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## **Original paper**

# **Patient and public views on UK electronic health record systems and their uses: cross-sectional survey**

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## Abstract

**Background:** The development and implementation of Electronic Health Records (EHRs) remains an international challenge. Better understanding of patient and public attitudes and the factors that influence overall levels of support towards electronic health records is needed to inform policy.

**Objective:** To explore patient and public attitudes towards integrated EHRs used simultaneously for healthcare provision, planning and policy, and health research.

**Methods:** Cross-sectional questionnaire survey administered to patients and members of the public who were recruited from a stratified cluster random sample of eight outpatient clinics of a major teaching hospital and eight general practices in London (UK).

**Results:** 5331 patients and members of the public responded to the survey, with 2857 providing complete data for the analysis presented here. There were moderately high levels of support for integrated EHRs used simultaneously for healthcare provision, planning and policy, and health research (62.5%), whilst 27.9% of participants reported being undecided about whether or not they would support EHR use. There were higher levels of support for specific uses of EHRs. Most participants were in favour of EHRs for personal healthcare provision (89.7%), with 66.7% stating that they would prefer their complete, rather than limited, medical history to be included. Of those 'undecided' about integrated EHRs, 87.2% were nevertheless in favour of sharing their full (46.7%) or limited (40.5%) records for health provision purposes. There were similar high levels of support for use of EHRs in health services policy and planning (79.5%), and research (81.4%), although 59.7% and 67.1% of respondents respectively would prefer their personal identifiers to be removed. Multivariable analysis showed levels of overall support for EHRs decreasing with age. Respondents self-identifying as Black British were more likely to report being undecided or unsupportive of national EHRs. Frequent health services users were more likely to report being supportive than undecided.

**Conclusions:** Despite previous difficulties with NHS technology projects, patients and the public generally support the development of integrated EHRs for healthcare provision, planning and policy, and health research. This support, however, varies between social groups and is not unqualified: relevant safeguards must be in place and patients should be guided in their decision-making process, also through increased awareness about the benefits of EHRs for secondary uses.

**Keywords:** electronic health records; patient attitudes; healthcare delivery; research; policy

## Introduction

Electronic Health Records (EHRs) are often heralded as the cornerstone of modern healthcare provision, although their development and implementation still remains an international challenge [1-6]. Over recent years in the UK there have been several policy initiatives aiming to alter the technological landscape in the National Health System (NHS). The initial focus on centralised, top-down national databases promoted by the National Programme for IT (NPFIT), has now been displaced by the most recent information strategy launched in 2012 - '*The Power of Information: Putting all of us in control of the health and care information we need*' [7]. This document emphasises information sharing to ensure local EHR systems work seamlessly '*across the entire health and social care sector, both within and between organisations*' to provide data to multiple stakeholders [7]. In line with this strategic vision, the Department of Health has announced that hospitals should have implemented electronic patient records by 2015, with fully digitised health records being deployed by 2018 across the healthcare sector [8-10]. In supporting these aims, the Information Governance Review, newly published at the time of writing, recognises that the duty to share information in the patients' interests can be as important as the duty to confidentiality, although the recommendations do not extend the use of identifiable data [11].

Within the policy arena, patients and members of the public are often presented as the primary beneficiaries of this technologically-orientated agenda [8-10]. However, their attitudes towards sharing medical information have been studied in a fragmented fashion. The larger part of previous research has either focused on specific EHR systems (e.g. Summary Care Record [12]) or on the use of segregated data for specific purposes (e.g. research [13] or care improvement [14]). Most people are generally in favour of EHRs and information sharing, but differences exist depending on the intended use, the type of information being shared and whether health information is anonymised or not [12-22]. As such public support is not unqualified. A range of concerns have been documented, including privacy, security, control over access, use and potential misuse of data [12, 17, 23-25]. Previous research further shows differences in opinion by age, education level, socio-economic situation and

health status [16, 17, 19, 26]. Furthermore, those with long-term conditions appear more supportive of EHRs for personal health benefit as well as for research [12, 23, 26].

As we progress towards implementing the information strategy we require a more in-depth understanding of attitudes towards EHRs and the factors that influence overall levels of support. Information flows in healthcare are often complex and data are used for multiple purposes, as for example at the interface of care and research [27]. For this reason, we should assess patient views about EHRs that acknowledge their use for multiple purposes including healthcare provision, health services policy and planning, as well as research. Previous research has provided only basic information on socio-demographic variables, and there has been little work on associations between attitudes to EHRs and the experience of patients in healthcare. People in regular contact with different health services may have encountered difficulties with information sharing between professionals and thus might perceive EHRs as a solution to these communication barriers.

Against this background of policy change within the UK, this paper surveys patient and public attitudes based on a more complex view of EHRs as systems that may be used for multiple purposes, as well as examining how attitudes differ when considering specific uses, including healthcare provision, policy and planning as well as research. The aim of this study is to enhance understanding of patient and public views about the development of universal patient EHRs and their willingness to share their personal records in a national EHR system by addressing the following questions:

1. What is the level of patient and public support for a national EHR system overall and for what purposes should it be used?
2. What is the relationship between overall support for a national EHR system and the use of EHRs for healthcare, planning and policy and health research?
3. How are health, healthcare use and socio-demographic characteristics associated with patient and public support for a national EHR system?

## Methods

We conducted a cross-sectional self-complete questionnaire survey using a stratified cluster random sample of patients and members of the public in an area of West London, UK. Participants were recruited in eight outpatient waiting areas of a university teaching hospital and the waiting rooms of eight general practice (GP) surgeries within the hospital catchment area over a six week period from 1 August 2011. Eligibility criteria for participation were: a) 18 years or older; b) first time filling in the survey; and c) able to understand the information describing the research study. 5331 individuals participated in the survey. Full details of the study protocol, as well as the survey questionnaire, are published elsewhere [28]. The study was approved by the London Dulwich Research Ethics Committee (Ref. No. 10/H0808/96).

Data were collected on patient and public views about a national EHR system and the purposes for which EHRs should be used if such a system existed. The front page of the questionnaire introduced participants to EHRs using the following definition: 'If created, your electronic health record would store everything about your health and the healthcare you receive from your birth until your death. Electronic health records would bring together in one record all of your separate files, whether stored on paper or a computer, in all of the different locations where you get healthcare.' The questionnaire made clear that the study concerned detailed EHRs rather than Summary Care Records. The 31-item questionnaire examined various aspects of patient and public views, but here we present the findings relating to the following four key questions: 1) If there was a national electronic health records system, would you want your record to be part of it for your own healthcare? ('Yes, complete record'; 'Yes, partial record'; 'No'); 2) If there was a national electronic health records system, would you want your record to be part of it for health services planning and policy? ('Yes, name and address present'; 'Yes, name and address removed'; 'No'); 3) If there was a national electronic health records system, would you want your record to be part of it for health research? ('Yes, name & address present'; 'Yes, name & address removed'; 'No'); 4) Overall, are you in favour of the development of a national electronic health records system? ('Yes'; 'No'; 'Undecided'). Further questions recorded details of respondents' health (whether respondent had a long-term condition or not), healthcare use (personal healthcare visits in the previous 6 months) and socio-demographic characteristics (birth year, sex, ethnicity, highest education level attained). The full survey instrument has been published in [28].

Only respondents providing complete data for the variables of interest were included in the final statistical analysis (N=2857). We first described the study variables including the number and proportion of the analysis sample. To assess the effects of excluding individuals with missing data, we used logistic regression to compare the distribution of responses for each variable between the analysis sample and

the missing sample. We examined the proportions of missing data for questions on the final page of the questionnaire compared with questions at the beginning of the questionnaire to assess the effect of questionnaire length on question completion.

We used descriptive analysis to examine our first two questions. The proportions of respondents who would support the development of a national EHR system in the UK and the proportions of respondents who would allow their EHR to be used for their personal healthcare, health services planning and policy and health research were calculated. We then examined the correlation between overall support for a national EHR system and views about the three proposed uses of EHRs using Chi-squared to test for statistical significance.

We also used a multivariable multinomial regression model to examine associations between views about a national EHR system and health, healthcare use, and socio-demographic characteristics. We tested for multi-collinearity between the independent variables and found all VIF scores to be approximately one, indicating that they were not highly correlated and could thus be combined in multivariable analyses. P-values and 95% confidence intervals were adjusted for the clustered design of the survey. All analyses were conducted using Stata IC version 9.0.

## Results

### Participants

We recruited 5331 respondents representing 85.5% of all individuals approached. 2857 out of 5331 (53.6%) respondents completed all relevant sections of the questionnaire and were included in the final analysis. There was no significant difference in the rate of completion for questions at the beginning of the questionnaire compared with those at the end, indicating that respondents were able to complete the questionnaire in the time available.

### Study population

The socio-demographic, health and healthcare use characteristics of the sample are shown in Table 1. The sample is relatively young, with a high proportion of women and people with high level of educational attainment, while it is also ethnically diverse. A larger proportion of respondents were sampled in outpatient clinics than in GP surgeries, which is a characteristic of the survey design. Hospital outpatient clinics were busier than GP surgeries and patients attending the hospital had a higher proportion of health problems than those routinely attending GP surgeries. The recruitment time was divided equally between the two settings to ensure that individuals with long term health conditions participated in the survey. The majority of respondents have at least one long-term condition and accordingly the sample population are moderately frequent healthcare users.

Variable	n (%)
Age category	
18-24	226 (7.9)
25-34 (base)	757 (26.5)
35-44	614 (21.5)
45-54	444 (15.5)
55-64	334 (11.7)
65-74	294 (10.3)
75+	188 (6.6)
Sex	
Female (base)	1700 (59.5)
Male	1157 (40.5)
Ethnicity	
White British (base)	1602 (56.1)
White Non-British	583 (20.4)
Black British	207 (7.2)
Asian British	229 (8.0)
Mixed	93 (3)
Other	143 (5.0)
Educational qualifications	
None	145 (5.1)
GCSE	319 (11.2)
A-Level	288 (10.1)
Vocational Qualification	335 (11.7)
Degree	1062 (37.2)
Higher Degree (base)	708 (24.8)
Clinic type	
GP (base)	953 (33.4)
Outpatient	1904 (66.6)
Number of health care visits in the past 6m	
0-2 visits (base)	1041 (36.4)
3-5 visits	998 (34.9)
6-9 visits	459 (16.1)
10 plus visits	359 (12.6)
Long term conditions	
None (base)	1007 (35.2)
At least one condition	1850 (64.8)

Table 1. Summary statistics of final analysis sample by socio-demographics, health and healthcare use characteristics (N = 2857).

#### Support for a national EHR system and for what purposes

Respondents' overall level of support for a national EHR system and the use of EHRs for healthcare, planning and policy, and health research are presented in Figure 1.

When asked to consider the development of a national EHR system (that would simultaneously support healthcare, planning and policy, and research), 1785 out of 2857 respondents reported overall support (62.5%), while a large minority of people reported being undecided in their views (n = 798,

27.9%). A smaller proportion (n = 274, 9.6%) said they would not support a national EHR system used for multiple purposes.

In terms of personal healthcare provision, responses are more positive with a striking proportion supporting the development of EHRs for this specific purpose (2563 out of 2857, 89.7%). Although 66.7% (n = 1907) of respondents would support the use of their complete medical history, almost a quarter of participants (n = 656) would only allow limited health information to be part of a national EHR system. 294 out of 2857 (10.3%) said they were opposed to the use of EHRs for healthcare purposes.

A significant proportion of respondents supported the use of EHRs for planning and policy (n = 2274, 79.5%). However, the majority reported that they would only allow their records to be included in an integrated EHR system if personal identifiers had been removed (n = 1707, 59.7%). Just one fifth (n = 567, 19.8%) supported the use of identifiable data, with a similar proportion (n = 583, 20.4%) opposed to any use of their EHRs for planning and policy.

With regard to using national EHRs for health research, 2325 out of 2857 participants would be similarly supportive of having their records included in the system (81.4%). Yet, only 408 (14.3%) of respondents answered that they would allow their identifiable records to be shared, while 1917 (67.1%) of respondents would prefer having their name and address removed. Almost one fifth (n = 532, 18.6%) said they would not wish their record to be used at all for health research specifically.

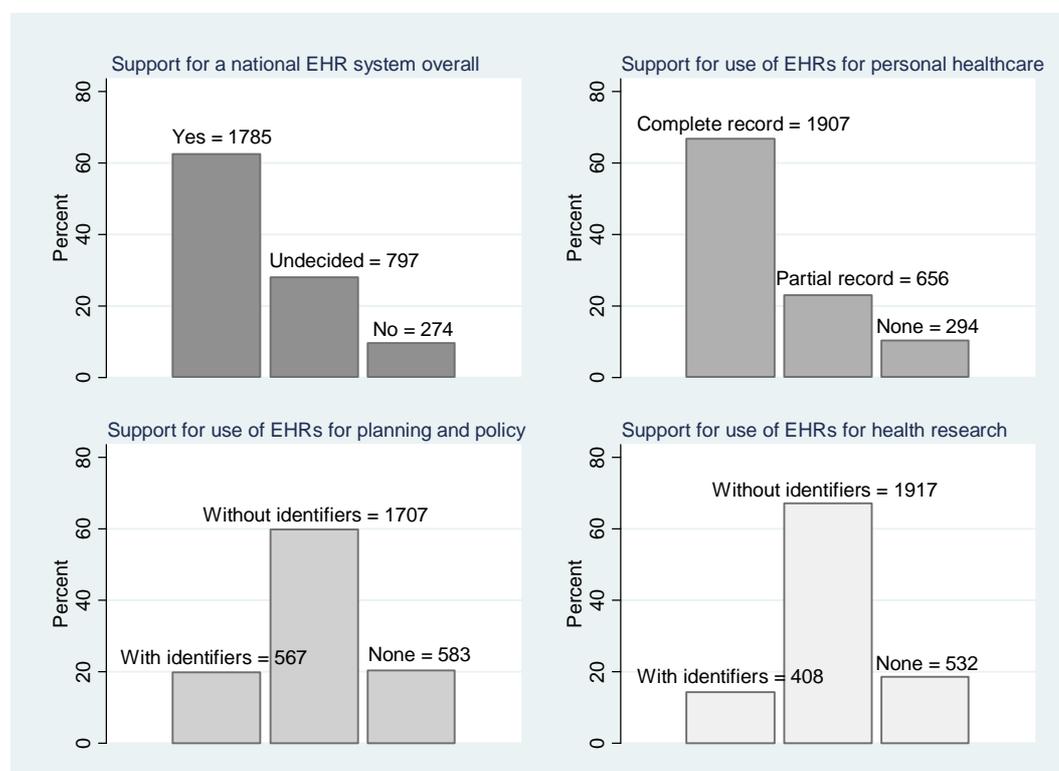


Figure 1. Respondents' overall preferences for the development of a national Electronic Health Records (EHR) system and their views on the use of complete or partial records for healthcare purposes, and identifiable or anonymised records for health services planning and policy, and health research (N = 2857).

#### Relationship between overall support and support for specific purposes

The relationship between individuals' expressed level of support for a national EHR system and their views about using EHRs for the specific purposes of personal healthcare, planning and policy and research are shown in Table 2.

For the 798 (27.9%) of respondents undecided about supporting a national EHR system, the majority (n = 696, 87.2%) report that they would support the use of EHRs for their own healthcare, with 373 out of 798 (46.7%) favouring the use of their complete records and 323 (40.5%) supporting the use of records with limited health information.

Approximately two thirds of those undecided (n = 798) about their overall support for EHRs would support their use for planning and policy (461, 57.8%), and for health research purposes (538, 67.4%), provided the records did not contain personal identifiers.

The majority of those who responded positively (n = 1785) to the development of a national EHR system said they would allow their records to be used for healthcare (1752, 98.1%), planning and policy (1616, 90.6%), and health research (1617, 90.6%). Of those who said they would not be in favour of a national EHR system (n = 274), around 40% reported that they would support using EHRs for specific purposes (115 for healthcare, 101 for planning and policy and 108 for health research).

	Support for a national EHR system				$\chi^2$	P
	Yes n (%)	Undecided n (%)	No n (%)	Total n (%)		
Personal healthcare						
Complete record	1484 (83.1)	373 (46.7)	50 (18)	1907 (66.7)		
Partial record	268 (15.0)	323 (40.5)	65 (24)	656 (23.0)		
Neither record	33 (2)	102 (12.8)	159 (58.0)	294 (10.3)		
Total	1785 (100)	798 (100)	274 (100)	2857 (100)	1107	<.001
Health services planning and policy						
With identifiers	451 (25.3)	96(12)	20 (7)	567 (19.8)		
Without identifiers	1165 (65.3)	461 (57.8)	81 (30)	1707 (59.7)		
Neither record	169 (9.5)	241 (30.2)	173 (63.1)	583 (20.4)		
Total	1785 (100)	798(100)	274 (100)	2857 (100)	511	<.001
Health research						
With identifiers	338 (18.9)	62 (8)	8 (3)	408 (14.3)		
Without identifiers	1279 (71.7)	538 (67.4)	100 (36.5)	1917 (67.1)		
Neither record	168 (9.4)	198 (24.8)	166 (60.6)	532 (18.6)		
Total	1785(100)	798(100)	274(100)	2857(100)	467	<.001

Table 2. Relationship between overall support for a national Electronic Health Records (EHR) system and views about the use of EHRs for personal healthcare, health services planning and policy and health research. Chi squared ( $\chi^2$ ) tests used to test for statistical significance (N = 2857).

#### Associations between overall support and socio-demographics, health and healthcare use

Associations between respondents' overall level of support for a national EHR system and their socio-demographics, health, and healthcare use characteristics are shown in Table 3. This multinomial multivariable analysis is interpreted by comparing those who are undecided to those who would support a national EHR system, as well as comparing those who would not be supportive of EHRs to those who expressed positive attitudes. In effect, it is similar to interpreting two separate logistic regression models.

There was no clear pattern of association between age and being undecided on support for EHRs overall, or between age and being supportive of such a system. However, there was a graded association between age and lack of support for a national EHR system with older people increasingly more likely to report that they would not be in favour of such a system compared with 25-34 year olds (the largest age category in the sample).

Women were more likely to report that they were undecided than positive in relation to EHRs than men (RR = 0.68, 0.59 to 0.79). Black and Asian British respondents were also more likely to say that they were undecided in their views on EHRs than to say that they would be supportive compared to White British respondents (RR = 1.96, 1.34 to 2.86). Black British respondents were more likely to say they would not support the development of a national EHR system compared with White British respondents (RR = 3.72, 2.33 to 5.94).

Respondents with fewer or no academic qualifications are more likely to report being undecided about their attitudes to EHRs than to report being supportive, compared with those with a higher degree. There are no statistically significant educational differences between people who would support the development of national EHRs and those who would not. There were also no significant differences in this respect between those recruited in GP surgeries and those recruited in hospital outpatient clinics. However, respondents from GP surgeries are more likely to report that they were undecided than positive about national EHRs, compared with those who completed the survey as outpatients in the hospital (RR = 1.21, 1.08 to 1.36).

Individuals who use health services more frequently were less likely to report being undecided about EHRs than to answer that they would be in favour of such a system, compared with less frequent users of health services (0-2 times in the past 6 months). The association is statistically significant for very regular users of healthcare services (10 or more times in the past six months) (RR = 0.69, 0.60 to 0.79). Having a long term condition is not associated with respondents' views about a national EHR system.

Overall views on the development of a national EHR system <sup>a</sup>						
(base: In favour)						
Respondent characteristics	Undecided			Against		
	Adjusted RR	95% CI	P	Adjusted RR	95% CI	P
Age (base: 25-34)						
18-24	1.59	[1.13,2.24]	0.008	1.56	[0.83,2.92]	.17
35-44	1.02	[0.79,1.31]	.90	1.66	[1.17,2.34]	0.004
45-54	1.19	[0.94,1.51]	.14	2.29	[1.39,3.77]	<.001
55-64	1.49	[1.09,2.03]	.01	2.60	[1.70,3.98]	<.001
65-74	0.84	[0.58,1.23]	.37	2.53	[1.51,4.22]	<.001
75+	0.97	[0.65,1.46]	.89	2.86	[1.83,4.47]	<.001
Sex (base: female)						
Male	0.68	[0.59,0.79]	<.001	0.88	[0.67,1.15]	.36
Ethnicity (base: White British)						
White Non-British	1.14	[0.93,1.40]	.22	1.00	[0.75,1.32]	.98
Black British	1.96	[1.34,2.86]	<.001	3.72	[2.33,5.94]	<.001
Asian British	1.43	[1.03,1.99]	.03	1.37	[0.88,2.14]	.17
Mixed	1.40	[0.97,2.04]	.08	1.07	[0.55,2.09]	.85
Other	1.23	[0.80,1.90]	.35	1.18	[0.79,1.78]	.42
Education (base: higher degree)						
None	1.58	[1.03,2.44]	.04	1.25	[0.60,2.57]	.55
GCSE	1.96	[1.40,2.75]	<.001	1.27	[0.75,2.16]	.38
A-Level	1.51	[1.08,2.10]	.02	1.00	[0.56,1.77]	1.00
Vocational	1.51	[1.20,1.90]	<.001	0.85	[0.47,1.55]	.59
Degree	1.29	[1.05,1.59]	.02	0.93	[0.76,1.14]	.48
Clinic type (base: GP clinic)						
Outpatient clinic	1.21	[1.08,1.36]	<.001	1.13	[0.86,1.48]	.38
Number of healthcare visits in the past 6 months (base: 0-2 visits)						
3-5 visits	0.93	[0.76,1.15]	.51	0.80	[0.60,1.05]	.11
6-9 visits	0.86	[0.67,1.09]	.21	0.67	[0.40,1.12]	.13
10 plus visits	0.69	[0.60,0.79]	<.001	1.21	[0.71,2.06]	.49
Reports long term medical conditions (base: no conditions)						
At least one condition	1.21	[0.92,1.58]	.17	1.35	[0.93,1.95]	.11

<sup>a</sup> The questionnaire asked: Overall, are you in favour of the development of a national electronic health records system? ('Yes'; 'No'; 'Undecided').

Table 3. Relative Risks (RR) indicating associations between overall support for a national Electronic Health Records (EHR) system and socio-demographic, health and healthcare use characteristics. Multinomial logistic regression model comparing those that would support the development of EHRs overall (base = Yes), compared with those who are undecided and those who would not support EHRs. *P*-values and 95% confidence intervals are adjusted for clustering by sampling site (N = 2857).

#### Missing data analysis

The analysis of missing data in table 4 shows that those included in the sample have the same age and sex distribution of those not included in the sample. However, respondents with missing data are significantly more likely to be Black ( $P < .001$ ) or Asian ( $P = .02$ ) than White British. Those with lower education levels are also more likely to have missing data than those with a higher degree.

The analysis of missing data also shows that the clinical setting did not affect respondents' likelihood of providing complete data. However, those who have missing data are significantly more likely to use healthcare services more often and to report no long term health problems.

Approximately 10% of respondents had missing data on their views about EHRs (9.4-11.2%), which is lower than for the other analysis variables. However, the analysis showed that those who were excluded from the final analysis sample were significantly more likely to have favourable views towards EHRs for all four outcome variables than those who were included ( $P < .001$ ).

Variable	Missing (%)	Odds ratio	95% CI	<i>P</i>
Age category (base: 25-34)	799 (15.0)			
18-24		0.87	[0.67,1.15]	.33
35-44		0.95	[0.81,1.13]	.56
45-54		0.90	[0.71,1.13]	.36
55-64		0.95	[0.81,1.13]	.58
65-74		0.97	[0.77,1.21]	.78
75+		0.87	[0.68,1.11]	.25
Sex (base: female)	611 (11.5)			
Male		1.10	[0.96,1.27]	.17
Ethnicity (base: White British)	1109 (20.8)			
White Non-British		1.14	[1.00,1.31]	.047
Black British		0.62	[0.51,0.75]	<.001
Asian British		0.71	[0.53,0.94]	.02
Mixed		0.86	[0.68,1.10]	.23
Other		0.77	[0.56,1.05]	.10
Educational qualifications (base: higher degree)	833 (15.6)			
None		0.61	[0.49,0.75]	<.002
GCSE		0.90	[0.78,1.03]	.13
A-Level		0.76	[0.61,0.94]	.01
Vocational Qualification		0.87	[0.65,1.16]	.33
Degree		0.91	[0.78,1.06]	.21
Clinic type (base: GP)	0 (0)			
Outpatient		1.01	[0.86,1.20]	.87
Number of health care visits in the past 6m (base: 0-2 visits)	686 (12.9)			

3-5 visits		1.16	[1.05,1.29]	.003
6-9 visits		1.48	[1.27,1.74]	<.002
10 plus visits		1.17	[0.97,1.41]	.10
Long term conditions (base: None)	1103 (20.7)			
At least one condition		0.68	[0.58,0.81]	<.001
Overall Support for EHRs (base: Yes)	584 (10.9)			
Undecided		0.67	[0.59,0.74]	<.001
No		0.43	[0.36,0.50]	<.001
Support for EHRs used for healthcare purposes (base: Complete record)	499 (9.4)			
Partial record		0.71	[0.59,0.84]	<.001
No		0.43	[0.37,0.51]	<.001
Support for EHRs used for health services planning and policy purposes (base: Without identifiers)	566 (10.6)			
With identifiers		0.78	[0.68,0.90]	.001
No		0.56	[0.49,0.65]	<.001
Support for EHRs used for health research purposes (base: Without identifiers)	599 (11.2)			
With identifiers		0.78	[0.68,0.89]	<.001
No		0.50	[0.44,0.58]	<.001

Table 4. Support for Electronic Health Records (EHR): Univariable logistic regression of missing data by respondent characteristics (N=5331).

## Discussion

This study suggests that there is general support for the development of a national EHR system that would simultaneously use data for multiple purposes, such as personal healthcare, policy and planning, as well as health research. However, an important minority – about a quarter of participants (n = 798, 28%) – remain undecided in their views, and nearly 10% (n = 274) would be opposed to such a system. When asked about specific purposes for EHRs, over two thirds of all respondents would support the inclusion of their full medical history and personally identifiable information for personal health care provision. In contrast, for health policy/planning and research uses, higher support was expressed for use of anonymised EHRs. Even in the group expressing overall negative views towards an integrated EHR system (n = 274, 9.6%), there are respondents who would still choose to participate in EHRs if their information was used for specific purposes, such as for their personal health care (n = 115, 42%), policy and planning (n = 101, 37%) or health research (n = 108, 39%). Similarly, over 86% of those undecided (696 out of 798) in their level of support for a national EHR system are supportive of full or partial records being used specifically for their personal healthcare.

This study also shows significant differences in levels of support depending on socio-demographic characteristics. Age appears to play an important role in support for EHRs with older participants significantly less in favour of EHRs than younger respondents. Black British respondents also show significantly less support than respondents of other ethnic groups. In addition, educational attainment and patterns of healthcare use differentiate those who report being undecided in their views on EHRs from those who answer that they would be in favour of a national EHR system. However, there is no association between having a long term condition as measured in this study and support for a national EHR system.

## Strengths and Limitations

This is the first large study to explore patient and public attitudes towards EHRs in the UK and also the first to draw on a more complex and comprehensive picture of the different potential uses of EHRs, rather than only examining their use for specific purposes. To minimise selection bias, we recruited participants at different days and times following a random sampling design. Although the overall

response rate was very high (85%), only half of the participants completed the questions for the variables analysed in this paper (2857 out of 5331, 54%). The analysis of missing data shows that there are no age or sex differences between those who were included in the final analysis sample and those who were excluded, but there were ethnicity and education differences. Notably, those with less favourable views were more likely to be excluded from the final analysis. In terms of confounding factors, we measured and adjusted for the main confounding variables in our multivariable analysis; however, the results could still be affected by unmeasured confounders, such as overall levels of trust in the government and authorities. Other methodological considerations related to possible sources of measurement bias are discussed in [28].

### Previous Studies

While other quantitative and qualitative studies have reported that patients and the public would generally support EHRs [12, 16] our results contradict previous studies in the UK and Ireland which have found higher levels of support in older age groups for information sharing in medical research or GP summary records [17, 29]. However, our findings are consistent with similarly large studies in other countries that have found older age groups to be less supportive of EHRs [16]. Our study resonates with previous research showing that ethnic background affects attitudes towards health information sharing: people from BME communities or people who do not identify themselves as White British have been shown to be less inclined to allow their data to be used for public health and medical research [19, 30, 31]. In addition, our results on educational differences in opinion between being undecided and being in favour of integrated EHRs extends previous work showing that higher levels of educational attainment are associated with willingness to share health information and support for EHRs [17, 29]. Recruitment was carried out in the outpatient and GP population of West London, UK. Respondents were ethnically diverse with a spectrum of educational backgrounds, which allowed us to sample opinions from a wide range of socio-demographic groups. Overall patterns of opinions may be similar in other areas of London given similarities in socio-demographic and healthcare characteristics.

### Implications for Research and Policy

The study shows that a proportion of people currently unsupportive or undecided about national EHRs for multiple purposes may nevertheless be amenable to EHRs being used for clearly defined purposes. Patient and public perceptions about inclusion of their records in EHRs for their personal healthcare mirror levels of overall support for national EHRs, suggesting that considerations of personal health needs might be driving these opinions. Additionally, socio-demographic disparities in levels of support indicate that preferences cannot be considered homogeneous. Introduction of national EHRs may risk widening inequalities for BME groups and the elderly, who are more likely to be against the development of this system. Wider sharing of information may have an effect on their trust towards the healthcare system and their willingness to seek medical help. Less information on conditions affecting BME and elderly groups may also impact negatively on the potential for health research relevant to these populations and on the planning for services to support their needs. More in-depth research on patient views is needed to draw out the nuances involved in decision-making processes related to wider sharing of health information. Qualitative research studies would enhance our understanding in this area. A more nuanced understanding also has practical relevance in terms of framing policy messages when an EHR is launched and publicised: gaining the support of undecided or opposed groups as well as the public in general could determine whether or not EHRs can be successfully implemented as planned.

Given the well-documented problems inherent in current systems for exchanging patient information between healthcare professionals and organisations, we hypothesised that the respondents with greater levels of exposure to the healthcare system would be more acutely aware of the limitations of the current systems and therefore show greater levels of support for EHRs. However, our results in this paper have not indicated a clear relationship between personal health or healthcare experience and levels of support for EHRs. This suggests that we need to consider how or whether the nuances of healthcare experience might affect levels of support and use of EHR systems. Understanding an individual's broader relationship with healthcare including the need to visit different types of health services, levels of trust and satisfaction with previous healthcare encounters may provide greater insight into the relationship between individuals and their support for EHRs.

### Conclusions

Despite the limited success of the NPfIT programme in the UK there are high levels of support among patient populations for the establishment of national EHRs. Levels of support are not homogenous and the perspectives of the elderly and Black British populations in particular need to be understood more thoroughly to ensure EHRs do not contribute to widening inequalities in health.

Support is greatest for use of EHRs for personal healthcare. While support for policy and planning and research is also high, most respondents preferred partial or anonymous data to be used for information sharing rather than complete health records. Our results also suggest that individuals who are currently opposed to, or undecided about the introduction of EHRs for multiple purposes, are nevertheless more likely to be supportive if specific conditions are met regarding the content and purpose of EHRs. Such knowledge can help inform the provision of information for and engagement with specific patient and public groups to ensure that the design of any EHR system is acceptable and effective.

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**Conflicts of Interest:** None declared.

## **Authors' contributions**

All authors of this study meet the requirements for authorship and have approved the final version of the paper to be published. SL designed the data collection tools and sampling methodology, planned and conducted the data analysis, and drafted and revised the paper. JR conceived of the study, provided oversight to its design and coordination, contributed to the interpretation of the data and drafted and revised the paper. CM contributed to the design of the study, data collection tools, and the interpretation of the data and revised the paper. CP contributed to the interpretation of the data and drafted and revised the paper. AM contributed to the design and coordination of the study and reviewed the paper. DB conceived of the study and contributed to its design and coordination and revised the paper. DB is guarantor of the study.

## References

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1. Majeed A. Sources, uses, strengths and limitations of data collected in primary care in England. *Health Stat Q* 2004;21:5-14. PMID: 15615148.
2. Sheikh A, Cornford T, Barber N, Avery A, Takian A, Lichtner V, Petrakaki D, Crowe S, Marsden K, Robertson A, Morrison Z, Klecun E, Prescott R, Quinn C, Jani Y, Ficociello M, Voutsina K, Paton J, Fernando B, Jacklin A, Cresswell K. Implementation and adoption of nationwide electronic health records in secondary care in England: final qualitative results from prospective national evaluation in "early adopter" hospitals. *BMJ* 2011;343(d6054). PMID: 22006942.
3. McGinn CA, Grenier S, Duplantie J, Shaw N, Sicotte C, Mathieu L, Leduc Y, Légaré F, Gagnon M-P. Comparison of user groups' perspectives of barriers and facilitators to implementing electronic health records: a systematic review. *BMC medicine* 2011;9(1):46-56. PMID: 21524315.
4. Hiller J, McMullen MS, Chumney WM, Baumer DL. Privacy and Security in the Implementation of Health Information Technology (Electronic Health Records): US and EU Compared. *BUJ Sci & Tech L* 2011;17:1-39.
5. Coiera E. Do we need a national electronic summary care record. *The Medical Journal of Australia* 2011;194(2):90-2. PMID: 21241224.
6. Nazi MK. The Personal Health Record Paradox: Health Care Professionals' Perspectives and the Information Ecology of Personal Health Record Systems in Organizational and Clinical Settings. *J Med Internet Res* 2013;15(4):e70. PMID: 23557596.
7. Department of Health. 2012. The power of information: Putting all of us in control of the health and care information we need. London, UK. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/134336/dh\\_134205.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/134336/dh_134205.pdf.pdf) . Archived at: <http://www.webcitation.org/6H6Lu1G6a>
8. Department of Health. 16 January 2013. Press release: Jeremy Hunt challenges NHS to go paperless by 2018. London, UK. <http://www.dh.gov.uk/health/2013/01/paperless/> . Archived at: <http://www.webcitation.org/6H6N7aICc>
9. Department of Health. 2012. The Mandate - A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015. London, UK. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/127193/mandate.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf.pdf) . Archived at: <http://www.webcitation.org/6H6MckbDd>
10. NHS Commissioning Board. 2013. Everyone counts: Planning for Patients 2013/14. London, UK. <http://www.england.nhs.uk/wp-content/uploads/2013/04/ec-tech-def.pdf> . Archived at: <http://www.webcitation.org/6H6MefY3E>
11. Department of Health. 2013. Information: to share or not to share? The Information Governance Review. London, UK. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/192572/2900774\\_infoGovernance\\_accv2.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_infoGovernance_accv2.pdf) . Archived at: <http://www.webcitation.org/6H6MiAqBp>
12. Greenhalgh T, Wood GW, Bratan T, Stramer K, Hinder S. Patients' attitudes to the summary care record and HealthSpace: qualitative study. *BMJ* 2008;336(7656):1290-5. PMID: 18511764.
13. Willison D, Swinton M, Schwartz L, Abelson J, Charles C, Northrup D, Cheng J, Thabane L. Alternatives to project-specific consent for access to personal information for health research: Insights from a public dialogue. *BMC Medical Ethics* 2008;9(1):18. PMID: 19019239.
14. Weitzman E, Kelemen S, Kaci L, Mandl K. Willingness to share personal health record data for care improvement and public health: a survey of experienced personal health record users. *BMC Medical Informatics and Decision Making* 2012;12(1):39. PMID: 22616619.
15. Whiddett R, Hunter I, Engelbrecht J, Handy J. Patients' attitudes towards sharing their health information. *International Journal of Medical Informatics* 2006;75(7):530-41. PMID: 16198142.
16. EKOS Research Associates. 2007. Electronic Health Information and Privacy Survey: What Canadians Think: Canada Health Infoway, Health Canada, and the Office of the Privacy Commissioner of Canada. [http://www.infoway-inforoute.com/index.php/resources/reports/privacy/doc\\_download/78-ekos-survey-on-electronic-health-information-and-privacy-full](http://www.infoway-inforoute.com/index.php/resources/reports/privacy/doc_download/78-ekos-survey-on-electronic-health-information-and-privacy-full) . Archived at: <http://www.webcitation.org/6H6MnEhBu>
17. Ipsos MORI. 2007. The Use of Personal Health Information in Medical Research: General Public Consultation Final Report: Medical Research

- Council. [http://www.mrc.ac.uk/consumption/idcplg?IdcService=GET\\_FILE&dID=10983&dDocName=MRC003810&allowInterrupt=1](http://www.mrc.ac.uk/consumption/idcplg?IdcService=GET_FILE&dID=10983&dDocName=MRC003810&allowInterrupt=1) . Archived at: <http://www.webcitation.org/6H6MpN5Av>
18. Kass NE, Natowicz MR, Hull SC, Faden RR, Plantinga L, Gostin LO, Slutsman J. The Use of Medical Records in Research: What Do Patients Want? *The Journal of Law, Medicine & Ethics* 2003;31(3):429-33.
  19. Barrett G, Cassell JA, Peacock JL, Coleman MP. National survey of British public's views on use of identifiable medical data by the National Cancer Registry. *BMJ* 2006;332(7549):1068-72. PMID: 16648132.
  20. Department of Health. 2009. Summary of Responses to the Consultation on the Additional Uses of Patient Data. UK: Department of Health. London, UK. [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_110715.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_110715.pdf) . Archived at: <http://www.webcitation.org/6H6Mvdf5o>
  21. Campbell B, Thomson H, Slater J, Coward C, Wyatt K, Sweeney K. Extracting information from hospital records: what patients think about consent. *Quality and Safety in Health Care* 2007;16(6):404-8. PMID: 18055882
  22. Powell J, Fitton R, Fitton C. Sharing electronic health records: the patient view. *Informatics in Primary Care* 2006;14(1):55-7. PMID: 16848967.
  23. Pyper C, Amery J, Watson M, Crook C. Access to electronic health records in primary care—a survey of patients' views. *Medical science monitor : international medical journal of experimental and clinical research* 2004;10(11):17-22. PMID: 15507869.
  24. Paterson L, Grant L. 2010. Privacy and prejudice: Young people's views on the development and use of Electronic Patient Records. London: The Royal Academy of Engineering. [http://www.raeng.org.uk/news/publications/list/reports/Privacy\\_and\\_Prejudice\\_EPR\\_vIEWS.pdf](http://www.raeng.org.uk/news/publications/list/reports/Privacy_and_Prejudice_EPR_vIEWS.pdf) . Archived at: <http://www.webcitation.org/6H6N1yKel>
  25. Simon RS, Evans SJ, Benjamin A, Delano D, Bates WD. Patients' Attitudes Toward Electronic Health Information Exchange: Qualitative Study. *J Med Internet Res* 2009;11(3):e30. PMID: 19674960.
  26. Zulman DM, Nazi KM, Turvey CL, Wagner TH, Woods SS, An LC. Patient Interest in Sharing Personal Health Record Information. *Annals of Internal Medicine* 2011;155(12):805-10. PMID: 22184687.
  27. Powell J, Buchan I. Electronic Health Records Should Support Clinical Research. *J Med Internet Res* 2005;7(1):e4. PMID: 15829476.
  28. Luchenski S, Balasanthiran A, Marston C, Sasaki K, Majeed A, Bell D, Reed J. Survey of patient and public perceptions of electronic health records for healthcare, policy and research: Study protocol. *BMC Medical Informatics and Decision Making* 2012;12(40). PMID: 22621621.
  29. Buckley BS, Murphy AW, MacFarlane AE. Public attitudes to the use in research of personal health information from general practitioners' records: a survey of the Irish general public. *Journal of Medical Ethics* 2011;37(1):50-5. PMID: 21071570.
  30. Shavers VL, Lynch CF, Burmeister LF. Racial Differences in Factors that Influence the Willingness to Participate in Medical Research Studies. *Annals of Epidemiology* 2002;12(4):248-56. PMID: 11988413.
  31. Corbie-Smith G, Thomas SB, St. George DM. Distrust, race, and research. *Archives of Internal Medicine* 2002;162(21):2458-63. PMID: 12437405.