Engagement Report:

Your Patient Information Supporting Your Care –

A Consent Model for the local Health Information Exchange in Oxfordshire

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Status: Final

Date: 3 November 2011
Contents

1. About Us ............................................................................................................................................. 3
   1.1 The NHS Buckinghamshire and Oxfordshire Cluster ................................................................. 3
   1.2 About Oxfordshire .................................................................................................................... 3

2. Executive summary ........................................................................................................................ 5
   2.1 Purpose of the public engagement ......................................................................................... 5
   2.2 Process & Methodology ......................................................................................................... 5

2.3 Key Findings .................................................................................................................................. 6
   2.4 Conclusion .................................................................................................................................. 7

3. Background ....................................................................................................................................... 8
   3.1 What is the Oxfordshire Health Information Exchange? ......................................................... 8
   3.2 What are the consent options? .................................................................................................. 8
   3.3 Duration of Engagement ......................................................................................................... 9
   3.4 How will the feedback be used? ............................................................................................. 9

4. Stakeholders ..................................................................................................................................... 10

5. Engagement process ....................................................................................................................... 10

6. Survey Results ............................................................................................................................... 12
   6.1 Number and geographical spread of responses .................................................................... 12
   6.2 Gender of respondents .......................................................................................................... 13
   6.3 Age of respondents ............................................................................................................... 13
   6.4 Preferred Consent Model ...................................................................................................... 14

7. Discussion Forum .......................................................................................................................... 16

8. Key Recommendations ................................................................................................................ 16

9. Next steps ....................................................................................................................................... 17

10. Supporting information ............................................................................................................... 17
1. About Us

1.1 The NHS Buckinghamshire and Oxfordshire Cluster
NHS Buckinghamshire and NHS Oxfordshire have now become joined or ‘Clustered’.
NHS Clusters have been established by the Department of Health to ensure that the NHS
maintains business continuity of commissioning healthcare locally and to facilitate the
change to the new structure of the NHS in 2013, including the move to Clinical
Commissioning Groups (CCGs)

All NHS Clusters will have three principal functions:

- Delivery of the PCTs’ Operational Plans and driving clinical service change for
  2011 to 2013 and ensuring financial stability for the handover to Clinical
  Commissioning Groups
- Ensuring and supporting development of Clinical Commissioning Groups and
  transferring of other current cluster functions to the new organisations yet to be
  established i.e. the National Commissioning Board, Public Health England, Health
  Education England, Health and Wellbeing Boards, public health to Local Authorities
- Creating the relevant commissioning support organisation for Clinical
  Commissioning Groups after post PCT abolition.

1.2 About Oxfordshire

We are ambitious about improving the health and wellbeing of local people. The NHS
Oxfordshire & Buckinghamshire Cluster intends that, by 2013, the people of Oxfordshire
will:

- be healthier, particularly if they are vulnerable or live in our most deprived
  communities
- be working with us to promote physical and mental wellbeing and prevent ill health
- be actively supported to manage their health and care needs at home when this is
  appropriate
- have access to high quality, personalised, safe and appropriate health services
- get excellent value from their local health services

Oxfordshire is the most rural county in south east England and has a large geographical
area to cover as well as a diverse population to serve. The population of Oxfordshire
ranges from a predominantly older, white population in the rural areas to very ethnically
diverse populations in Banbury and Oxford city where one third of the population are
students.

The NHS in Oxfordshire works with our communities and our partners to improve health in
the area and to make sure that local people’s needs are being met. We also work with
organisations from the voluntary, private and community sectors so that we can make sure
that the organisations providing health and social care services are working effectively.
Area covered by NHS Buckinghamshire & Oxfordshire Cluster in Oxfordshire

The NHS in Oxfordshire serves a population of approximately 675,000 and covers the areas of Cherwell Vale District Council, Oxford City, South Oxfordshire, Vale of White Horse District Council and West Oxfordshire District Council.
2. Executive summary

2.1 Purpose of the public engagement
We are in the planning stages of a local Health Information Exchange (HIE)\(^1\) for Oxfordshire. This follows on from the Health Informatics Strategy consultation earlier this year where some of the key outcomes from the consultation activity indicated:

- Support for the potential benefits that both joined-up electronic patient information systems and telehealth could bring to patient care

BUT

- Concerns over the confidentiality/who is accessing information in joined-up electronic patient information systems and over the security/safety of electronically held patient information


The purpose of this engagement project was therefore to get further feedback from the public as to what sort of consent model they would want to be in place for a local Health Information Exchange and further insight into why that particular consent model would be more acceptable.

2.2 Process & Methodology
This engagement project ran from 8 September until the 1 November 2011 and made use of a survey about the consent model options as well as an online discussion group.

The project was shared with all those that participated in the Informatics Strategy consultation earlier this year to support continued engagement with those that are particularly interested in electronic patient information systems.

In addition the engagement project was shared to a wider audience using a variety of online methods, including ‘Talking Health’ – our online consultation and engagement system, social media sites, as well as hard copy surveys taken to public events that were taking place during the engagement period. E.g. Oxfordshire Clinical Commissioning Group’s (OCCG) engagement events and the Cluster Annual General Meeting.

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\(^1\) A virtual electronic health record of patient information. It does not upload any data or store information on a database. Instead, it provides a view or ‘snapshot’ of key patient information from clinical systems that already exist, as and when it is required to support patient care.
2.3 Key Findings

Analysis of the engagement survey and discussion forum findings on the local Health Information Exchange resulted in the following themes emerging:

- **Majority of respondents supporting Option 3: A hybrid consent model - Informed implied consent (with opt-out opportunity), plus explicit and audited 'Permission to View' requirement**

  The majority of respondents supported ‘Informed implied consent’ (i.e. the patient has to return an opt-out form if they do not wish to be included) but felt that the additional ‘permission to view’ element gave an extra degree of flexibility or control for the patient over who could access their record.

- **Support for the use of electronic records to support a patient’s care**

  The majority of respondents also indicated in their comments that the Health Information Exchange could improve healthcare, citing things such as improved information about medications, improved efficiency (not having to answer the same questions), and more data to support emergency situations.

- **Continued concern around data and system security**

  Many respondents continued to raise concerns around information governance, access control and security. Confidence in the security of any IT system remains mixed and so continued engagement with patients/the public on these issues is essential throughout the development of a HIE.

- **Confusion and dislike of some of the terminology**

  Some respondents felt that the wider public would not understand some of the terminology used in this project and that the term ‘Health Information Exchange’ was not meaningful to patients. Again, continued engagement with the public and clinicians on future communications/engagement materials is recommended to address these issues.

- **Other concerns**

  Other concerns expressed during the engagement project included concerns that patient data could be sold; whether funding is/should be available for this project in the current economic climate; how should patients with certain health conditions e.g. mental health problems be asked for their consent; and general concerns over misuse.
2.4 Conclusion

The report recommends that the engagement findings, including the consent model identified as well as stakeholders’ key concerns are addressed wherever possible throughout the design, development and implementation of local Health Information Exchange (HIE). This includes the key recommendations listed in section 8 which are:

- **Recommendation to use Option 3: The hybrid consent model**, when implementing the local Health Information Exchange and obtaining patient consent for their information to be accessed in this way. (This is also the same consent model as the national Summary Care Records.)

- **Improve communication** – Clear and easy to understand terminology needs to be developed to support any further engagement or communications for the Health Information Exchange. Recommend continued engagement with patients/the public in developing future communication messages associated with the HIE.

- **Focus on Information Governance and security** – These remain issues of high concern for the majority of respondents – even those that are supportive of electronic patient information systems. Therefore it is important that we continue to engage with the public, clinicians and other stakeholders regarding information governance and security issues throughout the development of the HIE.
3. Background

3.1 **What is the Oxfordshire Health Information Exchange?**

The proposed Oxfordshire Health Information Exchange (HIE) is a virtual health record of patient information. It does not upload any data or store information on a database. Instead, it pulls in key patient information live from clinical systems that already exist so that it can be viewed, as and when it is required to support patient care.

Its purpose is to improve patient care locally through access to the right patient information at the right time by clinicians. No data that isn't already shared on paper between clinicians will be shared electronically. The focus of the HIE and the type of information that will be accessed will be information relevant to support urgent care, the management of long-term conditions, and end-of-life care.

3.2 **What are the consent options?**

In order for the HIE to be implemented, we will need to ask patients in Oxfordshire for their consent before any of their information can be accessed on the local Health Information Exchange in this way. This would be done by a mailing to every registered patient aged 15 ¾ and above in Oxfordshire. There are three different ways that we could ask for consent. The options are:

- **Option 1: Informed implied consent (with opt-out opportunity)**
  This option means that if you do want your information included on the local Health Information Exchange you do not need to do anything - it will happen automatically. But, if you decide you do not want to be included on the local Health Information Exchange you would need to let us know by returning an opt-out form within a certain time period.

- **Option 2: Explicit opt-in**
  This is the opposite to option 1. This option means that if you do want your information included on the local Health Information Exchange you will need to let us know by returning an opt-in form. But, if you decide you do not want to be included on the local Health Information Exchange you do not need to do anything - you would automatically not be included. This method is likely to result in less patients benefiting from their information being accessed on the Health Information Exchange as they will have to actively choose to be involved.
- **Option 3: A hybrid consent model - Informed implied consent (with opt-out opportunity), plus explicit and audited 'Permission to View' requirement**

This option is the same as option one, a patient's information would be accessed on the local Health Information Exchange unless they decide to return the opt-out form. However it has one addition.

At the point at which a healthcare professional needs to view your patient information to actually use it to support your care, the patient must be asked - giving the patient the opportunity to 'change their mind' and deny access if they wish.

The exception to this is when the patient is unable to consent (e.g. they are unconscious and cannot communicate) and in this situation, emergency or 'break the glass' access can be justified as being in the patient's interest. This would be fully audited. This option has the benefit of clinicians being able to access essential information such as current medications, allergies you suffer from and any bad reactions to medicines you have had, in order to treat you safely in an emergency.

This is the same consent model that is used in the [Summary Care Record](#) that is being rolled out across England.

**3.3 Duration of Engagement**

This engagement project ran from 8 September until the 1 November 2011.

**3.4 How will the feedback be used?**

The feedback collated will inform the consent model and patient information programme developed for the local Health Information Exchange in Oxfordshire.
4. Stakeholders

The key stakeholders identified for this engagement project for the local Health Information Exchange (HIE) for Oxfordshire include:

Patients and the general public
This was the primary target group as the consent model/security is something that was highlighted of primary concern to an individual’s electronic patient record in the initial Informatics Strategy consultation earlier this year.

Healthcare professionals/clinical staff
In particular we also wanted to hear from any healthcare professionals that have a particular view on how electronic patient records should be implemented.

Other organisations and groups with an interest in electronic patient information systems

Other
When communicating this consultation with the key stakeholders listed above, encouragement was also given to share this information with any individual or organisation that may be interested in issues regarding electronic patient information systems.

5. Engagement process

A number of different communication and engagement methods were used in order to ensure we reached and received views and feedback from a wide variety of stakeholders:

Informatics Strategy consultation participants
It was important to continue engagement with those that had participated in the Informatics Strategy consultation earlier this year – as the Informatics Strategy has already informed the initial plans for the local Health Information Exchange.

NHS Oxfordshire’s Talking Health website
An online engagement site was established on the ‘Talking Health’ website to enable stakeholders to fill in the survey on the consent model, or to participate in the discussion groups if preferred.

Key organisations
Information about this engagement project was also shared with key organisations with encouragement to disseminate information further e.g. Oxfordshire’s Local Involvement Networks (LINKs) and Oxfordshire’s Community and Voluntary Association (OCVA)

Staff Intranets
NHS Oxfordshire’s intranet was used to communicate details of the engagement and available response methods to all staff, encouraging further dissemination of information to organisations and interested individuals.
Newsletters
The consultation was communicated widely to all internal and external stakeholders using a variety of electronic newsletters eg. using the Talking Health newsletter to reach external stakeholders and the NHS Oxfordshire weekly staff email news bulletin for internal PCT staff and the Oxfordshire Clinical Commissioning Group (OCCG) newsletter.

Social Media: Twitter and Facebook
A number of announcements and ‘tweets’ were made on the Twitter and Facebook websites for NHS Oxfordshire throughout the duration of the engagement project to remind people how they could give their views. These messages reach over 1,600 people on our Twitter page and 640 people on our Facebook page.

Email
Personal invitations to participate in the consultation were also emailed directly to all stakeholders that have told NHS Oxfordshire that they had a specific interest in patient information, as well as those that have expressed an interest in Long Term Conditions, end of life care or emergency care – the main areas of focus for the HIE.
6. Survey Results

6.1 Number and geographical spread of responses
There were 90 members of this engagement project.

The map below illustrates from where we received responses across Oxfordshire. A wide spread of responses was received from both the towns/city and rural areas. The area where we received least responses was the northeast of the county.

(The larger circles represent a greater number of respondents in that location)
6.2 Gender of respondents

The majority of responses to this engagement project were from women (57%). This reflects the distribution of the gender of responses to most healthcare related public consultations in Oxfordshire.

6.3 Age of respondents

Responses to this engagement project were received from a wide variety age categories, however the majority of responses were received from those aged 45 and over.
6.4 Preferred Consent Model

The online/hard copy survey focused on one key issue – the preferred consent model.

All stakeholders were provided with supporting information explaining the differences between the consent model options. They were then asked to respond to the questions. The graph below illustrates the response received.

**Please select the consent model that you would prefer to be used for the local Health Information Exchange in Oxfordshire...**

<table>
<thead>
<tr>
<th>Option</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Option 1: Informed implied consent (with opt-out opportunity)</td>
<td>29%</td>
</tr>
<tr>
<td>Option 2: Explicit opt-in</td>
<td>22%</td>
</tr>
<tr>
<td>Option 3: A hybrid consent model - Informed implied consent (with opt-out opportunity), plus explicit and audited 'Consent to View' requirement</td>
<td>48%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
</tr>
</tbody>
</table>

The most popular option for a consent model for local Health Information Exchange (HIE) was option 3. This is the hybrid consent model where consent to be included in the HIE is implied, however patients can opt-out using a freepost opt-out form if they wish. In addition to this it includes ‘permission to view’, which means that clinicians would need to verbally obtain the patient’s permission to view the record when they actually need to access it. This permission is then recorded as part of the audit trail.

Nearly a third of respondents also selected option 1, which is the same as option 3, but did not include the ‘permission to view’.

The least popular option was option 2, where patients would have to actively ‘opt-in’ to be included in the HIE.

One respondent indicated ‘Other’ as they felt there were serious risks of sharing information. The respondent was however supportive of patients’ holding their own records.

**Please let us know below any reasons for the consent option that you have chosen...**

Those that supported the most popular consent model – the hybrid consent model (option 3) – added some of the following comments about their decision.
“As we are approaching the age when we can expect increasing medical problems, this is the sensible route so that our medical problems are always readily to hand.”

“I would like my information to be readily available but I want some say over who can actually use it “

“I would support either option 1 or 3 but the latter has the advantage of giving the patient a degree of choice.”

“Gives the patient a chance to opt out later as time, illness and circumstances change“

“It allows the patients to change their minds.”

Many respondents that selected option 3 were supportive of electronic records but felt that the additional ‘permission to view’ element gave an extra degree of flexibility or control for the patient over who could access their record.

Some of the comments from those that supported the least popular consent model (option 2) – where patients would have to explicitly and actively opt-in to be included within the HIE, are shown below:

“I am not comfortable with the presumption that the state automatically knows best. If people don't wish to opt-in, or don't understand the implications of opting in, then it must be assumed they have not done so. ”

“I am sectioned and would like my consent to be required.”

“Security of the systems in use. Too many people have access to my personal data “

“The principle of doctors having access to information that would help them to treat me appropriately seems quite obvious. My doubts are about the hundreds of administrative staff who would now have easy access to confidential personal information.”

Many of the people that added their reasons for selecting this option either had generally little trust in IT systems, or in the people that would be using the systems and often wrongly believed that access would be shared around all NHS staff, not just those clinical staff caring for the patient.

A few comments also raised the issue of whether patients with certain conditions e.g. mental health, would also be asked for their consent in the same way as the wider population.

If you have any other comments about the Health Information Exchange or the Consent model options please let us know:

Respondents were also given the opportunity to let us know any other feedback or issues that they had regarding the local Health Information Exchange (HIE). Four key themes emerged with these additional comments. These were:
Confusing terminology ‘consent to view’, ‘HIE’ etc – respondents felt that there was too much confusing terminology which only made it harder to understand. Also the term Health Information Exchange did not mean anything to the wider public.

Concerns data would be ‘sold’ – a few people expressed concerns that patient data could be sold to externally companies e.g. pharmaceutical companies.

Funding – some concerns were raised as to whether funding for a local Health Information Exchange would be available/appropriate in the current economic climate.

General security concerns – as with many IT projects, general concerns were raised relating to the security of the data in the system.

7. Discussion Forum
An online discussion forum was also established on Talking Health – the consultation and engagement area of the PCT website (https://consult.oxfordshirepct.nhs.uk/consult.ti/healthinfoexchange/consultationHome)

This was to enable any stakeholders to share their views or ask questions about the Health Information Exchange in a more public way. There were just 5 people that chose to engage in this way however some of the suggestions received were very useful.

There were two discussion threads. These looked at:

- Communicating the message - What do you think would help people understand what the Health Information Exchange is and its benefits? Do you have any innovative ideas on how this could be communicated?
- Which consent model do you think would work best? Why?

Suggestions about communications to support the HIE included the use of case studies, pilots, working with the media and providing a balanced view of the HIE (not just advantages).

The two people that responded about the consent model felt that option 2: explicit opt-in, would work the best in terms of public acceptance as no ‘assumptions’ would be made that people had read and understood the mailing that they had received.

8. Key Recommendations
The engagement findings support the following recommendations for the local Health Information Exchange (HIE) for Oxfordshire:

- Recommendation to use Option 3: The hybrid consent model, when implementing the local Health Information Exchange and obtaining patient consent for their information to be accessed in this way. (This is also the same consent model as the national Summary Care Records.)
- **Improve communication** – Clear and easy to understand terminology needs to be developed to support any further engagement or communications for the Health Information Exchange. Recommend continued engagement with patients/the public in developing future communication messages associated with the HIE.

- **Focus on Information Governance and security** – These remain issues of high concern for the majority of respondents – even those that are supportive of electronic patient information systems. Therefore it is important that we continue to engage with the public, clinicians and other stakeholders regarding information governance and security issues throughout the development of the HIE.

9. Next steps

The recommendations made above will be taken forward and considered by the Cluster Executive Board and Oxfordshire’s Clinical Commissioning Group (OCCG) in the final plans for the development and implementation of the local Health Information Exchange for Oxfordshire.

The feedback and comments received by stakeholders in this engagement project will also be fed into the future workgroups that are established to support the communications/engagement and information governance/security for the HIE.

10. Supporting information

**Definitions**

- Stakeholders - A person or group with a direct interest, involvement, or investment in something. Stakeholders are individuals or organisations that have a direct interest in a service being provided.

**Glossary**

- OCCG – Oxfordshire Clinical Commissioning Group
- Facebook - Social networking website
- Intranet - A private computer network open to users working within an organisation to share information, news and documents
- NHS - National Health Service
- PCT - Primary Care Trust
- Twitter - Twitter is a social networking tool aimed at enabling its users to exchange up-to-the-minute news and opinions on specific topics.
- Talking Health - NHS Oxfordshire’s consultation and engagement area on our public website (see https://consult.oxfordshirepct.nhs.uk)