themes and trust-reference-objects:**	
Competence	Trust arises between a minimum of two individuals	Public trust is influenced by actors from outside and inside the healthcare system	**Conceptualising themes:**	**Framing themes:**
Cooperation between professionals	Trust can only develop by communication and truthful information	Public trust legitimises health care system's action	Active regulatory systems	Communication
Decision making	Trust develops in a free society and is voluntary	Public trust develops from public discourse in the public sphere	Anonymity	Fear
Development of profession	Trust is established for a reason	Public trust depends on valid information	Autonomy	General expectations of government
Efficient use of resources	Trust exists in the present, but is future-oriented	Public trust is linked to individual trust by someone's personal perception of both concepts	Benefit to others	Human error
Following advice	Trust is a risky ‘advanced payment’	Public trust in the health care system is distinct from other forms of public trust based on the underlying norms and values associated with health care	Certainty about the future	People's world view
Information	Trust enables action as well as grants autonomy for action		Familiarity	Public mood
Other	Trust reduces complexity		General perception of security	Religion and Afterlife
Professional behaviour	Trust and distrust can exist at the same time		Health system benefit	Risk
Quality of care	Trust is generally important for life, but its importance can vary depending on the situation		Information quality	Reason for the need of public trust
Reasonable costs	Trust and trustworthiness are not the same		Personal benefit	**Effect themes:**
Seeking a 2nd opinion			Privacy	Participation
			Public financial benefit	Legitimisation
			Recognised potential of the health care system	
			Respect	
			Time	

The contribution of the comparative analysis of existing public trust measures to the conceptualisation of public trust in the health care system (Chapter 3)

A comparative analysis of existing conceptual frameworks with the newly developed conceptual frameworks is considered as best practice (see Chapter 3). The comparison of the existing public trust measures revealed that present conceptual frameworks identify public trust as a relational construct between patients and selected health care system representatives. Building on the comparison presented in Chapter 3, now in more detail, the themes conceptualising public trust as developed in this research are compared with the existing conceptual frameworks of public trust following the Venn diagram in Figure 7.2, below.

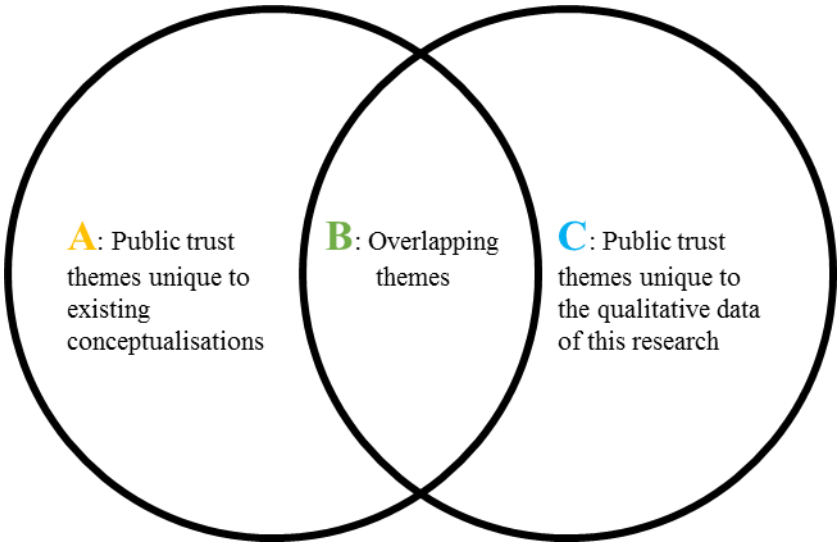


Figure 7.2: Venn diagram illustrating the overlap between public trust conceptualising themes as developed by previous research and the qualitative research of this study

Comparing the themes of the conceptual framework of this research against the themes from existing conceptual frameworks (see Chapter 3) is difficult, as the existing conceptual frameworks focus on patient trust in selected health care system contexts. This mirrors individual trust in parts of the health care system as described in Figure 5.2, Chapter 5. Looking retrospectively at the selection of the existing conceptual frameworks of public trust, one could argue with the insight gained throughout this research that the existing conceptual frameworks in fact do not qualify for this comparison, as they do not conceptualise public trust in the health care system. Nevertheless, the existing conceptual frameworks are described as public (social) trust conceptualisations in the accompanying publications and are the only conceptual frameworks available. The themes unique to the

existing conceptual frameworks should be reviewed carefully and not included in the new conceptual framework without further qualitative research to justify their inclusion. Nevertheless, the themes are helpful to explore further thematic areas and can be used as guidance into areas that are unexplored in this research.

An additional methodological difficulty emerges from the different levels of abstraction between the conceptual frameworks. As Figure 7.3 describes, questionnaire items of existing conceptual frameworks are at the level of the sub-themes of the current research. Hence, the conceptual frameworks need to be compared at this level. If one would use the key themes for comparison, the overlap between the themes would be much bigger, as it is possible to sort almost all questionnaire items into the key themes of the conceptual framework as developed in this research.

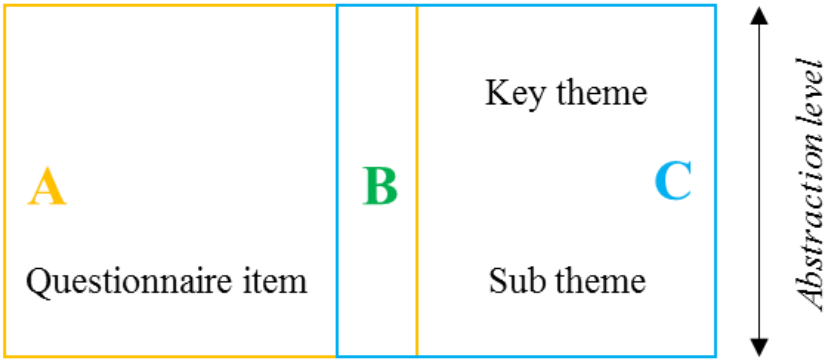


Figure 7.3: Illustration of different abstraction levels of the questionnaire items of existing conceptual frameworks of public trust and themes developed in this research

To aid readability, the comparison is presented in two tables: Table 7.2 presents the overlapping themes (indicated with an '**x**') between existing conceptual frameworks of public trust and the themes developed in this research (**B** and **C** in Figure 7.3). Table 7.3 presents public trust conceptualising themes that are unique to previous conceptualisations (**A** in Figure 7.3).

Table 7.2: Overlap between existing conceptual frameworks of public trust and the conceptual framework of this research

This research		Public healthcare system trust scale	Multidimensional Trust in Health Care System Scale	Public trust in Dutch health care
Key-theme	**Sub-theme**	**Anand & Kutty, (2015)**	**Egede & Ellis, (2008)**	**Straten, Friele, Groenewegen, (2002)**
Active regulatory systems	Denial of access to data by private companies			
	Government response to breach of data security			
	Regulation			
Autonomy	Choice	**X**		
	Personal control			
Anonymity	Anonymity			
Benefit to others	Altruism			
	Future benefit			
	Public benefit			
Certainty about the future	Certainty about future			
Familiarity	Confidentiality in the GP-patient relationship			
	Personal experience			
General perception of security	Existence of security measures			
	IT competence			
	Local storage			
	Perception of safety			
	Protection in numbers			
	Safe data handling			
	Unlawful data access			
Health system benefit	Advance in science			
	Improved quality of healthcare			**X**
Information quality	Clear information			
	Corroborated information	**X**	**X**	
	Explanatory information			**X**
	Honest information		**X**	
	Reliable source			
	Truthful information		**X**	
Personal benefit	Availability of help	**X**		
	Fear of negative consequences			
	Personal benefit			
	Reassurance			
Privacy	Privacy			
Public financial benefit	Financial benefit to the health system			
	Opportunity for reinvestment in medical research			
	Public funding			
Recognised potential of the health care system	Government integrating private companies with an overall aim			
	Professionals' ability to keep up with new knowledge			**X**
	Representative governance			
	Research by public institutions			
	Self-confident professionals			
	Structured project	**X**		
	Valid research			

This research		Public healthcare system trust scale	Multidimensional Trust in Health Care System Scale	Public trust in Dutch health care
Key-theme	**Sub-theme**	**Anand & Kutty, (2015)**	**Egede & Ellis, (2008)**	**Straten, Friele, Groenewegen, (2002)**
Respect	Data accuracy			
	Data kept in good condition			**X**
	Sensitive feedback			
	Professional reputation		**X**	**X**
	Respect for participants			
	Responsible management			
Time	Giving participants time to consider if they want to receive results	**X**		**X**
	Providing time for medical research			

Table 7.3: Unique themes of the existing conceptual frameworks

Anand & Kutty, (2015)				Egede & Ellis, (2008)		Straten, Friele, Groenewegen, (2002)			
ID	Questions	ID	Questions	ID	Questions	ID	Questions	ID	Questions
1	I believe my healthcare provider is technically competent.	18	The treatment expenses in my healthcare institution are reasonable.	1	My health care provider is usually considerate of my needs and puts them first.	3	Doctors will listen to their patients.	22	Doctors won't prescribe medicines too quickly.
2	My healthcare provider will give all the information available on the diagnosis and treatment of my illness.	20	I believe my healthcare institution has enough employees for providing health services.	5	I can trust my health care providers judgments concerning my medical care.	5	Doctors will always stick up for their patients.	24	Doctors won't do too few tests.
3	I believe that my healthcare provider will give me the right treatment.	22	My healthcare institution is a dependable one.	6	My health care provider will do whatever it takes to give me the medical care that I need.	6	Doctors will understand their patients' problems.	25	Doctors won't do too many tests.
4	My healthcare provider understands my economic and social conditions.			8	I can trust my health care provider's decisions on which medical treatments are best for me.	7	Cost-cutting will not be to the disadvantage of patients.	26	Doctors will give the patients the best treatment.
8	Even if my healthcare provider makes a mistake, I believe in him/her.			10	All things considered, I completely trust my health care provider.	8	Patients will be able to meet their own financial contribution requirement	27	Doctors will make the right diagnosis.
10	I believe that the health promotional messages given by my healthcare provider are valid or logical.			11	Health care payers are good at what they do.	10	Patients will not be the victim of the rising costs of health care.	28	Patients will get sufficient information about the effects of the treatment.
11	My healthcare provider listens to me patiently about my health problems.			12	When needed, health care payers will pay for you to see any specialist.	17	It is amazing the sort of operation surgeons carry out nowadays.	31	Patients will get sufficient information about the cause of their problem.
12	I think I can tell my healthcare provider everything, so that he/she can understand my condition better.			14	Health care payers will pay for everything they are supposed to, including treatment that is expensive.	18	Doctors are always looking for the right answer.	33	Doctors will make use of the patients' own understanding and insights.
13	My healthcare provider considers every patient equal.			15	Health care institutions only care about keeping medical costs down, and not what is needed for my health.	19	The right dosage will be given.	35	Doctors won't give conflicting information.

Anand & Kutty, (2015)				Egede & Ellis, (2008)		Straten, Friele, Groenewegen, (2002)			
ID	Questions	ID	Questions	ID	Questions	ID	Questions	ID	Questions
14	My healthcare provider will involve me in the decision-making process regarding my treatment.			17	When treating my medical problems, health care institutions put my medical needs above all other considerations, including costs.	20	Doctors won't prescribe medicines too late.	36	The tendency towards a high degree of specialization does not cause problems.
17	My healthcare institution has all the latest facilities for treatment and diagnosis.					21	Patients receive the correct medication.		

When looking at Table 7.2, it appears that there is some overlap between the themes developing from this research compared with existing conceptual frameworks. However, it is also visible that the conceptual frameworks are in large parts different. This is most likely due to the fact that existing conceptual frameworks focus much more on the patient-provider/doctor relationships and therefore include several specific themes describing this relationship.

Looking now at Table 7.3, four overarching categories of themes can be identified: first, effect themes that are not considered as conceptualising themes in this research; second, communication themes, which are not considered as conceptualising themes in this research; third, themes developing from the area of insurance and health care costs; and themes developing from the patient-doctor relationship.

The two effect themes from the studies by Anand and Kutty (2015), and Egede and Ellis (2008), suggest that an effect of a trusting relationship with a health care provider is that people follow the advice of the health care provider. Another effect theme is that a health care institution is suggested to friends. The *Friends-and-Family Test* was introduced in April 2013 as a quality and experience test in the English NHS (Dixon, Spencelayh, Howells, Mandel, & Gille, 2015; Sizmur, Graham, & Walsh, 2015). However, the test is only weakly (if not at all) associated with conventional quality measures of hospital care (Greaves, Laverty, & Millett, 2013; Manacorda, Erens, Black, & Mays, 2017).

Further, several themes in the existing conceptual frameworks build on communication which is categorised in this research as a framing theme. For example *Cooperation between professionals* can be understood as a necessity for the functioning of the health care system. Professionals need to communicate with each other and cooperate to make the health care system work, especially in processes and projects which combine several different actors in the health care system. If cooperation between the actors fails, public trust and system functionality is at risk.

Last, as the newly developed conceptual framework is based on data from the NHS where insurance companies (market actors) are less prominent system players, there is no overlap in the area covering trust in insurance companies. In this research insurance companies and alike developed as trust-reference-objects predominantly from the care.data case study and might be indirectly covered by the key themes *Active regulatory system* as well as *Public finical benefit*. Both themes 'regulate' private companies' impact and profit making within the health care system for the benefit of the public. More generally one can conclude that the questionnaire items in Table 7.3 describe detailed aspects of the patient-provider relationship. This content is covered by several key themes of the new conceptual framework such as *respect, recognised potential* or *information quality*, but not at such a detailed level as previous conceptual frameworks.

With the above in mind, the newly developed conceptual framework not only covers the content of the previous conceptualisations, but identifies unique domains not previously recognised as important in attempts to measure public trust, including*: active regulatory systems, autonomy, benefit to others, certainty about the future, familiarity, general perception of security and privacy*. The previous frameworks clearly omit themes that represent an anticipated net benefit to the public and the health care system, which was identified above as a distinctive characteristic of public trust. Nevertheless, the newly developed conceptual framework does not explicitly include themes conceptualising the influence of insurance companies on public trust, which would need to be considered, when transferring the conceptual framework to other health care systems where these actors are much more prominent compared to their role in England where the NHS dominates. Furthermore, since the case studies of this research deliberately do not focus on the direct patient – doctor/health care provider relationship, the newly developed

conceptual framework covers fewer themes describing this relationship as compared to the existing conceptual frameworks. To explore how and if these themes can be included would be the subject of further research.

The contribution of trust theory to the conceptualisation of public trust in the health care system (Chapter 4)

Trust theory contributed significantly to the conceptual framework of public trust in the health care system. The review of trust theory identified common elements across different theories as summarised in Table 7.1. In addition:

1. *the complexity of the concept of trust.* As discussed throughout this thesis, trust is a complex construct and is understood in many different ways. Its amorphous structure has the capacity to adapt to many different relational settings and change its conceptualisation accordingly, despite maintaining certain core characteristics. Given this observation, different trust researchers have conceptualised trust in many different ways and have partly argued in contradictory ways about the function of trust or how trust is developed. Deriving from this observation, the conceptual framework developed in this research was developed with a very open understanding of what trust is, and the awareness that trust can be understood in many different ways. This recognised complexity influences the understanding of how abstract the final conceptual framework should be and that a too narrow conceptual framework will only be applicable in exactly the same context where it was developed.

2. *the function of trust.* Trust theory always discusses the function of trust. Trust as a relational construct is bound up with an understanding of time and is generally understood as a function of *A* trusting *B* to (not to) do *X*. Here, trust leads to an anticipated outcome as well as having a function itself for the relationship between the trusting parties. Results from the case studies equally provided insight into the anticipated effect of trust, but to a lesser degree provided an understanding of the function of trust between the trusting parties. This is because the case studies provided data about one side of the relationship only.

3. *the process of learning to trust.* Trust theory provided some insight into how trust develops over the life course which was absent from the three case studies which were both cross-sectional and among adults in the main, or at least not specifically targeted on children or young people who might have been learning how to trust. An understanding of trust from a psychological perspective is important to better understand the themes emerging from the empirical work, especially in respect of their robustness to external influences. Certain themes are likely to be highly related to personal traits rooted in early childhood development, which implies that those themes (e.g. personal conviction) are less likely to change in response to present influences (e.g. health policy).

4. *the understanding of trust and similar terms.* Despite having a colloquial understanding of what the differences between trust and similar terms are, reviewing trust theory shows that this colloquial understanding is not necessarily reflected in the literature. Further, the understanding of what the conceptual differences and relationships between trust and similar terms are differs between theories. Treating trust and similar terms as equal concepts to conceptualise public trust allows for the use of a wider scope of terms and hereby detect a wider spectrum of conceptualising themes. This implies that the framework covers the entire conceptual space and, in psychometric terms, this will ensure that any eventual measurement instrument has content validity.

5. *the relationship of trust with other wider concepts such as social cohesion and religion.* Reading trust theory allows a better understanding of the relationship of trust with other concepts and how trust is understood in other disciplines such as economics, political science, psychology, etc. Especially in the context of public trust research, two other concepts are worth considering: social cohesion and religion. The relationship of social cohesion and public trust is generally discussed and public trust is understood as a catalyst for social cohesion. The relationship of religion and trust is valuable to understand, on the one hand due to the cultural and historical development of trust as a concept which might have developed from faith, and, on the other hand, because the relationship of faith in God and trust in humans nowadays has potentially an impact on trust, as religious conviction can strongly influence trust in humans.

6. *The difference between conscious decision and instincts: adding the conceptual theme 'gut feeling' to the conceptual framework of public trust.* Partly linked to the previous point, the understanding of how trust is decided at a personal level has shifted over time from theories based on appeals to intrinsic motivation to a conscious and somewhat calculated decision to trust. Most modern trust theory argues broadly in line with some version of rationality. Current conceptual frameworks of public trust in the health care system also represent a calculated conscious decision as the basis on which trust forms. However, when considering the historical development of trust, it is worth considering that present conceptualisations should incorporate a theme representing instincts or gut feeling. Hypothetically, it is short-sighted to assume that on a public level all trust is based solely on calculated decisions, given the complexity of the construct and the impossibility of taking all variables into account to make such a decision. People trust, in part, based on gut feeling or instincts which is described in the literature as *intuitive trust* (Ma-Kellams & Lerner, 2016). As a result, a conceptualisation of public trust in the health care system should include this form of motivation. This might be covered in part by the framing theme referring to axioms and personal convictions. It is likely to be inadequate to develop a conceptualisation of trust purely on the idea that trust develops from calculated decisions. How far instinct or gut feeling influence public trust in comparison to fact based calculated decision remains unanswered in this research. However, humans make decisions that are not purely fact-based and rational. Sometimes, people include other forms of motivation to decide to trust. Hence, this theme should be included in the framework for now, but future research needs to test whether gut feeling is a framing theme, indeed a conceptualising theme or an effect theme. Further, it needs to be tested how far intrinsic motivation can be included in the paradigm of calculated decision making. Also, one could think of trust being developed based on a gut feeling, as an alternative paradigm to trust being developed on the basis of calculated decision making. If one would follow this thought, a gut feeling would open an alternative conceptual framework based on intrinsic motivations, emotions or feelings, which might substantially differ from the conceptual framework as developed in this research. For now, ***gut feeling*** should be included in the conceptual framework as a conceptual theme and future research needs to verify its location in the conceptual framework.

7. *the contribution of trust theory to the separation of conceptual, framing, and effect themes in the qualitative data of Chapter 6.* The themes that developed from the case studies were sorted into three categories: framing themes, conceptualising themes and effect themes. To identify effect themes is fairly easy compared to separating framing themes from conceptualising themes. An understanding of trust theory was helpful to identify what others have understood as framing themes. In the end, the separation process was informed by the data themselves, discussions with other researchers and by trust theory.

8. *the distinctive characteristics of public trust.* Trust theories provide a good understanding of the defining characteristics of different conceptualisations of trust, for example, interpersonal trust versus individual trust in systems. Considering that public trust incorporates interpersonal trust as well as individual trust in systems, trust theory is necessary to understand the common themes and the distinctive characteristics of different forms of trust. When examining empirical data only, especially in the form of a secondary analysis, it is difficult to determine which themes are distinctive and which themes are common themes. This is where trust theories can be helpful (see Chapter 4).

9. *the generalisability of research findings.* The conceptualisation of public trust developed in this research is based on three case studies. One would assume that the conceptualisation mirrors trust relationships in these specific contexts. So, it is important to understand how far the findings of this thesis are generalizable to other health system settings, if not all health systems. Trust theory can help to assess how far the conceptualisation of public trust in the health care system represents other conceptualisations of trust in other disciplines and different health care settings. Whereas other research articles are informative for comparing the current conceptualisation to other conceptualisations of public trust in the health care system, theory can help to understand how far the conceptualisation mirrors trust theory more widely. Last, a review of trust theory can help to link the conceptualisation to existing theory and to explain which theories have influenced the newly developed conceptualisation. This allows the location of the newly developed conceptualisation in relation to previous conceptualisations and the explanation of its competitive advantage.

Researching public trust with the goal to conceptualise public trust in the health care system cannot be done without a review of trust theory. Trust theory develops an understanding of the complexity of trust research and provides insight into the function of trust in different settings. Further, trust theory informs the conceptualisation process of public trust and helps to identify the distinctive characteristics of public trust compared to other forms of trust. Last, trust theory helps to locate the newly developed conceptual framework amongst existing conceptualisations of public trust and also provides the opportunity to identify how and with which existing theories the newly developed conceptual framework is linked. In conclusion, trust theory is essential to inform the conceptualisation process and to reinforce the generalisability of the newly developed conceptual framework. The theory shows that the new conceptual framework is related to other forms of trust, but a distinct conceptual framework of public trust.

The contribution of the public trust in the health care system model to the conceptualisation process of public trust in the health care system (Chapter 5)

The model developed in Chapter 5 implies that public trust develops by public discourse, and therefore the conceptualisation of public trust in the health care system needs to tie in with this understanding. A summary of the findings is presented in Table 7.1. In particular Chapter 5 contributed to the understanding that public trust is not only influenced by trust-reference-objects inside the health care system, but also by trust-reference-objects outside the health care system. Chapter 5 described how public trust develops in the public sphere and how it is shaped, in contrast to the qualitative data of Chapter 6 that describes what public trust constitutes. This insight is important to consider when discussing the trust-reference-objects that evolved from the three case studies. Furthermore, the model helped to better understand the framing themes.

The contribution of the qualitative themes developed from the three case studies to the conceptualisation process of public trust in the health care system (Chapter 6)

The new themes and trust-reference-objects that developed from the three qualitative case studies are significant as they provide the thematic basis for the conceptual framework. The themes show how public trust is conceptualised, framed and what its possible effects are. Further, the trust-reference-objects indicate that a wide range of actors in the public sphere influences public trust.

Now the new conceptual framework of public trust in the health care system is presented.

A new conceptual framework of public trust in the health care system

Figure 7.4 shows the full conceptual framework.

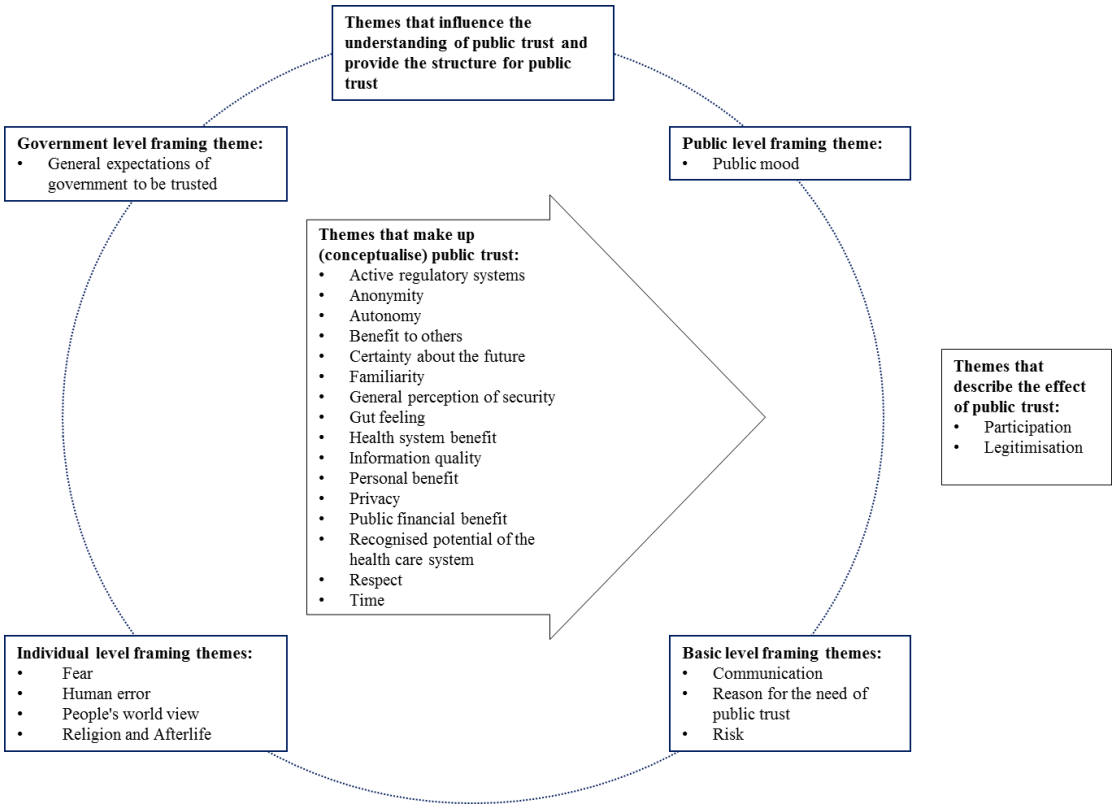


Figure 7.4: Conceptual framework of public trust in the health care system

Figure 7.4 shows that the concept of public trust consists of 16 (causal) conceptualising themes of which 15 developed from new qualitative data and one theme 'gut feeling' was included based on reviewed trust theory only. The conceptual themes are framed by nine framing themes which are categorised in four groups: basic level framing themes, individual level framing themes, public level framing themes and government level framing themes. Last, the conceptual framework consists of two effect themes of public trust describing the legitimising effect of public trust as well as the participatory effect of public trust.

Public trust develops from ongoing communication in the public sphere as outlined in Chapter 5 and builds on the conceptualising themes leading to the effects of public legitimisation of the trusted system as well as public participation in the trusted system. The distinctive characteristic of public trust as compared to other forms of trust is that public trust is developed in anticipation of a range of benefits, specifically a net benefit for the public and the system. It is safe to say that all conceptualising themes are equally important though their importance is likely to differ in specific cases, which resonates with general trust theory describing that trust is variable, see Chapter 4. In this research, there are no data that would enable one to distinguish between each of the conceptualising themes in terms of their relative importance. However, when comparing the chapters with each other, one can argue that themes covering *autonomy*, *communication*, *the need for a reason to establish trust, time, and (truthful/quality of) information* are dominant, see Table 7.1.

Underlying the themes is the understanding that public trust is a relational construct that develops in a free society from information relating to the past, present and anticipated future (see Chapter 4). Further, the results of this research with respect to the range of trust-reference-objects identified indicate that public trust is influenced by many actors, and not just by people themselves and health care system representatives. In addition, the data show that public trust is not purely intrinsic trust.

When integrating this framework (Figure 7.4) into the model describing where and how public trust develops (see Chapter 5), Figure 7.5 below shows both models combined. Simplified, one can say that the model from Chapter 5 describes *where public trust comes from* and the framework above (Figure 7.4), *what public trust consists of.*

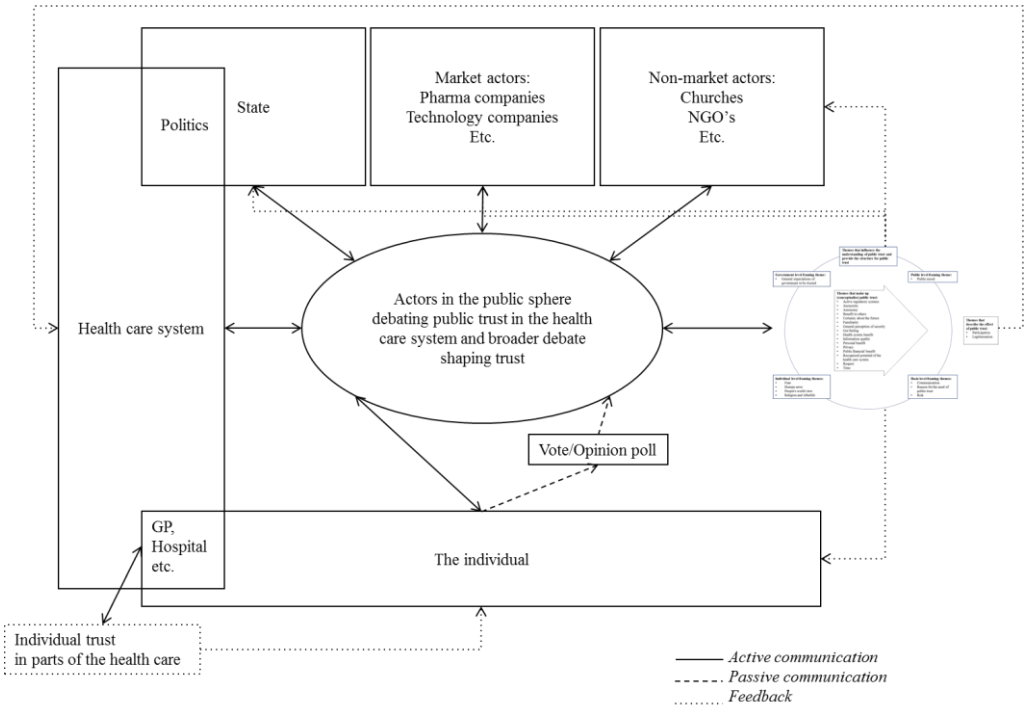


Figure 7.5: The combined model of public trust based on Chapter 5 and Chapter 7

Looking at Figure 7.5 and considering the case studies of this research (care.data, biobanking, and the 100.000 Genomes Project), one can argue that the case studies made it actually possible to conceptualise public trust. The three case studies overlap with different areas of Figure 7.5: the care.data case study covered most of the model. The biobanking case study covered much more the market actors, health care system, and the individual. Last, the 100.000 Genomes Project case study covered similar areas like the biobanking case study, but covers in addition the state. It is safe to say that the case studies altogether, covered actors from the entire model. Hence, as discussed below in Chapter 8, the conceptual framework is generalizable across the entire health care system and a robust representation of what public trust is.

The following chapter will discuss the implications of this research for policy making and for measurement and sets out some topics for future research.

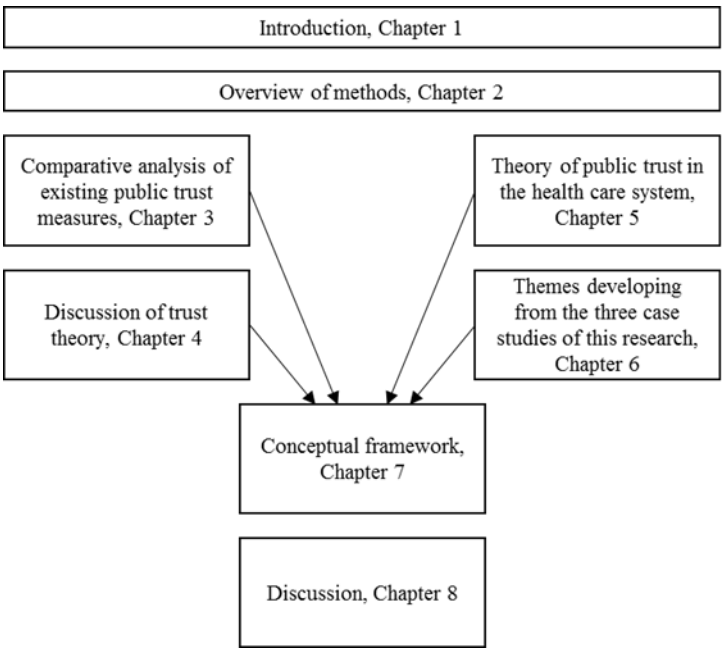
Chapter 8: Discussion

Key messages

- When developing health policy, policy makers need to recognise that public trust is central to their work
- Public trust can only develop if all health care system actors work together
- Public trust is measurable

Overview

As public trust develops from open debate in the public sphere, public trust legitimises the action of the health care system. If high levels of public trust are not maintained, the health care system is at risk of wasting resources, if not failing altogether: public health and social cohesion will deteriorate as a result. It is important for policy makers to understand that the act of trusting requires the public to expect a net benefit for themselves and the health care system. Further research is needed to develop a public trust measurement instrument that can be used to monitor changing levels of public trust in the health care system.



Introduction

This research has aimed to contribute to the theoretical and conceptual understanding of public trust in the health care system given the limitations of existing work in this field. The motivation to measure public trust developed from the need to understand levels of public trust in the health care system as public trust is not only related to health outcomes but also legitimises the operation of the health care system, as discussed in the previous chapters of the thesis. As this research was influenced by earlier research and theory, it is reasonable to say that the findings of this research relate most closely to the empirical work of Straten, Friele, and Groenewegen (2002) and, from a trust theory perspective, the work of Luhmann (1968), Misztal (1996) and Sztompka (1990). On the measurement side, the thesis makes the case for the importance of a clear conceptual framework. This research builds on and enhances the conceptual criteria of well established instrument development guidelines, see Chapter 3. In particular, this thesis adds to the understanding of the crucial role of theory for the development of conceptual frameworks designed for eventual use in measurement. It was possible to show the limitations of previous conceptual research in this area in that it focused too much on the patient-provider relationship and therefore missed large parts of the concept of "public" trust (see Chapters 3 and 5). The conceptual framework developed in this research incorporates the entire public and the entire health care system, and describes public trust deriving from an open public debate in the public sphere. Reflecting on Chapter 4 and the distinction between trust and trustworthiness, the conceptual framework developed in this research describes public trust and not the trustworthiness of the health care system only. This is so as the conceptual framework is not limited to attributes of the health care system to be considered as trustworthy, but also incorporates the effect of public trust as well as what frames public trust. Also from a methodological viewpoint, this research did not focus on the health care system only. Rather the trusting relationship between the public and the health care system was of interest.

This chapter will discuss the generalisability of the findings, and the strengths and limitations of this research, before outlining the implications of the findings for health policy making, the measurability of public trust, and the implications for existing trust theory. Lastly, a preview of future research is provided.

Generalisability of the research findings

The three case studies were chosen specifically on the grounds that they were likely to allow public trust in the system to be studied empirically, in that issues of public trust were likely to loom large in these cases. As the case studies are located in the field of biomedical research and large scale data use, the empirical data used to contribute to the conceptualisation of public trust are limited to this specific field. However, existing trust theory and trust research were an integral part of the development of the conceptual framework alongside the case studies in order to increase generalisability beyond the three case studies. As a result, there is both similarity and some important differences between the themes conceptualising public trust and those found in previous conceptualisations of individual trust in health care systems as well as interpersonal trust in other settings (Kelly et al., 2005; Ozawa & Sripad, 2013; Zheng, Hall, Dugan, Kidd, & Levine, 2002). Further, it is difficult to find other case studies that are not about individual patient care (which was explicitly an exclusion criterion for the choice of case studies for this research). Therefore, the case studies are good examples of settings where public trust becomes visible. Given the comparison with other studies on public trust and how their authors conceptualised public trust (see Chapter 1 and 3), it is unlikely that other contexts (e.g. public trust in organ donation or vaccination) would produce radically different themes. Naturally, there are a few themes which emerge from the empirical data which seem context-specific (e.g. themes relating to altruism or data use) and other contexts might produce some extra themes around the margins of the conceptual framework (e.g. in extreme situations such as emergency care), but there are good grounds for the view that the conceptual framework of this thesis should hold and be generalizable across the NHS.

How far the conceptualisation can be used in cultures and health care systems other than the NHS remains unanswered. It needs to be considered that in other cultures expressions of trust could be very different. This would result in very different themes and operationalised questionnaire items. Also concepts are sometimes not equivalent across cultures. It is important to focus on the equivalence of concepts rather than just translation of language when transferring the conceptual framework to other cultures. To transfer the conceptual framework to other cultures necessitates further empirical testing. However, established trust theory suggests that the conceptualisation will be most applicable to

societies with similar norms and values as well as a similar understanding of what a health care system is and should be (Fukuyama, 1995). Two criteria for the generalisability of the findings to other health care systems are: a) the principles and values of the health care system itself; and b) the degree of social cohesion in the relevant society and thus the willingness of individuals to engage in public discourse on trust. Maybe somewhat specific to this research context and concerning the principles and values of the health care system in England, the findings revealed that, in the mind of the public there seems to be a strong feeling of public ownership of the NHS. Hence, the public understanding of a seemingly sharp division between public health care and private companies influences public trust. Further, people are generally very proud of the NHS. After all, some people see the NHS like a religion (Barer, 2016; The Lancet, 2009). This perception of the English public partly explains why people willingly and somewhat passionately express their views on the NHS. With respect to social cohesion and the willingness to engage in public discourse about trust, it is clear from the conceptualisation of public trust that communication is essential. If individuals do not engage in public discourse the conceptualisation is likely to fail. Again, this research suggests that in England people discuss trust issues relating to the NHS in public in a passionate manner.

The conceptualisation also builds on an understanding of an open health care system with different actors in the public sphere (compare Chapter 5 and 7). Therefore, it is plausible to suggest that the conceptualisation is applicable to similar but not identical systems (e.g. in Denmark or Finland) and even less similar systems in terms of their architecture but with similar in goals such as in Germany or in the Netherlands. Other research suggests that, in principle, one conceptualisation of public trust can be used across health care systems and therefore such a conceptualisation is generalizable (van der Schee et al., 2007). From a social cohesion perspective, it is plausible to say that the conceptualisation will largely be applicable in societies with a similar or higher degree of social cohesion.

To strengthen the generalisability of the conceptual framework further, future research is needed to refine and test the system features and political as well as public conditions that shape public trust in the health care system. As identified in this research, many actors from outside the health care system are influencing public trust in the health care system. Hence, it is important to understand how this influence manifests and impacts the conceptual framework.

Last, it should be considered that the conceptual framework and model of public trust is not aiming to cover in detail the conceptual framework of individual trust. As described in chapter 5, individual trust plays an important role for the development of public trust, yet both are distinct concepts. The raison d'être for each concept is different. Individual trust describes a trusting relationship between one individual person and another person or system (see chapter 4) and public trust describes the relationship between a group of people (i.e. the public) and the health care system.

Strengths and limitations of this research

Throughout the previous Chapters, strengths and limitations of the methods were discussed. Now the general strengths and limitations of the thesis are outlined.

Deliberate simplifications to support the overall outcome of this research

The public, the health care system and trust as a relational construct between the two are highly complex concepts and difficult to describe in one grand theory of public trust. Consequently, any research on public trust in the health care system is subject to constraints and deliberate simplifications. As the focus of this research is on public trust, simplifications were made when describing the public as individuals debating in the public sphere and the health care system as an open system consisting of different actors who engage in public debate in the public sphere. Due to the simplification, this research does not engage with the composition and dynamics of the public itself or detailed discussions of theories of democracy. Probably, the composition of cultures and backgrounds of individuals acting in the public sphere will affect the discourse itself. Given previous research on the public, the health care system and how they interact, the simplifications were considered as reasonable and valid (Crossley & Roberts, 2004; Habermas, 1990, 1995; Stevenson & Scambler, 2005; White, 1990). These simplifications benefit the overall outcome of the research as they allow the focus to be much more on the complexity of public trust.

Trust terminology

It was decided to treat trust, belief, confidence, faith, hope and love as if they were synonyms in the empirical work, since there was little or no clear definitional distinction made between these terms in previous conceptual work (see Chapter 3). Also the data, as well as other researchers, show that people use the terms interchangeably in colloquial speech. A disconnect exists between the use of the terms in colloquial speech and trust theory (Pilgrim et al., 2011). Consequently, the study remained faithful to this pattern of verbal usage, which is central to the methodology of this research. While a linguist might be able to separate out the different terms and their nuances, in this particular study, this ability is negligible. The advantage of this approach is that it allowed a wider scope of themes to be identified as related to trust, thereby enabling a broader conceptual framework to be developed.

Using data that were not primarily collected for trust research

The choice to use qualitative data that was not primarily intended for trust research has several technical advantages and disadvantages that are inherent in the method (see Chapter 6). Using this data is considered as a particular strength and a distinctive feature of this study since the nature of the data implies that the participants and readership talked about trust in a more natural way. One of the difficulties of collecting data on concepts such as trust is that as soon as one sensitises participants to the purpose of the research, this alters the way they talk about trust. Based on the general research experience, it is also difficult to ask people to talk about relatively abstract phenomena such as public trust. The downside of this data is that it is not possible to probe in greater detail to understand the intrinsic motivation and personal experiences leading to the comments on trust or the responses in the interviews. However, as the data were generated in the course of a conversation context, the comments generally provide some information that helps understand why the word trust (or a similar term) was used. Furthermore, the wide-ranging review of trust theory compensated for some limitations of the data analysis, where the data were not informative enough. In addition, the reviewed theory provided good insight into the societal function of trust.

What are the implications for policy makers and managers of the findings of this research if they wish to maintain and build high levels of public trust in the English NHS?

The following policy implications are intended to help policy makers and managers if they wish to build and maintain high levels of public trust in the English NHS and similar health care systems. The policy implications are formulated from a general viewpoint on the entire health care system. The policy implications develop from the conceptual framework as presented in the previous Chapter. To explain where the implications develop from, the following will draw on the previous chapters and summarise previous points made where necessary as well as cross reference to previous chapters. The first six policy implications relate to the framing themes and different actors (trust-reference-objects). The remaining policy implications relate to each key theme of the conceptual framework and are therefore much more specific.

Policy implications 1 to 6, developed from the framing themes and the identified trust network

> **1st Policy implication:** *Communicate with the public to win public trust in a policy.*

Public trust is a communication-based, relational concept between the public and the health care system, which evolves from free and open public debate in the public sphere. The defining feature of public trust in contrast to other forms of trust is the expected net benefit for the public and the health care system as result of the trusting relationship. In public debate, individual members of the public (healthy individuals as well as patients) and different actors from inside and outside the health care system (e.g. doctors, health charities or global software companies) come together to discuss personal as well as collective experiences and perceptions of the health care system which shapes public trust in the health care system through a process of debate. As communication is central to building public trust, exchange of information is pivotal. This is so as public trust is mainly understood to be a calculated conscious decision based on truthful information. However, the understanding of public trust being a 'rational' conscious choice should not be taken for granted as trust can be partly if not entirely motivated by instinct. Also, it

should be recognised that religion or any other conviction has the potential to predetermine whether or not individuals engage in a trusting relationship given their understanding of whether such a relationship would be in agreement with their religion or convictions. Nevertheless, the information which is used to decide to trust relates likewise to past experiences, present perceptions and future expectations. Hence, the communication needs to contain insight into the anticipated net benefit, contain information about how the policy will be implemented and how the policy relates to past policies. Also, this information needs to contain insight about the content of the policy implications, below. In the context of this research, the leaflet which was distributed to the public about the care.data programme clearly did not relate sufficiently to past experiences (NHS, 2014). The information provided was rather superficial in explaining the present mechanisms in place to guard the care.data programme and there was little information on how future expected benefits would be achieved. Furthermore, it seems that public consultation (as a form of two-way communication between the health care system and the public) took place after the leaflet had been distributed and when the programme organisers realised that the information campaign was failing (National Data Guardian, 2016). The conceptual framework of public trust suggests that these types of communication as described above need to happen before a policy is to be implemented. It is important to understand that communication is the only way to inform the public and hereby influence public trust itself.

2nd Policy implication: *Observe and care about public trust.*

As the debate in the public sphere is open to all members of the public and actors in society, the debate legitimises state action, i.e. health care system governance. The fact that public trust legitimises the actions of the health care system should be the central reason why policy makers and the government care about high levels of public trust and engage in building public trust. If public trust in the health care system or parts of the health care system is missing, the health care system, including the government, is at risk of failing as it risks being increasingly perceived by the public as lacking legitimacy (e.g. the failed NHS care.data programme). Subsequently, the public will withdraw its mandate including the associated governing powers. An equally important reason to maintain public trust is the fact that high levels of public trust are associated with lower transaction costs, better health of the public and a higher degree of social cohesion (Arrow, 1974; Fukuyama, 1995; Papakostas, 2012; Putnam, 2000).

3rd Policy implication: *Take into account actors and events or trends in the wider society from outside the health care system that potentially influence public trust in the health care system.*

The health care system is not a closed system and therefore actors who are not naturally associated with health care can influence public debate and shape public trust in the health care system. Usually, the health care system is understood to be governed by the government which makes the health care system susceptible to spill-over effects of low levels of public trust in other societal systems which are equally associated with the government (Montinola, 2004). As described in the previous Chapter, public trust is not exclusively shaped by health care system actors, but also by other actors even at a global level. Hence, as well as focusing on actors within the health care system, it is worth engaging also with actors outside the health care system and to include these in policy processes or recognise their potential role in the public trust building process. Here, collaborative approaches are preferable which cross the conventional borders of health care systems. If health policy makers want to remain influential in the debate, the findings suggest that they need to engage with respective actors at an early stage, engage firmly in public discourse and not withdraw from public debate.

4th Policy implication: *Work together and in a coordinated way with a wide range of actors to maintain public trust.*

All links in the chain of health care action need to work together to build public trust. For example, when a research nurse is drawing blood from a research participant, but cannot answer in broad terms why the research project will need the blood sample, this can undermine trust. The responsibility to maintain and increase public trust is spread equally across the system or processes. It is false to assume, from a public trust perspective, that responsibility can be passed on to others in the hierarchy of a health care system or that the actors at the top of the hierarchy can act successfully in isolation or in their own interest.

5th Policy implication: *Adhere to democratic principles and altruistic motivations.*

The public expects that the government will represent the public interest and organise a health care system driven by altruistic motives at all levels of the system. In a public trust relationship, the health care system needs to act in such a way that the public can expect to benefit from its actions. The relationship between the government and the public fails as soon as 'the health care system' is perceived as acting in its own interest. This would mean specifically that the public feels betrayed by the health care system's representatives (e.g. politicians). Naturally, betrayal undermines trust. It is a necessity that health care system representatives are seen and believed not to be acting in their own interest, but in the interest of the public by following democratic principles such as the 'Nolan Principles'[4] (Committee on Standards in Public Life, 1995).

6th Policy implication: *Different forms of trust can coexist in the health care system.*

With respect to the concept of public trust, it is important to understand that public trust accommodates several other forms of trust that are essential for the development of public trust, namely: self-confidence, interpersonal trust and individual trust in the health care system. Self-confidence is important to be able to engage in any other trust relationship. Low levels of self-confidence are understood equally for both parties (in the case of the public, self-confidence is likely linked to identity and pride) in the trusting relationship to hinder the establishment of trust (see Chapter 4). As the public consists of private persons engaging with health care system representatives or knowing people who engage with health care system representatives, interpersonal trust, as well as individual trust in the healthcare system, are of crucial importance for public trust. Here, partly linked to policy implications below, it should be considered that a heavy-duty regulatory system aiming to reassure the public could be onerous to professionals and affect their relationships with individual patients. This implies that policies aimed at building public trust should also consider their impact on the individual and interpersonal relationships such as those between individual patients and their clinicians.

[4] Selflessness, Integrity, Objectivity, Accountability, Openness, Honesty, Leadership, (Committee on Standards in Public Life, 1995).

Policy implications of conceptualising themes

Turning to the conceptualisation of public trust, this research identified 16 key themes which can be reviewed in the previous Chapter, summarised in Table 8.1. The policy implications of themes* relating to privacy will be discussed together and of themes** referring to net benefit will be discussed together.

Table 8.1: Key themes contributing to the concept of public trust in the health care system.

Key themes conceptualising public trust in the health care system:	**Explanations**
Active regulatory systems	If regulatory systems are in place, then people trust more.
Anonymity*****	If private data is anonymised before shared within the health care system, then people trust more.
Autonomy	If health system actors enable people to maintain autonomy, then people trust more.
Benefit to others******	If action is benefiting others, then people trust more.
Certainty about the future	If researchers and officials do the best they can do to foresee risk in the future, then people trust more.
Familiarity	If people have positive experiences with the health care system, then people trust more.
General perception of security	If the health care system is perceived to be secure, then people trust more.
Gut feeling	If peoples' gut feeling 'tells' them to trust, people trust more.
Health system benefit******	If action is benefiting the health care system, then people trust more.
Information quality	If truthful and honest information is provided, then people trust more.
Personal benefit******	If action is benefiting the individual, then people trust more.
Privacy*****	If people's privacy is maintained, then people trust more.
Public financial benefit******	If health care system's action is benefiting the public health care system, then people trust more.
Recognised potential of the health care system	If a potential is recognised in the health care system, then people trust more.
Respect	If the public and the health care system respect each other, then people trust more.
Time	If action is not rushed, then people trust more.

7th Policy implication: *Develop health policy that incorporates active regulatory systems.*

Concerning the fragility of trust itself, two characteristics are worth considering: trusting is risky and, as a result, the trusting party is vulnerable to intentional betrayal of trust or unintentional errors (see Chapter 4). The risk develops from the fact that it is impossible to entirely foresee the outcome of a trusting relationship. A risk of error and failure always exists. This risk can be minimised by a range of mechanisms, such as professional training and codes of conduct, implementation of *active regulatory systems*, or conscientious policy planning. Further gathering of as much information as possible before engaging in a trusting relationship will minimise the perceived risk, but will never eliminate the risk entirely. As the health care system consists of a huge group of individuals, it would be naïve to assume that a health care system is free from intentional misconduct or misuse of power leading to a betrayal of public trust. Consequently, an open debate is necessary to explain these incidents if they occur.

8th Policy implication: *Develop health policy that fosters privacy by focusing equally if not more on responsible professional behaviour compared to anonymity, given the foreseeable problems and limitations of anonymity.*

The maintenance of *anonymity* will become increasingly difficult in the health care system due to the generation of huge amounts of data as well as improving data analytics. Already at present, researchers stress the fact that full anonymity is not possible or necessarily desirable (McGonigle & Shomron, 2016; Savage, 2016; Speed et al., 2016; Tsoukalas & Siozos, 2011). Hence, anonymity as a contributor to public trust may be impossible in a simple or pure sense. Nevertheless, current public debate and the findings of this research show that the public is not aware of the limits of anonymity and in parts considers complete anonymity to be an important contributor to public trust as anonymity is considered to foster privacy. This implies that better communication is needed to inform the public about the limits of anonymity and the different levels of anonymity that already exist in data systems. *Privacy* is essential to maintain when private information is communicated. A breach of privacy undermines public trust. Privacy is much more likely to be maintained by good professional conduct rather than attempts to guarantee anonymity (see Chapter 6). This means, in essence, privacy is maintained by, for instance, not leaking, losing or distributing private information inappropriately, regardless of the

degree of anonymity. In practice, this implies that the focus with respect to keeping data private must be more on the staff working with the data. Anonymity alone cannot keep data private if researchers and others do not work with the data in a respectful and considered manner. Policy makers need to be explicit with the public about the limits of anonymity in relation to personal information and the related risks.

> **9th Policy implication:** *Develop health policy that offers real choices and enables personal autonomy.*

Personal *autonomy* developing from personal control over private information as well as the ability to make choices in the health care system is one of the core principles of trust theory. This is the case as, according to wider trust theory, choice must be provided for someone to be able to trust (see Chapter 4). However, to make choices within the context of health care is considered especially difficult for lay people and often ‘’real’’ choices are not provided. This is the case as, for example, the quality of the alternatives are not equal, leading to the fact that no practical choice is offered. This implies in practice that the choices offered need to be of equal potential value and the people who want to make choices need to be informed and most likely also trained to make the right choices for themselves.

> **10th Policy implication:** *Develop health policy that can be expected to result in a net benefit for the individual, the public and the health care system itself.*

Four different types of benefits (to others, to finance, to the health care system itself and to the individual) constitute an anticipated net benefit for the health care system as an expected outcome of public trust. A *benefit to others* is fuelled by the understanding that altruistically motivated participation in health care research should lead to the benefit of others and future generations, and/or should allow others to use the health data created by personal treatment in the system. Further, the NHS in England, as a publicly financed health care system, might be considered by many as a public good which should intuitively benefit the public. Consistent with this, altruistically motivated action in the health care system should lead to a *financial benefit* to the public sector in the health care system. Public trust is particularly likely to be undermined if private companies can use the public health care system for their own profit without this financially benefiting the public realm. *Health system benefit* relates to advances in science as well as improved

quality of health care due to research. Quality is an established theme for trust in health care (Calnan & Rowe, 2008; Harrison et al., 2003; Pilgrim et al., 2011; Shore, 2006). Examples of advances in science can range from improved surgical techniques and shortened hospital stays to personalised medicine and tele-medicine. As the public consists of individuals, health care system action should lead naturally to a *personal benefit* for patients.

To be able to be trusted by the public to achieve this net benefit, the health care system as a whole and the representatives in the health care system must have a recognisable potential. This potential refers to the recognisable potential to make decisions that produce net benefits for different groups in the health care system. This applies at all levels in the health care system. At the professional level, self-confidence and the ability to keep up with cutting edge knowledge is important. At the governmental level, the government should act in a democratic way, research projects should be valid as well as well designed and there should be a central, overriding public good objective integrating private companies into research run by public institutions. In relation to self-confidence and appearance, it is important to understand, that how far a person is considered to be trustworthy will be judged by others and not by the person him/herself (Hartmann, 1994).

> **11th Policy implication:** *Increase future certainty by providing as much information as possible about the action expected.*

As a trusting relationship is based on a high degree of future uncertainty, actors in the health care system should do their best to increase future *certainty*. Logically, it is impossible to foresee the future. However, one can increase the information about the anticipated future as well as do one's best to achieve the anticipated future and hereby increase certainty about some aspects of the future. Also, one can implement evaluation cycles as well as check points in the policy process to control the policy process itself. As described in Chapter 4, deliberately chosen points of mistrust (e.g. quality control points) are likely to foster overall trust. Another example is monitoring of each other's performance in a policy team (Langfred, 2004). Here, it is important to keep in mind that similar to overregulation, intentional mistrust risks upsetting patient-clinician micro level relationships. In addition, this can undermine intrinsic motivation among professionals. As policy making and policies themselves are processes, the effort to maintain public

trust needs to continue throughout the entire process. One-off action will not do justice to public trust.

> **12th Policy implication:** *Develop health policy that ensures health care system representatives, patients and public representatives are aware of the policy.*

Familiarity with health care system representatives fosters public trust. *Familiarity* plays out at the interpersonal level and is most often associated with medical staff and governance board members and senior managers, i.e. health care system representatives. It is important to recognise that public trust is a reciprocal construct that is, on the one hand, influenced by positive personal experience of the health care system, but equally enables the health care system to act through its legitimising capacity. Coming back to the example of the care.data programme, this would imply that GPs would have been aware and supportive of the programme and therefore could have answered patients' questions. However, this was evidently not always the case. In fact, many of those who were aware did their best to make negative comments to patients and reduce their trust because they disagreed with the policy.

> **13th Policy implication:** *Be aware that despite the fact that public trust tends to be the result of a calculated decision on the part of members of the public, an element of 'gut feeling' can influence people's decisions to trust.*

Modern trust theory describes the process of placing trust as a primarily calculated conscious decision. Despite this widely accepted understanding, there exists a body of literature which describes trust as the result of intrinsic motivation and therefore as much more motivated by a 'gut feeling' compared to calculated decision making (Frevert, 2013; Seligman, 1997). Compared to the other aspects constituting public trust, a gut feeling is much more difficult to describe or to address, as it is an emotion. The current research can only encourage policy makers to be aware of its existence and likelihood.

> **14th Policy implication:** *Develop health policy that is perceived by the public as secure.*

The health care system should be perceived to be secure. A *perception of security* leads to higher levels of public trust as trust is associated with invulnerability. In the context of

data storage and data use, cyber security is particularly important as parts of the public suspect that foreign intelligence services or other organisations may be trying to hack national data bases. In this context, the IT competences of the government as well as its general conduct come into question. Some parts of the public favour local storage places over national data banks. Other parts of the public understand large data sets to be protective, as the odds substantially decrease in a large data set that one particular file is hacked among all the other files. Obviously, this causes a dilemma, as only parts of the public favour the one or the other storage place. However, from a more general point of view, a perception of security is necessary throughout the health care system and is by no means exclusive to data. Security (and safety) in all forms in the health care system is an important theme to build public trust and other forms of trust in health care (Goold & Klipp, 2002; Pilgrim et al., 2011; Shore, 2006; Walker et al., 2017). Here safety could refer to prevention of harm and medical errors.

> **15th Policy implication:** *Explain policies clearly, honestly and truthfully. The source providing the information must be perceived to be reliable and when several sources agree, people trust more.*

To develop public trust, the information provided by policy makers must be explanatory, clear, honest and truthful. The problem here will be that people have different perceptions of what is considered as truthful. This means that truthful information must be supported with robust scientific evidence and mirror similar values between the information provider and the public. The source providing the information must be reliable and when several sources agree, people trust more. The last point poses a particular problem where people consult online sources. Research shows that general health information provided online is usually of lower quality if not misleading or wrong compared to information provided by medical staff (Commission, 2013; Iverson, Howard, & Penney, 2008; Sillence et al., 2007; Zulman et al., 2011). Therefore, people need to be informed about the variable quality of online information and need to be informed about how to identify poor quality information. When considering patients seeking advice online concerning a specific policy, policy makers should be aware of the potentially negative impact of arbitrary information online.

16th Policy implication: *Develop health policy that supports respectful social interaction.*

Focusing on the relational aspect of public trust, *respect* among the trusting parties is essential as well as respectful interaction. This manifests itself further by respectful handling and management of data (e.g. not losing data as a result of indifference), as well as providing feedback to patients in a sensitive way. It is commonly understood that a respectful interaction strengthens the interaction and fosters trust. It is unlikely that a person would trust someone s/he disrespects.

17th Policy implication: *Developing trust takes time as well as trusted action needs time, i.e. should not be rushed.*

Last, *time* to decide to take part in a particular health care system activity, as well as time to conduct the trusted action, is needed to build public trust. Furthermore, one should not expect that trust will be established quickly. Trust can and should not be rushed.

To conclude, it is essential to maintain a public discourse and not to assume that public trust can be built by one-off action. Public trust is a fragile and most valuable construct that needs constant communication and effort from all parties engaged in the public discourse relating to the health care system. If public trust in the health care system is not maintained, the health care system as well as government is at risk of failing which will lead inevitably to unnecessary transaction costs, loss of health and potentially social division.

How much public trust is needed to run an efficient and effective health care system?

With respect to how much public trust is needed, one first needs to know what the benchmarks are or measure a baseline level for comparison. Assuming that 100% is full public trust, maybe 90% is enough public trust for a smooth functioning health care system. Given the results of this research, one can reason that generally speaking more public trust is better than less public trust. However, this understanding might change

when a certain level of public trust is crossed. On the other hand, trust theory and studies on trust in conflict zones as well as post-conflict zones suggest that close to no public trust could result in system as well as societal failure with all the related negative consequences such as chaos (Annan, 2014, p. 62; Fluri, 2011; Luhmann, 2009; Orjuela, 2003; Wessells, 1998). Further research would be needed to find an answer to this question.

With respect to the costs of implementing the policy implications, it needs to be considered that higher levels of public trust are understood to save resources including financial costs (e.g. transaction costs, control costs, legal costs, lower consumer satisfaction - see Chapter 4) (Beccerra & Gupta, 1999; Falk & Kosfeld, 2006; Montinola, 2004; Sztompka, 1998). Unfortunately, it is difficult to identify the costs of higher and lower levels of public trust in political systems. However, in situations where the costs of implementing the policy implications would exceed the anticipated benefit, the implementation might make no sense. Nevertheless, the implementation could be beneficial for other reasons (e.g. social cohesion, benefit to others, and benefit to the system or patient). Most likely, the decision will come down to a cost-benefit calculation, including deciding who is responsible for meeting the cost and who will benefit. To find an answer to this question remains the subject of future research.

What are the implications of this research for general trust theory?

This research focused largely on public trust theory and contributed to a better understanding of public trust. Nevertheless, this research also discussed general trust theory that focuses on trust as a social phenomenon in general and trust relationships beyond the health care system (see Chapter 4). This research does not appear to have contributed radically new ideas to general trust theory, but it has likely contributed to a better understanding of the relationship between general trust theory and public trust theory, more specifically. Nevertheless, there seems to be one implication of the current research which might add modestly to the social theory of trust: the understanding that the information needed to make a decision to trust must relate to the past, present and future. Previous theory has also described the time aspect of trust theory. Foremost, Luhmann argued for the importance of a theory of time as a precondition for a trust theory (Luhmann, 2009). Building on this understanding, one can argue that the implication of

this research is a more detailed understanding about the link between information needed to make a decision to trust and an underlying time theory.

Can the guidelines for developing conceptual frameworks be improved?

Guidelines documenting the requirements of good questionnaires stress that measurement instruments should be precise about what any instrument measures (see Chapter 3). Unfortunately, this is not always the case in the field of measuring public trust in the health care system. The goal for measurement instrument development is to develop a valid, reliable and responsive measure. Here, content validity is particularly important and a well developed conceptual framework. If a measurement instrument development process does not build on a robust conceptual framework, the remaining efforts in the development process are obsolete. Despite common agreement on the importance of a robust conceptual framework, existing development guidelines have focused vaguely on the process of developing a conceptual framework rather than substantive criteria for what constitutes a "good" conceptual framework (see Chapter 3). To overcome this imbalance and to suggest quality criteria for a good conceptual framework, this research has engaged with the theory and empirical conceptualisation of public trust in the health care system as well as modern measurement theory.

In the conceptual framework development process undertaken in this thesis, trust theory had a pivotal role. Theory allows the understanding of the differences and commonalities between different forms of trust in their cultural as well as historical context, the function of trust in a wider context as compared to the case studies used to conceptualise public trust, and the distinctive features of different conceptual frameworks. This would not be possible without an understanding of trust theory. An added advantage of trust theory is the initiation of self-reflection and how one understands the construct of interest as a researcher. In the case of trust research, one will quickly realise the diversity of understandings as well as the commonalities existing between the theories. Likely one will become more open minded and less obsessed with one or two points of view on trust. Given the subjectivity of trust this mind-set is important. At the end of the conceptual development process, the knowledge developing from the combination of reviewed research articles and trust theory allows one to locate the newly developed conceptual framework in relation to existing frameworks and to determine its competitive advantage.

In particular, trust theory was useful in separating conceptualising themes from framing themes and from effect themes, as well as in identifying whether other forms of trust were adequately represented within the conceptualisation of public trust.

Building on existing measurement instrument development guidelines (e.g. conducting a literature review, conducting qualitative research and reviewing existing conceptual frameworks, see Chapter 3), the experiences of the conceptual development process and review of wider trust theory helped to identify the following criteria for the development of a conceptual framework suitable to build a measurement scale on. These criteria, in conjunction with the already existing criteria, should lead to a robust conceptual framework:

1. A review of theory within and outside of the research field specific to the construct of interest should be conducted.
2. A working definition should be provided defining the construct and distinguishing the construct from similar terms.
3. It should be discussed how far other constructs can influence the construct of interest.
4. The competitive advantage of the newly developed conceptual framework should be assessed.
5. Effect and causal indicators should not be mixed within a conceptual framework/scale.
6. With modern psychometrics in mind the components of a conceptual framework ideally would have some kind of hierarchical structure to indicate how they might be positioned along the continuum.

Can public trust be measured?

Since existing public trust measurement instruments have conceptual limitations (see Chapter 3), the conceptual framework of public trust developed in this research should serve as a strong basis to develop a refined public trust in the health care system measurement instrument.

The main criticisms of previous public trust measurement instruments is, first, that existing conceptualisations are limited since they tend to focus on patients' personal trust in specific health care system representatives, missing the influence of various other actors on public trust as well as the openness of the health care system. In addition, they focus on patients excluding other members of the public. Further, this conceptual understanding overlooks the role of public trust in building discourse in the public domain relating to the health care system's trustworthiness, as well as the importance of anticipated net benefit for the development and maintenance of public trust. Public trust is largely understood to be an effect of health care system qualities i.e. an output of the system's performance rather than an input to enabling the system to function, missing the legitimising power of public trust to enable the health care system to act. And, public trust is measured by the average of aggregated individual patient trust in the health care system, implying that when a certain number of individuals participate in a questionnaire study, the aggregation of their responses represents 'public' trust. Here, it needs to be recognised that measurement inevitably takes place at the individual level, as a questionnaire is handed over to an individual. As public trust is understood in this research to be built by discourse in the public sphere, at first it might be difficult to imagine how public trust can also be measured at the individual level. The following will argue why public trust can indeed be reported by individual users of the health care system but will also engage with one alternative to conventional questionnaire measurement: turning the conceptual framework into a software supported *flagging system* for text analysis. As discussed below, an alternative to conventional measurement might be useful to cover different aspects of public trust itself or public trust discourse, but cannot substitute measurement.

Measuring public trust using a self-reported questionnaire

This research suggests that individual questionnaires are an appropriate method to collect data about public trust. This assumption is reasonable as the conceptual framework resolves the limitations of the existing conceptualisation of public trust and suggests that, at least in principle, the themes of the conceptual framework reported here could be operationalised into questionnaire items asking about public trust. In fact one can even argue that measurement of public trust is necessary at the individual level as the conceptual framework of public trust in the health care system develops from individual experiences and perceptions, plus the conceptual framework accommodates several themes which reflect interpersonal trust and individual trust in the health care system.

Also intrinsic motivations are covered by the conceptual framework which can only be measured at the individual level. This research shows how individual trust in the health care system and public trust in the health care system are linked via the individual who takes part in public discourse. Public trust and individual trust therefore influence each other but remain distinct.

As outlined in Chapter 3, to be able to measure public trust, the themes of the conceptual framework must be turned into questionnaire items which are ordered in a construct map as a continuum following a hierarchy from themes which reflect low trust to themes which reflect high trust (Wilson, 2005, p. 27). The actual hierarchy needs to be developed in future research (see below). Nevertheless, at present, it is possible to hypothesise that the conceptual framework developed in this research is a firm basis for measuring public trust. This is so as themes concerning a *net benefit* are distinctive for public trust (high levels of public trust). Further, themes like *choice*, *certainty about the future*, *recognised potential and information quality* are central to trust itself and might be in the middle of the continuum. Themes that connote low levels of public trust are likely to be themes, which can reflect unsatisfactory forms of social interaction, such as *respect*.

Observing public trust discourse with a flagging system

As an alternative to direct measurement of individuals (see Chapter 3), one could transfer the conceptual framework of public trust into a flagging system which is used to analyse public discourse. Here each theme is turned into a 'flag' and computer software analyses data sources such as readership fora online, to find words and strings of text which are associated with public trust. Such a software could count (as opposed to measuring) the number of times particular words or topics were discussed and whether positively for trust or negatively to be able to construct trend analyses of public discourse in relation to public trust in, for instance, the 100.000 Genomes Project or any other health care policy which is of public interest. This would mirror to a certain degree the method used to conceptualise public trust in this research. The underlying idea would be to search the public trust discourse and as soon as a range of words associated with public trust appears, the software would flag the text passages. The flagged text would be subject to further analyses to understand how trust is discussed. This analysis could provide insight into the discourse itself and how trust is discussed in the public sphere. One might be able to

interpret the changing content of the discourse to understand how far health care system action influences the public's experiences and perceptions of the health care system. This method would provide to a certain extent 'live' insight into how trust is discussed in public, but might provide to a lesser degree insight into the nuances of public trust. A flagging system is likely to detect observable themes rather than intrinsic motivation and the effect of health care action. The clear advantage of this approach is that one is able to observe public trust discourse permanently and one is able to collect data without the risk of introducing a bias by asking people about public trust. In conclusion, this approach is much more unobtrusive which would be helpful in understanding something as fragile as trust. Obviously, such software and research must be located in the public domain to not undermine public trust from the start. The risk here is that such software might be compared to surveillance software which is unlikely to be trusted by the public. This method will provide knowledge about the nature of the public trust discourse, but it will not provide a robust method of quantifying public trust as measurement would do.

In conclusion, public trust in the health care system is a potentially measurable concept. The themes of the conceptual framework described in this Thesis could be translated into questionnaire items, which in turn could be reported by individuals. If such a questionnaire was found to meet psychometric measurement criteria, public trust could be said to be measured. The strength of this method is to capture all forms of trust which are accommodated in public trust. Based on the conceptual framework of public trust as presented in this thesis, such a questionnaire would, in contrast to existing questionnaires of individual trust in the health care system, cover a range of items about the anticipated net benefit to the health care system. However, it should kept in mind that the work presented here gives only the first building block towards developing such a questionnaire. A flagging system supported by software might be the most efficient way to research public trust discourse on a larger scale. However, this approach will less likely discover intrinsic motivations and thus this method is less rigorous as it will not allow to quantify public trust in a robust and meaningful way. As this approach does not measure, but rather observes public trust. Which approach is most suitable to measure of levels and trends of public trust needs to be answered by future research and is a question of whether such a measure is fit for purpose.

With respect to the criticism raised in the introduction of Chapter 3, that measuring public trust in the entire health care system is less feasible compared to measuring public trust in selected branches of the system, this research provides no definite answer. On the one hand, research suggests that different levels of public trust can exist at the same time, as outlined in Chapter 4. Likely the answer to the question also depends on the question formulations and the target audience for the measure. Given that public trust in the health care system is an abstract concept, questions formulated will probably have to relate to selected processes, policies or health care system representatives. Otherwise, a measure might not work as participants find the questions too abstract and meaningless.

Future research

Throughout this thesis, several recommendations were made for future research. Future research should develop a public trust in the health care system measurement instrument with matching health policy guidelines. Here the 'if-then' statements can serve as a starting point to formulate measurement questions. When developing questions based on the themes of the conceptual framework, it is important that:

1. The instrument must consist of either causal or effect items, but not both. Whether the construct is considered to be a causal or an effect indicator determines the statistical (psychometric) techniques that can be used in evaluation of the measure.
2. The questions and items should be formulated without the term 'trust' and similar terms. If one would use 'trust' in the questions, the questions would lose their usefulness. One introduces a bias as using the term trust can undermine the participants' trust in the context of interest. The significance of such a question is diminished.
3. The items must be ordered along a continuum from low to high public trust in a construct map. Important to the idea is that there is a qualitative order of levels inherent in the construct and underlying that there is a continuum running from more to less trust (see Chapter 3).
4. Research needs to test whether *gut feeling* is a framing theme, indeed a conceptualising theme or an effect theme.
5. Additional research should explore in how far themes covering health care costs and insurance companies constitute public trust.

6. If the conceptual framework should be used as a basis for measuring public trust in a different health care system than the NHS, the themes need to be revalidated by further qualitative research for the new context. In doing so, it is pivotal to focus on the meaning and cultural understanding of the themes and not just focus on the translation of the themes into another language.

Concerning the measurability of public trust in the health care system, future research must not only develop a measurement instrument, but also improve the measurement instrument development guidelines with respect to recommending quality criteria for a conceptual framework. Last, future research needs to develop an understanding of how public trust is measured in the best way with respect to selected trust-reference-objects. For example, would it be better to measure public trust in a certain area of the health care system only, for example trust-reference-objects particularly strongly associated with a policy? Alternatively, would it be even possible to measure public trust in the entire health care system at once? Here, it is worth considering that previous research suggests that different levels of trust can co-exist and that measuring public trust in the entire health care system is likely to be too abstract to be meaningful (see Chapters 1 and 4).

Further research could attempt to validate the findings of the current research by publishing the findings in online news media and then analysing the subsequent readership comments, if they emerge. Another approach would be to validate the conceptual framework by researching public trust from different viewpoints representing different group of actors in the health care system; for example, how corporate companies, politicians or charities understand public trust. Furthermore, it is necessary to validate the conceptual framework for other health care systems, such as the German health care system, to increase generalisability. Subsequently, measurement and policy guidelines together can serve as an advanced tool kit to maintain, build and restore public trust in the health care system.

With respect to conceptual work and theory development, the accompanying theoretical body needs to be developed to explain in greater detail the dynamics of public trust in the public sphere, and how public trust and individual trust influence each other. This would imply, given that public trust is developed by communication, that trust and similar concepts which are treated as equal constructs to conceptualise public trust in this research must be examined to develop conceptual clarity concerning the boundaries of each

construct (for example: faith, hope, belief etc.). Furthermore, considering globalisation and free movement of people, research is needed to explain how public trust dynamics change in culturally diverse societies with different norms and values. This would also include to research how public and wider political system features from outside the health care system influence public trust inside the health care system.

Focusing on the implications for policy making, further research needs to address the potential spill over effect of low levels of public trust from other systems into the health care system. It is important to understand how the health care system can be safeguarded against this and how actors from outside the health care system can be incorporated in the public trust building discourse in such a way that public trust is maintained and increased. Here it will be helpful to develop communication guidelines that resemble the research finding that the public trust conceptualising themes are relating to different times and therefore communication must relate to the past, present and future.

Last, as this research did not focus in detail on the economic aspects of public trust, research is necessary to understand what the financial costs of different levels of public trust in the health care system are. Here it will be necessary to explore 'how much' public trust is needed for a health care system. Such research would be helpful to convince policy makers and managers of the financial value of public trust.

References

Aaronson, N., Alonso, J., Burnam, A., Lohr, K. N., Patrick, D. L., Perrin, E., & Stein, R. E. (2002). Assessing health status and quality-of-life instruments: attributes and review criteria. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *11*(3), 193–205.

Abelson, J., Miller, F. A., & Giacomini, M. (2009). What does it mean to trust a health system? A qualitative study of Canadian health care values. *Health Policy*, *91*(1), 63–70. http://doi.org/10.1016/j.healthpol.2008.11.006

Abraham, J. (2010). Pharmaceuticalization of Society in Context: Theoretical, Empirical and Health Dimensions. *Sociology*, *44*(4), 603–622. http://doi.org/10.1177/0038038510369368

Ahern, M. M., & Hendryx, M. S. (2003). Social capital and trust in providers. *Social Science & Medicine*, *57*(7), 1195–1203. https://doi.org/10.1016/S0277-9536(02)00494-X

Ahnquist, J., Wamala, S. P., & Lindstrom, M. (2010). What has trust in the health-care system got to do with psychological distress? Analyses from the national Swedish survey of public health. *International Journal for Quality in Health Care*, *22*(4), 250–258. http://doi.org/10.1093/intqhc/mzq024

Anand, T. N., & Kutty, V. R. (2015). Development and testing of a scale to measure trust in the public healthcare system. *Indian Journal of Medical Ethics; 12*(3),149-57.

Anderson, L. A., & Dedrick, R. F. (1990). Development of the trust in physician scale: A measure to assess interpersonal trust in patient-physician relationships. *Psychological Reports*, *67*(3f), 1091–1100. http://doi.org/10.2466/pr0.1990.67.3f.1091

Annan, K. (2014). *We the peoples - A UN for the 21st Century*. (E. Mortimer, Ed.). Boulder: Paradigm Publishers.

Arendt, H. (1958). *The human condition* (2nd ed.). Chicago, London: The University of Chicago Press.

Armstrong, K., McMurphy, S., Dean, L. T., Micco, E., Putt, M., Halbert, C. H., Schwartz, S. J., Sanker, P., Pyeritz, R. E., Bernhardt, B., Shea, J. A. (2008). Differences in the patterns of health care system distrust between blacks and whites. *Journal of General Internal Medicine*, *23*(6), 827–833. http://doi.org/10.1007/s11606-008-0561-9

Armstrong, K., Rose, A., Peters, N., Long, J. A., McMurphy, S., & Shea, J. A. (2006). Distrust of the Health Care System and Self-Reported Health in the United States. *Journal of General Internal Medicine*, *21*(4), 292–297. http://doi.org/10.1111/j.1525-1497.2006.00396.x

Arrow, K. J. (1974). *The limits of organization* (1st ed.). Toronto: George J. McLeod Limited.

Atkinson, R., & Flint, J. (2001). Accessing Hidden and Hard-to-Reach Populations: Snowball Research Strategies. University of Surry. Retrieved May 23, 2017 from http://sru.soc.surrey.ac.uk/SRU33.pdf

Barer, D. (2016). The NHS: national religion or national football? *British Medical Journal (Clinical Research Ed.)*, *352*, i1023. https://doi.org/10.1136/bmj.i1023

BBC. (2017). Moderation. Retrieved January 25, 2017, from http://www.bbc.co.uk/social/moderation/faqs/moderation#faqitem-3-1

Beccerra, M., & Gupta, A. K. (1999). Trust within the organization: Integrating the trust literature with agency theory and transaction costs economics. *Public Administration Quarterly*, *23*(2), 177–203.

Beltrán Salazar, O. A. (2015). Humanized care: A relationship of familiarity and affectivity. *Investigacion Y Educacion En Enfermeria*, *33*(1), 17–27. http://doi.org/10.1590/S0120-53072015000100003

Blendon, R. J. (2006). Why Americans don't trust the government and don't trust healthcare. In D. A. Shore (Ed.), *The trust crisis in healthcare* (pp. 21–31). Oxford: Oxford University Press.

Blendon, R. J., Benson, J. M., & Hero, J. O. (2014). Public Trust in Physicians — U.S. Medicine in International Perspective. *New England Journal of Medicine*, *371*(17), 1570–1572. http://doi.org/10.1056/NEJMp1407373

Bohman, J. (2004). Expanding dialoque: The Internet, the public sphere and prospects for transnational democracy. In N. Crossley & J. M. Roberts (Eds.), *After Habermas - New perspectives on the public sphere*. Oxford, UK: Blackwell Publishing.

Bonabeau, E. (2003). Don't trust your gut. *Harvard Business Review*, *81*(5), 116–23, 130.

Boudon, R. (2003). Beyond Rational Choice Theory. *Annual Review of Sociology*, *29*(1), 1–21. http://doi.org/10.1146/annurev.soc.29.010202.100213

Bouwman, R., Bomhoff, M., de Jong, J. D., Robben, P., & Friele, R. (2015). The public's voice about healthcare quality regulation policies. A population-based survey. *BMC Health Services Research*, *15*(1), 325. http://doi.org/10.1186/s12913-015-0992-z

Bowman, D. (2017). The Moral of the Tale: Stories, Trust, and Public Engagement with Clinical Ethics via Radio and Theatre. *Journal of Bioethical Inquiry*. *(14)*1, 43–52. http://doi.org/10.1007/s11673-016-9766-5

Boye, N. (2012). Co-production of Health Enabled by Next Generation Personal Health Systems. *Studies in Health Technology and Informatics*, *pHealth*, 52–58. http://doi.org/10.3233/978-1-61499-069-7-52

Bristol Royal Infirmary Inquiry. (2001). *The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: learning from Bristol*. Retrieved May 23, 2007 from http://webarchive.nationalarchives.gov.uk/20090811143745/http:/www.bristol-inquiry.org.uk/final_report/the_report.pdf

Brown, P. R. (2008). Trusting in the New NHS: instrumental versus communicative action. *Sociology of Health & Illness*, *30*(3), 349–363. http://doi.org/10.1111/j.1467-9566.2007.01065.x

Bruckner, B. K. (2016). *Organisationales Vertrauen initiieren*. Wiesbaden: Springer Fachmedien Wiesbaden. http://doi.org/10.1007/978-3-658-13492-1

Brykczynska, G. (1994). Implications of the Clothier Report: The Beverly Allitt case. *Nursing Ethics*, *1*(3), 179–181. http://doi.org/10.1177/096973309400100307

Burchardt, T., Evans, M., & Holder, H. (2015). Public Policy and Inequalities of Choice and Autonomy. *Social Policy & Administration*, *49*(1), 44–67. http://doi.org/10.1111/spol.12074

Calhoun, C. (1992). *Habermas and the Public Sphere*. Cambridge: MIT Press.

Calman, K. C. (2002). Communication of risk: choice, consent, and trust. *Lancet*, *360*(9327), 166–168. http://doi.org/10.1016/S0140-6736(02)09421-7

Calnan, M., & Rowe, R. (2008). *Trust matters in health care.* Maidenhead: Open University Press.

Calnan, M. (2004). Public trust in health care: the system or the doctor? *Quality and Safety in Health Care*, *13*(2), 92–97. http://doi.org/10.1136/qshc.2003.009001

Carter, P., Laurie, G. T., & Dixon-Woods, M. (2015). The social licence for research: why care.data ran into trouble. *Journal of Medical Ethics*, *41*(5), 404–9. http://doi.org/10.1136/medethics-2014-102374

Chaudhary, S., Avis, M., & Munn-Giddings, C. (2013). Beyond the therapeutic: A Habermasian view of self-help groups' place in the public sphere. *Social Theory & Health*, *11*(1), 59–80. http://doi.org/10.1057/sth.2012.14

Chong, D., & Druckman, J. N. (2007). Framing Theory. *Annual Review of Political Science*, *10*(1), 103–126. http://doi.org/10.1146/annurev.polisci.10.072805.103054

Coleman, S., Scott, A., & Morrison, D. E. (2009). *Public Trust in the News A Constructivist Study of the Social Life of the News.* Reuters institute for the study of journalism. Oxford, UK.

European Commission (2013). Trustworthy websites on "eHealth." Retrieved October 23, 2013 from http://ec.europa.eu/health/ehealth/portal/index%7B_%7Den.htm%7B#%7Dtab%7B_%7Deu%7B_%7Dactivities

Committee on Standards in Public Life. (1995). The 7 principles of public life. Retrieved January 10, 2017, from https://www.gov.uk/government/publications/the-7-principles-of-public-life

Cook, K. S. (2001). *Trust in society*. *Russell Sage Foundation series on trust*. New York: Russell Sage Foundation.

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*, *26*, 623–630. http://dx.doi.org/10.1046/j.1365-2648.1997.t01-25-00999.x

Crossley, N., & Roberts, J. M. (2004). *After Habermas: New Perspectives on the Public Sphere*. Oxford: Wiley-Blackwell.

Cukier, W., Bauer, R., & Middleton, C. (2004). Information Systems Research: Relevant Theory and Informed Practice. In B. Kaplan, D. P. Truex, D. Wastell, A. T. Wood-Harper, & J. I. DeGross (Eds.), (pp. 233–258). Boston, MA: Springer US. http://doi.org/10.1007/1-4020-8095-6_14

Damschroder, L. J., Pritts, J. L., Neblo, M. a, Kalarickal, R. J., Creswell, J. W., & Hayward, R. a. (2007). Patients, privacy and trust: patients' willingness to allow researchers to access their medical records. *Social Science & Medicine*, *64*(1), 223–235. http://doi.org/10.1016/j.socscimed.2006.08.045

Dan-Cohen, M. (1992). Conceptions of Choice and Conceptions of Autonomy. *Ethics*, *102*(2), 221–243. http://doi.org/10.1086/293394

Dane, E., Rockmann, K. W., & Pratt, M. G. (2012). When should I trust my gut? Linking domain expertise to intuitive decision-making effectiveness. *Organizational Behavior and Human Decision Processes*, *119*(2), 187–194. http://doi.org/10.1016/j.obhdp.2012.07.009

de Jonge, J. (2011). *Rethinking Rational Choice Theory - A Companion on Rational and Moral Action*. Basingstoke: Palgrave Macmillan.

Dean, M. (1998). London The NHS celebrates its 50th birthday. *The Lancet*, *352*(9121), 43. http://doi.org/10.1016/S0140-6736(05)79528-3

Denzin, N. K., & Lincoln, Y. S. (2005). *The SAGE handbook of qualitative research* (3rd ed.). Thousand Oaks: Sage Publications.

Department of Health, & Freeman, G. (2016). Written statement to Parliament: Review of health and care data security and consent. Retrieved August 2, 2016, from https://www.gov.uk/government/speeches/review-of-health-and-care-data-security-and-consent

Dietz, B. Y. G., & Gillespie, N. (2012). *The Recovery of Trust : Case studies of organisational failures and trust repair*. Retrieved May 23, 2017 from https://www.ibe.org.uk/userassets/publicationdownloads/ibe_occasional_paper_5_the_recovery_of_trust.pdf

Dixon, J., Spencelayh, E., Howells, A., Mandel, A., & Gille, F. (2015). *Indicators of quality of care in general practices in England An independent review for the Secretary of State for Health*. London: The Health Foundation.

Donnelly, L. (2014). Hospital records of all NHS patients sold to insurers. The Telegraph Online. Retrieved 7 December, 2016 from http://www.telegraph.co.uk/news/health/news/10656893/Hospital-records-of-all-NHS-patients-sold-to-insurers.html

Druckman, J. N. (2001). The Implications of Framing Effects for Citizen Competence. *Political Behavior*, *23*(3), 225–256. http://doi.org/10.1023/A:1015006907312

Dugan, E., Trachtenberg, F., & Hall, M. A. (2005). Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. *BMC Health Services Research*, *5*, 64. http://doi.org/10.1186/1472-6963-5-64

Egede, L., & Ellis, C. (2008). Development and Testing of the Multidimensional Trust in Health Care Systems Scale. *Journal of General Internal Medicine*, *23*(6), 808–815. http://doi.org/10.1007/s11606-008-0613-1

Ek, S., Eriksson-Backa, K., & Niemela, R. (2013). Use of and trust in health information on the Internet: A nationwide eight-year follow-up survey. *Informatics for Health and Social Care*, *38*(3), 236–245. http://doi.org/10.3109/17538157.2013.764305

Ekman, A., Hall, P., & Litton, J.-E. (2005). Can we trust cancer information on the Internet?-A comparison of interactive cancer risk sites. *Cancer Causes & Control*, *16*(6), 765–772. http://doi.org/10.1007/s10552-005-1722-3

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. http://doi.org/10.1111/j.1365-2648.2007.04569.x

Erikson, H. E. (1995). *Childhood and Society*. London: Vintage Books.

Eysenbach, G., Powell, J., Kuss, O., & Sa, E. R. (2002). Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. *Journal of the American Medical Association*, *287*, 2691–2700. http://doi.org/10.1001/jama.287.20.2691

Falk, A., & Kosfeld, M. (2006). The hidden costs of control. *The American Economic Review*, *96*(5), 1611–1630.

Feudtner, C. (2004). Assuring trust in insurance. *The American Journal of Bioethics*, *4*(4), 64–66. http://doi.org/10.1080/15265160490906745

Fitzpatrick, R., Davey, C., Buxton, M. J., & Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment*, *2*(14), i–iv, 1-74.

Fledderus, J., Brandsen, T., & Honingh, M. (2014). Restoring Trust Through the Co-Production of Public Services: A theoretical elaboration. *Public Management Review*, *16*(3), 424–443. http://doi.org/10.1080/14719037.2013.848920

Fluri, J. L. (2011). Bodies, bombs and barricades: geographies of conflict and civilian (in)security. *Transactions of the Institute of British Geographers*, *36*(2), 280–296. http://doi.org/10.1111/j.1475-5661.2010.00422.x

Fotaki, M. (2014). Can consumer choice replace trust in the National Health Service in England? Towards developing an affective psychosocial conception of trust in health care. *Sociology of Health & Illness*, *36*(8), 1276–1294. http://doi.org/10.1111/1467-9566.12170

Francis, R. (2010). *Robert Francis Inquiry report into Mid-Staffordshire NHS Foundation Trust*. Retrieved May 23, 2017 from http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113018

Freeman, R., & Schmid, A. (2008). *International Encyclopedia of Public Health*. *International Encyclopedia of Public Health*. Amsterdam: Elsevier. http://doi.org/10.1016/B978-012373960-5.00324-5

Frevert, U. (2013). *Vertrauensfragen: Eine Obsession der Moderne*. München: C. H. Beck Verlag.

Frost, J., Vermeulen, I. E., & Beekers, N. (2014). Anonymity versus privacy: selective information sharing in online cancer communities. *Journal of Medical Internet Research*, *16*(5), e126. http://doi.org/10.2196/jmir.2684

Fukuyama, F. (1995). *Trust : the social virtues and the creation of prosperity*. New York: Free Press.

Gambetta, D. (1988). *Trust: Making and Breaking Cooperative Relations* (1st ed.). Oxford: Basil Blackwell.

Genomics England. (2017). 100.000 Genomes Project. Retrieved May 17, 2017, from http://www.genomicsengland.co.uk/100k-genome-project/

Giddens, A. (1990). *The Consequences of Modernity* (1sr ed.). Cambridge: Polity Press.

Giddens, A. (1991). *Modernity and Self-Identity* (1st ed.). Stanford: Polity Press.

Gille, F. (2013). *A pilot study on measuring public trust in health systems.* Master Thesis. Karolinska Institute, Stockholm, Sweden.

Gille, F., Smith, S., & Mays, N. (2014). Why public trust in health care systems matters and deserves greater research attention. *Journal of Health Services Research & Policy*, *20*(1), 62–64.

Gille, F., Smith, S., & Mays, N. (2017). Towards a broader conceptualisation of "public trust" in the health care system. *Social Theory & Health*. *15*. 25-43.. http://doi.org/10.1057/s41285-016-0017-y

Gilson, L. (2003). Trust and the development of health care as a social institution. *Social Science and Medicine*, *56*(7), 1453–1468. https://doi.org/10.1016/S0277-9536(02)00142-9

Goold, S. D., Fessler, D., & Moyer, C. A. (2006). A measure of trust in insurers. *Health Services Research*, *41*(1), 58–78. http://doi.org/10.1111/j.1475-6773.2005.00456.x

Goold, S. D., & Klipp, G. (2002). Managed care members talk about trust. *Social Science & Medicine*, *54*(6), 879–888. https://doi.org/10.1016/S0277-9536(01)00070-3

Goudge, J., & Gilson, L. (2005). How can trust be investigated? Drawing lessons from past experience. *Social Science & Medicine, 61*(7), 1439–1451. http://doi.org/10.1016/j.socscimed.2004.11.071

Greaves, F., Laverty, A. A., & Millett, C. (2013). Friends and family test results only moderately associated with conventional measures of hospital quality. *British Medical Journal, 347*.

Green, A. K., Reeder-Hayes, K. E., Corty, R. W., Basch, E., Milowsky, M. I., Dusetzina, S. B., … Wood, W. A. (2015). The project data sphere initiative: accelerating cancer research by sharing data. *The Oncologist, 20*(5), 464-e20. http://doi.org/10.1634/theoncologist.2014-0431

Green, J. (2004). Is trust an under-researched component of healthcare organisation? *British Medical Journal (Clinical Research Ed.), 329*(7462), 384. http://doi.org/10.1136/bmj.38174.496944.7C

Green, J., & Browne, J. (2005). *Principles of Social Research*. Maidenhead: Open University Press.

Guardian News & Media Ltd. (2015). Accessing online articles on NHS Care.Data. London.

Habermas, J. (1990). *Strukturwandel der Öffentlichkeit - Untersuchungen zu einer Kategorie der bürgerlichen Gesellschaft* (13th ed.). Frankfurt am Main: Suhrkamp.

Habermas, J. (1991). *Erläuterungen zur Diskursethik*. Frankfurt am Main: Suhrkamp.

Habermas, J. (1995). *Theorie des kommunikativen Handelns*. *Suhrkamp Taschenbuch Wissenschaft* (1. Aufl.). Frankfurt am Main: Suhrkamp.

Habermas, J. (2014). *Faktizität und Geltung: Beiträge zur Diskurstheorie des Rechts und des demokratischen Rechtsstaats* (5th ed.). Frankfurt am Main: Suhrkamp.

Haddow, G., & Cunningham-Burley, S. (2008). Tokens of Trust or Toekn Trust? Public consultation and "Generation Scotland." In J. Brownlie, A. Greene, & A. Howson (Eds.), *Researching trust and health* (1st ed.). New York: Routledge.

Hagger-Johnson, G. E., Harron, K., Goldstein, H., Parslow, R., Dattani, N., Borja, M. C., … Gilbert, R. (2014). Making a hash of data: what risks to privacy does the NHS's care.data scheme pose? *British Medical Journal (Clinical Research Ed.)*, *348*, g2264. doi: https://doi.org/10.1136/bmj.g2264

Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? *Milbank Quarterly*, *79*(4), 613--39, v. https://doi.org/10.1111/1468-0009.00223

Hall, M. A., Zheng, B., Dugan, E., Camacho, F., Kidd, K. E., Mishra, A., & Balkrishnan, R. (2002). Measuring Patients' Trust in their Primary Care Providers. *Medical Care Research and Review*, *59*(3), 293–318. http://doi.org/10.1177/1077558702059003004

Hall, M. J., Forman, A. D., Montgomery, S. V, Rainey, K. L., & Daly, M. B. (2015). Understanding patient and provider perceptions and expectations of genomic medicine. *Journal of Surgical Oncology*, *111*(1), 9–17. http://doi.org/10.1002/jso.23712

Hardin, R. (2002). *Trust & Trustworthiness*. New York: Russell Sage Foundation.

Hardin, R. (2006). *Trust*. *Key concepts*. Oxford: Polity Press.

Hardin, R. (2009). Distrust: Manifestations and Management. In R. Hardin (Ed.), *Distrust* (pp. 3–33). New York: Russell Sage Foundation.

Harrison, J., Innes, R., & van Zwanenberg, T. (2003). *Rebuilding trust in healthcare*. (J. Harrison, R. Innes, & T. van Zwanenberg, Eds.) (1st ed.). Abingdon: Radcliffe Medical Press Ltd.

Hartmann, M. (1994). *Die Praxis des Vertrauens* (1st ed.). Frankfurt am Main: Suhrkamp.

Hawkins, A. K., & O'Doherty, K. (2010). Biobank governance: A lesson in trust. *New Genetics and Society*, *29*, 311–327. http://doi.org/10.1080/14636778.2010.507487

Hays, R., & Daker-White, G. (2015). The care.data consensus? A qualitative analysis of opinions expressed on Twitter. *BMC Public Health*, *15*, 838. http://doi.org/10.1186/s12889-015-2180-9

Healthtalkonline. (2014). Healthtalkonline.org. Retrieved May 23, 2017, from http://healthtalkonline.org/research/research-methods

Hewitt, P. (2007). *Trust, Assurance and Safety – The Regulation of Health Professionals in the 21st Century*. London.

Hobbes, T., & Mayer, J. P. (1936). *Leviathan : oder von Materie, Form und Gewalt des kirchlichen und bürgerlichen Staates*. *Europäische Reihe* (1. und 2.). Zürich: Rascher.

Holmström, S. (2007). Niklas Luhmann: Contingency, risk, trust and reflection. *Public Relations Review*, *33*(3), 255–262. http://doi.org/10.1016/j.pubrev.2007.05.003

Howard, N., Bennett, P., Bryant, J., & Bradley, M. (1993). Manifesto for a theory of drama and irrational choice. *Systems Practice*, *6*(4), 429–434. http://doi.org/10.1007/BF01061961

Hume, D. (1817). *A treatise of human nature: being an attempt to introduce the experimental method of reasoning into moral subjects* (New edition). London.

Hunter, P. (2016). The big health data sale: As the trade of personal health and medical data expands, it becomes necessary to improve legal frameworks for protecting patient anonymity, handling consent and ensuring the quality of data. *EMBO Reports*, *17*(8), 1103–5. http://doi.org/10.15252/embr.201642917

Hyde, P., & Davies, H. T. O. (2004). Service design, culture and performance: Collusion and co-production in health care. *Human Relations*, *57*(11), 1407–1426. http://doi.org/10.1177/0018726704049415

Igarashi, T., Kashima, Y., Kashima, E. S., Farsides, T., Kim, U., Strack, F., … Yuki, M. (2008). Culture, trust, and social networks. *Asian Journal of Social Psychology*, *11*(1), 88–101. http://doi.org/10.1111/j.1467-839X.2007.00246.x

Illingworth, P. (2002). Trust: the scarcest of medical resources. *The Journal of Medicine and Philosophy*, *27*(1), 31–46. http://doi.org/10.1076/jmep.27.1.31.2969

Ipsos MORI. (2008). Doctors Still Top The Poll As Most Trusted Profession. London: Ipsos MORI.

Ipsos MORI. (2015). Public Perceptions of the NHS and Social Care. Retrieved May 23, 2017, from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/444783/NHS_tracker_acc.pdf

Iverson, S. A., Howard, K. B., & Penney, B. K. (2008). Impact of internet use on health-related behaviors and the patient-physician relationship: a survey-based study and review. *The Journal of the American Osteopathic Association*, *108*(12), 699–711.

Jaccard, J., & Jacoby, J. (2010). *Theory Construction and Model-Building Skills : A Practical Guide for Social Scientists*. New York: The Guildford Press.

Jakowatz, S., & Habermas, J. (2008). *Politische Soziologie*. Bonn: GESIS-IZ Sozialwissenschaften.

Jalava, J. (2003). From Norms to Trust: The Luhmannian Connections between Trust and System . *European Journal of Social Theory*, *6*(2), 173–190. http://doi.org/10.1177/1368431003006002002

Jones, J., & Barry, M. M. (2011). Developing a scale to measure trust in health promotion partnerships. *Health Promot Int*, *26*(4), 484–491. http://doi.org/10.1093/heapro/dar007

Jovell, A., Blendon, R. J., Navarro, M. D., Fleischfresser, C., Benson, J. M., Desroches, C. M., & Weldon, K. J. (2007). Public trust in the Spanish health-care system. *Health Expect*, *10*(4), 350–357. http://doi.org/10.1111/j.1369-7625.2007.00466.x

Jucks, R., & Bromme, R. (2007). Choice of Words in Doctor–Patient Communication: An Analysis of Health-Related Internet Sites. *Health Communication*, *21*(3), 267–277. http://doi.org/10.1080/10410230701307865

Kamke, K. (1998). The German health care system and health care reform. *Health Policy*, *43*(2), 171–194. http://doi.org/10.1016/S0168-8510(97)00096-1

Katapodi, M. C., Pierce, P. F., & Facione, N. C. (2010). Distrust, predisposition to use health services and breast cancer screening: Results from a multicultural community-based survey. *International Journal of Nursing Studies*, *47*(8), 975–983. http://doi.org/10.1016/j.ijnurstu.2009.12.014

Kaye, J. (2012). The tension between data sharing and the protection of privacy in genomics research. *Annual Review of Genomics and Human Genetics*, *13*, 415–31. http://doi.org/10.1146/annurev-genom-082410-101454

Keating, N. L., Gandhi, T. K., Orav, E. J., Bates, D. W., & Ayanian, J. Z. (2004). Patient Characteristics and Experiences Associated With Trust in Specialist Physicians. *Archives of Internal Medicine*, *164*(9), 1015. http://doi.org/10.1001/archinte.164.9.1015

Kelly, J. J., Njuki, F., Lane, P. L., & McKinley, R. K. (2005). Design of a questionnaire to measure trust in an emergency department. *Academic Emergency Medicine*, *12*(2), 147–151. http://doi.org/10.1197/j.aem.2003.01.002

Kelly, J. J., Njuki, F., Lane, P. L., McKinley, R. K., Armstrong, K., McMurphy, S., … Redd, W. (2004). Mistrust of health care organizations is associated with underutilization of health services. *Journal of General Internal Medicine*, *23*(6), 2093–2105. http://doi.org/10.1007/s11606-008-0575-3

Langfred, C. W. (2004). Too Much of a Good Thing? Negative Effects of High Trust and Individual Autonomy in Self-Managing Teams. *Academy of Management Journal*, *47*(3), 385–399. http://doi.org/10.2307/20159588

Larson, H. J. (2016). Vaccine trust and the limits of information. *Science*, *353*(6305), 1207–1208. http://doi.org/10.1126/science.aah6190

Larson, H. J., Cooper, L. Z., Eskola, J., Katz, S. L., & Ratzan, S. (2011). Addressing the vaccine confidence gap. *The Lancet*, *378*(9790), 526–535. http://doi.org/http://dx.doi.org/10.1016/S0140-6736(11)60678-8

Larson, H. J., & Heymann, D. L. (2010). Public health response to influenza A(H1N1) as an opportunity to build public trust. *Journal of the American Medical Association*, *303*(3), 271–272. http://doi.org/10.1001/jama.2009.2023

Laveist, T. A., Isaac, L. A., & Williams, K. P. (2009). Mistrust of health care organizations is associated with underutilization of health services. *Health Services Research*, *44*(6), 2093–2105. http://doi.org/10.1111/j.1475-6773.2009.01017.x

Le Grand, J. (1997). Knights, Knaves or Pawns? Human Behaviour and Social Policy. *Journal of Social Policy*, *26*(2), 149–169. http://doi.org/10.1017/S0047279497004984

Lee, Y., & Lin, J. (2009). Trust but verify: the interactive effects of trust and autonomy preferences on health outcomes. *Health Care Analysis*, *17*(3), 244–260. http://doi.org/10.1007/s10728-008-0100-1

Levine, J. S. (2004). Trust: can we create the time? *Archives of Internal Medicine*, *164*(9), 930–2. http://doi.org/10.1001/archinte.164.9.930

Lewis, C. T. (1980). *A Latin Dictionary*. Oxford: Open University Press.

Lindström, M. (2011). Social capital, political trust, and health locus of control: a population-based study. *Scandinavian Journal of Public Health*, *39*(1), 3–9. http://doi.org/10.1177/1403494810382811

Locke, J., Shapiro, I., Dunn, J., & Grant, R. W. (2003). *Two treatises of government ; and, A letter concerning toleration. Rethinking the Western tradition*. New Haven; London: Yale University Press.

Locock, L., & Boylan, A.-M. R. (2015). Biosamples as gifts? How participants in biobanking projects talk about donation. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. http://doi.org/10.1111/hex.12376

Lohr, K. (2002). Assessing health status and quality-of-life instruments: Attributes and review criteria. *Quality of Life Research*, *11*(3), 193–205. http://doi.org/10.1023/A:1015291021312

Luhmann, N. (1988). Familiarity, Confidence, Trust: Problems and Alternatives. In D. Gambetta (Ed.), *Trust - Making and breaking cooperative relations* (1st ed., pp. 94–107). Oxford: Basil Blackwell.

Luhmann, N. (2009). *Vertrauen : ein Mechanismus der Reduktion sozialer Komplexität*. *UTB für Wissenschaft Soziologie fachübergreifend* (4. Aufl.,). Stuttgart: Lucius & Lucius.

Lythe, R. (2014). Insurance giants spy on medical history of thousands: Britain's biggest insurers demand unnecessary information from NHS. Retrieved October 27, 2016, from http://www.dailymail.co.uk/health/article-2641136/Insurance-giants-spy-medical-history-thousands-Britains-biggest-insurers-demand-unnecessary-information-NHS.html

Ma-Kellams, C., & Lerner, J. (2016). Trust your gut or think carefully? Examining whether an intuitive, versus a systematic, mode of thought produces greater empathic accuracy. *Journal of Personality and Social Psychology*, *111*(5), 674–685. http://doi.org/10.1037/pspi0000063

MacKenzie, S. B. (2003). The Dangers of Poor Construct Conceptualization. *Journal of the Academy of Marketing Science*, *31*(3), 323–326. http://doi.org/10.1177/0092070303031003011

MacLeod, S. P. (2011). *Celtic Myth and Religion: A Study of Traditional Belief, with Newly Translated Prayers, Poems and Songs*. Jefferson: McFarland.

Manacorda, T., Erens, B., Black, N., & Mays, N. (2017). The Friends and Family Test in general practice in England: a qualitative study of the views of staff and patients. *British Journal of General Practice*, *67*(658), e370 -e376. https://doi.org/10.3399/bjgp17X690617

Mays, N., Rees, S., Locock, L., Ryan, S., & Carrasqueiro, L. (2014). *Understanding experiences of recruiting for and participating in genomics research - Department of Health Application Form*. London: London School of Hygiene & Tropical Medicine.

McGonigle, I., & Shomron, N. (2016). Privacy, anonymity and subjectivity in genomic research. *Genetics Research*, *98*, e2. http://doi.org/10.1017/S0016672315000221

McKnight, D. H., & Chervany, N. L. (2001). Trust and Distrust Definitions: One Bite at a Time. In R. Falcone, M. Singh, & T. Yao-Hua (Eds.), *Trust in Cyber-societies*. Berlin: Springer.

McKnight, D. H., & Chervany, N. L. (2002). What Trust Means in E-Commerce Customer Relationships: An Interdisciplinary Conceptual Typology. *International Journal of Electronic Commerce*, *6*(2), 35–59.

Mechanic, D., & Meyer, S. (2000). Concepts of trust among patients with serious illness. *Social Science and Medicine, 51*, 657–668. http://doi.org/10.1016/S0277-9536(00)00014-9

Meyer, S., Ward, P., Coveney, J., & Rogers, W. (2008). Trust in the health system: An analysis and extension of the social theories of Giddens and Luhmann. *Health Sociology Review*. http://doi.org/10.5172/hesr.451.17.2.177

Mill, J. S. (2008). *On Liberty and Other Essays*. (J. Gray, Ed.). Oxford: Oxford Paperbacks.

Misztal, B. A. (1996). *Trust in Modern Societies* (1st ed.). Cambridge: Blackwell Publishers Inc.

Mohseni, M., & Lindstrom, M. (2007). Social capital, trust in the health-care system and self-rated health: the role of access to health care in a population-based study. *Social Science & Medicine*, *64*(7), 1373–1383. http://doi.org/10.1016/j.socscimed.2006.11.023

Montinola, G. R. (2004). Corruption, Distrust, and the Deterioration of the rule of law. In R. Hardin (Ed.), *Distrust* (p. 334). New York: Russell Sage Foundation.

Muñoz, A., Moreno, C., & Luján, J. L. (2012). Who is willing to pay for science? On the relationship between public perception of science and the attitude to public funding of science. *Public Understanding of Science (Bristol, England)*, *21*(2), 242–53. http://doi.org/10.1177/0963662510373813

Naghavi, S. H., Shabestari, O., Roudsari, A. V, & Harrison, J. (2012). Design and validation of a questionnaire to measure the attitudes of hospital staff concerning pandemic influenza. *J Infect Public Health*, *5*(1), 89–101. http://doi.org/10.1016/j.jiph.2011.11.002

Natalier, K., & Willis, K. (2008). Taking responsibility or averting risk? A socio-cultural approach to risk and trust in private health insurance decisions. *Health, Risk & Society*, *10*(4), 399–411. http://doi.org/10.1080/13698570802167413

National Data Guardian. (2016). *Review of Data Security, Consent and Opt-Outs*.

National Readership Survey. (2016). National Readership Survey. Retrieved May 24, 2016, from http://www.nrs.co.uk/

NHS. (2014). Better Information Means Better Care: NHS contacts all English households from today. Retrieved May 23, 2017, from http://www.england.nhs.uk/2014/01/06/better-info-better-care/

Nys, T. (2016). Autonomy, Trust, and Respect. *Journal of Medicine and Philosophy*, 41(1):10-24. http://doi.org/10.1093/jmp/jhv036

O'Hara, K. (2004). *Trust: from Socrates to spin*. Cambridge: Icon Books.

O'Neill, O. (2002a). *A Question of Trust: The BBC Reith Lectures 2002*. *Communication*. Cambridge: Cambridge University Press.

O'Neill, O. (2002b). *Autonomy and Trust in Bioethics (Gifford Lectures)* (1st ed.). Cambridge: Cambridge University Press.

Ong, A. D., & Weiss, D. J. (2000). The Impact of Anonymity on Responses to Sensitive Questions1. *Journal of Applied Social Psychology*, *30*(8), 1691–1708. http://doi.org/10.1111/j.1559-1816.2000.tb02462.x

Orjuela, C. (2003). Building Peace in Sri Lanka: a Role for Civil Society? *Journal of Peace Research*, *40*(2), 195–212. http://doi.org/10.1177/0022343303040002004

Ozawa, S., & Sripad, P. (2013). How do you measure trust in the health system? A systematic review of the literature. *Social Science and Medicine*, *91*, 10–14. http://doi.org/10.1016/j.socscimed.2013.05.005

Ozawa, S., & Stack, M. L. (2013). Public trust and vaccine acceptance-international perspectives. *Human Vaccines & Immunotherapeutics*, *9*(8), 1774–1778. http://doi.org/10.4161/hv.24961

Ozawa, S., & Walker, D. G. (2011). Comparison of trust in public vs private health care providers in rural Cambodia. *Health Policy and Planning*, *26 Suppl 1*, i20--9. http://doi.org/10.1093/heapol/czr045

Pagan, J. A., Balasubramanian, L., & Pauly, M. V. (2007). Physicians' career satisfaction, quality of care and patients' trust: the role of community uninsurance. *Health Economics, Policy and Law*, *2*(Pt 4), 347–362. http://doi.org/10.1017/S1744133107004239

Papakostas, A. (2012). *Civilizing the Public Sphere - Distrust, Trust and Corruption*. Basingstoke: Palgrave Macmillan.

Perrin, N. M. R. (2016). Using NHS data to improve health. *British Medical Journal*, *354*. https://doi.org/10.1136/bmj.i3852

Perron, B. E., & Gillespie, D. F. (2015). *Key Concepts in Measurement*. Oxford: Oxford University Press. http://doi.org/10.1093/acprof:oso/9780199855483.001.0001

Peters, D., & Youssef, F. F. (2014). Public trust in the healthcare system in a developing country. *The International Journal of Health Planning and Management*, *(31)*2, 227–241. http://doi.org/10.1002/hpm.2280

Picard, R., & Yeo, M. (2011). *Medical and Health News and Information in the UK Media: The Current State of Knowledge. The State of Public News and Information in the UK on Health and Health Care Research Project*. Oxford: Reuters Institute for the Study of Journalism.

Pilgrim, D., Tomasini, F., & Vassilev, I. (2011). *Examining Trust in Healthcare: A Multidisciplinary Perspective*. Basingstoke: Palgrave Macmillan.

Platt, J., & Kardia, S. (2015). Public trust in health information sharing: implications for biobanking and electronic health record systems. *Journal of Personalized Medicine*, *5*(1), 3–21. http://doi.org/10.3390/jpm5010003

Pollock, A. M., & Roderick, P. (2014). Trust in the time of markets: protecting patient information. *The Lancet*, *383*(9928), 1523–1524. http://doi.org/http://dx.doi.org/10.1016/S0140-6736(14)60727-3

Putnam, R. D. (2000). *Bowling alone : the collapse and revival of American community*. New York: Simon & Schuster.

Ramesh, R. (2014). NHS patient data to be made available for sale to drug and insurance firms. the Guardian Online. Retreived on 7 December 2016 from https://www.theguardian.com/society/2014/jan/19/nhs-patient-data-available-companies-buy

Ratcliffe, M., Ruddell, M., & Smith, B. (2014). What is a "sense of foreshortened future?" A phenomenological study of trauma, trust, and time. *Frontiers in Psychology*, *5*, 1026. http://doi.org/10.3389/fpsyg.2014.01026

Redfern, M., Keeling, J. W., & Powell, E. (2001). *The Royal Liverpool Children's Inquiry Report*. London. Retrieved May 23, 2017, from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250934/0012_ii.pdf

Reemstma, J. P. (2008). *Vertrauen und Gewalt* (1st ed.). Hamburg: HIS Verlagsges. mbH.

Reeve, B. B., Wyrwich, K. W., Wu, A. W., Velikova, G., Terwee, C. B., Snyder, C. F., … Butt, Z. (2013). ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. *Quality of Life Research*, *22*(8), 1889–1905. http://doi.org/10.1007/s11136-012-0344-y

Rolfe, A., Cash-Gibson, L., Car, J., Sheikh, A., & McKinstry, B. (2014). Interventions for improving patients' trust in doctors and groups of doctors. *The Cochrane Database of Systematic Reviews*, *3*, CD004134. http://doi.org/10.1002/14651858.CD004134.pub3

Rose, A., Peters, N., Shea, J. A., & Armstrong, K. (2004). Development and Testing of the Health Care System Distrust Scale. *Journal of General Internal Medicine*, *19*(1), 57–63. http://doi.org/10.1111/j.1525-1497.2004.21146.x

Savage, N. (2016). Privacy: The myth of anonymity. *Nature*, *537*(7619), S70–S72. http://doi.org/10.1038/537S70a

Scambler, G. (1998). Theorizing modernity: Luhmann, Habermas, Elias and new perspectives on health and healing. *Critical Public Health*, *8*(3), 237–244. http://dx.doi.org/10.1080/09581599808402911

Seligman, A. B. (1997). *The problem of trust*. Chichester: Princeton University Press.

Shea, J. A., Micco, E., Dean, L. T., McMurphy, S., Schwartz, J. S., & Armstrong, K. (2008). Development of a revised health care system distrust scale. *Journal of General Internal Medicine*, *23*(6), 727–732. http://doi.org/10.1007/s11606-008-0575-3

Shelton, R. C., Winkel, G., Davis, S. N., Roberts, N., Valdimarsdottir, H., Hall, S. J., & Thompson, H. S. (2010). Validation of the group-based medical mistrust scale among urban black men. *Journal of General Internal Medicine*, *25*(6), 549–555. http://doi.org/10.1007/s11606-010-1288-y

Shore, D. A. (2006). *The Trust Crisis in Healthcare*. Oxford: Oxford University Press. http://doi.org/10.1093/acprof:oso/9780195176360.001.0001

Siddiqi, S., Masud, T. I., Nishtar, S., Peters, D. H., Sabri, B., Bile, K. M., & Jama, M. A. (2009). Framework for assessing governance of the health system in developing countries: Gateway to good governance. *Health Policy*, *90*(1), 13–25. http://dx.doi.org/10.1016/j.healthpol.2008.08.005

Sillence, E., Briggs, P., Harris, P. R., & Fishwick, L. (2007). How do patients evaluate and make use of online health information? *Social Science & Medicine*, *64*(9), 1853–1862. http://doi.org/http://dx.doi.org/10.1016/j.socscimed.2007.01.012

Sizmur, S., Graham, C., & Walsh, J. (2015). Influence of patients' age and sex and the mode of administration on results from the NHS Friends and Family Test of patient experience. *Journal of Health Services Research & Policy*, *20*(1), 5–10. http://doi.org/10.1177/1355819614536887

Smith, J., Bartlett, J., Buck, D., & Honeyman, M. (2017). *Online Support - Investigating the role of public online forums in mental health*. London: DEMOS

Smith, S., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith, P., … Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, *9*(10), 1–93, iii–iv. http://doi.org/10.3310/hta9100

Social Analysis and Reporting Division. (2001). *Social Capital A review of the literature*. London: Office for National Statistics.

Speed, E., Davison, C., & Gunnell, C. (2016). The anonymity paradox in patient engagement: reputation, risk and web-based public feedback. *Medical Humanities*, *42*(2), 135–40. http://doi.org/10.1136/medhum-2015-010823

Stenner, J. (2001). The Necessity of Construct Theory. Retrieved September 10, 2016, from http://www.rasch.org/rmt/rmt151q.htm

Stevenson, F., & Scambler, G. (2005). The relationship between medicine and the public: the challenge of concordance. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, *9*(1), 5–21. http://doi.org/10.1177/1363459305048091

Stolle, D. (2002). Trusting Strangers - the Concept of Generalized Trust In Perspective. *Österreichische Zeitschrift Für Politikwissenschaft*, *4*, 397–412.

Straten, G. F., Friele, R. D., & Groenewegen, P. P. (2002). Public trust in Dutch health care. *Social Science & Medicine*, *55*(2), 227–234. https://doi.org/10.1016/S0277-9536(01)00163-0

Streiner, D. L., & Norman, G. R. (2003). *Health Measurement Scales* (3rd ed.). Oxford: Oxford University Press.

Sztompka, P. (1998). Trust, Distrust and Two Paradoxes of Democracy. *European Journal of Social Theory*, *1*(1), 19–32. http://doi.org/10.1177/136843198001001003

Sztompka, P. (1999). *Trust a sociological theory*. *Cambridge cultural social studies* (1st ed.). Cambridge: Cambridge University Press,.

Tavanxhi, N., Burazeri, G., & Laaser, U. (2008). *International Encyclopedia of Public Health*. *International Encyclopedia of Public Health*. Amsterdam: Elsevier. http://doi.org/10.1016/B978-012373960-5.00308-7

Tesch, R. (1990). *Qualitative Research: Analysis Types and Software Tools*. *Australian And New Zealand Journal Of Sociology* (Vol. 27).

The Lancet. (2009). The NHS: from religion to philosophy. *Lancet*. http://doi.org/10.1016/S0140-6736(09)60147-1

Thompson, H. S., Valdimarsdottir, H. B., Winkel, G., Jandorf, L., & Redd, W. (2004). The Group-Based Medical Mistrust Scale: Psychometric properties and association with breast cancer screening. *Preventive Medicine*, *38*(2), 209–218. http://doi.org/10.1016/j.ypmed.2003.09.041

The Stationery Office. (2005). *Sixth Report - Shipman: The Final Report*. Retrieved 23 May, 2017, from http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/finalreport.asp

Tsoukalas, I. A., & Siozos, P. D. (2011). Privacy and anonymity in the information society - challenges for the European Union. *The Scientific World Journal*, *11*, 458–62. http://doi.org/10.1100/tsw.2011.46

Tutton, R., Kaye, J., & Hoeyer, K. (2004). Governing UK Biobank: the importance of ensuring public trust. *Trends in Biotechnology*, *22*(6), 284–285. http://doi.org/10.1016/j.tibtech.2004.04.007

U.S. Department of Health and Human, & Administration. (2009). *Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims*. Retrieved May 23, 2017,from http://www.fda.gov/downloads/Drugs/Guidances/UCM193282.pdf

Ullmann-Margalit, E. (2009). Trust, Distrust, and In Between. In R. Hardin (Ed.), *Distrust* (pp. 60–82). New York: Russell Sage Foundation.

United Nations. (1999). *Istanbul Protocol - Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*. New York.

van der Schee, E., Braun, B., Calnan, M., Schnee, M., & Groenewegen, P. P. (2007). Public trust in health care: a comparison of Germany, The Netherlands, and England and Wales. *Health Policy*, *81*(1), 56–67. http://doi.org/10.1016/j.healthpol.2006.04.004

van der Schee, E., de Jong, J. D., & Groenewegen, P. P. (2012). The influence of a local, media covered hospital incident on public trust in health care. *The European Journal of Public Health*, *22*(4), 459–464. http://doi.org/10.1093/eurpub/ckr033

Walker, D. M., Johnson, T., Ford, E. W., & Huerta, T. R. (2017). Trust Me, I'm a Doctor: Examining Changes in How Privacy Concerns Affect Patient Withholding Behavior. *Journal of Medical Internet Research*, *19*(1), e2. http://doi.org/10.2196/jmir.6296

Wellcome Trust. (2015). Enabling data linkage to maximise the value of public health research data: full report. London.

Wessells, M. G. (1998). Children, Armed Conflict, and Peace. *Journal of Peace Research*, *35*(5), 635–646. http://doi.org/10.1177/0022343398035005006

White, S. K. (1990). *The recent work of Jürgen Habermas : reason, justice and modernity*. Cambridge: Cambridge University Press.

Wilde, A. (2013). Trust, uncertainty and identity in health-related decision-making: the role of key professionals. *Disability & Society*, *29*(2), 198–212. http://doi.org/10.1080/09687599.2013.796880

Williams, M. S. (1998). *Voice, Trust, and Memory -Marginalized groups and the failings of liberal representation.* (1st ed.). Princeton: Princeton University Press.

Williams, S. J., Martin, P., & Gabe, J. (2011). The pharmaceuticalisation of society? A framework for analysis. *Sociology of Health & Illness*, *33*(5), 710–25. http://doi.org/10.1111/j.1467-9566.2011.01320.x

Wilson, M. (2005). *Constructing Measures*. New York: Psychology Press.

Wise, J. (2014). UK research bodies agree steps to protect anonymity of study participants. *British Medical Journal (Clinical Research Ed.)*, *348*, g2372.

Young, T. A., Yang, Y., Brazier, J. E., & Tsuchiya, A. (n.d.). The use of rasch analysis in reducing a large condition-specific instrument for preference valuation: the case of moving from AQLQ to AQL-5D. *Medical Decision Making : An International Journal of the Society for Medical Decision Making*, *31*(1), 195–210. http://doi.org/10.1177/0272989X10364846

Zafirovski, M. (2013). Beneath rational choice: Elements of "irrational choice theory." *Current Sociology*, *61*(1), 3–21. http://doi.org/10.1177/0011392112465872

Zheng, B., Hall, M. A., Dugan, E., Kidd, K. E., & Levine, D. (2002). Development of a scale to measure patients' trust in health insurers. *Health Services Research*, *37*(1), 187–202. http://doi.org/10.1111/1475-6773.00145

Ziebland, S., & McPherson, A. (2006). Making sense of qualitative data analysis: An introduction with illustrations from DIPEx (personal experiences of health and illness). *Medical Education*, *40*, 405–414. http://doi.org/10.1111/j.1365-2929.2006.02467.x

Zulman, D. M., Kirch, M., Zheng, K., & An, L. C. (2011). Trust in the internet as a health resource among older adults: analysis of data from a nationally representative survey. *Journal of Medical Internet Research*, *13*(1), e19. http://doi.org/10.2196/jmir.1552

Appendix 1 for Chapter six:

Care.Data online news article

Date	Source	Title	Author	Readership comments	Accessed	Reference
2013-01-23	Guardian	Dragons' Den' event promotes innovation in healthcare	Claire Burke	0	2015-03-03	http://www.theguardian.com/healthcare-network/2013/jan/23/dragons-den-event-innovation-healthcare
2013-03-12	Guardian	Transparency in the NHS not only saves lives – it is a fundamental human right	Tim Kelsey	4	2015-03-04	http://www.theguardian.com/society/2013/mar/12/nhs-transparency-open-data-initiative
2013-04-25	Guardian	Big data and the NHS: can analytics tame the Leviathan?	David Downing	2	2015-03-05	http://www.theguardian.com/healthcare-network/2013/apr/25/big-data-nhs-analytics
2013-08-23	Guardian	It's right to worry about security, but sometimes data trawls can be useful	Polly Toynbee	291	2015-03-06	http://www.theguardian.com/commentisfree/2013/aug/23/wary-data-trawls-positive-results
2013-09-21	Daily Mail Online	GPs threaten to boycott 'Big Brother' NHS database which would force them to send confidential patient records to private firms	Stephen Adams	97	2015-02-13	http://www.dailymail.co.uk/news/article-2428211/GPs-threaten-boycott-Big-Brother-NHS-database.html
2013-10-05	Daily Mail Online	NHS climbdown over 'big brother' database after the Mail on Sunday highlighted serious concerns over the plan	Stephen Adams	20	2015-02-13	http://www.dailymail.co.uk/news/article-2468175/NHS-climbdown-big-brother-database-Mail-Sunday-highlighted-concerns-plan.html
2013-10-16	Independent Online	Care.data project to collate all NHS patients' records	Charlie Cooper	0	2015-02-16	http://www.independent.co.uk/life-style/health-and-families/health-news/caredata-project-to-collate-all-nhs-patients-records-8882379.html?origin=internalSearch
2013-12-02	Guardian	Work and surveillance in a post-Snowden world	Ross Anderson	0	2015-03-07	http://www.theguardian.com/world/2013/dec/02/work-surveillance-snowden-spying-security
2014-01-06	BBC Online	Patient data to be collected from GPs	BBC News	0	2015-02-12	http://www.bbc.co.uk/news/health-25588544
2014-01-12	BBC Online	GPs voice fears over giant patient records database	Nick Triggle	0	2015-02-12	http://www.bbc.co.uk/news/health-26151458
2014-01-12	Guardian	NHS database faces 'crisis of public confidence', GP body warns	Press Association	0	2015-03-08	http://www.theguardian.com/society/2014/feb/12/nhs-database-crisis-public-confidence
2014-01-14	Independent Online	Letters: Do you trust the NHS with your data?	Dr. Kevan Tucker	0	2015-02-16	http://www.independent.co.uk/voices/letters/letters-do-you-trust-the-nhs-with-your-data-9059471.html?origin=internalSearch

Date	Source	Title	Author	Readership comments	Accessed	Reference
2014-01-16	Independent Online	Your life in their hands: is the care.data NHS database a healthy step or a gross invasion of patient privacy?	Charlie Cooper	20	2015-02-16	http://www.independent.co.uk/life-style/health-and-families/health-news/your-life-in-their-hands-is-the-caredata-nhs-database-a-healthy-step-or-a-gross-invasion-of-patient-privacy-9042564.html?origin=internalSearch
2014-01-17	Guardian	How big data could be used to predict a patient's future	Wayne Parslow	11	2015-03-09	http://www.theguardian.com/healthcare-network/2014/jan/17/big-data-nhs-predict-illness
2014-01-19	Independent Online	The number crunch: Will Big Data transform your life - or make it a misery?	Mike Hodgkinson	2	2015-02-16	http://www.independent.co.uk/life-style/gadgets-and-tech/features/the-number-crunch-will-big-data-transform-your-life--or-make-it-a-misery-9065643.html?origin=internalSearch
2014-01-24	Guardian	Firm linked to drug makers sought pact on access to patient records database	Randeep Ramesh	0	2015-03-10	http://www.theguardian.com/society/2014/feb/24/drug-makers-patient-records-database
2014-01-24	Independent Online	40 per cent of GPs plan to opt out of the NHS big data sweep, due to a lack of confidence in the project	Charlie Cooper	1	2015-02-16	http://www.independent.co.uk/life-style/health-and-families/health-news/40-per-cent-of-gps-plan-to-opt-out-of-the-nhs-big-data-sweep-due-to-a-lack-of-confidence-in-the-project-9083806.html?origin=internalSearch
2014-01-26	Guardian	Why your health secrets may no longer be safe with your GP	John Naughton	48	2015-03-11	http://www.theguardian.com/society/2014/jan/26/health-secrets-not-safe-with-gp
2014-01-28	BBC Online	Are your medical records in danger?	Nick Triggle	199	2015-02-12	http://www.bbc.co.uk/news/health-25919399
2014-02-03	Guardian	Giving away your data: from Galton and Google to care.data	Vanessa Heggie	11	2015-03-12	http://www.theguardian.com/science/the-h-word/2014/feb/03/giving-away-your-data-from-galton-and-google-to-caredata
2014-02-04	BBC Online	Giant patient records database 'should be delayed'	Nick Triggle	0	2015-02-12	http://www.bbc.co.uk/news/uk-england-devon-26030479
2014-02-05	Daily Mail Online	NHS 'bullies' threaten to axe GP for keeping his patients' records private: He opts his entire practice out of scheme to harvest medical data	Andy Dolan and Sophie Borland	3	2015-02-13	http://www.dailymail.co.uk/news/article-2551900/NHS-bullies-threaten-axe-GP-keeping-patients-records-private.html
2014-02-06	Daily Mail Online	I won't give in to the NHS Thought Police who want to sell your private medical records: GP threatened by health chiefs hits back	Dr. Gordon Gancz	35	2015-02-13	http://www.dailymail.co.uk/debate/article-2552717/I-wont-NHS-Thought-Police-want-sell-private-medical-records-GP-threatened-health-chiefs-hits-back.html
2014-02-08	Daily Mail Online	Insurers 'could use new NHS database to track you down within two hours'	Sophie Borland	96	2015-02-13	http://www.dailymail.co.uk/news/article-2554437/Insurers-use-new-NHS-database-track-two-hours.html

Date	Source	Title	Author	Readership comments	Accessed	Reference
2014-02-09	Daily Mail Online	Big Brother' database will grab children's health records but parents are being kept in the dark	Martin Beckfor	101	2015-02-13	http://www.dailymail.co.uk/news/article-2554959/Big-Brother-database-grab-childrens-health-records-parents-kept-dark.html
2014-02-12	Daily Mail Online	Hack attack on NHS data 'is inevitable': MP claims relationships could be ended and careers destroyed if medical information is made public	Daniel Martin	2	2015-02-13	http://www.dailymail.co.uk/news/article-2557286/Hack-attack-NHS-data-inevitable-MP-claims-relationships-ended-careers-destroyed-medical-information-public.html
2014-02-13	Daily Mail Online	GPs warn of crisis in public confidence over NHS database: Royal College warns health service of failing to inform patients about data sharing	Sophie Borland	18	2015-02-13	http://www.dailymail.co.uk/news/article-2558135/GPs-warn-crisis-public-confidence-NHS-database-Royal-Collage-warns-health-service-failing-inform-patients-data-sharing.html
2014-02-15	Daily Mail Online	Two-thirds oppose plans for new NHS database that will see confidential medical records sold to private firms	Daily Mail Online	0	2015-02-13	http://www.dailymail.co.uk/news/article-2560335/Two-thirds-oppose-plans-new-NHS-database-confidential-medical-records-sold-private-firms.html
2014-02-17	Telegraph Online	NHS crisis talks over introduction of patients' records database	Laura Donnelly	0	2015-02-15	http://www.telegraph.co.uk/news/health/news/10644864/NHS-crisis-talks-over-introduction-of-patients-records-database.html
2014-02-17	Independent Online	Doctors raise fears over sharing NHS patient medical records	Jane Kirby and Ella Pickover	13	2015-02-16	http://www.independent.co.uk/life-style/health-and-families/health-news/doctors-raise-fears-over-sharing-nhs-patient-records-9133807.html?origin=internalSearch
2014-02-17	Daily Mail Online	Now doctors' union has 'grave doubts' over plan to harvest patient data: British Medical Association warns public has been left in the dark over the scheme	Sophie Borland	95	2015-02-13	http://www.dailymail.co.uk/news/article-2561662/Now-doctors-union-grave-doubts-plan-harvest-patient-data-British-Medical-Association-warns-public-left-dark-scheme.html
2014-02-18	BBC Online	Giant NHS database rollout delayed	Nick Triggle	0	2015-02-12	http://www.bbc.co.uk/news/health-26239532
2014-02-18	Telegraph Online	Patients should be warned before NHS shares medical records, doctors say	Laura Donnelly	19	2015-02-15	http://www.telegraph.co.uk/news/health/news/10646151/Patients-should-be-warned-before-NHS-shares-medical-records-doctors-say.html
2014-02-18	Independent Online	Victory for privacy as NHS database is delayed	Charlie Cooper	22	2015-02-16	http://www.independent.co.uk/life-style/health-and-families/health-news/victory-for-privacy-as-nhs-database-is-delayed-9137136.html?origin=internalSearch
2014-02-18	Daily Mail Online	NHS delays plan to harvest your details: Victory for the Mail as database is shelved for six months	Sophie Borland	203	2015-02-13	http://www.dailymail.co.uk/news/article-2562296/Controversial-plan-share-medical-records-NHS-hold-six-months.html
2014-02-19	BBC Online	NHS England: Database rollout 'not badly handled'	BBC News	0	2015-02-12	http://www.bbc.co.uk/news/health-26253440

Date	Source	Title	Author	Readership comments	Accessed	Reference
2014-02-19	Telegraph Online	NHS database 'vital' to improve cancer research	Laura Donnelly	65	2015-02-15	http://www.telegraph.co.uk/news/health/news/10649786/NHS-database-vital-to-improve-cancer-research.html
2014-02-19	BBC Online	Care.data: How did it go so wrong?	Nick Triggle	354	2015-02-12	http://www.bbc.co.uk/news/health-26259101
2014-02-21	BBC Online	Critics of giant NHS database 'are scaremongering'	Nick Triggle and Adam Brimelow	0	2015-02-12	http://www.bbc.co.uk/news/health-26277866
2014-02-21	Guardian	The NHS plan to share our medical data can save lives – but must be done right	Ben Goldacre	311	2015-03-13	http://www.theguardian.com/society/2014/feb/21/nhs-plan-share-medical-data-save-lives
2014-02-23	Independent Online	Privacy guardian Christopher Graham finds himself in the public eye	Ian Burrell	0	2015-02-16	http://www.independent.co.uk/news/uk/crime/privacy-guardian-christopher-graham-finds-himself-in-the-public-eye-9147738.html?origin=internalSearch
2014-02-23	Telegraph Online	Hacking' may reveal personal health risks	Sarah Knapton	6	2015-02-15	http://www.telegraph.co.uk/news/science/science-news/10656037/Hacking-may-reveal-personal-health-risks.html
2014-02-24	BBC Online	Medical records rules broken, NHS admits	Nick Triggle	0	2015-02-12	http://www.bbc.co.uk/news/health-26329748
2014-02-24	Telegraph Online	NHS medical records database could help prevent disease, senior doctors say	Claire Carter	18	2015-02-15	http://www.telegraph.co.uk/news/health/news/10657580/NHS-medical-records-database-could-help-prevent-disease-senior-doctors-say.html
2014-02-25	BBC Online	NHS data-sharing project at risk, say MPs	Nick Triggle	0	2015-02-12	http://www.bbc.co.uk/news/health-26347026
2014-02-25	BBC Online	Hunt challenged over patient-data sharing scheme delays	BBC Democracy Live	0	2015-02-12	http://www.bbc.co.uk/democracylive/house-of-commons-26339513
2014-02-25	Independent Online	Inside Whitehall: Care.data will help prolong our lives and those of our children	Oliver Wright	3	2015-02-16	http://www.independent.co.uk/voices/comment/inside-whitehall-caredata-will-help-prolong-our-lives-and-those-of-our-children-9152707.html?origin=internalSearch
2014-02-25	Telegraph Online	Sketch: Caring, sharing Jeremy Hunt	Michael Deacon	5	2015-02-15	http://www.telegraph.co.uk/news/politics/10660817/Sketch-Caring-sharing-Jeremy-Hunt.html
2014-02-25	Guardian	Remote control – why the government has hit pause on the Care.data project	Esther Addley	15	2015-03-15	http://www.guardian.co.uk/politics/2014/feb/25/remote-control-pause-care-data-project
2014-02-25	Guardian	NHS data: take more care	_	42	2015-03-14	http://www.theguardian.com/commentisfree/2014/feb/25/nhs-data-take-more-care-editorial
2014-02-26	Independent Online	Letters: NHS data-share a classic British mix-up	Yvonne Ruge, Ray Noy, Christopher Anton	0	2015-02-16	http://www.independent.co.uk/voices/letters/letters-nhs-datashare-a-classic-british-mixup-9155301.html?origin=internalSearch

Date	Source	Title	Author	Readership comments	Accessed	Reference
2014-02-26	Independent Online	Why has Atos been taken on to handle NHS care.data despite the unmitigated disaster of ‘fitness for work’ tests?	James Moore	0	2015-02-16	http://www.independent.co.uk/voices/comment/why-has-atos-been-taken-on-to-handle-nhs-caredata-despite-the-unmitigated-disaster-of-fitness-for-work-tests-9154197.html?origin=internalSearch
2014-02-26	Independent Online	Atos to work on NHS care data project despite ongoing 'mess' over disability benefit assessments	Felicity Morse	25	2015-02-16	http://www.independent.co.uk/news/atos-to-work-on-nhs-care-data-project-despite-ongoing-mess-over-disability-benefit-assessments-9153885.html?origin=internalSearch
2014-02-28	Independent Online	NHS boss apologises for tweeting Hitler video mocking Government health database scheme	Antonia Molloy	7	2015-02-16	http://www.independent.co.uk/news/uk/home-news/nhs-boss-apologises-for-tweeting-hitler-video-mocking-government-health-database-scheme-9161077.html?origin=internalSearch
2014-02-28	Independent Online	NHS chief Sir David Nicholson's experimentations with Twitter cause upset again as he posts a spoof video comparing one of his top officials to Hitler	Charlie Cooper	13	2015-02-16	http://www.independent.co.uk/news/uk/politics/nhs-chief-sir-david-nicholsons-experimentations-with-twitter-cause-upset-again-as-he-posts-a-spoof-video-comparing-one-of-his-top-officials-to-hitler-9161347.html?origin=internalSearch
2014-02-28	Telegraph Online	NHS legally barred from selling patient data for commercial use	Steven Swinford	231	2015-02-15	http://www.telegraph.co.uk/news/health/10669295/NHS-legally-barred-from-selling-patient-data-for-commercial-use.html
2014-02-28	Daily Mail Online	Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database	James Chapman and Andy Dolan	257	2015-02-13	http://www.dailymail.co.uk/news/article-2570567/Cashing-patient-records-banned-But-youll-opt-private-details-database.html
2014-03-01	Telegraph Online	NHS database: will it push up your insurance premiums?	Nicole Blackmore	111	2015-02-15	http://www.telegraph.co.uk/finance/personalfinance/insurance/10667245/NHS-database-will-it-push-up-your-insurance-premiums.html#disqus_thread
2014-03-03	Telegraph Online	NHS hospital records used by private marketing firms	Laura Donnelly	0	2015-02-15	http://www.telegraph.co.uk/news/nhs/10674639/NHS-hospital-records-used-by-private-marketing-firms.html
2014-03-03	Independent Online	Hospital records used to 'target ads on Twitter and Facebook' say privacy campaigners, in latest NHS data concerns	Charlie Cooper	22	2015-02-16	http://www.independent.co.uk/life-style/health-and-families/health-news/hospital-records-used-to-target-ads-on-twitter-and-facebook-say-privacy-campaigners-in-latest-nhs-data-concerns-9166633.html?origin=internalSearch
2014-03-06	Telegraph Online	Review to probe sale of NHS medical data	Laura Donnelly	0	2015-02-15	http://www.telegraph.co.uk/news/nhs/10680969/Review-to-probe-sale-of-NHS-medical-data.html
2014-03-10	BBC Online	Government outlines data-sharing safeguards	BBC Democracy Live	0	2015-02-12	http://www.bbc.co.uk/democracylive/house-of-commons-26518046
2014-03-11	BBC Online	MPs agree to data-sharing safeguards	BBC Democracy Live	0	2015-02-12	http://www.bbc.co.uk/democracylive/house-of-commons-26532173

Date	Source	Title	Author	Readership comments	Accessed	Reference
2014-03-12	Guardian	Neurological conditions among older people are falling off the health agenda	Natricia Duncan	3	2015-03-16	http://www.theguardian.com/society/2014/mar/12/neurological-conditions-older-people-polio
2014-03-13	BBC Online	Health data boom heralds new era of personalised medicine	Matthew Wall	0	2015-02-12	http://www.bbc.co.uk/news/business-26133269
2014-03-21	Guardian	NHS data-sharing 'a no-brainer', says health chief	Press Association	0	2015-03-17	http://www.theguardian.com/society/2014/mar/21/nhs-data-sharing-no-brainer-health-chief
2014-03-21	Independent Online	Larry Page wants everyone's medical records open for sharing. That would suit Google, but, after the Care.Data controversy, are we ready for it?	David Crookes	2	2015-02-16	http://www.independent.co.uk/voices/comment/larry-page-wants-everyones-medical-records-open-for-sharing-that-would-suit-google-but-after-the-caredata-controversy-are-we-ready-for-it-9206042.html?origin=internalSearch
2014-04-01	Guardian	Why technology is no longer a barrier in the NHS	Sarah Johnson	0	2015-03-18	http://www.theguardian.com/healthcare-network/2014/apr/01/technology-it-nhs
2014-04-04	Daily Mail Online	Hospital data sold without patients' consent to boost profits of private drugs companies	Jenny Hope	8	2015-02-13	http://www.dailymail.co.uk/news/article-2596492/Hospital-data-sold-without-patients-consent-boost-profits-private-drugs-companies.html
2014-04-06	Independent Online	Power to the people... Can't get a doctor's appointment? A Labour MP says there'd be no problem if GPs had to compete for their patients	Ian Austin	3	2015-02-16	http://www.independent.co.uk/voices/comment/power-to-the-people-cant-get-a-doctors-appointment-a-labour-mp-says-thered-be-no-problem-if-gps-had-to-compete-for-their-patients-9241038.html?origin=internalSearch
2014-04-08	Telegraph Online	NHS blunders put millions of records at risk	Laura Donnelly	16	2015-02-15	http://www.telegraph.co.uk/news/health/news/10753001/NHS-blunders-put-millions-of-records-at-risk.html
2014-04-10	Guardian	Information governance in the NHS: the challenges and the future	Gill Hitchcock	6	2015-03-19	http://www.theguardian.com/healthcare-network/2014/apr/10/information-governance-nhs-challenges-future
2014-04-18	BBC Online	NHS Care.data information scheme 'mishandled'	Chris Vallance	0	2015-02-12	http://www.bbc.co.uk/news/health-27069553
2014-04-18	Independent Online	Borderline insane': Government plans to let HMRC sell taxpayers' details to private companies	Lewis Smith	12	2015-02-16	http://www.independent.co.uk/news/uk/home-news/borderline-insane-government-plans-to-let-hmrc-sell-taxpayers-details-to-private-companies-9270395.html?origin=internalSearch
2014-04-19	Daily Mail Online	More delays for controversial NHS data harvesting programme as Government adviser says scheme was mishandled	Daily Mail Online	44	2015-02-13	http://www.dailymail.co.uk/news/article-2608134/More-delays-controversial-NHS-data-harvesting-programme-Government-adviser-says-scheme-mishandled.html
2014-04-19	Daily Mail Online	Now our tax data could be sold to businesses: Government planning change in law to allow release of 'anonymised' data to third parties	Jason Groves	110	2015-02-13	http://www.dailymail.co.uk/news/article-2608187/Now-tax-data-sold-businesses-Government-planning-change-law-allow-release-anonymised-data-parties.html

Date	Source	Title	Author	Readership comments	Accessed	Reference
2014-04-22	Guardian	Could controversial data sharing be good for patient health?	Craig Manson	7	2015-03-20	http://www.theguardian.com/healthcare-network/2014/apr/22/controversial-data-sharing-good-patient-health
2014-05-08	BBC Online	Care Bill passes Lords	BBC Democracy Live	0	2015-02-12	http://www.bbc.co.uk/democracylive/house-of-lords-27316368
2014-05-13	Daily Mail Online	NHS chief who blew £46K on expenses: Man in charge of plan to centralise patient records had highest expenses bill of top NHS officials	Emily Davis	0	2015-02-13	http://www.dailymail.co.uk/news/article-2626783/NHS-chief-blew-46K-expenses-Man-charge-plan-centralise-patient-records-highest-expenses-bill-NHS-officials.html
2014-05-20	Guardian	Can technology improve patient safety?	Mark Ryan	0	2015-03-21	http://www.theguardian.com/healthcare-network/2014/may/20/can-technology-improve-patient-safety
2014-05-21	Telegraph Online	Britons 'trust banks more than government' to protect their data	Laura Donnelly	1	2015-02-15	http://www.telegraph.co.uk/technology/internet-security/10846656/Britons-trust-banks-more-than-government-to-protect-their-data.html
2014-06-06	Telegraph Online	Ignorance of care quality is 'true scandal' facing NHS, warns health chief	Laura Donnelly	0	2015-02-15	http://www.telegraph.co.uk/news/nhs/10881782/Ignorance-of-care-quality-is-true-scandal-facing-NHS-warns-health-chief.html
2014-06-17	Guardian	NHS patient data audit uncovers 'significant lapses' in confidentiality	Randeep Ramesh	112	2015-03-22	http://www.theguardian.com/society/2014/jun/17/nhs-patient-data-audit-significant-lapses-confidentiality-hscic
2014-06-18	Daily Mail Online	Millions of NHS records sold to 178 private firms: And officials don't even know where details of 1.3m patients ended up	Sophie Borland	54	2015-02-13	http://www.dailymail.co.uk/health/article-2660800/Millions-NHS-records-sold-178-private-firms-And-officials-dont-know-details-1-3m-patients-ended-up.html
2014-06-25	Daily Mail Online	CONSENT CONCERNS ON MEDICAL RECORDS	Daily Mail Online	0	2015-02-13	http://www.dailymail.co.uk/wires/pa/article-2669307/CONSENT-CONCERNS-ON-MEDICAL-RECORDS.html
2014-07-15	Independent Online	Britain’s chief data protection agency reports record number of cases involving unlawful use of personal data	Jack Simpson	0	2015-02-16	http://www.independent.co.uk/news/uk/home-news/britains-chief-data-protection-agency-reports-record-number-of-cases-involving-unlawful-use-of-personal-data-9606807.html
2014-07-15	Guardian	UK privacy watchdog seeks 'stronger powers' and better funding	Tom Brewster	27	2015-03-23	http://www.theguardian.com/technology/2014/jul/15/uk-privacy-watchdog-funding-ico-snowden
2014-09-07	Telegraph Online	Hostile' Europe risks derailing medical innovation, warns minister	Sarah Knapton	5	2015-02-15	http://www.telegraph.co.uk/news/science/science-news/11077912/Hostile-Europe-risks-derailing-medical-innovation-warns-minister.html

Date	Source	Title	Author	Readership comments	Accessed	Reference
2014-10-07	Daily Mail Online	Storm as NHS gives go-ahead to patient database despite concerns: Pilot scheme will involve 1.7million people unless an individual specifically opts out	Sophie Borland	83	2015-02-13	http://www.dailymail.co.uk/news/article-2784269/Storm-NHS-gives-ahead-patient-database-despite-concerns-Pilot-scheme-involve-1-7million-people-unless-individual-specifically-ops-out.html
2014-10-08	Daily Mail Online	NHS trials patient database scheme	Press Association	0	2015-02-13	http://www.dailymail.co.uk/wires/pa/article-2784556/NHS-trials-patient-database-scheme.html
2014-10-08	Telegraph Online	NHS gives go-ahead to patient database despite privacy fears	Keith Perry	0	2015-02-15	http://www.telegraph.co.uk/news/nhs/11147730/NHS-gives-go-ahead-to-patient-database-despite-privacy-fears.html
2014-11-27	Telegraph Online	Why sharing medical data could be good for your health	Nick Partridge	0	2015-02-15	http://www.telegraph.co.uk/news/politics/11256622/Why-sharing-medical-data-could-be-good-for-your-health.html
2014-11-27	Telegraph Online	NHS to carry on selling patient records to insurers	ChristopherHope and Laura Donnelly	56	2015-02-15	http://www.telegraph.co.uk/news/health/news/11256570/Tens-of-thousands-of-medical-records-handed-to-researchers.html
2015-01-26	Independent Online	Anonymous' NHS database could still allow patients to be identified, expert warns	Steve Conner	5	2015-02-16	http://www.independent.co.uk/life-style/health-and-families/health-news/anonymous-nhs-database-could-still-allow-patients-to-be-identified-expert-warns-10001783.html?origin=internalSearch
2015-01-30	Independent Online	Letters: NHS data-sharing is good for patients	Dr. Stephen Black, Harry Phillips, Pete Rowberry, Chris Naylor	0	2015-02-16	http://www.independent.co.uk/voices/comment/letters-nhs-datasharing-is-good-for-patients-10013283.html?origin=internalSearch
2015-02-03	Independent Online	Government told to make it easier to opt out of care.data database	Steve Conner	5	2015-02-16	http://www.independent.co.uk/news/uk/politics/government-told-to-make-it-easier-to-opt-out-of-caredata-database-10019135.html?origin=internalSearch

Draft Focus Group plan

Introductions and ice breaker (15 mins)

- *Researcher intro, purpose of group, what's going to happen*
- *Researcher and participant intros + icebreaker e.g. one word to sum up your day today*
- *Confidentiality assurances*
- *Any questions?*

Short group discussion 1: Taking part in medical research (15 mins)

- *Have you, or any of your family, taken part in medical research before?*
- *If yes, what motivated you to take part?*
- *If no, have you ever been asked to take part? Why refused?*
- *Do any of you have any concerns about medical research generally?*

Brief overview/explanation of genomic research (20 mins)

Show DoH 'What is a genome?' video (2 mins) – once through, then if necc. second time with pauses for questions

- *Reactions to video re. genomes – do they feel they understand what a genome is?*

Show Genomics England 'About 100,000 Genomes Project' video (6 mins)

- *Reactions to video re. project – understanding of project, how will work, benefits, who are Genomics England? How are they related to NHS?*

Main group discussion 2: Genomic research, trust and regulation (45 mins)

- *What do you think about genomic research generally?*
- *What do you think the benefits might be? (For you, families taking part in project, wider society)*
- *Does anything concern you about this project? Possible prompts – negatives/other considerations about project? E.g. personal data, confidentiality, commercial aspects.*

[Possibly show video of Participant Stories – Arthur (3 mins) if discussion is slow]

- *Reactions to video re. issues raised – pharma companies, who is accessing data, security, might not directly benefit Arthur, data on file forever*

- *Would you take part if you were invited? Why/why not?*
- *What would encourage you to take part?*
- *Who do you think should be able to use your samples?*

- *Possible prompts: if mention 'trust', 'confidence', etc ask to clarify what they mean by that.*

Concluding thoughts and summing up (10 mins)

Focus group discussion consent form

Database reference number _____

FACE-TO-FACE FOCUS GROUP DISCUSSION CONSENT FORM

A study to explore the public's views on genome sequencing and health data sharing.

The purpose of the study is to hear what a wide range of people think about genome sequencing and health data sharing. A report will be written for the Department of Health and Genomics England about people's views.

	Please initial box
1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons, without my legal rights being affected.	
3. I understand that relevant data collected during the study will be looked at by the project research team at the Nuffield Department of Primary Care Health Sciences (HERG) which are part of the University of Oxford and researchers at the London School of Hygiene and Tropical Medicine.	
4. I agree that the face-to-face focus group will be recorded and transcribed.	
5. I understand that this project has been reviewed by and received ethics clearance through the University of Oxford Central University Research Ethics Committee.	
6. I understand how to raise a concern and make a complaint*	
7. I understand how the data will be stored and what will happen to the data at the end of the project.	
8. I agree to the use of anonymized quotes in publications.	
9. I agree to take part in the above study.	

Please sign overleaf

Name of Participant (**block capitals**)	Date	Signature
Researcher	Date	Signature

*If you have any questions about the project or wish to make a complaint please telephone Dr Sara Ryan on 01865 289328 at the Nuffield Department of Primary Care Health Sciences. The researcher should acknowledge your concern within 10 working days and give you an indication of how he/she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner.

Participant Information Sheet (Focus Groups)

Health Experiences Research Group • Nuffield Department of Primary Care Health Sciences • University of Oxford • Gibson Building, 1st Floor • Radcliffe Observatory Quarter • Woodstock Road • Oxford OX2 6GG •

Participant Information Sheet (Focus Groups):

A study to explore the public's views on genome sequencing and health data sharing*.

Thank you for getting in contact about our focus group research. My name is Elizabeth Holdsworth and I am a researcher working with the Health Experiences Research Group, Nuffield Department of Primary Care Health Sciences, at the University of Oxford.

We would like you to take part in a focus group discussion about genome sequencing and health data sharing*. This sheet explains the purpose of the project and what we are inviting you to do. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask any questions. Talk to others about the study if you wish.

What is the purpose of this study?

The purpose of this study is to fund out more about what people think about genome sequencing and health data sharing*.

*** A genome is one whole set of genes plus the DNA between them. Genomics research involves reading (or sequencing) the DNA which provides**

We want to hear what a wide range of people think about genome sequencing and health data sharing.

The information from this study will be shared with the Department of Health and Genomics England in the form of a written report.

Who can take part?

If you are over 18 and resident in England you can take part in one of the focus groups.

What will happen if I take part?

If you would like to take part please complete and send back the attached reply slip by email or post (pre paid envelope enclosed). We will contact you to let you know where and when the focus group will be held. You can ask us any questions you may have at this stage. If you do decide to take part we will give you a consent form to sign when we see you.

A focus group is a group discussion. We will invite up to 8 people to discuss their views on genome sequencing and health data sharing. There will be 2 researchers present. During the discussion we talk about issues such as:

- what people understand about genome sequencing and donating samples for health research
- whether they have taken part in any medical research or donated any samples (e.g. blood, body tissue, urine etc.)
- whether they would be willing to consider this and why
- what, if any, do they think might be the risks involved in taking part in medical research or sample donation
- what they think about health data sharing and confidentiality

The focus group will last around 1.5 hours. It will be audio recorded and a researcher will observe and make notes.

What will happen after the focus group?

The audio recording of the focus group will be given to a typist to type out everything that was said. The typist has signed a confidentiality agreement. All names will be removed from the typed up record (transcript), and your identity will remain anonymous. The project researchers will analyse what was said at all the focus groups and use this data to write a report. All data use will be strictly within the terms of the Data Protection Act (DPA 1998). At the end of the project the typed up record (transcript) of the focus group will be archived by the University of Oxford.

What will happen to the results of the study?

The information from this study will be shared with the Department of Health and Genomics England in the form of a written report.

Will everything we say be kept private?

The audio file and the typed up transcript will be kept in a secure place at the Nuffield Department of Primary Care Health Sciences at the University of Oxford. At the start of the focus group we ask everyone attending the focus group to keep everything that is said during the discussion confidential. In the transcript names of yourself and all other participants as well as any other names you mention will be removed. The researchers may use anonymised quotes from the focus groups in their report.

Do I have to take part?

It is up to you to decide. If you decide to take part you will be asked to sign a ‘consent form’. You are still free to stop at any time without giving a reason.

What are the benefits/risks of taking part?

People who take part in similar focus group based studies often say they found the experience rewarding.

If you decide to take part in the project, you can withdraw at any point before, during or after the focus group.

What if you change your mind about taking part?

If you decide to take part then this is your voluntary decision, therefore you are also free to withdraw from the study at any point you wish, without giving a reason, without your legal rights being affected.

Expenses and Payments.

We will reimburse any travel expenses you incur as a result of attending the focus group. After the focus group we will give you a £25 shopping voucher to thank you for your time

Who is organising and funding the research?

This research is being carried out by the Health Experiences Research Group at the University of Oxford in collaboration with researchers at the London School of Hygiene & Tropical Medicine. The research is funded by the Department of Health.

Who has reviewed the project?

This project has been reviewed by, and received ethics clearance through the University of Oxford Central University Research Ethics Committee (ref MS-IDREC-C1-2015-175)

We hope this information sheet has told you what you need to know before deciding whether or not to take part.

If you have any questions or would like more information concerning the research please contact:

Elizabeth Holdsworth, Research Fellow, London School of Hygiene & Tropical Medicine

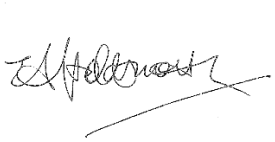
Tel: 020-7958-8347

Email: Elizabeth.Holdsworth@lshtm.ac.uk

What if there is a problem ?

If you wish to make a complaint please contact Dr Sara Ryan on 01865 289328. The researcher should acknowledge your concern within 10 working days and give you an indication of how she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner.

Thank you for taking the time to read this.



Elizabeth Holdsworth

This study is being conducted by researchers at the University of Oxford. We will only use your email for the purposes of this study.

Genomic Research poster V2 September 2015 MS-IDREC-C1-2015-175]

For display in non-NHS locations only

NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

OXFORD

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Health Experiences Research Group • Nuffield Department of Primary Care Health Sciences • University of Oxford • Gibson Building, 1st Floor • Radcliffe Observatory Quarter • Woodstock Road • Oxford OX2 6GG

Would you like to join our focus group discussion about genome sequencing?

What is our focus group about?

We are running a series of focus groups discussions to find out about what people think about genome sequencing and health data sharing.

A genome is one whole set of genes plus the DNA between them. Genomics research involves reading (or sequencing) the DNA which provides information about why some people may become ill while others do not. The government is funding research to sequence 100,000 genomes by 2017 to bring benefit to patients.

We want to know what you think about this development.

Who should come along?

We would like to hear from people who have rare genetic diseases. You don't need to know about genome sequencing as we will explain more about it during the focus group.

The focus group will be held on X, at X

Who we are?

We are researchers at the Health Experiences Research Group at the University of Oxford and London School of Hygiene and Tropical Medicine. We will use information from the focus groups to write a report.

For more information about the focus groups please contact Elizabeth Holdsworth on 020-7958-8347 or email Elizabeth.holdsworth@lshtm.ac.uk

The focus groups will be made up of no more than 8 people and will last approximately 1.5 hours. Refreshments will be provided. Those who take part will receive a shopping voucher for £25.

Genomic Research poster V2 September 2015 MS-IDREC-C1-2015-175]

Conceptualising themes of public trust in care.data

Altruism

People stated that altruistic motivations need to be respected, not misused and should guide care.data:

The NHS is on a downward spiral, and being driven there by political dogma rather than altruistic beliefs. I despair for the system under the current government that seems hell bent on having a management driven system, involving as much private input as possible and ignoring experienced professional medical staff. (Comment on article by Dr. Gordon Gancz, 'I won't give in to the NHS Thought Police who want to sell your private medical records: GP threatened by health chiefs hits back', Mail Online, 6 February 2014).

We are asking individuals to volunteer their private details for the good of others, a noble request which many of us would agree to if we thought our selflessness; sacrifice was being respected and matched by those to whom we gifted the data. Sadly it is hard to believe that, rather the data will be sold to a variety of organisations and companies some of whom will use it for cynical, grubby, commercial purposes. (Comment on article by Craig Manson, 'Could controversial data sharing be good for patient health?', Guardian, 22 April 2014).

Anonymity of data

People stated that anonymization of personal data is essential to be able to trust the care.data programme:

The pooling sharing of this anonymised data is a great idea. If I suspect there is a link between say depression in childhood, and Alzheimer later in life, without this I have limited access to datasets, and constructing a proper limited study takes decades. With this database it would take minutes. Science would speed up. We'd discover all sorts of surprise gems. Faith in anonymisation is key. (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

This from the Government that claims to believe in small state politics....big brother....actually big gangster, selling what does not belong to them to whoever is willing to pay. Don't believe a word of what they say about anonymity. (Comment on article by Martin Beckford, ''Big Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

Autonomy of people

People need to be able to keep their personal autonomy to be able to build trust in the health care system:

Both doctors and governments are getting far too much control over our lives. I keep away from doctors. I lost faith and trust in them a long time ago. (Comment on article by Martin Beckford, ''Big Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

"The fear is that patients will be identified, losing control of their records and trust in their GPs. But the protections are many and thorough"

Oh, that's all right then.

(Comment on article by Polly Toynbee, 'It's right to worry about security, but sometimes data trawls can be useful', Guardian, 23 August 2013)

Certainty about future use of data

Decreased certainty about the use of medical data in the future undermines trust:

I really don't trust this idea, we don't know that promises made now will be kept by future governments, or private companies. The thought of insurance companies getting hold of this data, and the potential use is frightening. There may be some benefits, but history tells me that these people cannot be trusted, when profits/cost savings can be made. (Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

I have opted out but can I really trust that I will be opted out. No one really knows this is happening, it isn't in the mainstream media and looks like the government is sneakily doing this without telling us all the facts, but it's a conservative government so no surprise there because they only care about financial figures and not people. I think this will make people more reluctant to confide in their doctor over sensitive issues for fear of this information being given to other parties in the future so this could have a detrimental effect on people's health. (Comment on article by Martin Beckford, ''Big Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

Choice

There needs to be a choice offered to take part in care.data and with this choice to be able to place trust in the care.data programme.

Give us a more useful choice. As well as "all in" or "all out", allow us to opt out of commercial/private/third party use but still allow our data to be used for academic and other public sector, non-profit research.

Whether you trust that choice to be upheld and not ignored either wilfully or through negligence, is another matter of course... (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

Confidentiality in the GP-patient relationship

Confidentiality is key for the general practitioner-patient relationship. Also the GP is the person who is able to opt out patients from the care.data programme. Readers raised concerns that the care.data program was threatening the GP-patient relationship:

If you cannot trust your doctor in the confidential relationship then folks won't go to the doctor (Comment on article by Dr Gordon Gancz, 'I won't give in to the NHS Thought Police who want to sell your private medical records: GP threatened by health chiefs hits back', Mail Online, 06 February 2014).

The doctor-patient relationship is and must be sacrosanct. Unbreakable confidentiality, nothing less. Destroy our faith and trust in that and there will be no return. (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

Data accuracy

The data entered into medical files at the general practice needs to be accurate for people to be able to trust care.data:

And the first is to get a copy of your own record and check its accuracy.

In this article there is a blind faith assumption that doctors record accurately what it is you might have told them, or interpreted correctly what they think they have heard.

On the few occasions I have seen my GP in the past ten years, he / she has been completing the previous patient's record on their computer while listening to me. (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 February 2014).

I have no fears about my medical data being held by the NHS and shared: but I do entirely understand your point about accuracy - when I was last in hospital, my discharge notes were a mixture of my details and another patient's who had been admitted at the same time, with a similar condition but different cause. I hope that's been corrected, otherwise anyone accessing my notes will believe I've suffered from a duodenal ulcer in the past.... (Comment on article by Charlie Cooper, 'Your life in their hands: is the care.data NHS database a healthy step or a gross invasion of patient privacy?', Independent, 06 January 2014).

Fear of consequences

People are anxious about negative consequences with respect to the care.data programme, which undermines trust:

I think this will make people more reluctant to confide in their doctor over sensitive issues for fear of this information being given to other parties in the future so this could have a detrimental effect on people's health. (Comment on article by Martin Beckford, ''Big Brother' database will grab children's health records but parents are being kept in the dark', Sunday Mail Online, 9 February 2014).

Government explaining care.data

The aim and objectives of care.data need to be explained to the public and information provided to be able to trust the programme:

"We believe the government must focus on educating the public on how their data will be treated and what security measures will be taken before its second attempt to launch the programme." (By Laura Donnelly, 'Britons 'trust banks more than government' to protect their data.' Telegraph, 21 May 2014).

Bread & circuses (pizza & TV) provide a convenient distraction but we can only hope that one day the penny will drop with the masses in the UK and we will then get the government we deserve. (Comment on article by Jason Groves, 'Now our tax data could be sold to businesses: Government planning change in law to allow release of 'anonymised' data to third parties', Mail Online, 19 April 2014).

Honesty

Honest communication is needed to be able to trust care.data:

Believe it or not politicians are not the most honest of all professions … (Comment on article by Claire Carter, 'NHS medical records database could help prevent disease, senior doctors say', Telegraph, 24 February 2014).

Improved quality of health care

Care.data needs to lead to improved quality of care to be trusted:

It is hoped that the resulting increase in preventative treatments, coupled with improvements in health management, will save billions and improve the quality of healthcare. The sticking point is patient confidentiality. (Comment on article by Mike Hodgkinso, 'The number crunch: Will Big Data transform your life - or make it a misery?', Independent, 19 January 2014).

IT competence

IT systems were not trusted by the readership. This applied to GP practices as well as governmental and private IT systems:

…as an IT professional I have zero confidence that there is any way to effectively secure this data, particularly if a Government-initiated IT project is involved. (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 February 2014,).

Never mind ATOS's lousy record in other matters (which makes ATOS management unable to be trusted), but why a French company rather than a UK company? And it would not surprise me to find that the IT servers will be remotely managed from India or elsewhere. (Comment on article by Charlie Cooper, 'Hospital records used to 'target ads on Twitter and Facebook' say privacy campaigners, in latest NHS data concerns', Independent, 03 March 2014).

Local storage place

Local storage places were more trusted compared to national storage places even if data were to be stored on a personal smart card:

Why do we need a centralised healthcare database? I cannot see how it can do very much to improve care, but can see plenty of risks with it. And the attempt to build one was the largest and most costly IT project in the history of the World, and failed. Limited authorised extracts from locally held trusted databases is far more sensible. (Comment on article by Polly Toynbee, 'It's right to worry about security, but sometimes data trawls can be useful', Guardian, 23 August 2013).

I believe we should all have a smart card with OUR data on it, and we choose to allow health professionals (and others) to see that data or not. Each provider would have a copy of the healthcare they deliver to us, but only we should have the complete picture. (Comment on article by Steven Swinford, 'NHS legally barred from selling patient data for commercial use', Telegraph, 28 February 2014).

Medical research

Using data for legitimate (probably university/public) research was considered to support trust:

Hopefully this will result in a move to new services that will have been designed to protect privacy and engender trust. (Comment on article by Mike Hodgkinson, 'The number crunch: Will Big Data transform your life - or make it a misery?', Independent, 19 January 2014).

Certainly I would hope that the grand cock-up that has been made by care.data over the opt-out issue is not the work of legitimate researchers: from the legitimate research perspective they have gone a long way to ensuring their own demise. (Comment on article by Oliver Wright, 'Inside Whitehall: Care.data will help prolong our lives and those of our children', Independent, 25 February 2014).

NHS's financial benefit

Throughout the readers' comments concerns were expressed that the data collected would be sold to private companies to be used for their own profit or the profit of the government (i.e. simply to generate revenue). However, it was considered acceptable that the data would be used to benefit the NHS:

Make no mistake if you believe the government is only interested in public welfare. WRONG it's about balancing the books. (Comment on article by Stephen Adams, 'GPs threaten to boycott 'Big Brother' NHS database which would force them to send confidential patient records to private firms', Mail Online, 21 September 2013).

I do not trust the NHS to keep the information safe and secure and I have grave fears it being sold on to private companies. (Comment on article by Sophie Borland by, 'NHS delays plan to harvest your details: Victory for the Mail as database is shelved for six months', Mail Online,18 February 2014).

Personal benefit

If that if people thought that the use of care.data would benefit themselves directly, not just patients in general, they were more likely to trust in the programme:

"They were supposed to believe it was all for their own good." (Antonia Molloy 'NHS boss apologises for tweeting Hitler video mocking Government health database scheme', Independent, 28 February 2014).

There seems to be a touching faith that gathering all this data will improve patient outcomes. (Comment on editorial (no author), 'NHS data: take more care', Guardian, 25 February 2014).

Privacy

Privacy needed to be respected by the care.data programme and not breached if people were to trust the programme:

Even if you opt out how do you really know that they have complied and removed your data? I think this govt would sell their granny for a fiver let alone trust them with my private details - thankfully I live in Scotland. (Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

Do you trust Whitehall mandarins and large commercial concerns to respect your privacy? (Comment on article by Polly Toynbee, 'It's right to worry about security, but sometimes data trawls can be useful', Guardian, 23 August 2013).

Protection in numbers

The size of the data set seemed to be perceived to have a protective effect against hacking in the sense of the high number of data files lowering the odds of someone's data file being identified:

Why would you believe that out of millions of records someone would be bothered to identify you and for what purpose? (Comment on article by Claire Carter, 'NHS medical records database could help prevent disease, senior doctors say', Telegraph, 24 February 2014).

Public benefit

Using data to generate public benefit supported trust:

Even if the NHS sincerely believes this is in the public interest, we should have no faith it will not be misused by business and other interests for their own purposes. (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

If I believed that my medical records were being used for the greater good, then I would have no problem with it. (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 Februrary 2014.)

Regulation

Regulatory mechanisms, legislation and safeguards were considered to support trust in care.data:

I work for a research company and we currently "extract" data from Primary care - the hoops we have to go through to do this are extensive - but I believe they are useful to maintain privacy and limit "mess ups". (Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

As part of the legislation proposed which will restrict the flow of information I would like to see hefty penalties imposed for companies which refuse or fail to delete data which they are not entitled to have. (Comment on article by Randeep Ramesh, 'NHS patient data audit uncovers 'significant lapses' in confidentiality', Guardian, 17 June 2014).

Representative governance

The powerlessness of the 'little man' and the feeling that government was by 'ruling elites' seemed to resonate in the public sphere. Therefore, the government needs to act in the public interest and not in its own (elitist) interest if care.data is to be trusted:

The reptilian ruling elite believe they own the human bodies they created on this physical level (but not the consciousness occupying the body) and so also own all the medical information to do with as they please. (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

You should not automatically believe there is any link between class and fraud. The idea that fraud is only committed by what you call 'working class' people is risible. (Comment on article by Nicole Blackmore, 'NHS database: will it push up your insurance premiums?', Telegraph, 1 March 2014).

Responsible management

Care.data needed to be managed responsibly to be trusted:

I have little faith in the management of any public sector controlled process. (Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

I have no problem with sharing medical records as part of an abstracted set of data, but I just wouldn't trust the present NHS to respect the confidence and manage it responsibly. (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

Truth

Health care system representatives communicating the truth supports trust:

Thin end of the wedge ... I have no trust in politicians or NHS to tell the truth. (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

It's hard to imagine a time where it was so easy to believe that the language of numbers and symbols could somehow create the elixir of wordless, idea truths …. (Comment on article by Vanessa Heggie, 'Giving away your data: from Galton and Google to care.data', Guardian, 3 February 2014).

Unlawful data access

Concerns about hacking, leaking and other unlawful data access were raised and were likely to reduce trust:

Given that we are now aware that foreign government agencies routinely obtain data illegally whenever possible, what confidence can the British public have in the confidentiality of such a system? (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

Big brother wants total control over every aspect of people's lives. Although they say they "will promise legislation to prevent personal information being shared for any ¿purely commercial¿ purpose", that information is only as secure as the computer system and those who access it. Given the record for government departments "losing confidential information", on laptops, cd's/dvd's and paper copies does not instil confidence whatsoever. Plus the added risk of being accessed by GCHQ, NSA and hackers, I do not believe the system will ever be secure. This should be an opt-in scheme, NOT opt-out! (Comment on article by James Chapman and Andy Dolan, 'Cashing in on patient records to be banned: But you'll still have to opt out to keep private details off database', Mail Online, 28 February 2014).

Framing themes of public trust in care.data

Communication

Communication (e.g. verbal or written communication, body language, one-way or two-way communication, etc.) is axiomatic to build and express trust. Public trust is formed by what is communicated (e.g. truth like seen below) and how it is communicated. Therefore, communication in the pure sense of exchanging information is a necessity and a pre-requisite to build public trust:

NHS competence has sunk to a level when you can't believe a lot of what is written there. (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

Nothing seems sacred anymore. People have become 'targets of opportunity' for big business profits. Politicians continually speak which they expect us to believe. Money rules (Comment on article by Steven Swinford, 'NHS legally barred from selling patient data for commercial use', Telegraph, 28 February 2014).

General expectation of the government

A normative expectation that the government should be trusted by the public was expressed. It seems that the public understands the government to be expecting to be trusted:

The finance industry is also very heavily regulated. All data has to be masked and anonymised. Yet another leakage and your financial data is again all over the web. Yet the Government expect us to trust a quango to do better with our very personal and private communications and records with our doctors. (Comment on article by Steven Swinford, 'NHS legally barred from selling patient data for commercial use', Telegraph, 28 February 2014).

You (politicians) *cannot rely on blind trust when it comes to sharing private medical records, so explain that you'll be coming back soon with a clear story.* (Comment on article by Ben Goldacre, 'The NHS plan to share our medical data can save lives – but must be done right', Guardian, 21 Februrary 2014.)

People's world view

Several times in the data, readers were referring to axioms, proverbs or personal conviction to express a certain generalised view. This view seems to be more fundamental to their world view so that it influences their decision making process to trust:

I tend to believe in the axiom "What can be done, will be done" (Comment on article by Claire Carter, 'NHS medical records database could help prevent disease, senior doctors say', Telegraph, 24 February 2014).

"Mundus vult decipi."
Sebastian Franck
Paradoxa Ducenta Octoginta, CCXXXVIII (1542)
(The world loves to be deceived)
(Comment on article by Steven Swinford, 'NHS legally barred from selling patient data for commercial use', Telegraph, 28 February 2014).

Risk

Perceptions of risk (e.g. misuse of medical data or personal harm due to misuse of personal data) results from the use of medical records. Here risk arises from individual and environmental action. If there would be no risk associated to the use of medical data or if one would have knowledge and power to counteract and control the risk, there would most likely be no need for trust, compare here Chapter 4:
Meanwhile, a risk assessment by NHS England, the organisation behind the scheme, raises concerns about the initiative. The document, obtained by The Daily Telegraph, states: "The extraction of personal confidential data from providers without consent carries the risk that patients may lose trust in the confidential nature of the health service." It adds: "The risks described include threats associated with 'cyberspace' such as hackers attempting to access the data illegally." (By Jane Kirby and Ella Pickover, 'Doctors raise fears over sharing NHS patient medical records', Independent, 17 February 2014).

Societal context and mood

In recent years, several trust crises in association with governmental systems and bodies were discussed in the UK media. It appears from the data that this discourse spilled over into the care.data discourse as comparisons were made between different crises and the care.data programme. This mood seemed to resonate in the public trust discourse:

With so many CRISES going on throughout the land. You would why people get out of BED?? We have this CRISIS of confidence, we have the Cost of living CRISIS, we have the flooding CRISIS, The cost of Housing CRISIS and so it goes on. CRISIS is obviously the Journalist word of the moment. All we have to do is ring the BBC, they have untold numbers of 'EXPERTS' (Comment on article by Sophie Borland, 'GPs warn of crisis in public confidence over NHS database: Royal College warns health service of failing to inform patients about data sharing', Mail Online, 13 February 2014).

Use of patients' medical data

The use of patients' medical data in the care.data programme is understood to be inevitable as the aim of the programme is to use the data. Therefore the use of the data per se is a framing theme. Levels of trust are influenced by the way medical data are expected to be used and by whom:

Even if the NHS sincerely believes this is in the public interest, we should have no faith it will not be misused by business and other interests for their own purposes. (Comment on article by Nick Triggle, 'Health by Care.data: How did it go so wrong?', BBC News, 19 February 2014).

I personally wouldn't trust Atos or this government with any data mining operation - it's bound to be misused (Comment on editorial (no author), 'NHS data: take more care', Guardian, 25 February 2014).

Effect theme of public trust in care.data

Legitimisation

Consenting to care.data is understood as an effect of trust. The critical public discussion of care.data set up as a programme where all patients were expected to opt in by default led to expressed low trust. Consequently, people were opting out and not consenting as an effect of low levels of trust, they withdrew the legitimisation of the programme:

*I'm afraid I don't trust them to do things properly. Nor do I want any information related to me shared with Big Pharma, so I'm opting out. (*Comment on article by Nick Triggle, 'Are your medical records in danger?' 28 January 2014, BBC News).

Conceptualising themes of trust in biobanks

Advance in science

Donations leading to scientific breakthroughs increased trust:

Yeah, well, I absolutely [um] trust, and I'm a hundred per cent confident that [um] all my, [er] our little collections for MND research will [um] eventually help towards that breakthrough. (BIO12).

Altruism

Altruistic motivations should lead to public benefit otherwise trust might be undermined:

And I have to believe that a lot of this is about public good, and particularly where research is concerned. (BIO1).

And I suspect that there is a large part of altruism on the part of these patients, that in participating in some trials they're looking rather than for hope for themselves to give hope to other people, and to find some purpose in what is [um] very trying times. (BIO3)

Anonymity

Anonymity of participants' data was needed to maintain participants' trust:

And although maybe anonymised, there are various bits of information that [um] would be necessarily attached to that in some studies. And [um] I would hope that -and I am confident really - that this will be respected. It's very public. (BIO1).

I think my [er] personal data and medical information getting into the wrong hands is a general worry, mainly because of confidentiality issues. I'm not entirely sure if anybody would be able to use that data [er] to harm me, other than to invade my privacy. [Um] But yes, I do think the [um] the security of the data, privacy, anonymity - where that's appropriate in a study - I think they're, they're very important. (BIO15).

Arrogance

Arrogant professional behaviour would undermine trust:

I, I think it was done with the best of intentions but I think it was done very badly and with a huge amount of arrogance on the part of the health professions. [um] A lot of the parents in some of the interviews that I saw said that they wouldn't necessarily have minded if they'd been allowed to consent. They knew that this was, this was happening but, and also it seemed to have been a lot of, with some of the cases, that they were taking huge amounts of the body away [um] rather than just, you know, tissue samples or what they had down was tissue samples whereas actually they were removing the whole heart or the whole liver or the whole, you know, and I think that was a, an issue of consent and an issue of trust as well. And I think if they'd been up front about what they wanted [um] it wouldn't have been so much of a problem. (Talks about Alder Hey, See Chapter 5) (BIO19).

Control Systems

Existing control systems are necessary to support trust:

But also I mean you've got, there are things like FOI [Freedom of Information] [er] requests to be put in. You know, I just wonder. [um] It's a concern over the last year I've had, about how much of this sort of information can be got on the basis of that. But I mean I guess the Data Protection, I mean hopefully the Data Protection Act controls some of that sort of stuff. (BIO20).

And again I, [um] I think you just have to decide whether you think that it is well enough regulated and secure, and that all possible systems are in place to make sure that it is. And you have to trust that that's done. (BIO1).

Corroboration

When several information sources online present the same information, the information is likely to be trusted:

But you know, more and more people – dare I say it - I won't say they trust the web, but they'll use the web to get information, because they know if they can get the same information from different sources - and I'm a bit like that, if I can get the same information from two or three sources then I start to believe it. (BIO11).

Data kept in good condition

Personal data need to be kept in good condition by the research team for trust to be built:
Well, it has, yes. You think, "Oh, I hope they're all kept in good condition." (BIO1).

Data security

Data needs to be secured for people to be able to trust the biobank:
And again I, [um] I think you just have to decide whether you think that it is well enough regulated and secure, and that all possible systems are in place to make sure that it is. And you have to trust that that's done. (BIO1).

I think I feel all the stuff that I've been told, and the, you know, the letters they write to you, I feel confident that they're as secure as anybody can make them. (BIO7).

Discussing clear information

Discussing clear information during the consent process with somebody who knows about the study is very important for trust:
I think the consent procedures are very important. It's good to have clear information and plenty of links to people who you might be able to ask questions of if you have questions. (BIO1)

But he was very clear and cogent at the time, and I believed him. So, you know, I was asking all sorts of questions and he was quite happy to talk, answer them, and carry on doing the work, and things like that, so. (BIO11).

Doing the best possible

Researchers need to do the best possible at the time to be trusted:
And they do the best we can do, with our current knowledge -I will put that caveat in - to balance the risk, the pain or other un-, yet unknown side effects of using this. And that's the best we can do. We can't do any more than that. We can't try and protect against things we don't yet know about. (BIO18).

Public Funding

Most of the funding should come from the public NHS:

And I would hope that most of the funding is related to the NHS. I got the impression that it's NHS-funded research we're talking about. (BIO11).

Honesty

Trust would be harmed by deliberate dishonesty about data use:

'*Yes, [um] right, so trust. [um] As a participant - I think the biggest way that my [er] trust could be [um] abused would be by misrepresenting the results, [um] being dishonest with the data. I think that's what would bother me most.* (BIO15).

Importance of research

If the research is perceived to be important, it is more likely that people will be willing to trust the programme:

I've complete trust that [um] it's important that [um] that question is answered and there is a reason for that. (BIO12).

Knowledgeable professionals

Professionals (including frontline staff) need to know about the programme if it is to be trusted by participants:

And certainly with the experiences of the first two [um] tissue samples through, related to my breast cancer, the fact that somebody, you can talk to somebody who knows about the study, even if it's, you know, fairly, fairly general level, is really important and gives you some sort of trust that this is something that they know, they know about. (BIO1).

Perception of safety

Participants feeling safe during human encounter while taking part in research:

I think that's personal choice. I think you've got to just make your own decision, and if you're comfortable, again, if you're comfortable with it, and you trust the people you're with, and you feel safe with them, do it. (BIO5).

Personal benefit

Participants might expect to personally benefit by taking part in a study, this expectation can foster trust:

I, there is a difference, yeah. I think for a number of people, [um] particularly, say, picking on cancer patients, they look for hope [um] to come through what is an appalling diagnosis and then potentially appalling treatment. (BIO3).

Privacy

Privacy of personal data of participants is important to be able to trust:

I think my [er] personal data and medical information getting into the wrong hands is a general worry, mainly because of confidentiality issues. I'm not entirely sure if anybody would be able to use that data [er] to harm me, other than to invade my privacy. [Um] But yes, I do think the [um] the security of the data, privacy, anonymity - where that's appropriate in a study - I think they're, they're very important. (BIO15).

Professionals' ability to keep up with new knowledge

Professionals keeping up with new knowledge and therefore are up to date are more likely to be trusted:

I believe even professionals within their own specialism can't often keep up with it. (BIO20).

Professional reputation

Professionals with high levels of reputations are more likely to be trusted:

I don't believe that they would compromise their integrity or the reputation of the unit and the quality of the care that they provide by associating themselves with something that wouldn't [um] reflect their service standards and their ethical standards, I think. (BIO17).

Protection in numbers

If data is stored in a large data bank, people trust more:

And biobanks, the actual biobank that does all the studies must be massive, and I can't believe there's that many people out there that are interested in something of mine, you know – "Miss S" sort of thing, you know, from whatever town, I don't know they're that bothered [um]. (BIO7).

Providing time for medical research

Time needs to be allowed for medical research to be trusted:

And if we don't allow the medical profession to make this research and undertake experiments on us as, you know, human beings, we're never going to find out, are we? So I'm, I'm a great believer that we give them as much time as possible. (BIO16).

Regulations

Regulations supports trust:

But at some point, and I know things like the [um] research regulations, research governance is sort of tightening things up, and we've got the Human Tissue Act which, you know, I know that there are licenses for storage and inspections and new regulations. So that does give me a little reassurance there. (BIO1).

Respecting for participants

Respectful interaction between participant and staff is supporting trust:

I'm allowed to and privileged to call my doctor by his first name, [um] and so we are friends and doctor and patient, and [um] all in one. And I think that's [um] a lovely place to be. They respect how I am giving as much as I can of my time and my love. And equally, I respect how they are giving their time and their love. (BIO12).

Self-confident professionals

Professionals who radiate self-confidence are trusted:

You - I don't know how well somebody without that confidence, without that –you kind of can't have one without the other. Because if you haven't got the education, the confidence, you can't do the confidence bit because you actually don't know what you're talking about… (BIO18).

Framing themes of trust in biobanks

Communication

Communication (e.g. verbal or written communication, body language, one-way or two-way communication, etc.) is axiomatic to build and express trust. Public trust is formed by what is communicated (e.g. truth like seen below) and how it is communicated. Therefore, communication in the pure sense of exchanging information is a necessity and a pre-requisite to build public trust:

I suppose the other thing that I would say about linking medical records is when you live in one county, and you're being treated at a centre for excellence in another county, and getting the two to speak to each other I find quite, [um] quite difficult sometimes. So I tend to just trot along with my own little message, so if I get a message from the hospital and I have to go to the GP, or in the early days when I was going to the hospice as a day patient, I'd actually deliver the message myself. Or if it were the other way on, I'd deliver the message myself, because I didn't really trust for the message to get from one to the other when it was cross-county, it didn't work. And I also felt that - unfortunately I had to move house about – well, I didn't have to move house, I chose to move house 18 months ago - and I found it quite upsetting that I had to change GP, because my GP had been through it all with me and I feel that the GP that I use has never really taken on board what happened. And I'm sure that they can read the notes and understand it, but it's not the same. (BIO5).

Data use

The use of patients' medical data is understood to be axiomatic as the aim of the research is to use the data. Therefore the use of the data per se is understood to be a framing theme, i.e. it is unavoidable if someone decides to participate. Levels of trust are influenced by the way that medical data are to be used and by whom:

I suppose it is, but you wouldn't turn up if you didn't trust that it would be used in the right way. Those people that don't believe in it would be not the people that would participate. (BIO6).

Fear

Fear is considered an underlying human characteristic and therefore influencing the decision process to trust:

I believe all of us have fear. There is no one immune to it. (BIO12)

Human error

Trust needs to take into account that human errors are inevitable. Therefore people need to arrange with this fact and should not unrealistically expect that human error will not occur in the trusted programme:

Everybody makes mistakes. I don't believe anybody in any job sets out in the morning to say, "When I go into work today I'm going to do that wrong. I'm going to really cause an issue today." (BIO7)

People's world view

Several times in the data, readers were referring to axioms, proverbs or personal conviction to express a certain generalised view. This view seems to be more fundamental to their world view so that it influences their decision making process to trust:

"I'm sorry, you can't finish it. You started it and you will finish it. I will carry on. I'm just a stubborn Englishman, and I have hope". (BIO10).

No, on a personal level I have a lot of trust in life. I ask my heart many questions and get an immediate response, and my heart says, "Trust in that way." (BIO12).

Religion and afterlife

Religious belief influences trust, see Chapter 4:

It's God's will, isn't it? Well, it might be God's will. I don't believe in him, anyway. So whatever happens, when I die, whether I go to the maker or not, as long as I can help somebody I'll be happy. (BIO8).

I think the, the point at which I carried a card was really [er] not being precious about my own body organs, for instance, and not believing in an afterlife, or that my organs would affect it even if I did. (BIO3).

Societal context and mood

Fears of a surveillance society misusing personal data were expressed. Here trust is influenced by the wider discourse in society:

Well, yes, I don't want to speak for him, but he, you know, he's concerned about [um] increasing surveillance society and things like [um] CCTV coverage, and all the information that is being gathered and stored somewhere by somebody and, you know, how easy it might be to, [um] for that to fall into the wrong hands. Who knows? You know, we trust and respect our government, hopefully, but [laughs] you never quite know what's round the corner. (BIO1).

Conceptualising themes of public trust in the 100.000 Genomes Project

Availability of help

Being able to find help builds trust:

And that is again, to hope to try and find and help xxx is an issue. (FG1).

Central objective how to work with commercial companies

A roper arrangements for any public-private partnership on how to work with commercial companies is needed to establish trust in the research:

R6: You can only go off your own experience and I, and I've worked in central government and local government and, you know, I know they are not perfect and things but I do know they are under major scrutiny all the time. And if they are choosing to spend this money at the moment on such a big initiative they are going to have to be qualifying that and they are going to have to be squeaky clean and if they are not then it is going to be a big problem. So I sort of, I think that does give you comfort but I wouldn't trust a private initiative to do it because I think they'd be doing it. They only do something for themselves.

R5: Saving money

R: Saving money or to

R6: Yeah

R: Commercial. I mean I know that in a way this is also doing that XXX

R6: But you would hope that there would be some integration and central sort of objective around it. (FG2).

Denial of access to data by insurance companies

Insurance companies should not get hold of personal data:

And I'm sure insurance companies would love to get hold of it. (FG1).

Experience of a local research facility

Local research facilities are trusted over research facilities which are located elsewhere:

It's funny when you said (name of a hospital) what made you think about using the words, having faith and trust because if a hospital that's not Liverpool but is in the North West I know was involved. (FG2).

You were asking about research before it just popped into mind they are doing [um] one for XXXX and the XXXX and, the nearest centre actually that's doing XXXXX is Birmingham which is too far for us. I was hoping you were going to do one in Liverpool. I would have signed up for it. [um] but that's in,. There's England doing it. I think a couple of European countries and the States and that seems to be all grouped together. But if we've got this one package that we can sell to other countries then I think that's, the commercial arm of that, think it's a great thing because it's going to benefit everybody and it's not like it's the pharmaceuticals are in it to make money for themselves. It's actually going to help other countries as well. I think it's good. (FG2).

Feedback and results

Feedback and results need to be provided in a sensitive way and in partnership with a consultant who can explain the results and is trusted by the participant. Also, only feedback should be provided which the participant consented to.

RF:I think it, it would be something that people need to consider. And I would hope in the study that people are given that time to consider what if we xxx something else that you didn't already know.

Interviewer: So if they did tell you something? Say you had xxx do you want to know in the future you might be susceptible to x, y, z. So when they did tell you the results, would you believe them? Would you have - you were mentioning that something might get lost in the system? Is that kind of - is that like distrust in the system, or?

RF: No, not really. I think it's, I think it's just more about making sure that all of that kind of thing is handled really sensitively, and in partnership with the consultants that the patients are under. Because I think - you know - patients tend to be very, very trusting of their consultants when they are in a situation where they've got incurable cancer, for example. (FG1).

R2: But what would you do if they said, "There's your data." It's all the genomes (genes) on it all mapped. What do you do. XXX that looks nice for the XXX Would you know what to do with it?

Rs: [laugh]

R: No, no but they wouldn't send me that I hope. (FG2).

Future benefit

Research should lead to future benefit to be trusted:

You kind of. You've got to get the data to kind of hope that it will help develop something for the future which means you can't then sort of hold them to ransom too much because you want them to have the data to try and do something. (FG1).

R1: Well this is, this is all not just for XXX but in 50 years time the NHS won't have to spend as much money as they are spending on us at the moment. That's the idea behind it isn't it.

R: Yeah exactly.

R: Yeah hopefully. (FG1).

Giving participants time to consider if they want to get results

Participants need time to decide which results they want to get from the study to be able to trust:

RM: It's a little xxx because a lot of these things xxx don't do tests unless you're prepared to do something about it. And you're potentially being in the situation where you've been given results to tests you wouldn't think you were having. So yeah, I think xxx

RF: Yeah. It's just - yeah.

RM: Mmm, yeah.

RF: I think it, it would be something that people need to consider. And I would hope in the study that people are given that time to consider what if we xxx something else that you didn't already know. (FG1).

Good feeling

When personal interaction with research staff is giving participants a good feeling, they trust:

I would agree with that a lot. I mean I think because, you know, if I thought I've had qualified because it had come through the route, coming through XXX and the genomics lady at Liverpool after that talk. You know that was really good and I was really impressed with her on her knowledge [um] you know so that gives you a good feeling you trust it. (FG2).

Governmental response to breach of data security

The government is responsible for following up security breaches and sacking thos who are responsible:

N. Why would they do that because the government is going to sell it to the company anyway. You know, they're going to sell it and make it available. So I have no problem with the trust side of it or anything because they are just doing a job. The ones, people get sacked for breaching security in all different things so I don't really have any issues with them taking the data there because I mean. (FG2).

Opportunity for reinvestment in medical research

Any income generated by the sale of data should be reinvested in medical research:

They'll see if they can commercialise the, the actual and package it, the whole process and sell, sell that to other countries that, that's going to be a massive income boost which will then hopefully [ah] be reinvested into other medical research or expansions to the current project and that sort of thing because I know they are doing. (FG2).

Personal experience

Personal and overall experience builds trust:

But that's what I am saying, you know, trust and. Your overall experience with that element, you know, …(FG2).

R: Yeah I would not have trusted them.

R: That's down to your personal experience. (FG2).

Public benefit

Research leading to public benefit is trusted:

You were asking about research before it just popped into mind they are doing [um] one for XXXX and the XXXX and, the nearest centre actually that's doing XXXXX is Birmingham which is too far for us. I was hoping you were going to do one in Liverpool. I would have signed up for it. [um] but that's in,. There's England doing it. I think a couple of European countries and the States and that seems to be all grouped together. But if we've got this one package that we can sell to other countries then I think that's, the commercial arm of that, think it's a great thing because it's going to benefit everybody and it's not like it's the pharmaceuticals are in it to make money for themselves. It's actually going to help other countries as well. I think it's good. (FG2).

Relationship with medical staff

Patients trust if they have a good relationship with their medical specialists:

No, not really. I think it's, I think it's just more about making sure that all of that kind of thing is handled really sensitively, and in partnership with the consultants that the patients are under. Because I think - you know - patients tend to be very, very trusting of their consultants when they are in a situation where they've got incurable cancer, for example. (FG1).

Reputation

Reputation linked to success is important to build trust:

Where you see a very. I mean I've had, you know, heart tests throughout well since, you know in the last 20 years that then when I went to, you know, the cardiomyopathy specialist unit were very different. And it was very different and you become exposed to different things when you go to what I call a centre of excellence. And that I think instils massive confidence when you are dealing with specialists like Cambridge or you know the people that you would hope are involved. (FG2).

It's the reputation as well isn't it.

R: Yeah I would not have trusted them.

R: That's down to your personal experience. The next person might. (FG2).

Research by private institutions

Research by private institutions is not trusted as it is assumed that they only do research for their own benefit:

So I sort of, I think that does give you comfort but I wouldn't trust a private initiative to do it because I think they'd be doing it. They only do something for themselves. (FG2).

Safe data handling

Data must not be lost to maintain trust:

You'd hope so. But that would be my worry, that - you know - something might get lost in that. Am I sounding very sceptical? (FG2).

Sensitive data handling

Data handling, including providing results, needs to be done carefully and in partnership with the patients' consultants for the process to be trusted:

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Structured Project

Structured projects to counteract human error are trusted:

Rf: Where I like do have more faith in, in the project that's going on there's a lot more trust if your with me.

R: Yeah there's going to be the element of human error but it, I think it's going to be a much more structured [you're laughing at] (FG2).

Framing themes of public trust in the 100,000 Genomes Project

Human error

Despite measures to counteract errors, there will always be an element of human error which needs to be considered when trusting:

R: You fill out an online questionnaire [laughs] And you don't even know anything about their authenticity or their ethics or

R: Or how they're sort of secure in storing that XXX

R1: That's where you're likely to get a mix up with somebody else's

R: Yeah just send it back in the post and it's like

Rf: Where I like do have more faith in, in the project that's going on there's a lot more trust if your with me.

R: Yeah there's going to be the element of human error but it, I think it's going to be a much more structured [you're laughing at]. (FG2).

People's world view

Several times in the data, readers were referring to axioms, proverbs or personal conviction to express a certain generalised view. This view seems to be more fundamental to their world view so that it influences their decision making process to trust:

They tend to say to their consultant, you know, "I trust, I trust you'll do the right thing." But actually, you know, sometimes all those risks are given and actually people aren't able to consider them all, I suppose, that's what I mean. (FG1).

But he did not believe in all of this 'doctor stuff' as he called it (FG1).

Risk

Risk (e.g. misuse of medical data or personal harm due to misuse of personal data) results from the use of personal data. Here risk arises from individual and environmental action. If there was no risk associated with the use of medical data or if one would had the resources, knowledge and power to counteract and control the risk, there would most likely be no need for trust:

They tend to say to their consultant, you know, "I trust, I trust you'll do the right thing." But actually, you know, sometimes all those risks are given and actually people aren't able to consider them all, I suppose, that's what I mean. (FG1).

Effect theme of trust in the 100.000 Genomes Project

Participation

Being comfortable with providing data is an effect of trust and can be understood as participation:

R6: It's trust. It's what you know.

R: You're not going to be completely

R6: There's not many options to go with that you don't know is there really that you would trust outside of a

R: About how comfortable you are trusting them with your data and obviously ultimately your money. [laugh] That your going to. (FG1)