



Notes of the Healthwatch Islington Public Meeting

care.data

22nd July 2014, Voluntary Action Islington

Healthwatch Islington has a role in gathering people's views and providing people with information about local services and health and care policy. We are not a decision-maker in this process, and we are not a campaigning organisation but we do want local people to be informed about services, and to be able to inform how services develop. We want to hold bodies to account on how they are engaging people on these important issues. Healthwatch Islington director Shelagh Prosser chaired the meeting.

This summarised report of the meeting will be available on our web-site (and can be sent in hard copy on request). It includes where to go for further information.

Robin Burgess, NHS England, Regional Head of Intelligence for London was invited to present on the aims of care.data and how this is progressing. NHS England commission primary care services including GP services as well as a range of specialised services. Sam Smith stood in for Phil Booth from Med Confidential to talk about some of the concerns that people may have about data sharing of this kind. MedConfidential is a campaign group which seeks to ensure that every flow of data into, across and out of the NHS and wider care system is consensual, safe and transparent.

Robin Burgess, NHS England began his presentation by outlining the aim of NHS England to use this data for improving outcomes and patient experience. He acknowledged the problems and limitations of the work undertaken so far to introduce this idea. In January 2014, leaflets were sent to homes across the country to let them know about NHS England's plans to share patient data and explaining how patients could opt out of this if they did not want their data shared. Only about one in ten households in London received this information.

Robin explained that patient data can be shared in two ways; for primary and secondary purposes. Primary sharing of data involves sharing data between two health or care professionals, such as from one clinician to another. It involves implied consent from us as patients.

The Summary Care Record, which also followed an opt-out model, is about primary data sharing. These records list a patient's medical records online for use by their consultants and which they can also access themselves. For more information see links below. They may include information such as a patient's allergy to penicillin for example. Care.data is a proposed programme of secondary data sharing, branded as 'better information means better care'. It would mean that researchers as well as organisations

including private companies such as GPs, insurance companies and others, could share patient data to improve health outcomes across the UK. This would build on existing data sets and could improve care and treatment. The overall aim is to link data from GP services, hospitals, community services and social care.

Currently clinical audits of this kind of data have resulted in improved care for people with diabetes, stroke and congenital anomalies. Information gathered on hip and knee replacements enabled researchers to ascertain which prosthetic implants were more effective, this resulted in one model being withdrawn altogether.

Robin outlined the flow of information. NHS providers share data with the health and Social Care Information Centre. This information then goes one of three ways. In an **identifiable form** data is shared with clinicians and patients, and also where a communicable (contagious) disease is concerned data on patients can be shared in order to avoid the spread of the disease. **Aggregate data**, which is anonymised, is shared with researchers and in publications to give an overview of health in Britain, and for many management and service improvement purposes.

The third way that data is stored and shared, and that which is relevant to the care.data discussions is in the form of potentially identifiable, **pseudonymised data**.

Pseudonymised data (data that contains identifiers but is encrypted) is different from anonymised data in that it can still include a lot of information that could identify us, for example our full post code and date of birth.

The Care Act 2014 is designed to improve care and support for adults and the law relating to support for carers, to make provision about safeguarding adults from abuse as well as integrating health and care services and setting out a role for Healthwatch organisations to be involved where health Trusts go in to administration. It includes a clause that states that the information centre may only share data for the purposes of *45 (1A) (a) the provision of health care or adult social care, or (b) the promotion of health.*” Some people have expressed concern that this clause is too broad. There are concerns about who could access this data and to what ends they would use it. The Health and Social Care Information Centre would include an ‘ethics’ committee, informed by a Code of Practice for determining who should have access to patient data.

NHS England want to introduce this scheme as an ‘opt-out’ scheme, meaning that those who don’t want their data shared have to contact their GP and inform them. The alternative is an ‘opt-in’ system where we make contact if we want to be part of this system. **Some people think that it would be better to create a system that patients consciously choose to be part of and ‘opt-in’ to.** NHS England believes that not enough people would contact their GP if they wanted to share their information and this would mean data sharing would be less valuable. Donor cards, where you choose and sign up (opt-in) to donate body parts after your death) was used to demonstrate that many

people do not opt-in to ideas even if they support them. **It has been suggested that the system could have two levels; opt-out of sharing for research purposes and opt-in to sharing for commercial purposes.**

Sam Smith, MedConfidential, talked about the risks of data that includes too many identifiers revealing the identity of patients. This could also lead to a break down in trust between patients and clinicians as patients would not feel that their data was safe. He gave examples of companies who already have access to patient data and advertise this as a business opportunity to others. He stated that the amendments to the Care Act, which mean that legislation now states that patient information should be shared for 'the promotion of health' but it is not clear how far this goes to restrict who can access our data.

Sam noted that the British Medical Association, which 'defends doctors rights and champions the profession' has voted for an opt-in service.

NHSEngland is proposing to test the care.data model in a few areas across the country. These areas will be called 'pathfinders' and learning from this experiment will inform the wider introduction of the system. Sam suggested that Healthwatch should make sure it knows where the 'pathfinder' pilot projects are and what can be learned from them, though the pilots will not include Islington.

Questions and answers

Participants asked about how they could opt out and raised concerns about who data could be shared with, breaches of security and undervaluing data that is being sold on.

Robin: NHS England recognise that they need to do some things differently in raising awareness of the opt-out system (for information on opting out, see below). Additional controls have been put in place to ensure that data is only shared when it should be, and a code of practice is being developed around this. He acknowledged that all systems have flaws and that this had given rise to some breaches of security, though NHS England would monitor and regulate against breaches.

Sam: Originally the Department of Health were not planning to provide any option to opt out of this scheme, but campaigns like MedConfidential have changed this. He felt that there was further to go in making this system workable and transparent. He reiterated the need to keep an eye on pathfinders. He questioned whether patients can only 'trust' government bodies such as the Health and Social Care Information Centre (HSCIC), to make good decisions about how our data should be used or whether they can actually know how their data has been used. He noted that the HSCIC did know where data is flowing and where this has been used and that patients could demand greater transparency around this.

Questions were raised about the accessibility of information about care data and how children and young people's information would be affected.

Robin: NHEngland are working with organisations such as Mencap to improve the reach of their communications to groups with special needs. The usual rules of consent will apply where children and young people's information is concerned.

One participant raised concerns that records still don't really belong to the patient, consent should be an on-going process, with the patient in control. Others argued we needed to take longer to get the opt-out system right

Robin: A full Opt-in system won't work, but we don't need to rush, we need take longer and make a better plan regarding how the data will be used and people express their views.

Sam: We still don't know how NHS England are planning to present this to the public and how they will ask them about their views on whether they agree with the system. How this question is posed will obviously have a big impact on what answers people give. Healthwatch organisations may be able to work with NHEngland on this.

Participants were keen to know why data could not be anonymised rather than pseudonymised to protect our identity and raised concern about how patients could be sure they can trust doctors with their information.

Robin and Sam had differing views on whether pseudonymised data was needed to give a sufficiently accurate picture of health and need in an area. Both emphasised that this programme of data sharing was about sharing information about large numbers of patients and not individual patient notes.

Issues to consider

Healthwatch Islington will raise the following issues with Healthwatch England and NHS England. Members may wish to consider them when deciding whether or not to opt-out.

- Using less identifiers or less specific identifiers when recording the data (for example year of birth instead of date of birth),
- Operating an opt-in system,
- Operating a two-tier system which would include an opt-in system for sharing data for commercial purposes.

Key terms

Care.data - proposal for data about large groups of patients to be shared with researchers and others. It would be **pseudonymised**.

Pseudonymised data - names have been removed, but other information that could identify us when noted together, such as full postcode and date of birth.

Identifiers - research terminology for information which identifies the subject (in this case this would include full date of birth and medical conditions).

Primary data sharing - sharing individual patient data between health professionals

Secondary data sharing - sharing data about large numbers of patients with researchers and others (which could include private companies)

Not to be confused with:

Primary care - care provided by GPs, dentists and opticians.

Secondary care - care for which we are generally referred, often takes place in a hospital setting.

Further information

- Care.data leaflet from NHS England

<http://www.england.nhs.uk/wp-content/uploads/2014/01/cd-leaflet-01-14.pdf>

- MedConfidential Opt Out information, including Opt-out letter (HWI is not recommending that you opt-out, just letting you know how to do so)

<https://medconfidential.org/how-to-opt-out/>

- The Summary Care Record

<http://www.nhscarerecords.nhs.uk/>