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**The Power of Information for Diabetes Research and Care:
Patient views in West London**

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Title Page

The Power of Information for Diabetes Research and Care:**Patient views in West London**

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Key Words: Electronic Health Records, Diabetes, Patient Views, Northwest London

Key Points:

- This is one of the few studies looking at the views of people with diabetes on electronic health records and data sharing in the UK.
- We found that 67% of people with diabetes would support the inclusion of their full health records on an integrated electronic health record system for personal health provision.
- The study also showed that 51% would allow their records to be shared without identifiers for research and 28% being supportive of access to their identifiable information.
- Participants expected electronic health records to improve communication between clinicians and allow more responsibility for self-care, but expressed concerns about sustaining patient confidentiality and avoiding commodification.

Abstract**Aims**

Data obtained during the care of people with diabetes mellitus (DM) may be used to advance research, improve quality, encourage innovation and support better self-care. However, the perspective of people living with diabetes is less well understood. This study examines the views of people with diabetes regarding access to electronic health records (EHRs) for healthcare and research.

Methods

Survey data from a sub-group of 404 individuals with diabetes were analysed from a dataset of 5331 West London participants randomly sampled in a cross-sectional survey. These

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3 findings were explored in more detail in a focus group discussion involving people with
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5 diabetes.
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10 11 **Results** 12

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14 Sixty seven percent of people with diabetes would support the inclusion of their full records
15 on a national EHR for purposes of personal health provision. The vast majority (91%) would
16 prefer to have access to their own full medical history rather than a truncated version. 79%
17 said they would allow their EHR to be used for research: 51% allowing their records to be
18 shared without identifiers and 28% being supportive of access to their identifiable
19 information. A number of themes emerged from the focus group discussion on integrated
20 electronic health records, including expectations for improved communication with health
21 professionals, increased participation in the consultation process, responsibility for self-care
22 and data sharing for the greater good.
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38 **Conclusions** 39

40 Wider sharing of health information may address some of the challenges diabetes care entails,
41 although striking a balance between information fragmentation and sharing remains crucial to
42 improve health, research and quality outcomes.
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Introduction

Multidisciplinary team-working, self-management¹ and integration of services are often championed as key strategies in addressing the national challenges in diabetes² with good communication and integrated information technologies frequently highlighted as essential tools.^{3,4} Several systems have been developed to support diabetes care, offering options for data viewing and sharing between primary, secondary and community healthcare practitioners in alignment with local/national priorities and evidence-based management.

The wealth of data captured within electronic records also holds enormous potential for research when aggregated. Leading health charities and research organisations in the UK have expressed support for the 'Sharing data saves lives campaign', which would enable approved researchers, amongst others, access to non-identifiable patient data. The National Health Service (NHS) in Scotland has successfully implemented the Scottish Care Information-Diabetes Collaboration project (SCI-DC), which now holds the Electronic Health Records (EHRs) of over 250,000 people with diabetes.⁵ Other examples of research databases include QRESEARCH⁶, the Clinical Research Practice Datalink (CPRD), The Health Improvement Network (THIN) and ResearchOne in the UK and the National Diabetes Register in Denmark.⁷

Despite the existence of sophisticated systems for data sharing across different levels of care, as well as research, implementation in England remains slow with potential benefits and risks of using integrated EHRs extensively considered in previous literature [Table 1]. To overcome concerns around data sharing, a 2010 report by a Diabetes UK task group encouraged people with diabetes to become actively involved in integration processes to ensure systems are underpinned by robust arrangements for information sharing.²⁰

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3 With this in mind, we sought to examine the views of people living with diabetes on EHRs
4 and data sharing. The data presented in this paper are drawn from a larger study looking at
5 patient and public perceptions on EHRs across a number of socio-demographic groups living
6 with different conditions.²¹⁻²² The views of people with diabetes are presented here
7 separately for a number of reasons:
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14
15 • Diabetes care presents many challenges including multi-organ and lifestyle
16 involvement that can necessitate frequent visits across various (multidisciplinary)
17 interfaces of care.
18
- 19 • Local (GP and hospital-held) electronic systems are commonly employed in diabetes
20 care to support long-term management. [Table 2]
21
- 22 • With self-care being a crucial component of diabetes care, systems linking EHRs with
23 home-based monitoring systems and self-management support tools have also been
24 developed and used. [Table 2]
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33 As wider data sharing holds potential for healthcare improvement and research, it is
34 important to engage with patient views and experiences adequately.
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45 **Methods**

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47 This paper presents data collected as part of a mixed methods study looking at patient and
48 public views on EHRs. The first phase of the study involved a large-scale quantitative survey.
49 We examined a sub-group comprising all survey participants who reported living with
50 diabetes (N=404). The second phase of the study included a number of focus group
51 discussions and interviews with patients and members of the public living with different
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3 health conditions. One of the group discussions was with individuals with diabetes, and we
4
5 include these data in our analysis. The study was approved by the London Dulwich Research
6
7 Ethics Committee (Ref. No. 10/H0808/96).
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10 11 12 13 **Quantitative methods** 14

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16 The survey was cross-sectional, using a stratified cluster random sample. It was administered
17
18 in 16 different healthcare sites (8 outpatient clinics in a 431-bed hospital in northwest London
19
20 and 8 general practice (GP) surgeries within the catchment area of the hospital) between
21
22 August and September 2011. This design was chosen to maximise variability in patients'
23
24 healthcare experiences. Each of the eight hospital outpatient clinics were sampled on five
25
26 days of the week totaling 40 sampling days. This design was chosen to ensure a wide array
27
28 of patient characteristics and to minimise selection bias. For GP surgeries, we used the
29
30 complete list of surgeries in the catchment area, stratified by borough, size and whether or not
31
32 they were research active, to select a random sample of surgeries. We selected one large
33
34 surgery (patient list ≥ 5000) and one small surgery (patient list <5000) from each borough,
35
36 for a total of eight surgeries. Recruitment was again conducted on five randomly selected
37
38 week days for each surgery over the period, for a total of 40 GP surgery sampling days.
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44 Participants self-completed the questionnaire while waiting for their appointments in the
45
46 clinics (response rate 85.5%). Recruitment was carried out at different days and times
47
48 following a random sampling design to minimise selection bias. Only adults over 18 years
49
50 old who were able to understand the information provided were eligible to participate in the
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52 study. Further details on the study protocol for the quantitative survey have been published
53
54 elsewhere.^{15,21}
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3 The survey examined a number of elements of patient and public views about a national EHR
4 system used for health provision; planning and policy; and research purposes. For the
5 purposes of this questionnaire, EHRs were defined as follows: *If created, your electronic*
6 *health record would store everything about your health and the healthcare you receive from*
7 *your birth until your death. Electronic health records would bring together in one record all*
8 *of your separate files, whether stored on paper or a computer, in all of the different locations*
9 *where you get healthcare.'*
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21 In this paper we are focusing on the survey questions that provide specific information
22 relevant to using EHRs for diabetes care:
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27 **1) EHRs for healthcare provision: If there was a national electronic health records**
28 **system, would you want your record to be part of it for your own healthcare?**
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30

- 31
32 - Yes, complete record (i.e. full medical history)
33
34 - Yes, partial record (i.e. limited health information such as prescriptions or
35 allergies)
36
37
38 - No
39
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42

43 **2) If your name and address were present, should these groups* have access to your**
44 **'complete record', 'partial record' or neither record?**
45
46

- 47
48 - You (e.g. reading your own record)
49

50 * In the context of the full survey, this referred to a number of occupational groups such as
51 doctors and nurses, pharmacists, accident and emergency staff. The question examined here
52 only relates to patients wishing to have access to their own EHR.
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3 **3) EHRs for research: If there was a national electronic health records system, would**
4 **you want your record to be part of it for health research?**
5

- 6 - Yes, name & address present
- 7 - Yes, name & address removed
- 8 - No

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16 **4) Now thinking about your ‘complete record’, should these groups have access to your**
17 **record with your name and address present, removed or not at all?**
18

- 19 - NHS researchers (e.g. healthcare research)
- 20 - Health charities (e.g. cancer research)
- 21 - Drug companies (e.g. drug research)

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31 The questionnaire also included items recording participants’ birth year, sex, ethnicity, level
32 of education, recruitment site, frequency of visits to healthcare providers in the 6 months
33 prior to the survey, previous participation in health research and long-term health conditions.
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41 **Qualitative methods**

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43 To further examine the results of the survey, we carried out a qualitative study including
44 focus group discussions and interviews with groups of people living with different conditions
45 and with different socio-demographic characteristics. Our sampling methodology was driven
46 by the survey findings and aimed to capture the widest range of perspectives possible. As a
47 result of the survey responses received specifically from people living with diabetes, one of
48 the focus group discussions was organised with a pre-existing diabetes support group in
49 Northwest London in October 2012. We established contact with this group through existing
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3 networks at CLAHRC NWL and invited their members to participate in a focus group
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5 discussion. Six people responded to our invitation and we provided them with an information
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7 sheet detailing all aspects of the study before the meeting. The focus group took place in the
8
9 premises where the group usually meets, with two postdoctoral researchers experienced in
10
11 qualitative research supporting the discussion. One researcher (CP) was primarily responsible
12
13 for facilitating the discussion and the other researcher (RL in acknowledgments) for taking
14
15 detailed notes. A focus group guide was used including questions on participants'
16
17 experiences with information sharing between different NHS providers, their hopes and
18
19 concerns around integrated systems used for healthcare, research, and planning purposes, as
20
21 well as their thoughts on the best ways to involve patients and members of the public in
22
23 decision-making about the future of EHRs. Following best practice in qualitative research,
24
25 the facilitator followed up discussions beyond the topic guide when themes emerged that
26
27 were of interest to participants. Additional materials in the form of comic illustrations were
28
29 also used to increase engagement and trigger discussion around the questions of the topic
30
31 guide.
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37 Half of the participants were women, average age of the group was between 50 to 60 years
38
39 old and most participants had a long history of diabetes. The focus group lasted 1 hour and 40
40
41 minutes, and was recorded and transcribed verbatim with participant consent. We offered
42
43 participants the option to view the transcript before the analysis but did not receive any
44
45 responses. The focus group facilitator (CP) and a third researcher (FR in acknowledgments)
46
47 carried out thematic analysis using a pre-defined coding framework which they refined
48
49 through iterative rounds of deductive (codes identified in advance) and inductive (codes
50
51 emerging from the data) coding. The researchers then compared their findings and discussed
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53 differences in their coding to enhance understanding and identify nuances in meaning.
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3 The qualitative findings presented in this paper only draw on the focus group discussion with
4 people living with diabetes, rather than the full qualitative study carried out for the same
5 project. Therefore, the aim is not to reach theoretical saturation or to cover the full range of
6 the views of people living with diabetes, but to elaborate on the findings of the quantitative
7 survey and place them in the context of patient experiences.
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21 Results

22 Characteristics of the 404 people with diabetes in the study population are shown in Table 3.

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25 Two-thirds (66.49%) of people with diabetes reported they would support the inclusion of
26 their full records on a national EHR system for purposes of personal health provision. The
27 majority of respondents said that they would prefer to have full access to their own medical
28 history (91.52%) rather than limited access to their health information (4.39%)[Table 4]
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35 These findings resonate with the discussion held with the diabetes groups. People often found
36 they had to repeat their medical history to a number of different health professionals each
37 time they had an appointment. They said this used up valuable consultation time and limited
38 the extent of their interaction with health services:
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45 *'If I only had a pound for every time I've had to do that [repeat medical history].*

46
47
48 (Participant 1)
49

50 Participants suggested that EHRs might improve communication between different health
51 professionals, which, they found, did not happen as systematically or as regularly as they
52 thought it should. When discussing patient access to their own health records and test results,
53 participants said they appreciated it when health professionals provided them with enough
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3 information to allow them to take a more active role in their care and to monitor their health.
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5 For instance, surgeries providing patients with a paper copy of their test results were
6
7 described as ‘progressive’:
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10 *‘The printout showed me my HbA1c, blood pressure, cholesterol level, weight, the*
11 *kidney function, protein, creatinine and all that stuff. So all these numbers were there*
12 *for this year and the previous, year before, so I could actually see whether there were*
13 *any changes [sic].’* (Participant 3)
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20 Yet, some felt there might be circumstances where it would be better for patients to have less
21
22 access to specific types of information:
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25 *‘Sometimes there’s information that you as the patient shouldn’t really [see], it isn’t*
26 *in your best interest to have. It’s not always in your best interest to know that you’re*
27 *terminally ill, it may be [in the best interest of] those that are caring [for you].’*
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32 (Participant 2)
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35 **EHRs for Research**

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37 In survey responses, 79.41% of people with diabetes said they would allow their EHRs to be
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39 used for research, with 51.07% allowing their records to be shared without identifiers and
40
41 28.34% being supportive of access to their identifiable information. However, one in five
42
43 (20.59%) said they did not want their EHRs to be accessed for research at all. [Table 5]
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47 Focus group participants also supported use of EHRs in health research, saying more
48
49 information available for research would allow better treatments to be developed:
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52 *‘Well I think we have to agree with that, if we want these diseases to be cured or*
53 *treated more effectively then information has to be passed to the researchers.’*
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57 (Participant 1)
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3 However, concerns were still expressed about how their information would be used:
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6 *'I have no personal objection [to sharing for research purposes] provided I am given*
7
8 *details of what it's for, whether I agree with that kind of research work.'*
9

10 (Participant 5)
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13 If information were anonymous, with specific name and address details excluded, it would be
14
15 less important, participants said, to seek permission for use of their data:
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17

18 *'If they're working on an improvement to metformin for example, which I'm sure we*
19 *would all love to have, they'll need information, won't they? From patients, and they*
20 *can't ask everybody, if the information is available anonymously anyway you don't*
21 *need to ask everybody.'* (Participant 4)
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31 Survey respondents distinguished between different users when responding whether or not
32 they would allow access to their identifiable EHRs. 28.84% of survey respondents suggested
33 that they would allow identifiable EHR access to NHS researchers, but far fewer would allow
34 access to health charities (16.76%) and pharmaceutical companies (15.34%). Even if their
35 record did not contain identifiers, only half of respondents said they would still allow access
36 to NHS researchers, charities or pharmaceutical companies. [Figure 1]
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45 Low levels of support were also reflected in the focus group discussion. Once the possibility
46 was raised that private companies (including pharmaceuticals) might have access to data (de-
47 identified or not) collected for clinical purposes, concerns were expressed about whether
48 these organisations could be held accountable for inappropriate use of information. One of
49 the participants suggested use of information for profit might affect patient confidentiality:
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3 *'Unfortunately my belief is that when people start making a profit out of it that's when*
4 *the ethics start getting a little bit less and a little bit less as the profit margin goes up*
5 *the less ethical you are the more money you earn.'* (Participant 1)
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10 In summary, participants were primarily concerned with achieving a good balance between
11 keeping information confidential and secure, while sharing it where needed to improve health
12 outcomes, research findings and the quality of diabetes care. They said sharing should only
13 occur between *'responsible'* parties and *'legitimate users'*, those who need to have access and
14 are *'reasonably entitled'* to do so:
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21
22 *'There is a balance though surely between electronic records being held and those*
23 *that need to know and how much they need to know. Not everybody needs to know*
24 *everything about you... but equally they do need, there is some information that does*
25 *need to be shared if we want that the best possible results.'* (Participant 2)
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37 Discussion

38 Sharing Data for Health and Self-Care

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40 The focus group discussion highlights that some patients expect EHRs to improve
41 communication and prevent repetition during clinical encounters. In the quantitative survey,
42 support for sharing with healthcare providers increased from 66.5% for sharing full medical
43 history to 88.2%, when including those who would only allow sharing of limited health
44 information.
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3 Supporters of full data sharing between healthcare professionals often draw attention to the
4 breadth and complexity of diabetes management and provide examples where full data
5 sharing has demonstrated improvements in clinical outcomes.¹⁰
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10
11 Self-care is deemed particularly important with an estimated 95% of diabetes care being self-
12 administered and supported by different technologies.²³ [Table 2] This is reflected in
13 significant support for full personal access to health records (91.5%) as recorded in the
14 survey presented here. Benefits of personal use of EHRs have been discussed in previous
15 research suggesting that access to health records is an important component of self-care as
16 patients who have access to their full health records use them to improve interactions with
17 healthcare providers, make decisions about their health and improve the quality of the care
18 they receive.²⁴
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33 **Sharing data for Research**

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35 Within our sample, a large majority (79.4%) of people with diabetes would allow their EHRs
36 to be used for research. This was supported within the group discussion which acknowledged
37 the value of such data for researchers, and where individuals expressed desire and
38 responsibility to share such data for societal benefit. An Ipsos MORI study similarly found
39 that although there is low awareness of medical research among the general public, those
40 with long-term conditions who have more experience of health services, and perhaps also
41 greater understanding of research, generally hold more positive views about such research.²⁵
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52 It is of interest that 28.3% of those who would allow their EHRs to be used for research,
53 would be comfortable sharing their full medical history *with identifiers* whereas 51.1% would
54 be comfortable sharing *without* identifiers. In real terms, population-based research is often
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3 conducted without the full identification of participants and follow-up is typically not
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5 required.
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8 The question posed in our study, 'If there was a national electronic health records system,
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10 would you want your record to be part of it for health research?' may imply to some that they
11
12 will be providing broad consent for all research. This may partly explain why proportions of
13
14 people comfortable with sharing identifiable data (28.3%) are lower than SCI-DC⁵ (70%) and
15
16 National Cancer Registry²⁶ (72%) models where people agree to provide *identifiable data* in
17
18 order to be contacted for future research and consent. This may be worth considering for any
19
20 future plans with EHR models and research consent.
21
22

23
24 In this study, trust appeared to be higher for NHS researchers compared with health charity
25
26 researchers (28.8% against 16.8% of people with diabetes would share their data with
27
28 identifiers), despite a large proportion of NHS research being funded by health charities.
29
30 Themes of confidentiality and consent emerge frequently during discussions about sharing
31
32 electronic records for research.²⁵ These principles, with legal underpinning and supported by
33
34 professional regulatory bodies are important to preserve in order to maintain trust between
35
36 patients and health care professionals. 'Caldicott guardians' (senior individuals responsible
37
38 for protecting patient confidentiality and enabling appropriate information sharing) and other
39
40 information governance mechanisms and structures, exist in every NHS organisation, but it is
41
42 unclear how aware patients are of their existence or role.
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51 **Conclusions**

52 Patient records are integral to the care provided by a range of professionals within the
53
54 National Health Service. As well as holding a legal record of care provided, health records, in
55
56 an electronic format, may also facilitate communication across interfaces of care, preventing
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3 duplication of effort and promoting cost-effective, individualised care. The vast quantity of
4
5 data accessible from electronic health records may also be harnessed to advance quality,
6
7 innovation, research and self-care as well as plan services and strategies.
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9

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11 In the case of diabetes, this is particularly pertinent as the quantitative nature of health data
12
13 combined with the vast array of health technologies available could enable easy data sharing
14
15 between individuals and across health boundaries. But, of course, patient's personal
16
17 boundaries and preferences should not be overlooked. Patient engagement is crucial in order
18
19 to preserve trust in existing systems and ensure new systems adequately meet patient needs as
20
21 well as to maximise the potential of new ones. The discussion is not straightforward as there
22
23 are multiple agencies involved but with a structured, collaborative, approach, excellent
24
25 progress can be made as illustrated by examples such as SCI-DC⁵.
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32 **Strengths and limitations**

33 To our knowledge, this is one of the few studies looking at the views of people with diabetes
34
35 on EHRs and data sharing in the UK. Views about EHRs are likely to differ according to
36
37 personal circumstances, such as medical status, age, socioeconomic position, and previous
38
39 healthcare experiences.¹⁵ Our population is not necessarily representative of the UK
40
41 population as it was selected from West London, an area of ethnic, cultural and socio-
42
43 economic variation. Nonetheless, the results offer an interesting insight into how people with
44
45 diabetes perceive their health records and the various agencies that may deal with them.
46
47 Future research along with meaningful patient and public involvement activities are needed to
48
49 fully incorporate patient views and experiences in the design and use of EHRs for care,
50
51 research and planning. The findings presented in this paper could be used as a foundation to
52
53 allow more contextualised enquiry around diabetes-specific systems and information sharing
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3 practices, and how these take in account patient preferences in the design of consent options
4
5 for example or how they might raise concerns when awareness and security mechanisms do
6
7 not match patient expectations.
8

9 10 11 **Funding** 12

13
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15
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17
18 interpretation of data; the writing of the paper; or the decision to submit it for publication. JR
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23
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31
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43 **Conflicts of interest** 44

45 None.
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20 References

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22
23
24 1) Diabetes UK. Patient choice, what does 'choice' mean to people with diabetes. May
25 2005. See: https://www.diabetes.org.uk/Documents/Reports/Patient_choice.pdf (last
26 checked July 2015)
27
28
29
30 2) Harris M, Greaves F, Patterson S, Jones J, Pappas Y, Majeed A, Car J. The North
31 West London Integrated Care Pilot: innovative strategies to improve care coordination
32 for older adults and people with diabetes. *J Ambul Care Manage* 2012;35(3):216-25
33
34
35 3) NHS Diabetes, Department of Health and other partners. Best practice for
36 commissioning diabetes services, an integrated care framework. March 2013. See:
37 <https://www.diabetes.org.uk/integrated-diabetes-care> (last checked July 2015)
38
39
40 4) Diabetes UK. Improving the delivery of adult diabetes care through integration.
41 Sharing experience and learning. Oct 2014. See:
42 <https://www.diabetes.org.uk/integrated-diabetes-care> (last checked July 2015)
43
44
45 5) Brearley S, McIntosh P. Using health informatics to increase study recruitment.
46 Scottish Diabetes Research Network Group (SDRN, www.sdrn.org.uk) see:
47 <https://www.sdrn.org.uk/node/406> (last checked July 2015)
48
49
50 6) Holt TA, Stables D, Hippisley-Cox J, O'Hanlon S, Majeed A. Identifying
51
52
53
54
55
56
57
58
59
60

- 1
2
3 undiagnosed diabetes: cross-sectional survey of 3.6 million patients' electronic
4 records. *Br J Gen Pract* 2008;58(548):192-6
5
6
7
8 7) Carstensen B, Kristensen JK, Marcussen MM, Borch-Johnsen K. The National
9 Diabetes Register. *Scand J Public Health*. 2011; 39:58-61.
10
11
12 8) EMIS web. See: <https://www.emishealth.com/products/emis-web/> (last checked July
13 2015)
14
15
16 9) Franklin C. A Healthy scepticism about electronic medical records. The *Guardian*
17 online 2011. See:
18 <http://www.guardian.co.uk/commentisfree/cifamerica/2011/apr/23/nhs-health>
19
20
21 (last checked July 2015)
22
23
24
25 10) Varroud-Vial M. Improving diabetes management with electronic medical records.
26
27 *Diabetes Metab*. 2011;37(4):S48-52
28
29
30 11) Shamliyan TA, Duval S, Du J, Kane RL. Just what the doctor ordered. Review of the
31 evidence of the impact of computerized physician order entry system on medication
32 errors. *Health Serv Res* 2008;43:32-53.
33
34
35
36 12) Coloma PM1, Trifirò G, Patadia V, Sturkenboom M. Postmarketing safety
37 surveillance : where does signal detection using electronic healthcare records fit into
38 the big picture? *Drug Saf*. 2013;36(3):183-97
39
40
41
42
43 13) Bowman S. Impact of Electronic Health Record Systems on Information Integrity:
44 Quality and Safety Implications. *Perspectives in Health Information Management*
45 2013;10:1c. See: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3797550/> (last
46 checked July 2015)
47
48
49
50
51 14) Peeples MM1, Iyer AK, Cohen JL. Integration of a mobile-integrated therapy with
52 electronic health records: lessons learned. *J Diabetes Sci Technol*. 2013;7(3):602-11.
53
54
55
56 15) Luchenski S, Balasanthiran, A, Marston C, Sasaki K, Majeed A, Bell D, Reed JE.
57
58
59
60

- 1
2
3 Survey of patient and public perceptions of electronic health records for healthcare,
4 policy and research: Study protocol. *BMC Medical Informatics and Decision Making*
5 2012, 12:40. See: <http://www.biomedcentral.com/1472-6947/12/40> (last checked July
6 2015)
7
8
9
10
11
12 16) Healthcare Information and Management Systems Society (HIMMS). Key issues in
13 EHR adoption and sustainability white paper. 2008.
14
15
16 17) Desai JR, Wu P, Nichols GA, Lieu TA, O'Connor PJ. Diabetes and asthma case
17 identification, validation and representativeness when using electronic health data to
18 construct registries for comparative effectiveness and epidemiological research. *Med*
19 *Care* 2012;50:S30-5
20
21
22
23
24
25 18) Nichols GA, Desai J, Elston Lafata J, Lawrence JM, O'Connor PJ, Pathak RD, Raebel
26 MA, Reid RJ, Selby JV, Silverman BG, Steiner JF, Stewart WF, Vupputuri S,
27 Waitzfelder B; SUPREME-DM Study Group. Construction of a multisite DataLink
28 using electronic health records for the identification, surveillance, prevention, and
29 management of diabetes mellitus: the SUPREME-DM project. *Prev Chronic Dis.*
30 2012;9:E110.
31
32
33
34
35
36
37
38 19) Piwernetz K. DIABCARE Quality Network in Europe – a model for quality
39 management in chronic diseases. *Int Clin Psychopharmacol* 2001;16(3):S5-13
40
41
42
43 20) Diabetes UK. Integrated care report 2010.
44
45 21) Luchenski SA, Reed JE, Marston C, Papoutsi C, Majeed A, Bell D. Patient and Public
46 Views on Electronic Health Records and Their Uses in the United Kingdom: Cross-
47 Sectional Survey. *J Med Internet Res.* 2013; 15(8): e160.
48
49
50
51 22) Riordan F, Papoutsi C, Reed JE, Marston C, Bell D, Majeed A. Patient and public
52 attitudes towards informed consent models and levels of awareness of electronic
53 health records in the UK. *Int J Med Inform* 2015;84:237-47
54
55
56
57
58
59
60

- 1
2
3 23) Diabetes UK. Improving supported self-management for people with diabetes. 2009
4
5 See: <http://www.diabetes.org.uk/supported-self-management> (last checked July 2015
6
7
8 24) Fisher B, Bhavnani V, Winfield M. . How patients use access to their full health
9
10 records: a qualitative study of patients in general practice. *J R Soc Med* 2009; 102:
11
12 538–544.
13
14 25) Ipsos MORI: The Use of Personal Health Information in Medical Research: General
15
16 Public Consultation. London: *Medical Research Council*; 2007
17
18 26) Barrett G, Cassell JA, Peacock JL, Coleman MP; National Cancer Registry. National
19
20 survey of British public's views on use of identifiable medical data by the National
21
22 Cancer Registry. *BMJ*. 2006;332(7549):1068-72
23
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Tables and Figure Legends

Potential Benefits of EHRs in Diabetes	Potential Risks & Concerns
Facilitation of integrated care, local diabetes networks and multidisciplinary team input. ⁸	‘Creeping depersonalisation’ with more attention paid to the computer than the patient. ⁹
Improved clinical outcomes and reduction in medication errors. ^{10,11} Facilitated post-marketing surveillance. ¹²	Typing/clinical errors easily propagated between health care professionals and across boundaries. ¹³
Integration with M-health technologies to facilitate self-care. ¹⁴	Narrative of patient story potentially lost in rigid software template and extraneous information. ⁹
Improved access of health records for health care professionals and patients. ¹⁵	Cost and complexity of implementation. ¹⁶
Support for prescribing, coding, referrals and Quality and Outcomes Framework (QoF) in primary care. ⁸	Public concerns regarding data security and misuse ¹⁵
Nationally, creation of registries for population surveillance, diabetes prevention and early detection of diabetes ^{17,18} as well as easier access to patient-level data for quality improvement, ¹⁹ research, policy planning, education and national diabetes audits.	Public concerns regarding personal privacy and ‘surveillance society’ ¹⁵

Table 1: Potential benefits, risks and concerns regarding EHRs in Diabetes

System	Examples
Shared electronic decision support systems	COMPETE II
Personal Health Records (PHR)	Diabetes specific PHR+care plan
Web-based Patient Portals	DIAMOND.net, Diabetes 24/7, MyDiabetesMyWay, Carelink™
Websites	Diabetes.co.uk
Smartphone technology	Few Touch Application, iBGStar Diabetes Manager App, Diabetes Buddy, LogFrog DB
EHRs integrated with smartphone technology	MIT-EHR
Telehealth	Integrated Telehealth and Clinical Pharmacy

Table 2: Examples of innovative applications that have enabled people with diabetes to manage their care

For Peer Review

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	% (N)
Gender	
Female	43.31 (175)
Male	49.51 (200)
Missing/Prefer not to say	7.18 (29)
Age category	
18-24	3.71 (15)
25-34	4.70 (19)
35-44	9.90 (40)
45-54	15.84 (64)
55-64	19.31 (78)
65-74	23.27 (94)
75+	12.13 (49)
Missing	11.14 (45)
Educational qualifications	
No academic qualification	11.64 (47)
GCSE	13.36 (54)
A-Levels	11.39 (46)
Vocational qualification	9.90 (40)
Degree	24.50 (99)
Higher Degree	14.85 (60)
Missing/Prefer not to say	14.36 (58)
Ethnicity	
White British	42.32 (171)
White Non-British	9.40 (38)
Black/African/Caribbean/British Black	8.42 (34)
Asian/Asian British	11.39 (46)
Mixed/Multiple	2.47 (10)
Other ethnic group	5.69 (23)
Missing/Prefer not to say	20.29 (82)
Recruitment site	
GP	25.00 (101)
Outpatient	75.00 (303)
Frequency of healthcare use in past 6 months	
0 to 2 visits	18.31 (74)
3 to 5 visits	39.35 (159)
6 to 9 visits	19.06 (77)
10 plus visits	16.09 (65)
Missing/Prefer not to say/Don't know	7.19 (29)
Previous participation in health research	
No	73.02 (295)
Yes	23.76 (96)

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Missing	3.22 (13)
Total	100 (404)

Table 3: Description of study sample by socio-demographic characteristics, recruitment site, frequency of healthcare use and previous participation in health research

For Peer Review

Own record as part of EHRs for healthcare	% (N)	Patient access to their own EHR	% (N)
Full medical history	66.49 (248)	Full medical history	91.52 (313)
Limited health information such as prescriptions or allergies	21.71 (81)	Limited health information such as prescriptions or allergies	4.09 (14)
Neither record	11.80 (44)	Neither record	4.39 (15)
Total	100 (373)	Total	100 (342)

Table 4: Preferences of diabetes patients on the inclusion of their records in EHRs for healthcare and own patient access

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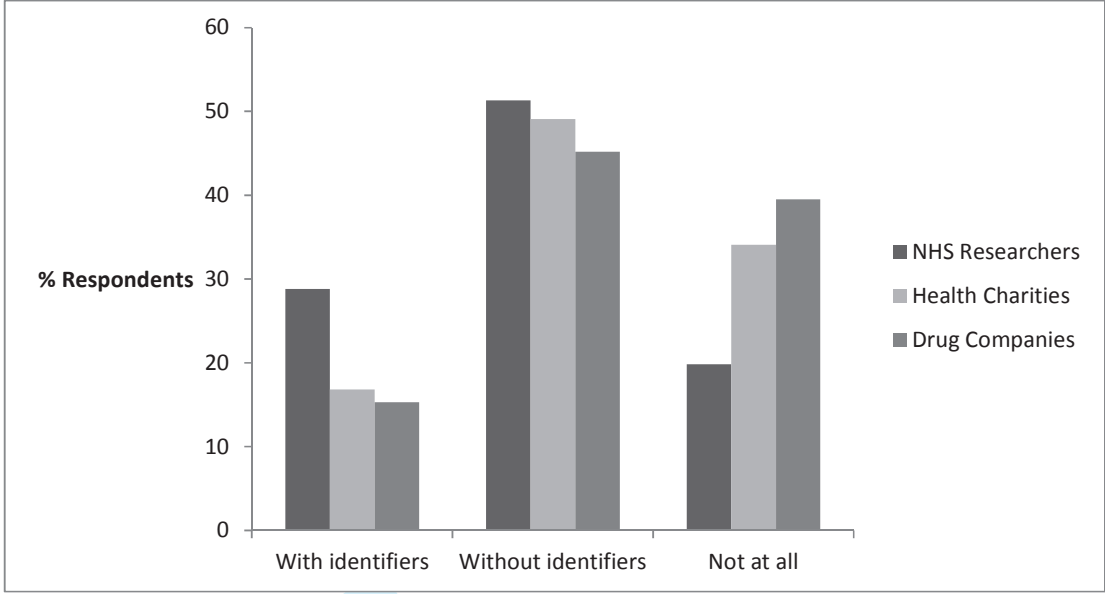


Figure 1: Preferences for access to EHRs with identifiers, without identifiers or no access at all by NHS researchers (n=378), Health charities (n=352), drug companies (n=354)

Own record as part of EHRs for research	%
With identifiers	28.34 (106)
Without identifiers	51.07 (191)
Not at all	20.59 (77)
Total	100 (374)

Table 5: Preferences of diabetes patients on the inclusion of their records in EHRs for research purposes

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