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

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<th>Journal:</th>
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<tr>
<td>Manuscript ID</td>
<td>PDINTL-15-058</td>
</tr>
<tr>
<td>Wiley - Manuscript type</td>
<td>Original Article</td>
</tr>
<tr>
<td>Date Submitted by the Author</td>
<td>24-Dec-2015</td>
</tr>
<tr>
<td>Complete List of Authors:</td>
<td>Zalin, Anjali; NIHR Collaboration for Leadership in Applied Health Research and Care for Northwest London; Chelsea and Westminster Hospital NHS Foundation Trust; Imperial College London Papoutsi, Chrysanthi; NIHR Collaboration for Leadership in Applied Health Research and Care for Northwest London, Imperial College London; Chelsea and Westminster Hospital NHS Foundation Trust; Imperial College London Shotliff, Kevin; Chelsea and Westminster Hospital NHS Foundation Trust, Beta Cell Centre for Diabetes Majeed, Azeem; Imperial College London, Department of Primary Care &amp; Public Health Marston, Cicely; London School of Hygiene and Tropical Medicine, Department of Social and Environmental Health Research Reed, Julie; NIHR Collaboration for Leadership in Applied Health Research and Care for Northwest London; Chelsea and Westminster Hospital NHS Foundation Trust; Imperial College London</td>
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<td>Keywords:</td>
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The Power of Information for Diabetes Research and Care:

Patient views in West London

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Manuscript word count: 3729 (excluding abstract, tables, references)

Statement of funding sources: Wellcome Trust

Abbreviated Title: The Power of Information for Diabetes Research and Care

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

Wiley-Blackwell
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
findings were explored in more detail in a focus group discussion involving people with diabetes.

**Results**

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

**Conclusions**

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

Multidisciplinary team-working, self-management\(^1\) and integration of services are often championed as key strategies in addressing the national challenges in diabetes\(^2\) 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 QRESEARCH\(^6\), 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.\(^20\)
With this in mind, we sought to examine the views of people living with diabetes on EHRs and data sharing. The data presented in this paper are drawn from a larger study looking at patient and public perceptions on EHRs across a number of socio-demographic groups living with different conditions. \(^{21-22}\) The views of people with diabetes are presented here separately for a number of reasons:

- Diabetes care presents many challenges including multi-organ and lifestyle involvement that can necessitate frequent visits across various (multidisciplinary) interfaces of care.
- Local (GP and hospital-held) electronic systems are commonly employed in diabetes care to support long-term management. [Table 2]
- With self-care being a crucial component of diabetes care, systems linking EHRs with home-based monitoring systems and self-management support tools have also been developed and used. [Table 2]

As wider data sharing holds potential for healthcare improvement and research, it is important to engage with patient views and experiences adequately.

**Methods**

This paper presents data collected as part of a mixed methods study looking at patient and public views on EHRs. The first phase of the study involved a large-scale quantitative survey.

We examined a sub-group comprising all survey participants who reported living with diabetes (N=404). The second phase of the study included a number of focus group discussions and interviews with patients and members of the public living with different
health conditions. One of the group discussions was with individuals with diabetes, and we include these data in our analysis. The study was approved by the London Dulwich Research Ethics Committee (Ref. No. 10/H0808/96).

**Quantitative methods**

The survey was cross-sectional, using a stratified cluster random sample. It was administered in 16 different healthcare sites (8 outpatient clinics in a 431-bed hospital in northwest London and 8 general practice (GP) surgeries within the catchment area of the hospital) between August and September 2011. This design was chosen to maximise variability in patients’ healthcare experiences. Each of the eight hospital outpatient clinics were sampled on five days of the week totaling 40 sampling days. This design was chosen to ensure a wide array of patient characteristics and to minimise selection bias. For GP surgeries, we used the complete list of surgeries in the catchment area, stratified by borough, size and whether or not they were research active, to select a random sample of surgeries. We selected one large surgery (patient list ≥ 5000) and one small surgery (patient list <5000) from each borough, for a total of eight surgeries. Recruitment was again conducted on five randomly selected week days for each surgery over the period, for a total of 40 GP surgery sampling days.

Participants self-completed the questionnaire while waiting for their appointments in the clinics (response rate 85.5%). Recruitment was carried out at different days and times following a random sampling design to minimise selection bias. Only adults over 18 years old who were able to understand the information provided were eligible to participate in the study. Further details on the study protocol for the quantitative survey have been published elsewhere.\(^{15,21}\)
The survey examined a number of elements of patient and public views about a national EHR system used for health provision; planning and policy; and research purposes. For the purposes of this questionnaire, EHRs were defined as follows: ‘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.’

In this paper we are focusing on the survey questions that provide specific information relevant to using EHRs for diabetes care:

1) EHRs for healthcare provision: 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 (i.e. full medical history)
   - Yes, partial record (i.e. limited health information such as prescriptions or allergies)
   - No

2) If your name and address were present, should these groups* have access to your ‘complete record’, ‘partial record’ or neither record?

   - You (e.g. reading your own record)

* In the context of the full survey, this referred to a number of occupational groups such as doctors and nurses, pharmacists, accident and emergency staff. The question examined here only relates to patients wishing to have access to their own EHR.
3) EHRs for research: 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 & addressed removed
- No

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

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

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

Qualitative methods

To further examine the results of the survey, we carried out a qualitative study including focus group discussions and interviews with groups of people living with different conditions and with different socio-demographic characteristics. Our sampling methodology was driven by the survey findings and aimed to capture the widest range of perspectives possible. As a result of the survey responses received specifically from people living with diabetes, one of the focus group discussions was organised with a pre-existing diabetes support group in Northwest London in October 2012. We established contact with this group through existing
networks at CLAHRC NWL and invited their members to participate in a focus group
discussion. Six people responded to our invitation and we provided them with an information
sheet detailing all aspects of the study before the meeting. The focus group took place in the
premises where the group usually meets, with two postdoctoral researchers experienced in
qualitative research supporting the discussion. One researcher (CP) was primarily responsible
for facilitating the discussion and the other researcher (RL in acknowledgments) for taking
detailed notes. A focus group guide was used including questions on participants’
experiences with information sharing between different NHS providers, their hopes and
concerns around integrated systems used for healthcare, research, and planning purposes, as
well as their thoughts on the best ways to involve patients and members of the public in
decision-making about the future of EHRs. Following best practice in qualitative research,
the facilitator followed up discussions beyond the topic guide when themes emerged that
were of interest to participants. Additional materials in the form of comic illustrations were
also used to increase engagement and trigger discussion around the questions of the topic
guide.

Half of the participants were women, average age of the group was between 50 to 60 years
old and most participants had a long history of diabetes. The focus group lasted 1 hour and 40
minutes, and was recorded and transcribed verbatim with participant consent. We offered
participants the option to view the transcript before the analysis but did not receive any
responses. The focus group facilitator (CP) and a third researcher (FR in acknowledgments)
carried out thematic analysis using a pre-defined coding framework which they refined
through iterative rounds of deductive (codes identified in advance) and inductive (codes
emerging from the data) coding. The researchers then compared their findings and discussed
differences in their coding to enhance understanding and identify nuances in meaning.
The qualitative findings presented in this paper only draw on the focus group discussion with people living with diabetes, rather than the full qualitative study carried out for the same project. Therefore, the aim is not to reach theoretical saturation or to cover the full range of the views of people living with diabetes, but to elaborate on the findings of the quantitative survey and place them in the context of patient experiences.

Results

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

Two-thirds (66.49%) of people with diabetes reported they would support the inclusion of their full records on a national EHR system for purposes of personal health provision. The majority of respondents said that they would prefer to have full access to their own medical history (91.52%) rather than limited access to their health information (4.39%)[Table 4]

These findings resonate with the discussion held with the diabetes groups. People often found they had to repeat their medical history to a number of different health professionals each time they had an appointment. They said this used up valuable consultation time and limited the extent of their interaction with health services:

‘If I only had a pound for every time I’ve had to do that [repeat medical history].

( Participant 1)

Participants suggested that EHRs might improve communication between different health professionals, which, they found, did not happen as systematically or as regularly as they thought it should. When discussing patient access to their own health records and test results, participants said they appreciated it when health professionals provided them with enough
information to allow them to take a more active role in their care and to monitor their health. For instance, surgeries providing patients with a paper copy of their test results were described as ‘progressive’:

‘The printout showed me my HbA1c, blood pressure, cholesterol level, weight, the kidney function, protein, creatinine and all that stuff. So all these numbers were there for this year and the previous year before, so I could actually see whether there were any changes [sic].’ (Participant 3)

Yet, some felt there might be circumstances where it would be better for patients to have less access to specific types of information:

‘Sometimes there’s information that you as the patient shouldn’t really [see], it isn’t in your best interest to have. It’s not always in your best interest to know that you’re terminally ill, it may be [in the best interest of] those that are caring [for you].’

( Participant 2)

**EHRs for Research**

In survey responses, 79.41% of people with diabetes said they would allow their EHRs to be used for research, with 51.07% allowing their records to be shared without identifiers and 28.34% being supportive of access to their identifiable information. However, one in five (20.59%) said they did not want their EHRs to be accessed for research at all. [Table 5]

Focus group participants also supported use of EHRs in health research, saying more information available for research would allow better treatments to be developed:

‘Well I think we have to agree with that, if we want these diseases to be cured or treated more effectively then information has to be passed to the researchers.’

( Participant 1)
However, concerns were still expressed about how their information would be used:

‘I have no personal objection [to sharing for research purposes] provided I am given
details of what it’s for, whether I agree with that kind of research work.’
(Participant 5)

If information were anonymous, with specific name and address details excluded, it would be
less important, participants said, to seek permission for use of their data:

‘If they’re working on an improvement to metformin for example, which I’m sure we
would all love to have, they’ll need information, won’t they? From patients, and they
can’t ask everybody, if the information is available anonymously anyway you don’t
need to ask everybody.’ (Participant 4)

Survey respondents distinguished between different users when responding whether or not
they would allow access to their identifiable EHRs. 28.84% of survey respondents suggested
that they would allow identifiable EHR access to NHS researchers, but far fewer would allow
access to health charities (16.76%) and pharmaceutical companies (15.34%). Even if their
record did not contain identifiers, only half of respondents said they would still allow access
to NHS researchers, charities or pharmaceutical companies. [Figure 1]

Low levels of support were also reflected in the focus group discussion. Once the possibility
was raised that private companies (including pharmaceuticals) might have access to data (de-
identified or not) collected for clinical purposes, concerns were expressed about whether
these organisations could be held accountable for inappropriate use of information. One of
the participants suggested use of information for profit might affect patient confidentiality:
‘Unfortunately my belief is that when people start making a profit out of it that’s when the ethics start getting a little bit less and a little bit less as the profit margin goes up the less ethical you are the more money you earn.’ (Participant 1)

In summary, participants were primarily concerned with achieving a good balance between keeping information confidential and secure, while sharing it where needed to improve health outcomes, research findings and the quality of diabetes care. They said sharing should only occur between ‘responsible’ parties and ‘legitimate users’, those who need to have access and are ‘reasonably entitled’ to do so:

‘There is a balance though surely between electronic records being held and those that need to know and how much they need to know. Not everybody needs to know everything about you… but equally they do need, there is some information that does need to be shared if we want that the best possible results.’ (Participant 2)

**Discussion**

**Sharing Data for Health and Self-Care**

The focus group discussion highlights that some patients expect EHRs to improve communication and prevent repetition during clinical encounters. In the quantitative survey, support for sharing with healthcare providers increased from 66.5% for sharing full medical history to 88.2%, when including those who would only allow sharing of limited health information.
Supporters of full data sharing between healthcare professionals often draw attention to the breadth and complexity of diabetes management and provide examples where full data sharing has demonstrated improvements in clinical outcomes.\textsuperscript{10}

Self-care is deemed particularly important with an estimated 95\% of diabetes care being self-administered and supported by different technologies.\textsuperscript{23} [Table 2] This is reflected in significant support for full personal access to health records (91.5\%) as recorded in the survey presented here. Benefits of personal use of EHRs have been discussed in previous research suggesting that access to health records is an important component of self-care as patients who have access to their full health records use them to improve interactions with healthcare providers, make decisions about their health and improve the quality of the care they receive.\textsuperscript{24}

\section*{Sharing data for Research}

Within our sample, a large majority (79.4\%) of people with diabetes would allow their EHRs to be used for research. This was supported within the group discussion which acknowledged the value of such data for researchers, and where individuals expressed desire and responsibility to share such data for societal benefit. An Ipsos MORI study similarly found that although there is low awareness of medical research among the general public, those with long-term conditions who have more experience of health services, and perhaps also greater understanding of research, generally hold more positive views about such research.\textsuperscript{25}

It is of interest that 28.3\% of those who would allow their EHRs to be used for research, would be comfortable sharing their full medical history \textit{with identifiers} whereas 51.1\% would be comfortable sharing \textit{without} identifiers. In real terms, population-based research is often
conducted without the full identification of participants and follow-up is typically not required.

The question posed in our study, ‘If there was a national electronic health records system, would you want your record to be part of it for health research?’ may imply to some that they will be providing broad consent for all research. This may partly explain why proportions of people comfortable with sharing identifiable data (28.3%) are lower than SCI-DC<sup>5</sup> (70%) and National Cancer Registry<sup>26</sup> (72%) models where people agree to provide identifiable data in order to be contacted for future research and consent. This may be worth considering for any future plans with EHR models and research consent.

In this study, trust appeared to be higher for NHS researchers compared with health charity researchers (28.8% against 16.8% of people with diabetes would share their data with identifiers), despite a large proportion of NHS research being funded by health charities. Themes of confidentiality and consent emerge frequently during discussions about sharing electronic records for research.<sup>25</sup> These principles, with legal underpinning and supported by professional regulatory bodies are important to preserve in order to maintain trust between patients and health care professionals. ‘Caldicott guardians’ (senior individuals responsible for protecting patient confidentiality and enabling appropriate information sharing) and other information governance mechanisms and structures, exist in every NHS organisation, but it is unclear how aware patients are of their existence or role.

**Conclusions**

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

In the case of diabetes, this is particularly pertinent as the quantitative nature of health data
combined with the vast array of health technologies available could enable easy data sharing
between individuals and across health boundaries. But, of course, patient’s personal
boundaries and preferences should not be overlooked. Patient engagement is crucial in order
to preserve trust in existing systems and ensure new systems adequately meet patient needs as
well as to maximise the potential of new ones. The discussion is not straightforward as there
are multiple agencies involved but with a structured, collaborative, approach, excellent
progress can be made as illustrated by examples such as SCI-DC\textsuperscript{5}.

**Strengths and limitations**

To our knowledge, this is one of the few studies looking at the views of people with diabetes
on EHRs and data sharing in the UK. Views about EHRs are likely to differ according to
personal circumstances, such as medical status, age, socioeconomic position, and previous
healthcare experiences.\textsuperscript{15} Our population is not necessarily representative of the UK
population as it was selected from West London, an area of ethnic, cultural and socio-
economic variation. Nonetheless, the results offer an interesting insight into how people with
diabetes perceive their health records and the various agencies that may deal with them.

Future research along with meaningful patient and public involvement activities are needed to
fully incorporate patient views and experiences in the design and use of EHRs for care,
research and planning. The findings presented in this paper could be used as a foundation to
allow more contextualised enquiry around diabetes-specific systems and information sharing

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practices, and how these take in account patient preferences in the design of consent options for example or how they might raise concerns when awareness and security mechanisms do not match patient expectations.

**Funding**

This paper presents independent research funded by the Wellcome Trust [086124/Z/08/Z]. The Wellcome Trust had no role in the study design; the collection, analysis, and interpretation of data; the writing of the paper; or the decision to submit it for publication. JR and DB are supported by NIHR CLAHRC for Northwest London, and JR is also supported by the Health Foundation, an independent charity working to continuously improve the quality of health care in the United Kingdom. This paper presents independent research commissioned by the National Institute for Health Research (NIHR) under the Collaborations for Leadership in Applied Health Research and Care (CLAHRC) program for North West London. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health.

**Conflicts of interest**

None.

**Acknowledgments**

We would like to thank the following contributions to this study: Kaori Sasaki contributed to the design and coordination of the initial phase of this study. Serena Luchenski contributed to the design and coordination of the study, drafted the survey questionnaire and carried out quantitative analysis in the early stages of the project. The acquisition of data was supported
by Rachael Aldersley, Cameron Bell, Sylvia Chalkley, Jason Curran, Shaun D’Souza, Stuart
Green, Sarah Hancox, Sina Iqbal, Uzoma Nnajiuba, Harsita Patel, Joshua Wolrich, and Jade
Zhao. We would also like to thank Ruth Lewis for contributing to data collection in the
qualitative component of the study and Fiona Riordan who helped with the analysis of the
focus group data for this paper. Thanks are also due to the three anonymous reviewers and
the journal editor for their constructive comments.

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Tables and Figure Legends

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<th><strong>Potential Risks &amp; Concerns</strong></th>
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<td>Facilitation of integrated care, local diabetes networks and multidisciplinary team input.</td>
<td>‘Creeping depersonalisation’ with more attention paid to the computer than the patient.</td>
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<td>Improved clinical outcomes and reduction in medication errors.</td>
<td>Typing/clinical errors easily propagated between health care professionals and across boundaries.</td>
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<tr>
<td>Integration with M-health technologies to facilitate self-care.</td>
<td>Narrative of patient story potentially lost in rigid software template and extraneous information.</td>
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<td>Improved access of health records for health care professionals and patients.</td>
<td>Cost and complexity of implementation.</td>
</tr>
<tr>
<td>Support for prescribing, coding, referrals and Quality and Outcomes Framework (QoF) in primary care.</td>
<td>Public concerns regarding data security and misuse.</td>
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<td>Nationally, creation of registries for population surveillance, diabetes prevention and early detection of diabetes as well as easier access to patient-level data for quality improvement, research, policy planning, education and national diabetes audits.</td>
<td>Public concerns regarding personal privacy and surveillance society.</td>
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Table 1: Potential benefits, risks and concerns regarding EHRs in Diabetes
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Table 2: Examples of innovative applications that have enabled people with diabetes to manage their care
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<tr>
<td>Missing/Prefer not to say</td>
<td>14.36 (58)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>42.32 (171)</td>
</tr>
<tr>
<td>White Non-British</td>
<td>9.40 (38)</td>
</tr>
<tr>
<td>Black/African/Caribbean/British</td>
<td>8.42 (34)</td>
</tr>
<tr>
<td>Black</td>
<td>11.39 (46)</td>
</tr>
<tr>
<td>Asian/Asian British</td>
<td>11.39 (46)</td>
</tr>
<tr>
<td>Mixed/Multiple</td>
<td>2.47 (10)</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>5.69 (23)</td>
</tr>
<tr>
<td>Missing/Prefer not to say</td>
<td>20.29 (82)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recruitment site</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>25.00 (101)</td>
</tr>
<tr>
<td>Outpatient</td>
<td>75.00 (303)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency of healthcare use in past 6 months</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 2 visits</td>
<td>18.31 (74)</td>
</tr>
<tr>
<td>3 to 5 visits</td>
<td>39.35 (159)</td>
</tr>
<tr>
<td>6 to 9 visits</td>
<td>19.06 (77)</td>
</tr>
<tr>
<td>10 plus visits</td>
<td>16.09 (65)</td>
</tr>
<tr>
<td>Missing/Prefer not to say/Don’t know</td>
<td>7.19 (29)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Previous participation in health research</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>73.02 (295)</td>
</tr>
<tr>
<td>Yes</td>
<td>23.76 (96)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-------</td>
</tr>
<tr>
<td>Missing</td>
<td>3.22 (13)</td>
</tr>
<tr>
<td>Total</td>
<td>100 (404)</td>
</tr>
</tbody>
</table>

Table 3: Description of study sample by socio-demographic characteristics, recruitment site, frequency of healthcare use and previous participation in health research
<table>
<thead>
<tr>
<th>Own record as part of EHRs for healthcare</th>
<th>% (N)</th>
<th>Patient access to their own EHR</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full medical history</td>
<td>66.49 (248)</td>
<td>Full medical history</td>
<td>91.52 (313)</td>
</tr>
<tr>
<td>Limited health information such as prescriptions or allergies</td>
<td>21.71 (81)</td>
<td>Limited health information such as prescriptions or allergies</td>
<td>4.09 (14)</td>
</tr>
<tr>
<td>Neither record</td>
<td>11.80 (44)</td>
<td>Neither record</td>
<td>4.39 (15)</td>
</tr>
<tr>
<td>Total</td>
<td>100 (373)</td>
<td>Total</td>
<td>100 (342)</td>
</tr>
</tbody>
</table>

Table 4: Preferences of diabetes patients on the inclusion of their records in EHRs for healthcare and own patient access
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)
<table>
<thead>
<tr>
<th>Own record as part of EHRs for research</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>With identifiers</td>
<td>28.34 (106)</td>
</tr>
<tr>
<td>Without identifiers</td>
<td>51.07 (191)</td>
</tr>
<tr>
<td>Not at all</td>
<td>20.59 (77)</td>
</tr>
<tr>
<td>Total</td>
<td>100 (374)</td>
</tr>
</tbody>
</table>

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