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1. About NHS Oxfordshire

NHS Oxfordshire is a Primary Care Trust (PCT) and serves a population of around 675,000.

We are ambitious about improving the health and wellbeing of local people. NHS Oxfordshire 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 NHS Oxfordshire 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.

NHS 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.
2. Executive summary

2.1 Purpose of the public engagement

NHS Oxfordshire embarked on a period of engagement from 15 November 2010 to 1 February 2011, to engage and involve all those patients, carers and organisations with an interest in how Information Technology (IT) and telehealth can be used to help improve and facilitate healthcare in Oxfordshire.

2.2 Process & Methodology

A number of consultation and engagement methods were used simultaneously to enable maximum feedback from a wide variety of stakeholders in the time available. This included face-to-face engagement at a public consultation workshop, hard copy surveys, online engagement methods on the ‘Talking Health’ website – this included an online questionnaire and the ability to comment online directly into the strategy document, as well as feedback to the communications and engagement team at NHS Oxfordshire via email, post or by phone.

2.3 Key Findings

Analysis of the consultation findings from the public consultation workshop, written responses, email and online responses interestingly resulted in very similar response themes. These included:

- **Support for more joined-up working and improved information flow between health and social services**
  This theme was reflected in both the survey responses and in face-to-face engagement activities and was often given as the key, underlying reason for respondents supporting the development of healthcare technology and IT systems in this strategy.

- **Support for the potential benefits that both joined-up patient information systems and telehealth could bring to patient care**
  All engagement methods highlighted strong support for the potential benefits that joined-up patient information systems and telehealth could bring to patient care and the strong desire to see these benefits realised. However the feedback from this engagement activity also indicated there was a level of uncertainty as to whether this could really be achieved based on the level of success of other IT projects – both in healthcare and other industries.

- **Concerns over the confidentiality/who is accessing information in joined-up electronic patient information systems**
  Whilst the support for more joined-up systems and joined-up working was clear, there were also many concerns over exactly who and which roles would be accessing this joined-up information - particularly in social care. The majority of respondents therefore indicated they would want to be asked first before information was shared in this way and that role-based access controls and full auditing would need to take place.
• **Concerns over the security/safety of electronic held patient information**
  There was generally a high level of concern throughout the consultation for the security/safety of information held electronically and therefore a need for very robust patient information systems. However whilst this concern was identified by over half of those respondents to this consultation, it was not held by everyone and there was some recognition of a growing confidence in the security of technology.

• **Concerns over misinterpretation of information in an electronic record**
  This concern over the quality of data held in electronic patient record systems was reflected in both the online and workshop responses. Clear, accurate and easy to understand information was highlighted as essential in a patient record – particularly if it is to be accessed, viewed and understood correctly by patients. A suggestion came forward in a number of the engagement methods that good training, particularly on information governance issues and data quality would be essential as part of a successful strategy.

• **A mixed response to the importance and use of telehealth in bringing care closer to home**
  Whilst there was clear support for the vision and goals in the Informatics Strategy, respondents were mixed in the support and importance they gave to telehealth. The workshop and some questionnaire comments indicated that this may be due to fears of isolation and of technology replacing care by real people. This report therefore recommends that this concern is investigated further.

### 2.4 Conclusion

The report recommends that the participants’ findings, including the key concerns as well as the main areas of support for the Informatics Strategy are addressed wherever possible throughout the design, development and implementation of the strategy goals and vision. In addition the key recommendations listed in section 9 need to be addressed when taking the strategy forward. These include:

- Continued engagement/testing with patients/key stakeholders as a joined-up patient information system is developed and telehealth projects are implemented
- Ensuring that ownership of the Informatics Strategy continues after Primary Care Trusts (PCTs) are abolished and GP commissioning is established
- Further investigation is needed into the mixed response to goal 2 in the Informatics Strategy for more home-based care and monitoring using technology – particularly as bringing care closer to home is the underlying focus of a number of other NHS programmes
3. Background

3.1 What is the Informatics Strategy?
The Informatics Strategy Roadmap is a plan to enable the current, fragmented state of many information systems in health and social care in Oxfordshire to become more joined-up, benefiting from modern technology and telehealth\(^1\) to improve quality and efficiency of patient care by 2013.

3.2 The local context
- Oxfordshire's health and social care services are currently fragmented and use many different systems, each holding information on patients and their treatment in that particular place.
- Communication between these services and the links between these separate systems is currently limited and is frequently done by post, in the form of letters, or faxes.
- Care can therefore be inefficient and inconvenient as detailed health information on a patient can be held in many different places and not shared between services. This results in patients having to explain their medical history or condition many times, or even have repeat tests.
- Hospital admissions and ill-health could be reduced in Oxfordshire by giving patients access to information to help themselves and manage their own health. E.g. This could benefit those patients with Long Term Conditions such as diabetes or asthma.
- Some patients are currently visiting hospital when they could potentially receive care closer to home if the technology or information systems were there to support them.

3.3 The Strategy Vision and Goals

The Vision
*Information technology will be a critical enabler of service change and improvement in Oxfordshire's health and social care system*

The Goals
- The information on a patient needed to support his/her care will be available when and where it is needed by any authorised member of the clinical / social care professional team caring for that person.
- Home-based and community-based clinical care and monitoring will be enabled by remote / mobile technology that reduces the need for physical attendance at a formal care setting, or for the clinician to visit the home, and speeds up clinical care.

\(^1\) See Glossary in 'Supporting Information' for a full definition.
• Patients will be able to access their own patient records to help them manage their own health, and check that the record is correct
• Patients and clinicians will be aware of and confident in the security and access controls applied in the management of any integrated care record, with clear opt-out and consent-to-view steps in place

3.4 Strategy Objectives
Through the production of the Informatics Strategy, we are seeking to deliver the following objectives:
• A new ‘health information exchange’ linking up the currently fragmented systems would allow authorised clinical staff caring for the patient to easily locate essential patient information as required to support patient care
• Patients would be able to access their own electronic patient record to help them manage their own personal health, and check that the record is correct
• Mobile and telehealth technologies would support more flexible home and community based care so that quality care is possible for patients in the comfort of a familiar environment
• Patients would be asked for their consent before their record is viewed, or they will be able to “opt out” of the ‘health information exchange’ if they prefer

3.5 What was the purpose of this consultation?
The purpose of the public consultation was to:
• Develop an ongoing dialogue with the general public, carers, staff, clinicians and other key stakeholders around the vision and key goals of the Informatics Strategy
• Raise awareness of the case for integrated IT systems to support high quality, efficient and effective patient care
• Raise awareness of the potential benefits of telehealth to support improved patient care in Oxfordshire
• Identify any key areas of concern regarding the proposals in the informatics strategy
• Identify any alternative approaches and ways in which integrated IT systems or telehealth could be used to bring benefits to patient care
• Identify any trends in the above two points and priorities as identified by the consultation participants
• Ensure the project meets fully its ‘Duty to Involve’ and consult patients and the public

3.5 How will the feedback be used?
The opinions gathered from all of the consultation methods - including the workshop, the online consultation, and the questionnaire responses - are being used to help shape the Informatics Strategy and if/how the recommendations will be taken forward and implemented in the coming months in Oxfordshire.
4. Stakeholders

The stakeholders for the Informatics Strategy consultation are all individuals, organisations or groups with an interest in the benefits and impact of using joined-up IT systems and telehealth to support healthcare in Oxfordshire.

4.1 Stakeholders

The key stakeholders identified for this consultation included:

The Public, Patients and Carers
Joined-up IT systems and telehealth has potential benefits for the healthcare of all members of the public, patients and carers in Oxfordshire and communication about this consultation therefore tried to reach as wide as possible across the county.

Organisations and groups with an interest in supporting Long Term Conditions
Telehealth in particular has many potential benefits for those with longer term health problems – helping to support the management of healthcare at, or closer to, home. Therefore groups/patients with Long Term Conditions were targeted with information on this consultation.

Staff at NHS organisations across Oxfordshire
Staff at NHS organisations in both Primary and Secondary Care are required to use various IT systems and technology in their daily roles to support and care for patients. Therefore it was important to include and engage with staff in this consultation.

Voluntary and Community Groups
Information on the Informatics Strategy consultation was shared with many voluntary and community groups across Oxfordshire. e.g. Local Involvement Networks (LINKs), Patient Participation Groups (PPGs), Oxfordshire Community and Voluntary Action (OCVA)

Partner organisations
This consultation was communicated to our partner organisation for further dissemination to any interested individuals or groups e.g. Local county, district and parish councils.

The Local Informatics Strategy Group (LISG), the Information Governance Group (IG) and the Clinical Executive etc.
The Informatics Strategy consultation was shared with all relevant strategy groups and meetings at NHS Oxfordshire.

The Media
Throughout the Informatics Strategy consultation media activity was developed when and where appropriate to ensure communication was open and helpful, and that positive messages were provided to support and enable maximum stakeholder involvement.

Other
When communicating this consultation to the key stakeholders listed above, encouragement was also given to share this information with any individual or organisation that may be interested in IT and telehealth in Oxfordshire.
5. Engagement process

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

5.1 Face to face engagement

Creating a Healthy Oxfordshire (CAHO) workshop

The key concepts behind the Informatics strategy were first introduced for the Creating a Healthy Oxfordshire (CAHO) event on the 29th October 2010. This event looked at how health and social care could work together better to ensure that we provide high quality sustainable health and social care services in the future. The event used many different topics for round-table discussion. An opportunity was therefore taken to include a discussion question related to the use of integrated (joined-up) IT systems at the event.

The Informatics Strategy Workshop

A specific Informatics Strategy workshop was planned to give individuals a chance to come and listen to an explanation of the strategy in more detail, including the opportunity of a question and answer session to clarify points made in the strategy. This workshop used round-table discussion methods in addition to general discussion across the room to bring out the key issues of concern as well as the main areas of support for the Informatics Strategy.

5.2 Online engagement

NHS Oxfordshire's Talking Health website

An online consultation site was established on the ‘Talking Health’ website to enable stakeholders to view the full Informatics Strategy and to enter their own comments and feedback. We pro-actively contacted 413 members of Talking Health who had already registered and expressed an interest in getting involved with consultations in this subject area.

NHS Oxfordshire's website

A press release on the consultation was written and published on NHS Oxfordshire’s own website. This was also shared with all local press organisations and the press release was tweeted and posted on our Facebook site.
Websites of key organisations
Information about this consultation was published on NHS Oxfordshire’s own websites and was also shared with various key organisations with a request to publish on their own websites to raise awareness e.g. LINKS, OCVA.

Informatics Strategy Questionnaire
An online questionnaire on the Informatics Strategy was set up on NHS Oxfordshire’s ‘Talking Health section of the website to ask key questions about the strategy vision and goals A copy of the questionnaire can be seen in Appendix 1.

Parish and Town council websites
Information about this consultation was shared with parish and town councils in Oxfordshire and a number of these also published the information on their own websites. E.g. Fulbrook and Hook Norton’s parish websites and Witney Town council website.

Staff Intranets
NHS Oxfordshire’s intranet was used to communicate the consultation and available response methods to all staff, encouraging further dissemination of information to organisations and interested individuals.

Newsletters
Encouragement was given to all stakeholders to communicate the consultation in any online or hardcopy newsletters e.g. LINKs newsletter, OCVA newsletter.

Email
The consultation was communicated widely via email to many key stakeholders and partner organisations for them to then communicate to their own staff and patients. It was also communicated widely to all staff through email distribution networks e.g. using the NHS Oxfordshire weekly staff email news bulletin.

Twitter and Facebook
A number of announcements and ‘tweets’ were made on the Twitter and Facebook websites for NHS Oxfordshire about this consultation and the associated public consultation workshop. These messages were also re-tweeted by some followers. Together, NHS Oxfordshire’s Twitter and Facebook followers include an audience of over 1200 followers/friends.
5.4 Written engagement

Hard copy, printed versions of the online Informatics Strategy questionnaire were made available and distributed to many stakeholder groups, shared at all face-to-face engagement opportunities and were also sent out as requested to various organisations, individuals and groups.

Stakeholders were also invited to send in written feedback by post or email if they preferred.
6. Engagement Findings

6.1 Number of online responses

Overall, 79 people registered their interest in the Informatics Strategy consultation online on Talking Health.

The majority (64%) of these participants were women, and about a third of these were men (32%). The gender of the remaining participants was not stated.

6.2 Consultation Workshop – County Hall, Oxford, 14 January 2011

6.2.1 Purpose and format

The purpose of the Informatics Strategy consultation workshop was to:

- Provide an opportunity for the public to tell us what they think will work and to highlight areas of greatest concern
- Give attendees an opportunity to prioritise and say what they think are the most important and least important areas of the strategy.

An introductory talk was given by Andrew Fenton, Chief Information Officer at NHS Oxfordshire. His presentation gave a brief insight into the informatics strategy and how NHS Oxfordshire sees this working. We then separated into four discussion groups to look at the discussion questions in more depth. All groups worked on both questions which were:

1. What do you like most/support about the Informatics Strategy?
2. What risks/concerns can you think of for the Informatics Strategy?
6.2.1 Results

In total 26 people attended the consultation workshop at County Hall, Oxford (excluding staff). Those that attended included people from a wide variety of backgrounds – including Carers, private companies, housing organisations, dental practices and LINKs representatives as well as members of the general public in Oxfordshire.

When the stakeholders were asked what they supported or liked most in the Informatics Strategy a number of key themes emerged. These included support for:

- The opportunity to support and improve patient care
- The ability to provide care closer to/at home
- The speed/immediacy at which patient information could be available
- The benefits of patient access to their own record
- The opportunity for more joined-up working

Suggestions under these themes included:

“Enabling self management for Long Term Conditions.”

“It could improve communication between consultants and GPs.”

“Would be less reliant on patient’s memory”

“Gives clinicians info at point of care.”

“Info could be more structured with categorisation.”

“Less travel would be needed for both patient and professionals.”

When asked to identify risks or concerns related to the Informatics Strategy, the attendees again identified a number of key themes. These included concerns relating to:

- Understanding the information contained in the electronic patient record – both for the patient if they have access and also for the clinician
- Confidentiality of patients’ records and concerns for who might be seeing this information
- Security of an integrated electronic record system as there is mixed confidence in security of IT systems generally
- The quality of the information and data contained in the patient’s record

Suggestions under these themes included:

“I have concerns about data entry and quality.”

“Giving vulnerable people access to records could be a danger i.e. mental health”

“Information governance at the moment does have pitfalls.”

“Misinterpretation with language used in records – poor English and technical terms”

“Confidentiality – e.g. some patients may not want family to know.”

“Security of the system – can it be hacked?”
Attendees were asked to do a prioritisation exercise at the end of the event to identify three things that were most important to them regarding the Informatics Strategy. They could select these three issues from any of the areas of support or areas of concern.

This exercise highlighted six key issues of importance above all others. These issues identified by attendees of the workshop were (in order of importance):

1. The promotion of joined up working was welcomed
2. Concerns over potential isolation of patients due to the use of telehealth
3. An audit of all patient records would be needed (of who accessed the records and when)
4. Social care – concerns about who/which agencies in social care would be able to access information in a patient's medical record
5. The opportunity for more effective patient care
6. Concerns about data entry and quality in an electronic record – the information is only as good as the person that enters it

Other notable points that were brought out in the Q&A and general discussion included concerns about excluding those people that do not have technology or do not understand it; whether the budget required to successfully implement this is actually there; and support for the fact the strategy is focused on the outcomes rather than the systems/technology.
7. Questionnaire

7.1 *Number and geographical spread of responses*

In total, 50 people responded to the questionnaire on the Informatics Strategy. This included 11 hard copy responses and 39 online responses. The distribution of responses came from a wide geographical spread across the county as illustrated in the map below, with the greatest concentration of responses coming from the Oxford city area.

(The larger red circles represent a greater number of respondents in that location)
7.2 Questionnaire Results

Each of the questions asked is shown below along with the results received.

The Vision

*Information technology will be a critical enabler of service change and improvement in Oxfordshire's health and social care system*

**Question 1: To what extent do you agree or disagree with this vision statement?**

The majority of respondents of the survey either agreed or strongly agreed with the Informatics Strategy vision statement that “Information technology will be a critical enabler of service change and improvement in Oxfordshire's health and social care system”.

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Question 2: Please score the importance of each goal within the strategy listed below.
(0 = not important and 5 = extremely important.)

The majority of respondents either agreed or strongly agreed with goal 1, that “The information on a patient needed to support his/her care will be available when and where it is needed by any authorised member of the clinical / social care professional team caring for that person.”

The response to goal 2 had a mixed response to the importance of “Home-based and community-based clinical care and monitoring will be enabled by remote / mobile technology that reduces the need for physical attendance at a formal care setting, or for the clinician to visit the home, and speeds up clinical care.” Respondents ranked this goal as being significantly less important than the other goals, but still gave it a medium level of importance.

The majority of respondents either agreed or strongly agreed with goal 3 that “Patients will be able to access their own patient record to help them manage their own health and check that the record is correct.”

The majority of respondents either agreed or strongly agreed with goal 4 that “Patients and clinicians will be aware of and confident in the security and access controls applied in the management of any integrated care record, with clear opt-out and consent-to-view steps in place.”
Question 3
To what extent do you agree or disagree with the following statements?

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<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<td>We need to make better use of modern technology in healthcare</td>
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<td>Technology has many potential benefits for health and social care services</td>
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<td>We need to improve the flow of information about a patient as they move</td>
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<td>between health and social care services</td>
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<td>systems across health and social care services</td>
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The majority of respondents either agreed or strongly agreed with the statements relating to the Informatics Strategy. The statement which people agreed with the most was the need to “…improve the flow of information about a patient as they move between health and social services”. This was followed by support for better use of technology and benefits of technology.

The statements relating to improving patient safety and quality of care by linking patient information systems across health and social care services had a slightly lower level of agreement.
Question 4
What area(s) of technology in healthcare do you think need to be improved/developed?

When asked what areas of technology need to be improved/developed, respondents were generally in support of all four suggestions for mobile devices; electronic systems in health/social care that work together; online/electronic prescribing and appointment booking. Only 2 respondents (4%) indicated that nothing was needed and that things were fine as they are.

15 respondents added their own suggestions. These included:

“Any system is fine IF the information is correct and updated AND people concerned READ it.”

“On-line systems that help people both with information about what they are entitled to and that helps them find the care and support they need.”

“There is no substitute, electronic or otherwise, for person to person contact!!!!!”

“User-friendly systems for older people.”

“Training of all professionals in data protection and e-working.”

Question 5
Thinking about the option(s) you have just selected for improvement/development, please give any reasons for your answers

37 full answers were given to this question, many of which were quite detailed, with respondents explaining the reason(s) why they supported development(s) in different areas of technology for healthcare. Some of the supporting reasons given are shown below:

“Health and social need to be joined up in terms of information sharing, funding and service delivery as people fall through the cracks between services and information is lost because professionals aren’t working in a joined up way.”

“At present scans are not sent to GPs so my scan which showed a fragment of bone in the muscle as not seen by my GP, who could not see where to put the cortisone injection.”

“The more mobile devices to support healthcare at home the quicker recovery is.”

“Electronic systems that work across all patient pathways are so important it is almost laughable that they don’t. How much money has been spent on different systems?”

“Telephone (appointment) booking is virtually impossible.”

“At the top of my agenda is working together flawlessly. By having systems in place that work together across health and social care, we are reducing waiting times, inconsistency, and service ommitance as well as increasing the chances of prevention tenfold.”
**Question 6**

Social workers and health professionals will be working closer together to find solutions to support the care and needs of local people. As part of this, we are looking for information systems to become more joined-up so that up-to-date patient information is available to support patients as they move from one service to another.

![Bar chart showing responses to Question 6](image)

In response to this question about joined-up information systems, 27 people (54%) felt that this would improve their care. Only 2 respondents believed it would make no difference to the care they received.

Whilst just under half of respondents were happy for their information to be shared, the majority of respondents indicated that they would only want their information shared across different services if they had given their permission first. A small number of respondents (10) did not want to be consulted for their permission to share their information - they just wanted it to happen.

This pattern of responses was also echoed in an NHS Oxfordshire consultation entitled ‘Urgent and Specialist Care Closer to Home’. This consultation was running at the same time as the Informatics Strategy consultation and involved a pilot project in Abingdon looking at providing care closer to home for patients in Abingdon who might otherwise have gone to hospital. No respondents to the ‘Urgent and Specialist Care Closer to Home’ consultation objected to their information being shared.
Question 7
Would you find it useful to access your own patient record online?

- **58%** Yes - I would want to be able to view my patient information and have the ability to update it myself too
- **18%** Yes - but I would only want to be able to view it and see what information it contains
- **14%** Yes - but I probably wouldn't look at it very much
- **8%** No - It would not be of interest to me
- **6%** No - I do not have a computer/mobile device
- **2%** No as I would not want my patient information held online/electronically
- **0%** I don't know/ not sure

The majority of respondents (58%) indicated that they would want to be able to view their patient information and also have the ability to update it too. 18% of respondents also wanted to be able to access their patient record, but only to view it and a further 14% wanted to view it but felt they probably would not use this facility very much.

A total of 8% of respondents indicated that they did not want to access their patient record and only 6% of all respondents did not want their patient information held electronically.
Question 8
Do you think having access to your own medical record would help you manage your own healthcare better?

- Definitely, I am very interested... 46%
- Possibly, it depends on what information it contains and if it is useful to me 38%
- Probably not, I am unlikely to change my actions... 6%
- No, I would still manage my own health in the same way 6%
- I don't know/ not sure 2%
- Other 2%

Nearly half of all respondents said that they were definitely interested in accessing their medical record and knowing more information which could improve their health. A further 38% of respondents indicated that access to this information might help them manage their health better – it would depend on the information it contained and how useful this was.

12% of respondents said either ‘no’ or ‘probably not’ as they would be unlikely to change their actions with regards to their healthcare or would manage their health in the same way regardless.
Question 9
Do you think joined-up electronic patient information systems will improve the safety of patient records?

When asked about the safety of joined-up electronic patient information systems, the response was much more mixed. 40% of respondents felt it would be much safer; however 12% felt that it would be about the same as paper-based or non-integrated systems. However, nearly a quarter of respondents indicated that joined-up electronic patient information systems would reduce safety.

Nearly a quarter of respondents did not know or gave another response to this question. Some of these other responses included:

“I want to be certain the systems are secure -- quite difficult. I don't have anything to hide but maybe some do or would be embarrassed.”

“It would be so good to see this finally work. These questions have all been asked so many times before with no further development”

“Given the number of part-time and foreign workers in the social care industry, confidentiality and security of personal information will be paramount here. We know of some regrettable lapses in the standard of social care.”

“The response above would depend on if the information (in the system) is accurate.”
Question 10
What do you think of using mobile devices/telemedicine to help more patients to be treated closer to home?

An example of telemedicine: A patient has a heart monitor installed at home which enables medical staff to remotely monitor a patient's health and identify any problems early, and also means that frequent trips to hospital for monitoring are not necessary.

The majority of respondents (58%) indicated that mobile devices/telehealth would help patients to be treated closer to home. A further 14% of respondents also said that the use of telehealth is a good idea but felt that money should spent on other areas at the moment. 6% indicated that they would prefer to continue using existing services just a small number (4%) had concerns about using the equipment/technology. 10% gave their own response, which included:

“Sometimes the visits to see health professionals also serve to reduce isolation and monitor wellbeing, so I think it's a good idea but there needs to be an awareness that this could further isolate very vulnerable people”

“It's a good idea for certain conditions and certain patients I'm not convinced the NHS is able to do this at the moment - there are so many more basic issues to sort out.”

“It is a good idea but only if used in conjunction with hospital visits. Sometimes people need that contact, so that doctors can spot symptoms that may not show up on monitors.”
Question 11
If you have any other comments, ideas, or queries that you would like to raise about any part of the Informatics Strategy, please include them below:

Respondents to the survey were given the opportunity to add anything else they wished to say about the Informatics Strategy. Key themes in these responses again included support for patients accessing their own record; concerns over data quality within the patient record; the potential benefits that telehealth and joined-up systems could bring to the patient as well as some new concerns over budget, and highlighting the growing support and confidence in technology generally.

"This is really important, especially between patients discharged from hospital and their GP practice. However any IT system is only as good as the information input."

"There is no substitute for personal contact with patients - home monitoring etc is fine, but that wouldn't reassure someone who is worried."

"It's great in principle, but there are a number of concerns. Firstly, is it 'do-able' within the time and budget?"

"I think access to one's medical records would be a great move forward."

"The use of technology will not be beneficial for everybody as there are still many people who do not use or are distrustful of IT systems. However, the number of people who feel this way is reducing and the number of people who embrace technology and use it as part of their everyday lives is increasing rapidly."

"Build on existing systems, such as the improvements that enable hospitals to send test results to GP surgeries electronically..."

"Any NHS Informatics Strategy must, at its heart, consider information itself to be a treatment. Numerous studies have shown that better informed patients are healthier and, when they are ill, have improved outcomes..."

7.3 Comments on the Strategy Document

The full Informatics Strategy document was also included online on Talking Health (the consultation area of NHS Oxfordshire’s website) so that the public could enter their own comments or suggested edits at key points throughout the document. 20 comments were made directly on the strategy document and themes included concerns around security and confidentiality, the need for a local approach but with systems that are interoperable and for the focus to be on the patient. Key comments included...
“These are the right goals, but I would change the sequence to put patients first…”

“Unfortunately the government strategy for the NHS is unlikely to succeed and will put uncertainty and disorder into the system for years to come. I think you are right to define the needs at a local level and to aim to implement them come what may.”

“Sounds like a good plan. Information sharing can only lead to enlightenment and better healthcare. ”

“I am worried that information about individuals will be too widely available. Safeguards will need to be in place so that privacy is safe guarded. Tight parameters on 'need to know'. Will there be an opt-out for patients?”

“Whilst I agree that a focus on the integration and connectivity of systems is correct you cannot ignore the underlying systems used by the providers. These represent the data and information inputs into the integration and the whole approach will fail unless these providers are firmly bought into developing and running systems that will provide compatible information for integration…“
8. Engagement Findings – Other methods

8.1 Creating a Healthy Oxfordshire (CAHO) workshop

The CAHO workshop on 29 October 2010 was attended by over 100 people from across Oxfordshire. One of the focus questions for discussion included in this workshop was:

What are your feelings on healthcare teams having access to and sharing your care record?

The following common themes emerged from the group discussions at this event.

This shouldn’t be a problem if standards are adhered to
Participants positively discussed health care teams having access to and sharing records, provided that standards were adhered to and security was considered. Other points raised under this discussion included:

- It needs a good IT system, could be costly
- All staff are ethically bound
- Need clarity about which professionals access the records
- Need reassurance there is good security of records
- It could be open to corruption
- People / healthcare professionals should only have access to what they need to know

What about confidentiality and consent?
Confidentiality and consent were considered to be important factors to participants. Other points raised under this discussion included:

- Access for patients with dementia
- Transparency and trust
- General consent from the patient
- Who makes the decision on behalf of people with mental health problems or dementia?
- The importance of relevant people having access to information can outweigh confidentiality
- Should be shared with NHS unless people have opted out

For full details on the CAHO consultation see 
https://consult.oxfordshirepct.nhs.uk/consult.ti/CAHO/consultationHome

8.1 Related feedback from other public consultations

A consultation by the Department of Health on "Liberating the NHS: An Information Revolution" also took place whilst the local Informatics Strategy consultation was running. This national consultation is about transforming the way information is accessed, collected, analysed and used by the NHS and adult social care services so that patients are at the heart of those care services. The relevant feedback themes from this consultation were
very similar to those from this Informatics Strategy consultation for Oxfordshire and included:

- That people are concerned that patient sensitive information is not secure or joined up.
- Concern that health professionals do not accurately complete data and that they are unable to share data across systems.
- For information relevant to an individual's care, information should be provided face to face.
- Information can be lost in translation and should be written in clear English, staff should be trained to communicate clearly with patients using good levels of spoken English.
- Data protection and privacy around patient information and reassurance that this adequately happens in all services.
- Information needs to be up to date and accurate with training provided to staff to ensure reliable and consistent data entry.
- That not all people will be able to access web-based information or use web-based tools to communicate. Consideration should therefore be given to ensuring that any information system that is developed is done so in such a way to ensure that those people without access to a computer or internet are also able to access the information.
- It is clear that people are interested in the issues relating to Informatics and information but at a local level, rather than national level.

A full report of the findings from across Oxfordshire in response to this consultation can be seen here https://consult.oxfordshirepct.nhs.uk/gf2.ti/f/230786/5169221.1/doc/-/Final%20Consultation%20Report.doc
9. Key recommendations

The key findings from the consultation and engagement activities on the Informatics Strategy have highlighted the need for:

- Continued engagement/testing with patients/key stakeholders as a joined-up patient information system is developed and telehealth projects are implemented
- Ensuring that ownership of the Informatics Strategy continues after Primary Care Trusts (PCTs) are abolished and GP commissioning is established
- Further investigation is needed into the mixed response to goal 2 in the Informatics Strategy for more home-based care and monitoring using technology – particularly as bringing care closer to home is the underlying focus of a number of other NHS programmes

10. Next steps

A copy of this consultation report will be made available by electronic or hard copy to all those that participated in the informatics strategy consultation workshop, questionnaire and online consultation. It will also be available for download on NHS Oxfordshire’s website:  http://www.oxfordshirepct.nhs.uk

The consultation report will used by NHS Oxfordshire to inform if / how the recommendations from the Informatics Strategy are taken forward. In addition results from the recent national consultation by the Department of Health’s consultation “Liberating the NHS: An Information Revolution” will also be fed into the local Informatics Strategy Roadmap for Oxfordshire.

11. Thanks

Our thanks is extended to all those individuals, groups and organisations that responded to this consultation.
12. 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

- NHS - National Health Service
- PCT - Primary Care Trust
- GP Commissioning - In order to shift decision-making as close as possible to patients, power and responsibility for commissioning (buying) health services will be devolved to local consortia of GP practices.
- Facebook - Social networking website
- Twitter - Twitter is a social networking tool aimed at enabling its users to exchange up-to-the-minute news and opinions on specific topics.
- Intranet - A private computer network open to users working within an organisation to share information, news and documents
- Talking Health - NHS Oxfordshire’s consultation and engagement area on our public website (see https://consult.oxfordshirepct.nhs.uk )
- Telehealth/Telemedicine - Telehealth or telemedicine is a new monitoring system that will allow patients to update nurses or relevant health professionals on their health via remote devices in their own home and empower them to be more actively involved in their own treatment and care. This detailed monitoring acts as an early warning system so that patients can be treated before their condition deteriorates.
- Integrated information systems – This is an IT system which links together or ‘joins-up’ information in different software systems to deliver one over-arching system.
13. Appendices

Appendix 1: Informatics Strategy Questionnaire

The Informatics Strategy – Using IT and telehealth to improve care for patients

The Vision

*Information technology will be a critical enabler of service change and improvement in Oxfordshire’s health and social care system*

Question 1.

To what extent do you agree or disagree with this vision statement?

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Question 2.

Please score the importance of each goal within the strategy listed below. Circle a value from 1 to 5. From 1 = not important to 5 = extremely important.

<table>
<thead>
<tr>
<th>Goal 1: The information on a patient needed to support his/her care will be available when and where it is needed by any authorised member of the clinical/social care professional team caring for that person</th>
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<tbody>
<tr>
<td>1 2 3 4 5</td>
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<table>
<thead>
<tr>
<th>Goal 2: Home-based and community-based clinical care and monitoring will be enabled by remote/mobile technology that reduces the need for physical attendance at a formal care setting, or for the clinician to visit the home, and speeds up clinical care</th>
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<tbody>
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<td>1 2 3 4 5</td>
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</table>

<table>
<thead>
<tr>
<th>Goal 3: Patients will be able to access their own patient record to help them manage their own health, and check that the record is correct</th>
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<tbody>
<tr>
<td>1 2 3 4 5</td>
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</table>

<table>
<thead>
<tr>
<th>Goal 4: Patients and clinicians will be aware of and confident in the security and access controls applied in the management of any integrated care record, with clear opt-out and consent-to-view steps in place</th>
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<tbody>
<tr>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>
Question 3.
To what extent do you agree or disagree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>We need to make better use of modern technology in healthcare</td>
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<td></td>
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<tr>
<td>Technology has many potential benefits for health and social care services</td>
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<tr>
<td>We need to improve the flow of information about a patient as they move between health and social care services</td>
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<tr>
<td>Patient safety will be improved by linking patient information systems across health and social care services</td>
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<tr>
<td>The quality of patient care will increase by linking patient information systems across health and social care services</td>
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</tbody>
</table>

Question 4.
What area(s) of technology in healthcare do you think need to be improved/developed? (Select as many as you want)

- Mobile devices to support healthcare at home
- Electronic systems in health/social care that can work together
- Online/electronic prescribing
- Online/electronic appointment booking
- None - I think things are fine as they are
- Other (please specify below)

Thinking about the option(s) you have just selected for improvement/development, please give any reasons for your answers below:
**Question 5.**

Social workers and health professionals will be working closer together to find solutions to support the care and needs of local people. As part of this, we are looking for information systems to become more joined-up so that up-to-date patient information is available to support patients as they move from one service to another.

For example, this will mean that you will not have to keep repeating the same information or have repeat tests and your details will be passed between authorised care professionals with very strict protection of your information.

(Please select as many of the options which apply to you)

- I am happy for my information to be shared in this way
- I would only want this to happen if I have given my permission first
- I do not want to have to give my permission first I just want it to happen
- I think this will improve my care
- I don't believe this will make any difference to my care
- I would be unhappy for my information to be shared in this way
- I would only be happy for this to happen in an emergency but not at any other time
- I do not have a view on this
- Other (please specify below)

**Question 6.**

Would you find it useful to access your own patient record online?

(please choose one option which most applies to you)

- Yes - I would want to be able to view my patient information and have the ability to update it myself too
- Yes - but I would only want to be able view it and see what information it contains
- Yes - but I probably wouldn’t look at it very much
- No - It would not be of interest to me
- No - I do not have a computer/mobile device
- No, as I would not want my patient information held online/electronically
- I don’t know/ not sure
- Other (please specify below)
**Question 7.**

Do you think having access to your own medical record would help you manage your own healthcare better? (please choose one option which most applies to you)

- Definitely, I'm very interested in knowing more information to help improve my health
- Possibly, it depends on what information it contains and if it is useful to me
- Probably not, I am unlikely to change my actions due to reading my online patient record
- No, I would still manage my own health in the same way
- I don't know/ not sure
- Other (please specify below)

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**Question 8.**

Do you think joined-up electronic patient information systems will improve the safety of patient records? (please choose one option which most applies to you)

- Yes - joined-up electronic patient information systems would be much safer so that care professionals across different services have access to accurate patient information
- It will be about the same - joined-up electronic patient information systems would be about the same as some of the paper systems currently in use
- No - linking information systems across many organisations may mean it is less safe
- I don't know/ not sure
- Other (please specify below)

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**Question 9.**

What do you think of using mobile devices/telemedicine to help more patients to be treated closer to home?

An example of telemedicine: A patient has a heart monitor installed at home which enables medical staff to remotely monitor a patient's health and identify any problems early, and also means that frequent trips to hospital for monitoring are not necessary. (please choose one option which most applies to you)

- It's a good idea - patients would not have to travel so far to receive some of their care and would be benefiting from advances in technology
- It's a good idea, but funding should focus on other areas at the moment
- I would prefer to continue visiting existing services in primary/acute/social care even if it means travelling
I would be worried about how to use the equipment/technology or that it might not work properly
I don’t know/ not sure
Other (please specify below)

Question 10.
If you have any other comments, ideas, or queries that you would like to raise about any part of the Informatics Strategy, please include them below:

About You

Your age
☐ Under 16
☐ 16-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65 and over
☐ Prefer not to say

Gender
☐ Male
☐ Female
☐ Prefer not to say

Ethnicity/Race
☐ White
☐ Mixed
☐ Asian or Asian British
☐ Black or Black British
☐ Chinese
☐ Prefer not to say
☐ Other (please specify)
Postcode
Please give your postcode below. This will be used to assess where we are receiving responses from across Oxfordshire

Please provide your name and address or email below if you would like to receive a copy of the consultation report and final strategy

Thank you for answering this survey – the closing date is 1 February 2011
Once completed, you can send it back to us freepost, no stamp required to:

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