

# Information

## A report from the NHS Future Forum

### Workstream members

- **Professor David Haslam – Chair, Information group**  
National Clinical Adviser, Care Quality Commission and Expert member, National Quality Board
- **Jeremy Taylor – Chair, Information group**  
Chief Executive, National Voices
- **Sally Brearley**  
Patient Representative and lay member, National Quality Board
- **Professor Mike Cooke CBE**  
Chief Executive, Nottinghamshire Health Care NHS Trust
- **Dr Jonathan Fielden**  
Chief Medical Officer, Royal Berkshire NHS Foundation Trust
- **Dr Paul Hodgkin**  
Founder and Chief Executive, Patient Opinion
- **Professor David Kerr**  
Professor of Cancer Medicine, Oxford University
- **Joanna Killian**  
Chief Executive, Essex County Council
- **Anthony McKeever**  
Managing Partner, The Clinical Commissioning Collaborative
- **Dr Kathy McLean**  
Clinical Transitions Director, NHS Medical Directorate
- **Dr Shaibal Roy**  
National Institute for Health Research, CLAHRC for North West London
- **Francis Wells**  
Consultant Cardiothoracic Surgeon, Papworth Hospital NHS Foundation Trust

# Contents

Foreword.....	3
Summary.....	4
Introduction.....	7
• Vision.....	8
What we heard and recommendations.....	10
• Information as an integral part of care.....	10
• Patient ownership of data.....	14
• Data sharing.....	17
– The IT story.....	18
– The culture story.....	19
• Information governance.....	21
• Using data to drive quality improvement.....	24
• Transparency.....	27

# Foreword



Information really matters. Following the 2010 consultation, *'An Information Revolution'*, the Government undertook to develop an information strategy. This workstream of the NHS Future Forum has been asked to advise on the content of such a strategy. We formed our views by



taking account of the responses to that consultation, and through listening to a wide range of people and organisations in the NHS, public services, the voluntary sector and industry, including patients, service users and carers across England. Our conclusions are essentially threefold.

Firstly – that if health and social care systems used and communicated information effectively, this would make a major difference to the quality of care and to the ability of hard-pressed services to manage demand in tighter financial conditions. It would also ensure that people's rights under the NHS Constitution are better protected. There is a pressing need to get this right.

Secondly – that the barriers to making the 'information revolution' a reality are much more cultural than they are technological. What is needed more than anything is a change of mindset in the NHS, so that it is taken for granted that the provision of information to patients and service users is an integral part of the therapeutic process; that communication matters; that the records about my health are "my records"; that responsibly sharing data is vital for patient safety and continuity of care; that consent matters; that as a health professional, I must be hungry to know how well I am doing and how I can improve; and, that openness and transparency are vital to building public trust.

Thirdly – that this is doable and is already being done, but this remains patchy. We have been struck by the range of good practice examples from England, the rest of the UK and overseas. What is now needed is an organised push to get it good everywhere. We would like to call for 2012, the year in which the Government's information strategy will be published, to be the year that the information revolution really starts to support better health outcomes; tackle unexplained variation and narrow inequalities; promote health and self-care; and engage patients, service users, carers and all citizens.

A handwritten signature in black ink, appearing to read 'David Haslam'.

**Professor David Haslam**

**Chair, Information Group  
National Clinical Advisor  
Care Quality Commission,  
Expert Member,  
National Quality Board**

A handwritten signature in black ink, appearing to read 'Jeremy Taylor'.

**Jeremy Taylor**

**Chair, Information Group  
Chief Executive  
National Voices**

# Summary

## Vision

People see massive untapped potential for information to underpin and drive great care. By engaging through our listening exercise, they have painted a picture of:

- Informed and involved citizens, responsive healthcare professionals, and a system that enables both groups;
- Information integrated around the needs of people, rather than (as often at present) around organisations;
- Excellent communication as well as excellent information;
- Moving from a focus on collecting data (often too much data) to a focus on using data to generate intelligence to inform action;
- Every encounter between the citizen and care systems being appropriate, because the information is right for the citizen and because it is an opportunity for the system to learn from the person. Citizens should be equal partners in their care rather than passive consumers.

The NHS Future Forum's recommendations focus on six key areas:

## Information for patients and service users

**1. Information is an integral part of the service to patients and service users and the Government's information strategy must clearly set out the responsibilities of commissioners and providers in affirming this principle.**

**2. Service providers must ensure that information integrates around the needs of the individual, and commissioners must ensure that they do so. The NHS Commissioning Board must lead by example in its direct commissioning of primary care and other services. It should also ensure that the levers and enablers it uses for improving quality align with this requirement.**

## Patient ownership of data

**3. In the Chancellor's 2011 Autumn Statement, the Government announced new measures as part of its Growth Review<sup>1</sup>, which set a deadline for patient access to their online GP held records by the end of this Parliament. We support this commitment as a first step, but the information strategy must now make clear how this will be achieved, recognising that there is both a financial and time burden to GP practices and by providing meaningful help and support to them.**

---

<sup>1</sup> [http://www.hm-treasury.gov.uk/as2011\\_index.htm](http://www.hm-treasury.gov.uk/as2011_index.htm)

4. **The Royal College of General Practitioners, in partnership with the British Medical Association, NHS Commissioning Board and relevant patient organisations, should be invited by the Department of Health to develop a plan that delivers the roll-out of access to patient records by 2015.**
5. **Switching on patient access alone is not enough, and potentially detrimental if appropriate support structures are not in place for patients so that they understand and know how to use the information. The planned roll-out of patient access to electronic records by the Government must acknowledge this and ensure that a support structure is in place, including a proper consent process.**

### **Data sharing is vital for safety, quality and integrated care**

6. **The NHS must move to using its IT systems to share data about individual patients and service users electronically – and develop a consent model that facilitates this – in the interests of high quality care. How this is achieved should be for individual providers to decide, but with common goals and standards. The key requirement is interoperability – IT systems talking to each other – not a “national programme for IT”. The information strategy must clearly set out what is expected for providers of NHS services, and a challenging deadline for when this must be achieved.**
7. **There should be a clear contractual requirement that all organisations delivering care in the NHS or in adult and child social care have systems that allow full electronic data sharing against set standards. There can be no opt-out, regardless of whether the provider is in the NHS, private or voluntary and community sector. Commissioners must strive to ensure that this does not unfairly exclude smaller organisations which would otherwise be accepted as “any qualified providers”.**
8. **The information strategy should set out how the Government will ensure the establishment of technical interoperability standards and of common standards for the structure and content of health records.**
9. **There must be a clear presumption in favour of hospital discharge summaries being made available to the GP and patient (or their nominated carer) at the point of discharge, and of GP referral letters being made available at the point of referral.**
10. **The universal adoption of the NHS number at the point of data capture and across health and social care must be turned from a long-held – and generally ignored – aspiration into a reality by 2013.**

## **Information governance**

- 11. The Government should commission a review of the current information governance rules and of their application, to report during 2012. The aim of the review should be to ensure that there is an appropriate balance between the protection of patient information and the use and sharing of information to improve patient care.**

## **Using data to drive quality**

- 12. Using data to drive quality is a fundamental governance responsibility for health and social care organisations. The NHS Commissioning Board and Monitor must be charged with ensuring that commissioners and providers uphold this principle.**
- 13. The kind of cultural change we want to see needs to be 'championed' at every level. A clinician who is responsible for organising information in support of better patient care should be identified in every organisation.**

## **Transparency**

- 14. The Government should set a clear deadline within the current Parliament by which all information about clinical outcomes is put in the public domain.**
- 15. The Government should set out a clear plan for the progressive development of quality and outcome measures to underpin the new outcomes frameworks and support frontline clinicians in measuring for quality improvement.**
- 16. The information strategy should emphasise the growing importance of patient-generated comments via all forms of social media, and the need for the NHS and social care to learn how to use these to improve services. It should set out a clear way forward.**

# Introduction

Good information, well used, is a vital component of improving health, wellbeing and quality of care. It is both increasingly feasible and necessary to turn the vision in the Government's "information revolution" into a reality.

The NHS Future Forum has been asked to advise the Government on the content of its forthcoming information strategy. We have not attempted to write a shadow strategy or cover the entire territory. Rather, based on the evidence that we have heard, this report sets out a few key steps, which we believe will move health and social care closer to a "tipping point" in the use of information. With drive and leadership, these can be embedded and built upon.

A number of factors come together to create a powerful case for change:

- **A new culture of transparency and public voice** is being fuelled by the digital revolution. Health apps, social media and telehealth are changing behaviour and redistributing power. It is now possible to involve individuals and communities in decisions about services and commissioning in ways that would have been difficult in the past. The eventual impact of these changes is one that we cannot foresee. Adapting to this world and exploiting its potential will make health and social care more responsive and resilient, and will build public trust. The converse is also true.
- **Technological advance is drastically lowering the cost** of collecting, sharing and using data. The vision behind the National Programme for IT can now be realised at much lower cost and in more flexible and responsive ways.
- **Getting information and communication better will be crucial for driving quality and reducing waste and duplication in the current financial squeeze** – a critical underpinning of health promotion, self-care, self-management, quality improvement and integrated care.
- **Our recommendations are all exemplified by existing good practice** in England, the wider UK and overseas. The future is already here but not evenly distributed. Indeed, by a number of international benchmarks, the English health economy scores very well on its use of information. Good practice now needs to be built on and take place consistently and systematically.
- **The Government needs to re-establish a clear sense of direction.** Delay in the publication of an information strategy and decisions to discontinue parts of the National Programme for IT have reduced momentum for change and created a climate of uncertainty and drift at a time when there have been other pressing concerns for health professionals and managers. Clear national leadership is needed to unlock local leadership and drive.

## Vision

People see great and untapped potential for information to underpin high quality care. By engagement through our listening exercise, they have painted a picture of:

- informed and involved citizens; responsive healthcare professionals, and a system that enables both;
- information integrated around the needs of people, rather than (as often at present) around organisations;
- excellent communication as well as excellent information;
- moving from a focus on collecting data (often too much data) to a focus on using data to generate intelligence to inform action; and,
- the citizen and care system contributing as equals to every encounter because the information is right for the citizen and because it is an opportunity for the system to learn from the person. This sees citizens as partners in their care not passive consumers.

As an example of how this vision might be experienced by a patient, we include an illustrative example of a 'perfect' patient information journey created by the Patient Information Forum<sup>2</sup>. This was used for discussion in two workshops that fed into the work of the Forum.

### A perfect patient information journey?

Maria is 34 years old. She has been encouraged throughout her life to take responsibility for her health. She attended an enlightened school that encouraged physical exercise, regardless of sporting prowess, and incorporated health literacy into the curriculum. She is therefore aware of what is normal for her body and of where to access information if she needs it.

Recently, she has noticed that unexpected things have been happening: she has been dropping pencils or tripping over things that are not there. Maria looks at a symptom-checker on the internet, but decides that the things she has been experiencing are too infrequent to be a concern just at the moment. One morning, Maria wakes up with blurred vision. She is shocked and scared by this, but manages to get an emergency appointment to see her optician. Her optician tells Maria that it is likely to be a temporary blurring due to optic neuritis, but suggests that she visits her GP in case it is a sign of something more serious.

Maria rings her GP practice and gets an appointment to visit her GP. By now, her vision is getting better. She makes a note of 'optic neuritis' in her personal health record. Her GP listens to her story and proposes a referral to a neurologist. The GP

---

<sup>2</sup> <http://www.pifonline.org.uk/>

explains to Maria that she has a choice of a consultant-led team and that there is an information advisor in the GP practice who can help her to choose a consultant. The GP also suggests information sources that she may find helpful. Maria spends some time with the information advisor, reviews options on an online information intermediary tool and makes an appointment with a consultant-led team.

Whilst waiting for her appointment with the neurologist, Maria decides to do some research of her own. The GP mentioned that the optic neuritis may be a sign of multiple sclerosis, so Maria rings the MS Society helpline one evening after work.

At Maria's appointment with the neurologist, she shares the notes on her personal health record, so that the consultant can see details of when she dropped things unexpectedly as well as the date when she had the optic neuritis and how long the blurred vision lasted. The neurologist advises Maria that tests will be needed to establish a diagnosis; the neurologist suggests that Maria watches a YouTube video about having an MRI scan.

The diagnosis of multiple sclerosis takes some time, but Maria is supported through it by her Clinical Nurse Specialist. Once she has a diagnosis, she is given an information prescription which contains short pieces of information from charities that has been compiled for her, with details about information centres, support groups, voluntary sector organisations and online forums. As well as including health information, information is also provided on social issues such as employment and finances. The information prescription has been emailed to her, so she forwards it to her brother in Australia, so that he knows what is happening. She also uses the information prescription to help her to work out the questions she wants to ask at her information centre.

Maria is keen to stay in control of her life. She asks at a self-help group and through online forums about other people's experiences of living with multiple sclerosis and about the treatment options. She uses experience gathered from the forum and self-help group to help her to ask questions about treatment options and to support her choices.

She chooses to take a treatment that she needs to inject herself. She agrees with her Clinical Nurse Specialist that she will keep in touch mostly by email, but she also has the option of speaking on the telephone or making an appointment. Maria uses a treatment diary on her mobile phone to help her to monitor her treatment. She also sets up a personal health diary so that she can track her mood and her fatigue over time.

Above all, Maria continues to ask questions, to access and share information, and to make her own decisions about living with multiple sclerosis.

Not everyone's patient journey is the same and not everyone has the health and IT literacy enjoyed by Maria. Many contributors to our work pointed out the need to ensure practical, emotional and social support alongside information throughout the journey, and to ensure that these cross organisational boundaries, including those between health and social care.

# What we heard and recommendations

This report is divided into six themes, each containing a series of recommendations which support the vision already set out.

1. Information as an integral part of care
2. Patient ownership of data
3. Data sharing
4. Information governance
5. Using data to drive quality improvement
6. Transparency

## Information as an integral part of care

**Information for patients and service users is an integral part of care.** Like medicine, good information can heal but poor information or poor handling of information can harm. We need to regard poor information as poor quality care and as such a potential breach of the minimum standards that the NHS Constitution is intended to safeguard. The wider quality and economic case for good information is often insufficiently appreciated. Good information and communication promote health literacy, treatment adherence, self-management, shared decision-making, confidence and realistic expectations.

A consistent message in our listening exercise from patients and their representatives, and voluntary organisations in health and social care, was that information must be seen as a service. There are several strands to this:

- Users of services want good, timely, relevant information at all stages through their journey of care. People do not want to be swamped with information, nor do they want to have to struggle to find the right information.
- People want information about their conditions, their treatment options, the implications of their treatment choices, available services and their choices more widely. A consistent message was that patient and other voluntary organisations are frequently good sources of information, but that signposting to these sources is inconsistent. There was a strong plea for renewed momentum behind earlier national Government initiatives to promote the availability of high quality patient information – especially the

information prescription and The Information Standard scheme (for accrediting the quality of written information for patients).

- People require information in an accessible form and format that meets their needs, and everyone benefits from 'Plain English'. We heard from a wide range of communities and their representatives in the voluntary and community sector. These included children and young people, elderly people, people with sensory impairments, vulnerable and disadvantaged communities, black and minority ethnic communities, and others who do not often come into contact with the NHS.
- It was put to us in the strongest terms that people have legal rights to accessible information, but that these rights, for example in the case of visually impaired people, are commonly breached. It was also stressed to us that information without good communication is of little value. Many people need face-to-face information along with an explanation of the information. Likewise, for many, access to an interpretation service is vital.
- Many people want to be more involved in decisions about their care and there is a large body of evidence which demonstrates the health and economic benefits of this. They want a partnership with their health professionals and greater support to manage their health and conditions more independently. There is a small but growing demand among patients for access to their health records. Those with access value it highly and find it supports independence and self-management. People also want to be able to assert and record their own needs, preferences and experiences, and have these taken account of by professionals. In particular, they find it frustrating constantly having to repeat fundamental information about themselves, for example their sexual orientation or their need for large print information.
- Many people want help, guidance, support and advocacy in order to obtain information, understand information, navigate through the complexities of their care journey, obtain and offer support to "patients like me", understand and exercise choices and assert their rights. There is a consistent and widespread plea for a "person wrapped around the information". It is especially important for vulnerable and excluded groups. Much informal help of this sort comes from family carers and friends, and a wide range of more structured support from trained staff and volunteers in the voluntary and community sector. Statutory agencies often do not sufficiently recognise or facilitate this support – for example resisting requests to share information about a person's care with carers or voluntary bodies.
- People's need for information is often most acute at key decision points and in transitions between care organisations. Many people want support in making choices, to be able to take away a record of their conversation with a health professional (or have it emailed or have access to the electronic version), to be told where to get further information, advice and support, and to have immediate access to a GP referral letter and a consultant's discharge

summary. None of these practices is routine, but all should be: they reflect the rights and pledges set out in the NHS Constitution.

- A highly consistent message from patients and voluntary and community organisations is that many health professionals do not always display the behaviours, skills and attitudes that are conducive to good communication, information sharing and shared decision-making. Poor communication can be harmful to physical and mental health and is sometimes a killer.
- Many people want to be able to engage as conveniently with the NHS – for example in booking appointments, ordering repeat prescriptions, viewing test results, getting text reminders for appointments, or seeing correspondence that relates to them – as they do with other services.
- In all these aspects there is a considerable gap between the ideal and the reality, but there are also significant opportunities to close that gap.

## Recommendations

- 1. Information is an integral part of the service to patients and service users and the Government's information strategy must clearly set out the responsibilities of commissioners and providers in affirming this principle.** The strategy must be clear about how people's legal rights to accessible information will be protected. It needs to set out the future for information prescriptions (IPs) and 'The Information Standard Scheme', and the reinforcing links between these. It should set out a clear strategy for ensuring that recruitment, training and development of the health and social care workforce are geared towards excellence in communication and health coaching skills. It should be clear how the information strategy will relate to and reinforce the work to embed shared decision-making.
- 2. Service providers must ensure that information integrates around the needs of the individual and commissioners must ensure that they do so. The NHS Commissioning Board must lead by example in its direct commissioning of primary care and other services. It should also ensure that the levers and enablers it uses for improving quality align with this requirement.** Care pathways need information built into the key decision points (for example, decision aids and information prescriptions) and with care coordination and information navigation built in to help people use the available information. This is especially important for those with long-term conditions and complex needs and those from vulnerable groups. As part of this, commissioners need to give full consideration to the pivotal role of primary care, carers and the role and potential of the voluntary and community sector as providers of information, guidance, support and advocacy.

These changes will also be supported by improving the sharing of data about individuals, with their consent, and by enabling people to have access to their own care records.

## Supporting patients to make sense of the information

A clear message we heard from many contributors, particularly those representing patients with long-term conditions, is that, as important as getting the right information is, patients must also receive it at the right time and with the right support in place to be able to make shared decisions about their care. A number of people referenced the work being carried out in the 'Year of Care Programme'<sup>3</sup> as a good example of the benefits of providing information in a supportive environment. They also highlighted the important contribution that the voluntary sector can make in supporting patients to make sense of information, such as the work being carried out by Macmillan Cancer Support<sup>4</sup> and the Stroke Association information advice and support service<sup>5</sup>.

### *Care Planning*

The Year of Care Programme has demonstrated how to deliver personalised care in routine practice for people with long-term conditions, using diabetes as an exemplar. The approach puts people firmly in the driving seat of their care and supports them to self-manage.

A key component is a new pathway within the clinic, which involves sending people with diabetes personal information on their test results prior to the care planning consultation. Putting information exchange at the heart of routine care significantly improved patient experience and engagement, and altered the power relationships with clinicians. However these benefits were only seen in the context of supportive systems and attitudes; healthcare professionals being committed to partnership working, having the skills to work in this way, and the system being designed to support it. This was good for everyone, whatever their cultural background: better self-care by patients, a better working life for professionals and better use of resources.

### *Information Prescriptions*

Macmillan is a key partner in the Information Prescriptions programme available on NHS Choices.<sup>6</sup> IPs can be used to provide and signpost to information so that, throughout the cancer care pathway, patients have access to personalised information and the opportunity to talk through their concerns and needs with a healthcare professional or trained worker. NHS Choices provides the infrastructure for the system, while most of the content is populated by the voluntary sector (with the National Cancer Action Team performing a commissioning and quality assurance function in relation to content). IPs are based on information pathways, which indicate the various points in the patient journey at which information should be

<sup>3</sup> [http://www.diabetes.nhs.uk/year\\_of\\_care/](http://www.diabetes.nhs.uk/year_of_care/)

<sup>4</sup> [www.macmillan.org.uk](http://www.macmillan.org.uk)

<sup>5</sup> [www.stroke.org.uk](http://www.stroke.org.uk)

<sup>6</sup> <http://www.nhs.uk/ips>

offered. Macmillan is currently funding facilitators to work directly with clinical teams to seek to embed the information pathways. Good coordination with other information services is also encouraged. Such services include Macmillan's local information services, which provide personalised information and the space and time for trained workers to give support to patients to understand the information.

### **Care Navigation**

The Stroke Association provides stroke survivors, families and carers with information, emotional support and practical assistance in the aftermath of a stroke. It works closely with individuals and families to make sure their needs are being met and to help them come to terms with the prospect of life after a stroke.

## **Patient ownership of data**

**The data belongs to the patient and service user** – and we need a system that works on that assumption – with people's ability to access and use their own care records being the default. Technically and legally, patients do not "own" their health records, though they have the legal right to access them. However, we heard that health professionals sometimes make this access difficult and there is often a charge for this service. A consistent message from many different groups in the listening exercise was that the legalities are less important than the mindset. Health and social care should operate as if it is the patient's or service user's data, as one of the key ingredients for making a reality of "no decision about me without me".

- Almost all GP practices hold electronic health records, and there are no serious technical barriers to opening them to patients. People have a right of access to their records as part of the NHS Constitution, yet such access is still the exception to the rule. Where records have been made available to patients, we have heard that this has resulted in clear benefits for patients and for practices, with patients becoming more engaged and their demands on their GP practices declining.
- Though patient demand for access to their health records is currently low, it is growing, in line with wider trends in society. Access to records will in future be an important contributor to maintaining and building enduring trust in an evolving NHS and, conversely, a lack of access could be harmful to trust.
- Patient organisations want patient access to records opened up, but also want the right protections and support for patients to go alongside. Patients with access to their electronic health records value it highly and use it as a platform to improve their health literacy, self-management, and engagement with their health, and to transact more conveniently with services. It has been put to the NHS Future Forum that patient access to records will be a vital underpinning of a developing culture of self-care and self-management.
- We heard from some GPs that they were concerned about rolling out access to patient records, including potential workload implications, concerns about

information governance and a potential negative impact on doctor-patient relations. The broad experience of those GP practices that have led on record access is that GPs' fears are not realised, the practicalities can be dealt with, and the benefits clearly outweigh the costs and risks. However, it is very important that the concerns of GPs and practices are acknowledged and taken account of in rolling out access.

## Recommendations

- 3. In the Chancellor's 2011 Autumn Statement<sup>7</sup>, the Government announced new measures as part of its Growth Review, which set a deadline for patient access to their online GP-held records by the end of this Parliament. We support this commitment as a first step, but the information strategy must now make clear how this will be achieved, recognising that there is both a financial and time burden to GP practices, and by providing meaningful help and support to them.**

The information strategy must also describe a clear business case for making this change, which includes better use by GP practices and more empowered patients. It must also build an awareness campaign involving patient organisations, which is likely to need to emphasise the benefits and convenience for patients – for example booking appointments and reading test results, as well as access to the record.

The information strategy should ensure that GP systems are “switched on” to technically allow patient access within the agreed deadline. GP practices will need a mixture of pressure, support and reassurance to make this happen – and the strategy should be clear about the mix of mechanisms that will be used to achieve this.

- 4. The Royal College of General Practitioners (RCGP), in partnership with the British Medical Association (BMA) and the NHS Commissioning Board and relevant patient organisations, should be invited by the Department of Health to develop a plan that delivers the roll out of access to patient records by 2015.** This should cover inducting, training and supporting practice staff; data security and information governance issues; the “offer” to patients (for example remotely booking appointments, repeat prescriptions, viewing test results, links to relevant health information etc); and the targeted stimulation of patient demand. This work should draw on the earlier work and guidance developed by the RCGP and other professional bodies, and the learning from current exemplars in England, the rest of the UK and overseas.

---

<sup>7</sup> [http://www.hm-treasury.gov.uk/as2011\\_index.htm](http://www.hm-treasury.gov.uk/as2011_index.htm)

This plan should include the roll out of accessible, hand-held records (as exemplified by the personal child health record – the “Red Book”<sup>8</sup>). This is vital to ensure that all those who are not online, including excluded groups such as homeless people and Gypsies and Travellers, do not lose out.

- 5. Switching on patient access alone is not enough and potentially detrimental if appropriate support structures are not in place for patients so that they understand and know how to use the information. The planned roll-out of patient access to electronic records by the Government must acknowledge this and ensure that a support structure is in place, including a proper consent process.**

### **Online access to electronic health records – patient owned records**

Approximately 100 GP practices around the country are offering patients access to their GP electronic health record online from any computer (or smartphone). The GP practice determines how much of the record can be viewed by the patient and whether the patient can view the record at all.

We visited Houghton Thornley Medical Centres and Manor House surgery in Hyde, a group of GP practices, with among the longest and greatest experience of offering patients electronic access to their health record. Over 1500 patients (13% of the patient population) have requested access over 5 years, and the numbers are growing. We also visited a nearby nursing home, where a pilot has started enabling nurses in the home to have access to their residents’ patient notes.

Houghton Thornley Medical Centres has created its own bespoke practice website<sup>9</sup>, which provides trusted information to its patients and links to other websites, as well as information to help patients and the public, clinicians and managers to understand how access to their records can help patients get better quality care.

We heard from patients of all ages who booked appointments and repeat prescriptions online, checked blood test results ahead of speaking to their GP in order to have an informed discussion about the results and next steps, and kept track of their health concerns by comparing their information with guidance on websites such as NHS Choices (Map of Medicine)<sup>10</sup>. Patients were also able to share their notes with other health professionals treating them and ensure that discharge summaries and other correspondence about treatment they had received got back to their GP and their health record.

<sup>8</sup> The child health record exists as a paper copy for parents to be used as the main record of their child's growth, development, and uptake of preventive health services. The record serves the following purposes: to i) assist with discussions between parents and health professionals; ii) ensure continuity of care; and iii) increase parental understanding of their child's health and development.

<sup>9</sup> [www.htmc.co.uk](http://www.htmc.co.uk)

<sup>10</sup> [www.mapofmedicine.com](http://www.mapofmedicine.com)

We also heard that being given access to your record alone is not enough; patients need the support of their GP and access to information that supports their understanding of the data in their health record and which will allow them to better manage their own health.

Electronic access to your own health records is not unique to primary care. Kidney patients have been provided with direct online access to their hospital records through RenalPatientView.<sup>11</sup> This is a UK project representing patients and clinicians. It aims to provide online information about renal patients' diagnosis, treatment, and their latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world.

The concept of patient owned records is not a new one. Maternity Records have been written for patients and owned by them through the duration of their pregnancy for over 20 years now. Websites such as *Patients Know Best*<sup>12</sup> already offer clinicians the opportunity to give patients access to their medical records.

## Data sharing

**Data sharing is vital for patient safety and providing high quality and integrated care.** Poor flow of information about individual patients and service users is one of the key barriers to ensuring that people receive a safe, effective, joined-up service, especially those with multiple and complex conditions and disabilities whose care crosses organisational boundaries. The presumption must be that, with appropriate consent, all individuals involved in caring for a patient or service user has access to the records of that person's care and a responsibility to share and communicate key information. It is particularly important that such communication occurs at the key decision and handover points – rather than later – and across all organisational boundaries traversed by a person's pathway or package of care.

Aggregated, anonymised data also needs to flow well for purposes other than direct patient care, in the interests of clinical audit, research and wider quality improvement efforts, as recently highlighted by the Government's strategy for UK life sciences<sup>13</sup>. This is only possible with rigorous information governance practice, ensuring that identifiable data are used only where absolutely necessary, with the default position being to use data with patient identifiers removed.

---

<sup>11</sup> [www.renalpatientview.org](http://www.renalpatientview.org)

<sup>12</sup> [www.patientsknowbest.com](http://www.patientsknowbest.com)

<sup>13</sup> <http://www.dh.gov.uk/health/2011/12/nhs-adopting-innovation/>

## *The IT story*

Whilst virtually all GP practices have been computerised for many years, many hospitals continue to rely on paper-based systems to record patient information and have separate IT systems that are not integrated and do not allow for data to flow around departments.

- The NHS Future Forum heard a consistent story about the failure of the national programme for IT to achieve the vision of a shared electronic health record. We were told that the approach was top down, centralising and intolerant of dissenting advice; dominated by technology considerations (rather than a focus on what the technology should achieve); insufficiently challenging of the commercial interests of major IT suppliers; and poor value. It tried to impose a one-size-fits-all technology solution and – fatally – failed to secure local support from clinicians and managers early enough in the design phase of the programme.
- An equally powerful message received by the Forum was that, despite these failings, the aspiration of electronically shared health and social care records remains right. Moreover, technology has advanced to the point where this is now eminently achievable and affordable.
- In particular, we received a strong and consistent message about the issue of “interoperability” – the capacity for different computer systems to “talk to each other”. Lack of interoperability is an impediment to patient safety, high quality and integrated care and the continuity of care that patients deserve. It has been made clear to the Forum that there are no significant technical barriers to ensuring interoperability between systems. This means that data sharing across organisational boundaries is possible using existing IT systems as the foundation, and without the need for a single technology solution. We also heard about the potential afforded by open source technology systems that have allowed several countries to adopt effective, integrated electronic record systems for their entire health economies at a fraction of the cost of proprietary systems.
- It was stressed to the Forum that full interoperability requires clear national technology standards, as well as national data standards for the structure and content of health records. The Royal College of Physicians and others drew our attention to existing work to develop such standards, and urged the creation of a professional body to take forward this work.

## National standards for the content and structure of records

The RCP's Health Informatics Unit (HIU) led a project that developed standards for the structure and content of the admission, handover and discharge records of hospital inpatients<sup>14</sup>. The standards were endorsed by the Academy of Medical Royal Colleges (AoMRC) as fit for purpose for the whole medical profession in April 2008. They are now embedded in the recommendations of the General Medical Council (GMC), NHS Litigation Authority (NHSLA) and Care Quality Commission (CQC), and in the AoMRC educational curriculum for junior doctors and guidance for revalidation of senior doctors. The RCP is currently leading the development of standards for the structure and content of outpatient records.

We heard from stakeholders who supported the establishment of a body to lead and provide governance for the development of clinical record standards for paper and electronic records across all specialties and disciplines in health and social care.

- The Forum also took opinions on the summary care record (SCR) – an initiative which is attempting to ensure that in all parts of the NHS key summary patient information – for example, on their conditions, medicines and allergies – is available when patients are admitted to hospital, in the interest of safety. The Forum asked if the SCR was a useful staging post to full data sharing, or a distraction from that goal. The prevailing view was that the SCR was a useful transitional development but could not be seen as a final destination. Where it could be demonstrably bettered locally – in terms of safety, quality and continuity of care – people should be free to get on with their local solution.

### *The culture story*

The NHS Future Forum is acutely aware that information technology is only part of the story about data sharing, and not the main part. Time and again it was put to us that the effectiveness with which information is shared is primarily a matter of culture and behaviour. During our exercise, our attention was drawn to three kinds of cultural “blocker”.

- The first is a tendency for commissioners and providers of NHS-funded care not to take timely communication seriously enough, even when it is clearly expected and in the interests of safe and effective care and informed patients. Two examples put to us were systemic failures to ensure that patients and their GPs have timely receipt of hospital discharge letters and that patients have timely receipt of GP referral letters. The requirement that patients receive a copy of the discharge summary was introduced several years ago and included as a right in the NHS Constitution, but is still widely breached. Many GPs report frustration that they do not receive discharge

---

<sup>14</sup> <http://old.rcplondon.ac.uk/clinical-standards/hiu/Pages/Record-keeping.aspx>

summaries quickly enough. More generally, the widespread inability of the NHS to communicate electronically and its reliance on “snail mail” is a cause of much frustration, at sharp odds with practice in almost every other walk of life, and is increasingly a matter of reputational risk for the NHS.

- The second “blocker” could be described as “organisational jealousy” – a reluctance to share based on suspicion of other organisations; territoriality and tribalism (“they are our patients, not yours”); or commercial considerations.
- The third “blocker” relates to information governance. This is dealt with in the next section.

## Recommendations

- 6. The NHS must move to using its IT systems to share data about individual patients and service users electronically – and develop a consent model that facilitates this – in the interest of high quality care. How this is achieved should be for individual providers to decide, but with common goals and standards. The key requirement is interoperability – IT systems talking to each other – not a “national programme for IT”. The information strategy must clearly set out what is expected for providers of NHS services, and a challenging deadline for when this must be achieved.** This must be possible across England in all local health and social care economies and allowing data to be shared and viewed across all organisational boundaries.

The information strategy should set out the roles and responsibilities of the key players and the system levers that will be deployed in order to meet this deadline. Given the reputational harm caused by the failure of key aspects of the national programme for IT, the strategy must set out how the lessons have been learned from that exercise. In particular, it seems clear that central Government should not prescribe the local IT solutions, but that it must ensure certain national standards. There is an informatics market ready to take up the opportunities once the standards are set.

- 7. There should be a clear contractual requirement that all organisations delivering care in the NHS or in adult and child social care have systems that allow full electronic data sharing against set standards. There can be no opting out, regardless of whether the provider is in the NHS, private or voluntary and community sector. Commissioners must strive to ensure that these requirements do not unfairly exclude smaller organisations which would otherwise be accepted as “any qualified providers”.**
- 8. The information strategy should set out how the Government will ensure the establishment of technical interoperability standards and of common standards for the structure and content of health records.** In the latter case, the Forum is sympathetic to the calls for a professional standards development organisation and believes that the process should be clinically-led, with patient and lay involvement. Record standards should include

common standards for recording patient wishes, preferences, care plans, and own inputs.

The information strategy should set out the behavioural expectations underpinning data sharing; in particular to ensure that all those with a legitimate need to have access to an individual's data are able to do so. This is particularly important if fully integrated care is to be achieved for those with complex conditions, with the full involvement of carers, voluntary and community sector organisations and the social care sector.

These developments are conditional on a revisiting of the current rules for information governance and of their application. Good information governance is an essential enabler of responsible data sharing and the Forum's findings on this matter are set out in the next section.

- 9. There must be a clear presumption in favour of hospital discharge summaries being made available to the GP and the patient (or their nominated carer) at the point of discharge, and of GP referral letters also being made available at the point of referral.** The strategy should reaffirm the necessity of getting some of the basics of communication right now – and set out the levers for making this happen.
  
- 10. The universal adoption of the NHS number at the point of data capture and across health and social care must be turned from a long-held – and generally ignored – aspiration into reality by 2013.** The information strategy should set out the mechanisms and incentives through which this will be achieved. This will greatly improve interoperability and the potential for data linkage. It will also make it easier to provide continuity of care for people who don't access the NHS very often, such as homeless people and Gypsies and Travellers.

## Information governance

### Good information governance is vital to enable responsible data sharing

We have heard a number of concerns about current information governance arrangements.

- There are concerns about the seriousness with which data security is treated, as exemplified by a growing number of breaches of data protection laws in which identifiable patient information has been lost or inappropriately shared or exposed.
  
- Concerns have also been expressed that the Health and Social Care Bill confers powers on national bodies to extract identifiable patient information that are too sweeping; concerns expressed more recently following the

publication of the Government's Strategy for UK Life Sciences<sup>15</sup>, which proposed changes to the use of NHS patient data, with more information shared with independent healthcare organisations and data automatically included in clinical research unless individuals opt out.

- Patients are generally unaware of how their personal data is shared and used within the health and social care systems.

But we also received a clear message that not sharing information has the potential to do more harm than sharing it. It is also a major annoyance for patients, who feel that they should not constantly have to repeat the same information about themselves as they pass through the treatment pathway.

- A very strong and consistent message in our listening exercise has been that current information governance arrangements constitute an obstacle to the responsible sharing of data. Much frustration has been expressed about a tendency to refuse requests to share information about individuals in the interest of their care, or to share or extract information for secondary sources such as audit and research. This has been put to us as “the default answer of the Caldicott Guardian<sup>16</sup> is no” or, as one person wittily put it, “governance is an anagram of “never can go””.
- Voluntary and community sector organisations have told us that there is often a reluctance for health and social care organisations to share relevant information with them which would assist in their care of individuals – with the consent of those individuals, and similarly for health staff to share information with carers, for example with relatives of a person with dementia. We frequently heard the complaint that there is a reluctance to share information between health and social care services.
- It has been suggested that the current arrangements are conditioned too much by fear of sharing personal data inappropriately and insufficiently by an awareness of the risks to safety, quality and continuity of care of *not* sharing data. It has also been pointed out that the current arrangements do nothing to recognise or validate the natural desire of many – possibly most – patients and service users to safely share their data for the benefit of others.
- Within the constraints of our exercise, we have not been able to determine the extent and patterns of any systematic bias against sharing data, and the extent to which this might reflect the nature of the rules as set out and overseen by the National Information Governance Board (NIGB), the way the rules are interpreted – or some combination. The NIGB itself has told the Forum that it believes there are widespread deficiencies in the understanding

---

<sup>15</sup> <http://www.dh.gov.uk/health/2011/12/nhs-adopting-innovation/>

<sup>16</sup> A senior staff member in the NHS and Social Services appointed to protect patient information. There is a requirement for all NHS and social care organisations to appoint a Caldicott Guardian and to place their name on a national register.

of the rules and in the confidence of those applying them, and that the arrangements would benefit from review.

In short, the current rules for data security and information governance, as applied, seem to suffer both from problems of carelessness about the handling of confidential data and of excessive caution and defensiveness about sharing data in the interests of good patient care and wider quality improvements.

## Recommendations

- 11. The Government should commission a review of the current information governance rules and their application, to report during 2012. The aim of the review should be to ensure that there is an appropriate balance between the protection of patient information and the use and sharing of information to improve patient care.**

Based on the evidence we have heard, we believe that the system of information governance needs to embody – and be understood to embody – the following principles:

- Responsible data sharing is an important underpinning of safety, quality and continuity in the care of individuals and, through secondary uses such as clinical audit and research, a vital component of wider learning and quality improvement.
- Information governance should be seen as the enabler of responsible sharing and extraction of data in the interests of improving the care of individuals and of wider quality improvements.
- It is the patient's and service-user's data and needs to be treated with respect.
- There should be a normal presumption that all those individuals involved in the care of a patient or service user have access to the data about that person – with their consent.
- The implicit “deal” or “contract” between service and service-user needs to be made explicit. It would be along the lines of:

“You have a right to access your data and a right to withhold consent to its being shared. You have a corresponding responsibility to let us use your data in the interests of your own care and of improving the service for others.

We have a right to use your data, and a corresponding responsibility to tell you exactly what we plan to do with it and, when sharing it, to take all reasonable steps to protect your confidentiality.”

- There should be a normal presumption that, when an individual’s data is used for purposes other than for the care of that individual, it is transmitted in an anonymised or pseudonymised form. Where there is a need to use identifiable data, there needs to be an information governance framework that controls this. This framework should be transparent to patients.

Patient information produced by Cervical Screening Wales sets out very clearly what patients can expect and demand in relation to the sharing and protection of their personal data<sup>17</sup>. This was brought to the Forum’s attention as an example of good practice.

## Using data to drive quality improvement

**Using data to drive quality improvement** – including user feedback and experience data – is a fundamental governance priority of all health and social care organisations. Boards and governing bodies need to be held rigorously to account for how well they collect, use and publish this information.

The Forum learned of several examples of health organisations taking a rigorous approach to the collection and use of both clinical and patient experience data to drive up quality. It was clear that there was no consistency of approach and wide variation. It was also clear that there were opportunities for the systems and approaches being adopted by some organisations and health economies to be more widely adopted, which could be readily grasped if the will were there.

Based on the evidence put to the Forum, we believe that the key features of a rigorous approach to using data to drive quality include the following:

- a focus on quality, driven from the top of organisations;
- a focus on gathering information at the point of care; incentivising staff to take this seriously; and making it easy for them (for example, through the use of mobile devices);
- a hunger for comparison and benchmarking: “how well am I doing?”, underpinned by a national library of indicators with associated methodologies that are assured and available;
- a commitment to participation in local and national clinical audits;
- Clinical ownership at board level of the health informatics function;
- A hunger for patient and service user insight gained at the point of care and by a variety of other means, including surveys and patient experience

<sup>17</sup> [www.screeningservices.org.uk/csw/pub/info/leaflets/use\\_info.asp](http://www.screeningservices.org.uk/csw/pub/info/leaflets/use_info.asp)

measures, a welcoming approach to receiving and handling complaints, and a culture of “you said; we did”; and,

- openness, transparency and a willingness to share data and enable patient access to their records.

## Recommendations

- 12. Using data to drive quality is a fundamental governance responsibility for health and social care organisations. The NHS Commissioning Board and Monitor must be charged with ensuring that commissioners and providers uphold this principle.** The NHS Commissioning Board should affirm the principle that it is unacceptable for health and social care organisations not to know how well they are doing, demonstrate how well they are doing, and demonstrate how they are improving in the light of this knowledge. They should also seek and take account of comments and suggestions they receive from their patients and service users. We envisage that this will be driven to a considerable degree by the NHS Commissioning Board.
- 13. The kind of cultural change we want to see needs to be ‘championed’ at every level. A clinician who is responsible for organising information in support of better patient care should be identified in every organisation.** Organisations should support the development of professional informatics skills and behaviours, including encouraging accreditation of informatics professionals across the sector. This is particularly important where those specialist skills and competencies directly support health and social care practice. In order to ensure all staff – including clinicians, general management and social care staff – understand and use informatics appropriately in daily activities, informatics needs to be fully included in education, training and continued development programmes across the sector.

### Improving the functionality and interoperability of trust IT systems – using data to drive quality improvement

We visited the University Hospitals Birmingham NHS Foundation Trust, which has developed an in-house integrated IT system with the following functionality:

- an electronic prescribing system – PICS (prescribing information and communications system). This system provides staff with automated reminders to ensure patients get the drugs they have been prescribed. The same system also includes prescribing decision support and safety alerts that issue warnings to prevent doctors and nurses accidentally giving prescriptions that could harm the patient. PICS also includes a clinical dashboard, which shows how departments and wards are performing against each other, compared to previous weeks and against national targets;

- a patient administration system – Clinical Portal – which supports paperless working and the sharing of care records across the hospital and primary care;
- a digital dictation and electronic data capture system;
- a patient records portal – myhealth – which allows patients in long-term care to remotely access much of their clinical information held at the hospital. This system demonstrates that a national programme is not required to drive developments in IT.

In the United States, the Department of Veterans' Affairs (VA), which provides health care to over 20 million ex-servicemen and women, developed an electronic health record system, "VistA", in the 1990's. The system was developed in-house by clinicians for clinicians, aimed at supporting them to deliver safe and effective care. The VA uses VistA to run its entire health and social care system. It includes computerised ordering of tests and viewing of results, bar-coded medicines administration, electronic prescribing and clinical guidelines and reminders. At the heart of VistA is a single care record for each patient. This record is accessible to patients online and can be shared by professionals working across primary care, social care and all hospitals nationwide. VistA reduces duplication and improves care coordination, and saves the VA over \$3 billion a year from improved efficiency.

VA clinicians remain closely involved in the development and ongoing improvement of VistA, because they can make adaptations to the system without the need to pay an outside software developer. Because it was written by Federal employees, the VistA system is available free of charge as open-source software. Several other countries have taken advantage of this fact, and VistA has been successfully adapted and rolled out in countries such as Jordan, Finland and Mexico.

The VistA electronic health record is available free for download and use at

[http://www.ehealth.va.gov/EHEALTH/CPRS\\_Demo.asp](http://www.ehealth.va.gov/EHEALTH/CPRS_Demo.asp)

## The public voice – how was it for you? Acting on patient feedback

We listened to contributors' concerns that patient feedback is not routinely recorded whenever a patient receives a service from the NHS and that patients often have no way to know whether organisations have heard or acted on the feedback offered.

We concluded that providers and commissioners of health and social care and HealthWatch should routinely use patient, service user and carer feedback to help services listen, learn and maintain or develop a patient-centred culture. In particular, there is already a rich and constantly growing public resource of feedback from service users available on websites such as *I want great care* and *Patient Opinion*.

*Patient Opinion* provides a useful tool for both patients and staff alike. Patients are able to offer feedback in a way which preserves confidentiality, and see whether their comments are heard. Providers are able to respond to comments made about their services, log patient-initiated improvements, or use the site to seek views and experiences on specific issues.

## Transparency

The drive for greater transparency from organisations providing publically-funded services has already started. This year, the Prime Minister, in an open letter to Cabinet Ministers, committed to publishing key data on the NHS, schools, criminal courts and transport. The Department of Health has committed to publishing a series of health data, including clinical audit data detailing the performance of publicly funded clinical teams in treating key healthcare conditions, from 2012. The Cabinet Office's open data consultation proposed, among a series of recommendations, that publically-funded organisations should publish by default and that organisations should make routine use of feedback delivered via web-based and mobile media platforms.

We support these recommendations and believe it important that the process of implementing them is owned by clinical and patient representative communities, rather than experienced as a top-down imposition.

Meanwhile, a wider culture of openness and transparency is being created by the digital revolution. Health apps, social media and telehealth are changing behaviour and redistributing power. In particular, they are making it increasingly possible to harness the power of information and communication which is generated by patients and users of services themselves. In the coming years, the ability of services to access and learn from such communications will be a key determinant of quality improvement. Conversely, a failure to do this well will be a marker of being out of touch and a source of increased reputational risk for the NHS.

## Recommendations

- 14. The information strategy should set a clear deadline within the current Parliament by which all information about clinical outcomes is put in the public domain.**

The information strategy should propose a process for ensuring that the preparations for releasing outcome data are owned by clinical communities working in partnership with patient and lay representatives.

It is a state responsibility to ensure that the information in the public domain is meaningful, usable and presented to common, comparable standards.

- 15. The information strategy should set out a clear plan for the progressive development of quality and outcome measures to underpin the new outcomes frameworks and support frontline clinicians in measuring for quality improvement.** This is vital to energise and underpin quality improvement, clinical audit, innovation, research and patient choice. There remain gaps in the information we have about certain NHS services and there is a lack of data relating to the quality of services in social care.

This work needs to be owned and co-designed by clinical and professional communities working in partnership with patient leaders.

- 16. The information strategy should emphasise the growing importance of patient-generated comments via all forms of social media and the need for the NHS and social care to learn how to use these to improve services. It should set out a clear way forward.**



