

Equality Analysis

The power of information: Putting all of us
in control of the health and care information
we need – May 2012



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Aims of 'The Power of Information', the Information Strategy

The power of information: Putting all of us in control of the health and care information we need covers public health, the NHS and social care across England and is underpinned by provisions in the Health and Social Care Act 2012. It aims to harness information – and new technologies – to achieve higher quality care and improve outcomes. Information can drive safer, more integrated care and more effective prevention of ill health. The strategy sets a ten-year framework for transforming information for health and care – information for patients, service users, carers, clinicians and other care professionals, managers, commissioners, councillors, researchers, and many others. The focus is on information in its broadest sense – including the support people need to navigate and understand the information available. This is about ensuring that information benefits all of us and serves to reduce inequalities – not increase them.

There are a number of existing pieces of legislation or guidance where information sharing is already a core responsibility or requirement (see the annex to this analysis, page 29). In the strategy, we are looking to change the concept and culture of information sharing, the way information is collected and the way in which people can access and use it. Key ambitions of the strategy include:

- information used to drive integrated care – within and across organisations, and across the health and social care sector as a whole;
- information regarded as a health and care service in its own right – with appropriate support in using information available for those who need it, so that information benefits everyone and helps to reduce the inequalities gap;
- a change in mindset, so that our health and care professionals, organisations and systems recognise that the data in each of our own care records is fundamentally about us – and where our ability to access our own records online becomes the default position;
- information recorded once, at first contact, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow whilst keeping our confidential information safe and secure;
- our electronic care records become the main source for all professional information – reducing bureaucratic data collections and measuring quality;
- a culture of transparency, where the information held by Government and health and care services about services and care quality is openly and easily available;

- an information-led culture where all health and care professionals – and local bodies whose policies influence our health, such as local councils – take responsibility for recording, sharing and using information to improve our care;
- the widespread use of modern technology to make health and care services more convenient, accessible and efficient; and
- an information system built on innovative and integrated solutions and local decision-making, within a framework of national standards which will ensure that information can move freely and safely around the system.

Specifically, when thinking about **the information held within our own individual care records**:

- our ability to access our health and care services – including our own records – online will become the default position;
- electronic access to our own GP records by 2015 with access to our local authority social care records and assessments of need and care/support plans online as soon as IT systems will allow. Work with patient, service user and professional bodies will enable this to expand progressively across all of our care records;
- letters from health and care professionals about our care need to be available electronically to us, and to other professionals involved in our care;
- increasingly we will be able to interact with health and care services online, for instance by booking appointments or communicating by email; and
- increasingly, we will be able to obtain personalised information on opportunities to improve our own health or manage the consequences of any illness.

When thinking about **how our health and care professionals can use connected information to integrate and improve services and to inform decision-making**:

- health and care professionals will be able to access relevant records online – simply, securely and all in one place;
- to enable interoperability¹ – so different parts of the health and care system can connect and communicate with each other – information standards will be set nationally for the whole system. The NHS Number will be used consistently;
- data from our records – linked together with other data in a secure environment and made available in anonymised aggregate form – will be used to improve services, guide commissioning, to identify trends and other patterns of health;

¹ The ability of a system or a product to work with other systems or products without special effort on the part of the user. Interoperability is a property of a product or system, whose interfaces are completely understood, to work with other products or systems, present or future, without any restricted access or implementation.

- the research and life sciences community² will have access to a greater wealth of core data to help drive improvements in health and care; and
- over time, aggregated records will replace cumbersome national data collections.

When thinking about **how we access information**:

- there will be a single comprehensive online 'portal' provided by Government from 2013, as a link to trusted information on the NHS, social care and public health services;
- other providers of information will be able to take a broader role in making information accessible and useable for people – alongside a continuing role for Government in core information;
- more information about care at clinical or professional team level and information that enables us to 'benchmark' services, such as clinical audit data will be publicly available.
- we will be encouraged to provide more feedback, in real-time wherever possible, which will be used to improve our services – making each encounter count;
- there will be a 'presumption of openness' in relation to data and information about the quality and performance of health and care services, as part of a wider drive to increase public sector transparency; and
- the NHS and local government will be encouraged to do more to offer support to those of us who need help in accessing and understanding information, so that no parts of society are unfairly disadvantaged.

In addition, when thinking about **elements required to underpin the information strategy**, including the cultural shift required so that information drives higher quality, more integrated care with better outcomes:

- better use of information – and more innovative use of technology – will drive more effective and efficient services. Better quality and outcomes information will drive service improvement and professional engagement with information;
- leadership from the top down will support more efficient and effective use of information to improve health care and outcomes;
- lead health or care professionals within individual organisations will be responsible for organising information in support of better care;

2 The term 'life sciences' covers a whole range of scientific disciplines. This includes neurosciences, plant sciences, physiology, pharmacology, cancer studies, microbiology, genomics, bioinformatics, biotechnology and stem cell research. They are close to the medical sciences but also cross over into other areas, such as biochemistry. Research scientists work in commercial or government laboratories, hospitals and higher education institutions.

- to ensure anonymised data about our health and care is available to improve health and care for all, the Information Centre will become the focal point for data collection across the health and care system in England and will set up a secure data linkage service, with a more specialist service serving research and life sciences needs; and
- an independent review of information governance will ensure the right balance between sharing and protecting information across health and care.

Executive Summary

This equality analysis looks at the potential effect that *The power of information: Putting all of us in control of the health and care information we need* will have. A major issue that we are aware of is the link between literacy and health outcomes. Studies have highlighted that many people's level of literacy and therefore, their ability to access and understand health information and services is limited. This affects many different groups in this country and means that they do not achieve their best possible health and care outcomesⁱ. Low literacy levels is a bigger problem than can be solved by the health and care system, but improving the health and care information available to us all, and the ways in which it can be accessed, could help to improve health and care outcomes for everyone.

By far, the area of most concern that came to the fore when consulting on the Information strategy was around digital exclusion. We know that:

- 9.2 million adults have never accessed the internet;
- those aged 65+ are much more likely to be offline than younger people;
- 60% of adults aged 65+ have never accessed the internet;
- adults in lower socio-economic groups are also less likely to access the internet;
- only 15% of people living in deprived areas used online government services in 2009
- 40% of UK population do not use online channels, including websites such as Directgov and NHS Choices;
- some are digitally excluded by choice:
 - of those who do not have the internet at home 55% say they have no interest/see no use for it, only 12% cite financial reasons;
 - some are aware that services exist online but choose to access them by other means.ⁱⁱ

We recognise that different people will want and need to access information in different ways and that it is therefore essential to remember that information must never only be web based. In health and care we are talking about making more information available in a way that is 'digital first' rather than 'digital by default'.

Other key effects on equalities that the analysis of this strategy identified include:

- the fact that some people will not be able to access information online due to reasons beyond not having access to the internet. People who do not speak or read English and/or those who have learning disabilities often cannot access existing health and care information;

- access to online records raises safeguarding risks for vulnerable individuals;
- people who do not have a fixed address (such as some Travellers and the homeless) will not necessarily have access to or know how to obtain an NHS number; and
- confidentiality and consent is a concern for many. Whether they be a young person who does not want information shared with their parents, a person who is Lesbian, Gay, Bisexual or Transgender (LGB&T) who does not want their personal information shared with all health and care professionals or a person being cared for who needs their carer to access some of their health and care record.

The actions planned or currently being taken forward to address any potential negative effect on equality are detailed in the 'Action planning for improvement' section (page 25) section of this document but they include:

- making clear that information that is available online must always be available in other formats, where necessary (including face-to-face and assisted learning/support needs);
- encouraging the NHS and Local Government to do more to offer support to people who need help in accessing and understanding information, so that no parts of society are unfairly disadvantaged;
- giving access to electronic services and health and care records and asking the Royal College of General Practitioners to review its guidance on access to records with reference to safeguarding;
- making the NHS number a standard identifier on a persons health and care record. Though the strategy will explain how we can help those providing our care by, wherever possible, knowing and being ready to quote our own NHS Number, it will also make clear that 'some of us may not remember or know how to access this, and, for those reasons our records will always be identifiable in other ways.';
- encouraging greater collection of data relating to the Equality Duty protected characteristics; and
- a review (to be led by Dame Fiona Caldicott) of the current information governance rules and their application, to ensure that there is an appropriate balance between the protection of confidential and identifiable information within our health and care records and the use and sharing of information to improve the quality and safety of our own care and for the benefit of wider society.

Full equality analysis

Title: The power of information: Putting all of us in control of the health and care information we need

Relevant line in DH Business Plan 2011-2015:

'Our government's 2010 White Paper consultation document – Liberating the NHS: An Information Revolution – sought views on our proposals for an information revolution for health and adult social care in England, to transform the way information is accessed, collected, analysed and used in the NHS and adult social care services – so that people are at the heart of those care services. The consultation closed on 14 January 2011 and responses are now being analysed. We have been very keen to listen and will use the responses to the consultation and also from recent listening exercise to develop a detailed information strategy for health and adult social care in England and further plans to put this information revolution into effect.'

The intended outcomes of this work

Key elements of the Information Strategy include:

- information as a health service in its own right – and the need to provide better support to those who need more help to access and use information effectively across all sectors of society;
- enabling information to put patients and service users in control of their own health, care and choices – and making ‘no decision about me, without me’ a reality by enabling people to become real partners in shared decisions about their care;
- giving patients and service users electronic access to and greater control of the information held about them in their own health records;
- collecting data once at the point of care and sharing appropriately for the benefit of improving peoples care and improving the care of other patients and service users;
- transparency of all aggregate data collections to stimulate a market of information providers, which in turn will support citizens, patients and users of care services in making more informed choices;
- setting out a coherent ‘channel strategy’ making it easier for people to access the information they need;
- greater use of information to support clinical benchmarking and improved quality services and outcomes, and to support the research that will lead to better health and better treatment and services for all;
- greater use of latest digital technology in gathering and sharing information (eg real-time patient/service user feedback), and in provision of effective high quality services (eg. electronic prescriptions, telehealth, telecare etc).

Who will be affected?

Everyone, be they patient, service user, carer, health and care professional or someone who has never yet accessed the health and care system should be affected by the aims of this strategy.

Evidence

The evidence considered

While conducting this analysis we reviewed and included responses to the original consultation on *Liberating the NHS: An Information Revolution*, as well as relevant research available online (see references at page 38). In addition to this, members of the stakeholder group who co-produced the document (see 'Engagement and Involvement' section of this document, page 20) provided evidence and input from their respective organisations, which represent a cross section of the protected characteristics identified within the Public Sector Equality Duty.

Disability

- Low levels of literacy affect many different groups in this country and mean that they do not achieve their best possible health and care outcomes.ⁱⁱⁱ The average reading age of the UK population is 9 years,^{iv} 1 in 6 people in the UK struggle with literacy and this means their literacy is below the level expected of an 11 year old.^v However, there are issues around how to identify who needs easy read information. Only 20% of adults with learning disabilities are known to learning disability services.^{vi} As a result of this, there is a risk that those with learning difficulties will not benefit from access to information such as medical records to the same degree as the rest of the population. People with low levels of literacy may have problems in reading web-based information. Even 'Easy Read' Information may need explaining as many are not familiar with the language of health or do not have basic health literacy. As a result of this, there is a risk that some groups such as Gypsies and Travellers (who traditionally have low literacy levels) and/or those with learning difficulties will not benefit from access to health and care information such as medical records to the same degree as the rest of the population.
- We have heard that people with learning disabilities as well as those with low reading-age levels struggle to navigate complicated websites and pinpoint the information they need, or deal with electronic information via e-mail etc. without support, particularly if it is written only. These people usually benefit from face to face discussion of issues, preferably supported by accessible resources to aid explanation and later recollection. We have also heard that if easy read health information has been produced it is less likely to be reprinted or updated, probably as a result of being produced by one-off funded projects to provide easy read rather than being included in general information provision strategies. As a result of this, there is a risk that those with learning difficulties or low reading-age levels will not benefit from access to information via the online portal to the same degree as the rest of the population.

- More than 9 out of 10 people with a learning disability are sexually abused at some point in their life. This could mean that a move towards greater access of information through technology will increase the risk for people with learning disabilities with abusive partners, family or carers who may be able to gain access to personal medical information.^{vii}
- A concern raised during consultation was that, as the market and intermediaries react to this information, they will only begin to develop areas that are cost effective and information around disability may not be deemed to be. This would have a negative impact on groups, such as those suffering with a disability, where information may not be developed.
- Studies indicate that information and advice is best provided through a range of channel and formats.^{viii} There is an opportunity here to improve information sharing throughout the system by opening up a number of different channels, as recommended in the strategy.
- We heard from the Royal College of General Practitioners in their response to the initial Information Revolution consultation that for some people with mobility difficulties, greater use of digital technology could be helpful as it may provide them with electronic access to health and care services. There is an opportunity here to improve things for people with mobility issues enabling them to contact their GP surgery electronically rather than having to attend in person/travel and therefore reducing a pre-existing inequality.
- Blind and partially sighted people all too often receive inappropriate formats of information and are not asked about their information needs.^{ix} If blind people are not asked about their information needs or these needs are not prominently recorded, letters from hospital consultants or outpatients are often in a type too small for them to read. There is therefore an opportunity to reduce an inequality here by enabling the recording of a person's communication needs on their record. However, there is a risk that those who are blind or partially sighted will not benefit from access to information such as medical records to the same degree as the rest of the population.
- We heard from Breakthrough UK in their response to the Information Revolution consultation that realising the benefits of seamless and joined up information is a really important issue as many disabled people find themselves having to repeat the same information to lots of different services, all working in isolation from each other. There is an opportunity to reduce the inequality that currently exists for disabled people by having their information shared securely by the services they interact with, so that they do not have to repeatedly give it.

Sex

- We heard from the Women's Health and Equality Consortium, in response to the Information Revolution consultation that 'a move towards greater access of information through technology will lead to risks for women with abusive partners or family who may be able to gain access to personal medical information'.
- A concern raised around the risk that online patient access to records for women who have abusive partners was echoed by those representing female Gypsies and Travellers who may have abusive partners. However, it was also thought that a lack of paper records could be useful to those living in close proximity to their partner. There is an opportunity to offer people a more secure way of accessing their records.
- Specialist women's voluntary sector organisations can be an important avenue for disseminating information and ensuring specific groups of women can access that information. Platform 51 (a lead partner of The Women's Health and Equality Consortium) working with young mothers in Kent, helped to produce a film, funded by the PCT, aimed to reduce second births among young mothers. The film 'Informed Choices' shows the young women discussing appropriate contraception and was given out in the local hospitals to young women who had recently given birth.^x There is an opportunity to improve information sharing with these groups by encouraging commissioners of health and care services to work with community-led and user-owned organisations, to reach people in ways they can engage with.
- 75% of calls to NHS Direct and 75% of those visiting NHS Choices are female. There is a risk that putting more health and care information online will only increase the inequality between male and female access to information.
- We heard from the Men's Health Forum that despite men's often-reluctant engagement with traditional health services, most men do still care about their health and do respond to messages when the information is presented in formats that appeal to them. We know that men are enthusiastic users of wide range of digital technologies – online systems, mobile phone applications, social networking, gaming, etc. 80% of men used the internet in the last three months.^{xi} 99% of 'Pre-Family Men' say they go online every day or nearly every day, according to Microsoft research, and 50% of them use their mobile phones to go online. There is an opportunity to improve the access men have to health and care information by presenting information on line in formats we know work for them.
- The Men's Health Forum consumer website^{xii} attracts 1.8 million unique visitors a year. 70% of respondents to a malehealth survey in 2009 said the internet was their first stop for health information mainly because it was quick, private and free. The most heavily used sections of the site concern issues that many men find embarrassing to talk and ask for help about (e.g. urological or sexual health problems). Lloyds pharmacy's Online Doctor has also reported that the men using its service consult for similar concerns.

- In partnership with Men's Health Forum, BT developed a pioneering intranet-based lifestyle change programme ('Work Fit') for its workforce that attracted over 16,000 users, most of whom were men. There is good evidence that Work Fit produced significant behaviour change among participants: it was possible to track about 5,000 participants over the 16-week programme and the average weight loss (the main indicator of compliance) was 2.3kgs. A six-month follow-up survey found that a majority of those who lost weight either maintained the weight loss or lost more weight.
- Relate reports that over 40% of users of its online consultation services are male, a much higher proportion than uses its face-to-face counselling services.

Race

- We know that there are members of BME communities who cannot speak and/or read English. There is an opportunity to reduce an existing inequality here by ensuring that accessible information tools such as easy read images are available online for third parties to use to help make information accessible for this group.
- Even if information is available in translated forms, people may not be able to read their own language. Over half of older Bangladeshi and Pakistani women are illiterate in any language and about 20% of older men.^{xiii} We heard from the Race Equality Foundation about the importance of Interpretation (face to face) and translation (remote understanding). Whilst the case of translated documents has been questioned, the need for interpretation is widely understood to be essential to patient experience and care. In old age, the reversion to first language is well documented as it is in mental health conditions. The freedom and control needed is impacted by language and literacy issues, not confined to foreign language needs, but also learning and ability needs. There is evidence from the voluntary and community sector (VCS) that partnerships between specialist VCS groups and GPs, Trusts, and clinics help to improve patient understanding, choice, use of and access to information and therefore the patient ability to manage conditions and make effective decisions. There is an opportunity to improve information sharing with these groups by encouraging commissioners of health and care services to work with community-led and user-owned organisations, to reach people in ways they can engage with. Partnerships with VCS organisations can help the flow of Information and the use of new technologies. Examples of these are seen in:
 - a GP Partnership with and HIV Charity working with HIV positive men, mainly from black and minority ethnic (BME) backgrounds (due to local demography), encouraging them to access their records, attend GP appointments and manage their health. There have been interesting results from this project;

- a charity for blind BME women, has highlighted the pattern and high numbers of women who are going blind as a result of diabetes, due to lack of understanding and reluctance to engage with the medical system. They have championed a number of programmes to encourage women to understand how diabetes can affect them and to self-care effectively whilst using the medical service effectively.
- We know that a lack of primary care data in relation to ethnicity means we have no systematic data available for ethnic health inequalities.^{xiv} The OFCOM (2008) report investigating media use and skills of adults from ethnic minority groups found that, the situation is broadly encouraging in relation to the UK population as a whole. Ethnic minority groups tend to access and use the internet at similar rates in the under 45 age groups although differences are apparent between for example the relatively high levels of use for Indian, Pakistani and Black African and Black Caribbean groups in the C2, D and E categories. All groups in these socio-economic categories have higher rates of access than the UK average of lower employment status groups, indicating that the access of the white population in this socio-economic category group is below average. There is an opportunity here to decrease an existing inequality by improving BME access to health and care information by making more available online. However, it is important to remember that general internet usage does not equal use of 'official'/government resources. There is no information about language used on websites accessed by BME groups, which may not be English.
- There was a concern raised that when peoples health and care data is collated for a particular area or region and used for research or for making local commissioning decisions there is a potential risk that in areas with low BME populations there may be a loss of anonymity, which breaches confidentiality.
- A consistent message from literature on access to healthcare is the need for better ethnic monitoring data in the NHS, and for greater use to be made of these data to justify its collection. There is an opportunity to improve the ethnic monitoring data we have through having better electronic records and systems that can share this data effectively.
- Online patient access to records could be a problem for some Travellers who may not have formally identified themselves and many Gypsies and Travellers will not have or will not know how to get an NHS number. There is a risk therefore that making records available for access online and increasing use of the NHS number will make an existing inequality for Gypsies and Travellers worse.
- We have some evidence that due to a lack of health education some Gypsies and Travellers will share medication. Lack of face-to-face contact, without proper information could exacerbate this.

Age

- Only 18% of older people have ever used the DirectGov website.^{xv} Just 2% of those aged over 65 use the internet on mobile phones. Over-65s are significantly less likely than younger age groups to have home internet access, although take-up is increasing, with 55% of 64-74s and 26% of over-75s having home internet access.^{xvi} Over 60 per cent of 70-79 year olds and 75% of those over 80 never use computers.^{xvii} For older people, we know that the preferred method of receiving information is face-to-face.^{xviii,xix,xx,xxi,xxii} Because of this, there is a risk that older people will not benefit from access to information, such as medical records or health and care information made available on an online portal, to the same degree as the rest of the population.
- Despite a low level of understanding by older people about how the internet works, knowledge of its potential benefits is surprisingly high. Some are already accessing these benefits indirectly through friends and family using the internet on their behalf.^{xxiii} There is an opportunity to improve older people's knowledge by making more information available through a number of channels. Some older people could therefore benefit from accessing information online if we look to make more information available in a way that is 'digital first' rather than 'digital by default'.
- A paper published in the Journal of Clinical Nursing^{xxiv} states that many older adults, discharged from hospital with complex post operative and rehabilitation plans have limited understanding of their discharge instructions. This can lead to high complication rates and costly readmissions. The problem is partly caused by discharge instructions that are not presented in a way that people with poor literacy can understand. There is an opportunity to reduce an existing inequality here by ensuring that accessible information tools such as easy read images are available online for third parties to use to help make information accessible for this group.
- Those under the age of 45 in the BME community are more likely to access the internet than those under 45 in the white community. There is an opportunity therefore to reduce an existing inequality by making more health and care information available to the BME community online.
- We know that younger people have expressed concerns about privacy and who else would have access to their records e.g. parents.^{xxv} The majority of a group of children and young people, surveyed by the Royal Academy of Engineering, supported, in principle, the use of anonymous data to be used for medical research, albeit with significant conditions in place relating to the Electronic Patient Record data regarding security, safety, consent, access and control. Keeping personal data such as medical records private from parents was considered paramount to young people, and a frequently mentioned view.^{xxvi}

- The National Children's Bureau (NCB) ran five health consultation events focusing on health and care information with 79 children and young people aged 10-17 over the past three years. Key messages from their consultation included:
 - 'when accessing information about the quality of health services, young people felt reassured by good and bad feedback as it showed that bad feedback was not being ignored.' 'Young people want to be able to let people know about the quality of services that they have used. They are generally willing to give short amounts of time to feedback about health services but the mechanisms for doing this need to be free, simple, quick, confidential and enable feedback to happen soon after the service.' There is an opportunity to provide more opportunities for online feedback about health and care services;
 - 'there should be a central point for finding out information about health, making appointments and feeding back about services in order to reduce the number of websites you would need to go to.' There is an opportunity for the online portal to bring all these aspects together;
 - 'not everybody has access to smart phones and computers, and traditional methods of engagement are still useful and liked as resources for health information (if well done)'. There is a risk that those without access to the internet will not benefit from access to information via the online portal to the same degree as the rest of the population; and
 - 'young people understand digital media and use it in their day-to-day lives. They should be included in developing new resources, feeding in their thoughts about how the full potential of new technology should be harnessed in a way that creates trust and credibility.' There is an opportunity to improve information sharing with children and young people by encouraging commissioners of health and care services to work with community-led and user-owned organisations, to reach people in ways they can engage with.

Gender reassignment (including transgender)

- We know that one of the biggest healthcare barriers for transgender people is waiting times for gender reassignment and inappropriate general healthcare.^{xvii} There is an opportunity to improve health and care outcomes for transgender people by making more information available to them online, making better transgender information available to health and care professionals and through better data collection specific to the transgender community.

Sexual orientation

- We know that there is a lack of knowledge and awareness among NHS staff about LGB&T health needs; the undergraduate medical curriculum, nursing education and the training of allied health professionals include little input about sexual orientation.^{xxviii} GPs do not always know the questions to ask and their personal feelings may form a barrier to open discussion. Research highlights the need for training and experiential learning opportunities (eg the use of role-play).^{xxix} This may disadvantage the LGB&T community from being able to feed back or engage their GP in shared decision-making. There is an opportunity to improve health and care outcomes for LGB&T people by making more information available to them online, making better transgender information available to health and care professionals and through better data collection specific to the LGB&T community.
- We have heard anecdotal evidence from the LGB&T community about them not being able to access some information electronically due to strict firewalls blocking words such as 'gay' or 'lesbian'.
- A survey of older lesbian, gay and bisexual people's experience of general practice conducted by Age of Diversity in 2011^{xxx} found that some people did not want their sexual orientation recorded on their health record for fear of discrimination if it was shared with people they did not want it to be shared with.

Religion or belief

- We heard from FaithAction that there is a potential negative impact when health information available for individuals who are either being brought up in or who are part of a religious community may not be 'practising' these religions. For example, a young Muslim man who may come from a strict Muslim family but is gay. There is an opportunity here to improve access to information for these individuals by having more information available to them to access through the online portal. We also heard from FaithAction, that for these individuals, there is a potential safeguarding risk if family or community members are able to gain access to personal medical information.
- There is an opportunity to consider how information about health and care can be disseminated to those from different religions. For example, NHS Choices has previously run a healthy eating programme with Tower Hamlets PCT targeted at the South Asian community, aiming to reduce the high levels of diabetes and coronary heart disease. The key strategy was to support local Imams in disseminating health information to their communities by training them on how to use the NHS Choices website and providing them with printed information to distribute.

Pregnancy and maternity

- A survey asking about the NHS Choices website found that a 25% of women reported being given information about the site during their pregnancy though only 12.4% went on to use it. However, first time mothers were twice as likely to use the website as those who had previously given birth.^{xxxix} There is an opportunity to increase the amount of information available to pregnant women by GPs and others working in the health and care system signposting them to the online portal.
- In their response to the Information Revolution consultation, The Royal College of Midwives told us 'The use of information across organisational boundaries is particularly important for mothers and babies within maternity services. The information can be used to compare services by pregnant women, whilst organisations tend to share information regarding vulnerable women and children and best practice' – Similarly there may be an opportunity to improve access to information for nomadic families where maternity care can break down. Gypsies and Travellers have 3 times higher infant mortality than the average.
- The organisation 'CHANGE' has indicated that a lack of support available to mothers with learning difficulties in some areas of the country has resulted in high numbers of children being taken into care. This is only made worse by a lack of statistics at national and local levels in relation to mothers with learning disabilities.^{xxxix} There is an opportunity to improve health and care outcomes for this group who may be able to access better information about their circumstances as well as the services available in their area if learning difficulties data collection is improved.

Carers

- We heard from the Princess Royal Trust for Carers during the Information Revolution consultation that carers often have to coordinate complex care that involves many professionals and agencies and could greatly benefit from meaningful access to and use of information across boundaries.
- We have heard that some carers face problems accessing the information they need about the individual they care for. This is particularly problematic for young carers. There will be times when there is a need to maintain the confidentiality of the person being cared for but there will also need to be appropriate consent arrangements so that the carer has access to the information they need. There will be an opportunity to improve consent and confidentiality arrangements through a review of Information Governance.

The homeless and transient communities

- All acute hospitals should have admission and discharge policies ensuring homeless people are identified on admission and linked into services on discharge. However, an audit of the health and wellbeing of people who are homeless, conducted by Homeless link found only a quarter (27%) of clients admitted to hospital had help with their housing before they were discharged. 85% of clients said they were registered with a GP, the majority permanently. However, this still leaves 15% unregistered, and nearly 1 in 10 (9%) said they had been refused access to a GP or dentist. Like Gypsies and Travellers, the homeless will often not have or will not know how to get an NHS number. There is a risk therefore that making records available for access online and increasing use of the NHS number will make an existing inequality for the homeless worse.
- Poor access to, and uptake of, health services is a major factor in Gypsy and Traveller health. More attention needs to be paid to coordinating and disseminating good practice in Gypsy and Traveller health to avoid duplication of effort and patchy provision. For example, hand-held records (i.e. records that are held by patients themselves rather than by their GP), which have been piloted in Scotland as well as in maternity services within the UK, could be used by all PCTs rather than each PCT devising separate, costly duplicates.^{xxxiii} There is an opportunity to improve access to records for Gypsies and Travellers by enabling them to hold a hard copy of their record.

Engagement and involvement

This work was subject to the requirements of the cross-government Code of Practice on Consultation: <http://www.bis.gov.uk/policies/better-regulation/consultation-guidance>

Gathering and testing the evidence available and testing the policy proposals

Liberating the NHS: An Information Revolution, was part of the Government's agenda to create a revolution for patients – giving people more information and control and greater choice about their care. The Department consulted on the proposals in *An Information Revolution*. A summary of the responses received along with an initial analysis of the impact on equality was published in August 2011 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_129405

This updated equalities analysis has been co-produced and developed with representatives from:

- Afiya Trust;
- Age UK;
- CHANGE;
- Disability Rights UK;
- FaithAction;
- Friends, Families and Travellers;
- Men's Health Forum;
- National Children's Bureau (NCB);
- National LGB&T Partnership;
- Patient Information Forum;
- Race Equality Foundation;
- VoiceAbility; and
- Women's Health and Equality Consortium.

To these organisations, we are very grateful for their insight, expertise and experience.

Summary of Analysis

There are three parts to the Public Sector Equality Duty that the Department of Health, as a public body, has had due regard to while conducting this analysis. The three parts are:

- the need to eliminate unlawful discrimination, harassment and victimisation;
- advance equality of opportunity between people who share a protected characteristic and people who do not; and
- promote good relations between people who share a protected characteristic and those who do not.

Eliminate discrimination, harassment and victimisation

- Any online patient access to records will need to be secure. Similarly, there may need to be a system in place so that certain information – with the patient's full agreement, or indeed at their request – is only viewable at certain access points, for example, the GP surgery.
- There will need to be appropriate advice and support available to patients accessing records. The risks associated with being able to print and share records may not be well understood by some people.
- There will also need to be advice and support to patients who have a dependence on family members who do not wish them to see their confidential information.
- The Royal College of General Practitioner guidance on access to records needs to be reviewed and updated.
- Information that is available online must always be available in other formats. Face to face and assisted learning/support needs to be a strong theme throughout the Information Strategy. In health and care we are talking about 'digital first' rather than 'digital by default'.
- It will be important to keep contact information up-to-date – which may be difficult for highly mobile groups.
- Patient records stored electronically will need to be secure at all times.
- Information needs to be targeted to reach particular groups and co-produced to meet the needs of those particular groups.
- There must be a clear line of responsibility to ensure people understand the information they are given.
- The online portal will need to have design and planning focused around not just using accessible language, but also easy read and appropriate images.

- Work will still be required to explain to Gypsies and Travellers why it is useful to collate ethnic data. Many are still not identifying themselves.
- The centre will need to monitor the market to ensure that information gaps do not open up that negatively affect any of the equality groups.
- The anonymity of data must be ensured.
- 3rd parties will need to consider other means of communicating information, in addition to what is available online. However, online information will be a useful way of informing/reaching some people who may then have the means to spread the word through their community.
- We need to ensure that the facility to book appointments, obtain a prescription and access test results is always maintained in traditional methods (over the phone or face-to face) as well as online.
- There will need to be a cultural change element for staff. There will need to be good change management from senior staff.

Advance equality of opportunity

- For some people with mobility difficulties, greater use of digital technology could be helpful by providing them with electronic access to health and care services.
- There will be an opportunity to improve outcomes for people of different races through improved ethnicity data collection and use.
- There may be benefits around being able to adapt settings i.e. spoken/translated, or easy words and pictures.
- The Gender Identity Research and Education Society (GIRES) response to the Information Revolution consultation stated that, 'Given that 12,5000 people have sought medical care for gender dysphoria and, in most cases, have received or are receiving treatment for the condition – counselling and/or hormone medication and/or surgery – the NHS possesses a substantial quantity of data that could be used to develop precise and up-to-date assessments of their treatment needs and outcomes.'
- The Men's Health Forum has told us that, in their view, the expansion of health information in digital formats will be of particular use to men. A recent initiative supported by the Men Health Forum allowed men to access GP consultations online. Pfizer's ManMOT online health advice service^{xxxiv} attracted 15,000 visitors in the 3.5 months up to mid-November 2010 but, more significantly, enabled 341 men to have a live consultation with a GP or another health specialist on Monday evenings.

- Recent research by Imperial College for NHS Choices found that a significantly large proportion of the population of internet users have been influenced by medical websites to change their health services-seeking behaviour. 37% of NHS Choices users (men and women equally) who use the information service for the GP consultation (70% of all users) reported that it decreased their use of GP services (and did so appropriately). Imperial College estimated that this saves the NHS some £44 million per year. The study also found evidence suggesting that increased GP consultation was seen in male, non-white men who rate their health poorer than the average. This suggests that NHS Choices might be encouraging this group to present with chronic illness earlier and therefore facilitating earlier diagnosis, treatment and potentially slower progression of diseases such as diabetes.
- The new Information Service for Parents aimed at pregnant and new mums and dads will deliver regular targeted NHS information by SMS and email at specific intervals. This is one of the strategy's case studies. SMS will reach over 90% of the target audience.
- Better data collection on quality and outcomes, broken down into the protected group characteristics, should lead to better understanding and improved outcomes for these groups.
- Signposting to pre-existing information can help many vulnerable groups. Websites like Find an Advocate³⁵ can be particularly helpful.
- A positive impact of shared information would be to build up a picture of how many people with learning disabilities access particular health services such as maternity, oncology, dental etc. These are figures that are currently hard to ascertain. Developing an understanding of where in the UK people with learning disabilities are more likely to access particular services would also help to identify where health services are more inclusive.
- People who have learning disabilities can be found in every other group that is classed as vulnerable. Good quality easy read information and accessible web sites developed for people with learning disabilities will be equally useful to other marginalised groups including: older people, BME communities, Gypsies and Travellers, young people and anyone who finds reading hard. However, accessible information should not be 'labelled' as being for people with learning disabilities as it is likely to not only put off other groups, but people with learning disabilities themselves who do not wish to identify as such.
- Given the vast amount of information that the online portal is likely to contain and signpost to it is unlikely that all of it will ever be accessible to everyone, for example, those with learning disabilities or those who are illiterate. Those wishing to access easy read information should be signposted from the moment they enter the online portal into an easy read area where they can access the best easy read information. The accessible information area should not be a dead end, and must link back to other relevant resources/websites.

Promote good relations between groups

- Better data collection on quality and outcomes, broken down into the protected group characteristics, should lead to better understanding and improved outcomes for and between these groups.

Overall impact

The overall impact of this strategy should be a positive one. Detailed above are a number of identified opportunities to advance equality of opportunity. However, as identified in this analysis, there are some groups who have expressed concern about potential negative impacts (for example, victims of domestic abuse and Gypsies and Travellers), but the actions planned or currently being taken to mitigate against these are detailed below.

Action planning for improvement

- There are many groups who are **digitally excluded** and who will not be able to access services and information if they are only available online. The strategy sets out a 'digital first' rather than 'digital by default' approach, making a clear commitment to adopting digital methods to deliver healthcare but making clear that face-to-face contact with health and care professionals will remain an essential, core part of care. Where there are high quality, low cost alternatives to face-to-face contact with health and care professionals then, increasingly, people should have the choice to use them. Many people will need some support to access, use and benefit from technology and information, such as online access to records. Over time, the use of digital and online technologies will simplify services for most people, and will enable care professionals to focus more time on face-to-face care when it is really needed, reaching out to those who have the greatest need for support. Using technology to improve services – and reaching out to the most vulnerable and disadvantaged – can help to ensure that face-to-face and personal support can be made available.
- The NHS and local government will be encouraged to do more to offer **support to people who need help in accessing and understanding information**, so that no parts of society are unfairly disadvantaged. HealthWatch will have a signposting function and should connect to and involve local groups and organisations who work with and are part of communities of interest, geography, demographic and characteristic. This will mean that, locally, people can have access in different ways to the information they need.
- Many community organisations exist to meet the needs of **people who are vulnerable, disadvantaged or because of cultural issues face barriers** when accessing state or publicly run services and do not receive the support they need. Services can work with community-led and user-owned organisations to reach people in ways that help ensure they are fully engaged with their own care. Commissioners of health and care services and provider organisations have a particular responsibility to work with and build on the expertise in these, often very small, groups and organisations (as information 'intermediaries') who can increase access and support, including the interpretation of health and care information into more accessible formats and mechanisms, to those who suffer the greatest inequalities.
- The strategy makes clear that **information needs to be targeted to reach particular groups, kept up-to-date and co-produced to meet the needs of those particular groups**.

- Expansion of our **access to electronic services and to our own health and care records** will need to be accompanied by appropriate safeguards³ – such as confirming our identity, ensuring there is appropriate support for those of us who particularly need it, and in the protection of our personal information. The British Computer Society is leading work to support people in understanding how to access personal health and care information safely and securely.
- As identified in this analysis, there are particular elements **of risk in access to records for vulnerable people** – for instance, people in abusive relationships where access could mean that their partner sees their record and may use this knowledge against them. The Royal College of General Practitioners has agreed to review its guidance on access to records with reference to safeguarding – covering it in more depth and detail.
- As identified by this analysis, there are groups of people who will not know their **NHS number**, or how to find it. Though the strategy will explain how we can help those providing our care by, wherever possible, knowing and being ready to quote our own NHS Number, it will also make clear that some of us may not remember or know how to access this, and, for those reasons our records will always be identifiable in other ways.
- There are currently **gaps in our understanding of health and care outcomes for groups who sit within the protected characteristics**. An early priority will be to unify and standardise the recording and use of information that links to demographics (such as age, sex, and ethnicity), including the NHS Number as the default unique identifier and the information used for hand-over between services.
- By April 2013, the strategy sets out that clinicians and other professionals, systems suppliers and developers, should expect to see an agreed 'route map' setting out provisional dates for specific information standards, prioritised according to need – for instance, including considering ways to ensure we fill the gaps that currently exist in relation to protected characteristics equality data.
- The NHS Commissioning Board, Public Health England and the Department of Health will work together to encourage and support organisations to meet our expectation that **people can provide instant feedback and ratings at every encounter with health and care services**. In the short term, this will supplement national surveys currently undertaken for commissioning and accountability purposes.

3 In particular, for women and girls experiencing violence and abuse or where an individual is experiencing abuse by a carer.

- The Department of Health has made tackling inequalities and promoting equality a key principle in designing the NHS Outcomes Framework. It is using equalities and inequalities breakdowns to assess data availability in order to monitor this commitment. The process of selecting outcomes and determining how to measure them included active consideration as to how the indicators can be analysed by equalities and inequalities dimensions to support action on reducing health inequalities. In addition to the legally protected characteristics, consideration has been given to socio-economic groups and area deprivation, as these are key drivers of poor health outcomes. **Improved information collection and flows are vital to understanding and improving health and care outcomes for the whole population.**
- The Government has commissioned a review (to be led by Dame Fiona Caldicott) of the current information governance rules and their application, to ensure that there is an appropriate balance between the **protection of confidential and identifiable information within our health and care records** and the use and sharing of information to improve the quality and safety of our own care and for the benefit of wider society.
- The Government has committed to consulting on an amendment to the NHS Constitution. Following on from the independent review of information governance, this will make more explicit proposals for the 'consent deal' – and will ensure that all interested parties have a chance to express their views on how they would like **consent for the sharing of personal information** to be sought and recorded.
- Beyond the core national information offer and creating the right environment to support the development of an **information market**, the state will intervene in the information market if it deems it necessary to prevent a significant adverse impact on outcomes, equalities or efficiency.
- The Equality Delivery System (EDS)^{xxxvi} was launched in 2011 to help NHS organisations improve their equality performance, comply with the public sector Equality Duty and strengthen the accountability of services to those who use them. This framework is based on good practice in the NHS and beyond. There has been huge involvement from patients, carers, volunteers and those who work in the NHS in creating the EDS. The EDS, has been designed so that evidence, insight and information are collected and utilised effectively to develop services and create workplaces that are more responsive to the needs of all patients and staff. This also supports organisations as they respond to the requirements of the public sector Equality Duty to **publish equality information** by 31 January 2012 and at least annually after then.
- The Equality and Diversity Council are looking at ways to best utilise the information and data available through the requirements of the public sector Equality Duty and the implementation of the EDS.

- By April 6th 2012 all NHS organisations should have published their Equality Objectives (a requirement of the public sector Equality Duty). The Department of Health has published its **Equality Objectives**^{xxxvii} in line with the NHS Equality Delivery System goals of:
 1. better health outcomes for all;
 2. improved patient access and experience;
 3. empowered, engaged and included staff; and
 4. inclusive leadership at all levels.

Name of person who carried out this assessment:

Abigail Merrett, Department of Health (with stakeholders from relevant organisations – see ‘Engagement and Involvement’ section of this document, page 20).

Date assessment completed:

19 April 2012.

Name of responsible Director/Director General:

Giles Wilmore, SRO for the Information Strategy and Director of Quality Framework and QIPP, Department of Health.

Date assessment was signed:

18 May 2012.

Annex: Where information is a core responsibility or requirement

Legal

- **Health and Social Care Act 2012** – The Act is available online in full at www.legislation.gov.uk/ukpga/2012/7/contents/enacted/data.htm. It includes a duty for the NHS Commissioning Board and Clinical Commissioning Groups to promote the involvement of patients and their carers in decisions about their care and treatment (shared decision making). Although the Act does not set out requirements for patient information in the context of consumer health information, it does underline the importance of evidence-based information in setting out the function of the National Institute for Health and Clinical Excellence. It makes particular mention of the NICE quality standards, advice and guidance (Part 8). There is also a section on Health and Social Care Information (Part 9) relating to the processing of information and the publication of information about health and social care services, (as opposed to publication or provision of health and social care information to patients).
- **NHS Constitution** – The constitution sets out seven key principles, which guide the NHS. One of these relates to shared decision-making:

'4. NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment.' (page 6)

The constitution sets out patients' legal rights and pledges, which the NHS makes to patients over and above their legal responsibilities. Under the heading of *Respect, consent and confidentiality*, these include:

'You have the right to be given information about your proposed treatment in advance, including any significant risks and any alternative treatments which may be available, and the risks involved in doing nothing'

The NHS also commits to share with you any letters sent between clinicians about your care (pledge).' (page 10)

Under the heading of *Informed choice*, these include:

'You have the right to make choices about your NHS care and to information to support these choices. The options available to you will develop over time and depend on your individual needs.'

The NHS also commits to inform you about the healthcare services available to you, locally and nationally (pledge); and to offer you easily accessible, reliable and relevant information to enable you to participate fully in your own healthcare decisions and to support you in making choices. This will include information on the quality of clinical services where there is robust and accurate information available (pledge).' (page 11)

Under the heading of *Involvement in your healthcare and in the NHS*, these include:

'You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this.'

The NHS also commits...to work in partnership with you, your family, carers and representatives (pledge).' (page 11)

The constitution also sets out the legal responsibilities of NHS staff and expectations which the NHS has of them, over and above their legal responsibilities. These include:

'You should aim to view the services you provide from the standpoint of a patient, and involve patients, their families and carers in the services you provide, working with them, their communities and other organisations, and making it clear who is responsible for their care.' (page 17)

- **Public Sector Equality Duty** – The public sector equality duty consists of a general equality duty, which is set out in section 149 of the Equality Act 2010 itself, and the specific duties which came into law on the 10th September 2011 in England and 6 April in Wales (tbc in Scotland) which are imposed by secondary legislation. The general equality duty came into force on 5 April 2011. In summary, those subject to the equality duty must, in the exercise of their functions, have due regard to the need to:
 - eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act;
 - advance equality of opportunity between people who share a protected characteristic and those who do not; and
 - foster good relations between people who share a protected characteristic and those who do not.

These are sometimes referred to as the three aims or arms of the general equality duty. The Act helpfully explains that having due regard for advancing equality involves:

- removing or minimising disadvantages suffered by people due to their protected characteristics;
- taking steps to meet the needs of people from protected groups where these are different from the needs of other people; and
- encouraging people from protected groups to participate in public life or in other activities where their participation is disproportionately low.

Regulatory

- **Care Quality Commission** – The CQC is the independent regulator of health and social care services in England. It checks that services meet the standards set by the government. Three of the 16 essential standards checked by the CQC are of particular relevance to patient information. These are:

Outcome 1: Respecting and involving people who use services;

Outcome 2: Consent to care and treatment; and

Outcome 9: Management of medicine.

As part of their registration with the Care Quality Commission, health service providers are already required to enable 'service users to make, or participate in, making decisions relating to their care or treatment' (Regulation 17 of Health and Social care Act 2008)

- **NHS Litigation Authority** – The NHSLA 'handles negligence claims made against NHS organisations and works to improve risk management practices in the NHS'. It sets out risk management standards, reviewed annually, against which healthcare services are assessed.

The 2012-13 standards 'for NHS trusts providing acute, community, or mental health & learning disability services and non-NHS providers of NHS care', published in January 2012, are available on the NHSLA website: www.nhsla.com/riskmanagement.

- **National Institute for Health and Clinical Excellence** – NICE is tasked with developing quality standards, to be used by the NHS Commissioning Board. NICE is expected to produce 150 standards over the next five years. Those published to date (see <http://www.nice.org.uk/aboutnice/qualitystandards/qualitystandards.jsp>) emphasise the importance of patient information and shared decision making. NICE also produces guidance for commissioners, specific to topics including types of service. (<http://www.nice.org.uk/usingguidance/commissioningguides/bytopic.jsp>) These guides explicitly value information for patients. NICE also produces guidelines for specific health conditions, which include the importance of giving information to patients. Recently,

NICE published guidance on patient experience, which underpins these. *Clinical guidance Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. February 2012. Available online at: <http://publications.nice.org.uk/patient-experience-in-adult-nhs-services-improving-the-experience-of-care-for-people-using-adult-cg138>*

- **Quality Accounts**^{xxxviii} – Most providers of NHS services are required to annually produce and publish a Quality Account to give an account of the quality of those services and their priorities for improvement. Quality Accounts are currently not required in relation to primary care services and NHS Continuing Healthcare, or from organisations classed as ‘small providers’. Roll-out to primary care services (such as GP and dentist services) is under evaluation; in the meantime, organisations that provide primary care services to NHS patients are encouraged to provide an account of their quality where appropriate.
- **Monitor** – Monitor’s role as regulator is to ensure that foundation trusts are well-led, that their leaders are focused on the quality of care patients get and that they are financially strong. NHS foundation trusts are required to provide board statements certifying ongoing compliance with their Authorisation and other legal requirements. Such requirements include, but are not limited to putting in place, maintaining and complying with arrangements for the purpose of improving the quality of healthcare provided by and for that trust – having assessed against Monitor’s *Quality Governance Framework*, complaints and serious incidents. Monitor, through its *Quality Governance Framework* asks NHS Trusts:
 - ‘does the board actively engage patients, staff and other key stakeholders on quality?’;
 - ‘is appropriate quality information being analysed and challenged?’;
 - ‘is the board assured of the robustness of the quality information?’; and
 - ‘is quality information being used effectively?’
- **The Commissioning for Quality and Innovation (CQUIN) payment framework** – The CQUIN payment framework links a proportion of providers’ income to local quality improvement goals. Indicators are set in local areas, but the schemes are advised to address three areas: safety, effectiveness and patient experience. Guidance on using the CQUIN framework is available on the Department of Health website: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091443
Although most goals and indicators are set locally, there is a national goal, ‘To improve responsiveness to the personal needs of patients’.
- **Information Governance (IG)** – Information Governance contains the set of standards that the NHS must follow to make sure that it carries out its duty to maintain full and accurate records of the care provided and keep those records confidential, secure and

accurate. Information governance is a framework or umbrella term. It informs the NHS and its partner organisations of the processes and procedures that it must have to ensure:

- your confidentiality is respected;
- your records are held in secure conditions; and
- information about you is recorded clearly and accurately, so that it can be easily read and relied upon by others providing you with care.

<http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Informationgovernance/index.htm>

Dame Fiona Caldicott has agreed to lead an independent from Government review of the balance between protecting patient information and its sharing, to improve patient care. The Department expects to respond to the panel's recommendations when the review publishes during 2012. The recommendation for a review of the balance between protecting patient information and its sharing, to improve patient care was part of the Future Forum's recommendations to Government on the modernisation of health and care.

- **General Medical Council** – The General Medical Council is the body which registers and regulates doctors practising in the UK. It publishes guidance on good medical practice, which includes providing information in the context of consent:

'36. You must be satisfied that you have consent or other valid authority before you undertake any examination or investigation, provide treatment or involve patients in teaching or research. Usually this will involve providing information to patients in a way they can understand, before asking for their consent.'

Good communication:

'22. To communicate effectively you must:

- a. listen to patients, ask for and respect their views about their health, and respond to their concerns and preferences*
- b. share with patients, in a way they can understand, the information they want or need to know about their condition, its likely progression, and the treatment options available to them, including associated risks and uncertainties*
- c. respond to patients' questions and keep them informed about the progress of their care*
- d. make sure that patients are informed about how information is shared within teams and among those who will be providing their care.*

23. You must make sure, wherever practical, that arrangements are made to meet patients' language and communication needs.'

And providing information to support self-care:

'4. You should encourage patients and the public to take an interest in their health and to take action to improve and maintain it. This may include advising patients on the effects of their life choices on their health and well-being and the possible outcomes of their treatments.'

Policy

- **NHS Commissioning Board (Authority)** – The NHS Commissioning Board (NHS CB) is a new part of the NHS structure, established as a special health authority in October 2011 and expected to take on its responsibilities from April 2013: <http://www.commissioningboard.nhs.uk>

Plans for the board are already in development. The following quote is taken from the document (available at the above weblink) *Developing the NHS Commissioning Board*. The board's stated role is to ensure that the NHS delivers better outcomes for patients within its available resources. This includes:

'the Board will also oversee the extension of patient choice and the expansion of information available to patients. The Board will promote innovative ways of demonstrating how care can be made more integrated for patients and will lead the way in engaging patients and the public in decisions about self care.' (page 9)

NHS Operating Framework – The Operating Framework for the NHS in England 2012/13 (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131360) mentions the importance of patient information:

'3.26 Choice will be of little value to patients without meaningful information. NHS organisations need to prepare for the forthcoming Information Strategy for Health and Social Care and work to:

- *give patients better access to their records;*
- *provide information on outcomes to support choice;*
- *support integrated care through enabling the appropriate sharing of information between organisations; and*
- *allow for better use of aggregated information.*

3.27 On 7 July 2011, the Prime Minister set out a number of key NHS datasets that have been identified for public release¹³ and these will be added to during 2012/13. NHS organisations must ensure the availability and quality of these data sets.

3.28 Patients who have been written to about the Summary Care Record should have a record created by March 2013 at the latest. Data is being published on the proportion of patients with greater control of their care records and we are considering the feasibility of making this an entitlement from 2013/14.

3.29 No single technical change has greater power to improve the integration of services than the consistent use of the NHS number. NHS organisations are expected to use the NHS number consistently in 2012/13 and commissioners should link the use of the NHS number to contractual payments in line with the guidance. There will be punitive contract sanctions for any organisation not compliant by 31 March 2013.

3.30 The protection of sensitive patient information remains a top priority for the NHS. Incidences of data loss continue to occur and in some cases these are both significant and clearly in breach of national guidelines. Data loss is not acceptable where adherence to agreed national policies would have prevented the breach. We expect all organisations to be vigilant at all times and to ensure that appropriate governance policies and guidelines are implemented and followed in practice. This is particularly important during this time of change and transition.

13 <http://www.number10.gov.uk/news/letter-to-cabinet-ministers-on-transparency-and-open-data/> '

- **Quality, Innovation, Productivity and Prevention (QIPP)** – The QIPP programme aims to effect change across the NHS, improving the quality of care (see <http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPP/index.htm>) A key workstream is on long-term health conditions and part of its focus is on supporting people to understand and manage their own conditions.

'Self care / Shared decision making – There needs to be a systematic transfer of knowledge and power to patients to empower patients to maximise self-management and choice. This includes ensuring that; patients engage in shared decision making in order to co-produce a care plan, that both patients and their carers have access to the appropriate information about how to manage their condition and that there is 'no decision about me without me' and that patients are active participants in all decisions about their care.'

- **The Right Care programme** is a QIPP workstream which is developing work around shared decision making: <http://www.rightcare.nhs.uk/index.php/shared-decision-making/about-the-sdm-programme/>

There are three connected aims, to create patient decision aids and a patient decision support service; to embed these in practice; and to create a receptive culture for shared decision making.

'Medicine is traditionally a paternalistic 'doctor knows best' culture where not enough emphasis has been given to the patient's own individual needs, values and preferences. Patients want more information, more support for decision making and self care and more involvement in health care decisions. Unfortunately, healthcare has not always understood this and has therefore not delivered on it. Right Care for Patients – Shared Decision Making will work with the many other groups who are working in this space to move from a paternalistic culture to one of mutual respect and co-production. We do not underestimate the challenge.'

- **Information Standard** – The Information Standard is a quality mark scheme, set up by the Department of Health, to help the public identify sources of evidence-based health and social care information. The scheme evaluates the systems used by information producers and accredits organisations with robust systems – rather than evaluating individual resources. Organisations (including NHS bodies, local authorities, businesses and charities) who wish to be accredited by the scheme are rigorously assessed. For more details visit the Information Standard website: <http://www.theinformationstandard.org>
- **Information Prescriptions** – Information prescriptions aim to make it easier for professionals to find and tailor trusted information on health conditions for patients: <http://www.nhs.uk/ips>

The *User Guide for health and social care professionals* sets out some of the thinking behind the scheme:

'Reliable, accurate information is fundamental to making informed decisions and choices. It helps people regain a sense of control over their lives and can reduce the fear that the diagnosis of life-threatening or long-term illness may bring.'

There are clear benefits to the NHS in offering patients reliable, accurate information. There is good evidence that patients who are given and supported to use information to make decisions about their care:

- *are able to manage their long-term conditions more effectively;*
- *use NHS services less often than patients who have not been given information;*
- *choose less invasive (and less expensive) treatment options;*
- *have fewer repeat consultations with health professionals;*
- *have fewer unscheduled admissions to hospital, and lower rates of readmission;*
and
- *comply better with medicines regimes, leading to fewer wasted drugs.'*

- **The NHS Future Forum** – The NHS Future Forum was set up as part of the government's listening exercise on the *Health and Social Care Bill*. Its recommendations and summary report are available on the Department of Health website: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127443

One of the key areas the Future Forum highlighted was information.

'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.'

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