



On behalf of the care.data Advisory Group

Care.data and the future of health data sharing (1): Report from the first care.data workshop in Peterborough; 26th July 2014

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Foreword

As Chair of the care.data Advisory Group, I am pleased to send you the summary of the group's first public discussion session about the work we are developing to inform and assure the programme known as 'care.data'.

As a group, we have been keen from the beginning to ensure that we not only have discussions as experts and as interested organisations, but that we also have a discussions with those who would be involved in the implementation of such a system, who see particular risks or benefits for 'data linkage', or who are just simple interested. We wanted to do this to ensure we remain grounded in what 'real' people think and to allow us to sense-check the much bigger and broader comms the programme itself is running.

The NHS in England already has some of the best information and data systems in the world and our hospital episode statistics (HES) system has been collecting information about every hospital admission, nationwide, since the 1980s. However, we are currently missing information for most of the care provided outside of hospital which means there is a gap in our knowledge. For example, we would like to know the average time taken – in every area of the country - between someone seeing their GP with bowel symptoms, to being diagnosed with colon cancer at the hospital. In order to know this, we would need to link GP and hospital data together.

The intention of the care.data programme is that the NHS will know more about care being provided to patients locally, and how well GP practices and hospitals are working together to provide that care. The goal is to improve health care in local communities, and also to do some broader research which will improve the health of everyone in the longer term. By studying this information in formats that identify conditions but not the people who have them, analysts can check that patients are receiving safe care in every NHS setting, and understand what needs to be done to improve it.

The care.data Advisory Group is considering the questions and concerns being raised by all stakeholders - patients, the public, health professionals, NHS staff, privacy experts and others - and advising NHS England and the Health and Social Care Information Centre about what should be the potential solutions or ideas for amendments to the care.data programme.

This first summary of the Advisory Group discussion we recently held in Peterborough in July, will be the starting point of a series of our next session in London on the 6 September. At each meeting we intend to examine more deeply the issues of interest to stakeholders and begin to refine what we say back to both NHS England and to the Health and Social Care Information Centre about how to address the concerns and issues of staff, patients and members of the public.

Ciarán Devane

Chair, care.data Advisory Group
Chief Executive of Macmillan Cancer Support and NHS England non-executive director

Introduction

On the 26th July 2014 Regional Voices, on behalf of the care.data Advisory Group, organised a meeting in Peterborough. The meeting involved a number of stakeholders and partners across the voluntary, private and statutory sectors to discuss issues and potential solutions relating to care.data. Geraint Lewis (NHS England Chief Data Officer) set the scene with an overview of the care.data programme followed by questions and facilitated discussion. This document, produced by Regional Voices, is a record of that meeting.

Key to respondees:

CD	Ciarán Devane	Non-Executive Director, NHS England. CEO, Macmillan. Chair of the care.data Advisory Group
SS	Sam Smith	MedConfidential, member of care.data Advisory Group
All other responses from members of the NHS England team		

Questions

Q1. Are there circumstances when identifiable patient data that reveals who the patients are could be released?

NHS England – Yes but only in defined circumstances such as a public health emergency or a court order. Source data is collected with four identifiers:

- NHS number
- Postcode
- Date of birth
- Gender

This information is sent to the Health and Social Care Information Centre (HSCIC) accompanied with a series of codes reflecting individual conditions and treatments. On arrival at the HSCIC, the data is joined up with any other information held about the patient (such as information collected from NHS hospitals) and then the four identifiers are removed and replaced with a unique, meaningless pseudonym. There are only very limited circumstances in which access to source data with the identifiers will be allowed:

- Court order (e.g. during a murder investigation)
- Major public health outbreak (e.g. to track those likely to have come into contact with the outbreak)

In the future, such information may also be made available to organisations that have obtained the patient's explicit consent, or that have been granted legal approval following independent advice from the Confidentiality Advisory Group (CAG). In order to achieve CAG approval, applicants to the CAG would need to demonstrate:

- Firstly that accessing the information was in the public interest and for the benefit of the health service;
- Secondly that it is not possible to just use information that does not identify patients;
- And thirdly that it is not possible to ask patients for their permission.

SS – There is still some risk that although identifiers have been removed the data record itself could still be identifying. E.g. newspaper reports of a road traffic accident could be cross referenced with road traffic accident admissions data and date of admission to identify the individual.

CD – There needs to be a level of protection even for the data with pseudonyms requiring a level of security of access and restrictions on use.

NHS England – Yes indeed. There are a range of existing safeguards for data plus some new protections as a result of the Care Act. Protections include civil and criminal penalties for data misuse (including large fines) and a 'one-strike and you're out' policy for anyone that misuses the data. In addition, we will be encouraging analysts to come to the HSCIC to access the data rather than receiving the data on a hard drive. These new 'secure data facilities' are being worked through at the moment but could include requiring swipe cards to get into the room and preventing analysts from taking any paper out of the room.

Q2. This must be very expensive – who will pick up the cost? Will NHS England make money out of selling this data?

NHS England – There are two potential profit-making opportunities with this data:

1. Selling access to the data for research or other purposes. We have heard three voices on this question:
 - Give the data away free of charge in order to encourage better use of the data to improve patient care.
 - Make a profit from selling the data and reinvest the profits in the NHS.
 - Middle ground – cost recovery from who we are sharing it with.

We are adopting the middle ground.

2. Profit as a result of using the data – e.g. companies developing new products and services as a result of the findings of data analysis. Parliament debated this issue recently and the Care Act was introduced with the requirement that data must only be used where there is a benefit to health care, social care, or public health. It will be illegal to make the data available for purely commercial purposes.

CD - The Office of National Statistics works like this. But it does cause technical issues when needing to add in other data for comparison, such as comparing Welsh and Scottish data with English.

**Q3. Are patients asked when they go into hospital if their data can be shared?
Can you opt out of hospital data?**

NHS England – No, you are not asked as a matter of course. All hospitals do however have to follow fair processing protocols. Patients undoubtedly need to be better informed of both the benefits and risks of sharing their data. However, there is a wide variation in the messages we are receiving from patients about the level of control they are seeking; some want a simple opt-in / out, others want more detailed control over how exactly their data is used and shared.

Yes you can opt out of hospital data sharing at the moment; however this is not easy to do. You have to contact the hospital in question directly, usually via the Information Controller, and ask to opt out.

Q4. Will patients be able to view / amend / annotate their data?

NHS England – Patients can already view their own data but we would like to make this easier for patients than it is at the moment. We have to be sure the information is correct as there are concerns around the quality of data. We have heard that many patients are keen to annotate their own data. In terms of correcting data, this is a complicated issue especially if national statistics have already been generated from the incorrect data. This is a topic we need to do more work on.

SS – There is a complex debate about whether you should be able to remove data from the record. For example incidents of misdiagnosis of a particular condition could be

analysed to improve future practice and service improvement in relation to that condition and would therefore be helpful if it remained on the record. However, misdiagnosis of certain conditions (e.g. alcoholism) could negatively impact on an individual for example if it were raised during court proceedings.

[An attendee commented that misdiagnosis in itself is a valid research area; you wouldn't want to remove all cases of misdiagnosis.]

Q5. What happens to the data when you die? Can future generations access it after my death?

NHS England – Again, this is a complex topic due to inconsistencies in different laws. However, in general, care.data is aiming to ensure the same level of data security whether the patient is alive or deceased. There is guidance on this issue from NHS England, the GMC and the Information Commissioner's Office, which we will follow when implementing care.data.¹ Posthumous data could be / is extremely useful for investigating hereditary diseases or in tracking the safety (survival rates) of particular interventions; particularly surgical.

SS – the last data entry in the record is 'cause of death'. Some privacy laws no longer apply after death however the NHS constitution affords some level of privacy and there is current debate over the ethics of who should have access to the data after death.

Q6. Will carers, nearest relatives and other appointed representatives have the same rights to accept or refuse data access? Can data be viewed by carers for those with reduced capacity e.g. learning disability?

NHS England – Yes if there is a Lasting Power of Attorney for health and welfare in place.

¹ This guidance can be accessed at:

<http://www.nhs.uk/chq/Pages/access-to-medical-or-health-records-of-someone-who-has-died.aspx>

http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_after_death_disclosure.asp

http://ico.org.uk/for_organisations/guidance_index/~/media/documents/library/Freedom_of_Information/Detailed_specialist_guides/information-about-the-deceased-foi-eir.pdf

Q7. Will patient complaints also be recorded in a national database?

NHS England – There isn't a separate organisation to undertake this role however there is an ongoing programme to try and learn from complaints recorded.

Q8. Is there consensus over opt-in or opt-out?

SS - According to MedConfidential surveys 20% of the general public want to opt-out, 20% want to opt-in and 60% either don't care or will do nothing; they trust the NHS to look after their data. Transparency to patients of exactly who has used their data allows us to stop asking the question 'where does my data go?' and ask more sophisticated questions such as 'why did they get access?' and 'what are they doing with it?'

NHS England – Some people only want one form to opt out, others want more nuanced control.

SS referenced the discussion earlier; if you were diagnosed wrongly, do you remove it or annotate it? It poses a huge range of issues.

Discussions

Discussions were then focused around four topics on the sticky wall.

Keeping you Informed

“What about assurance of security – how can you give this?”

NHS England - No data can ever be 100% safe, but we have many securities and safeguards along with penalties in place.

“How will these be communicated?”

NHS England - Through a variety of channels and in varying depths.

Confidentiality and Security

A HealthWatch representative commented that they had attended several Healthwatch workshops on this and we assumed that confidentiality and security is in place.

SS – Gave the example of a screening company that shared the same username and password across the organisation giving rise to a security breach of health data.

NHS England – Yes but this hasn't been communicated well enough. Free text will not be extracted from patient notes, just the coded information.

“Will social care and the NHS be joined up by data sharing?”

NHS England – The vision is to bring together data about health and social care. Only with this joined-up data can we test the hypothesis that improved social care leads to better health.

The Opt-Out Process

“We need a consistent approach to opting out of the process nationally.”

SS – 10% of GPs nationally had opt-out problems. Is learning from that being taken forward?

GL – Yes, we will be working with a group of pathfinder GPs to flush out all these issues.

“A single opt-out is a good idea. But if you put complicated bits in then they'll say no. Frustrating but you don't want to push patients.”

NHS England – There are others who take the opposite view. When we consulted with learning disability groups many people asked to make the form simpler and clearer, whereas the Autism charities said the exact opposite: they were requesting much more detail.

“I remember getting a leaflet and all I remember from it was ‘do nothing’, so I did.”

There followed some discussion around two tracks of sharing data amongst GPs and hospitals, one being for secondary use and one for direct care for medicines and allergies (Summary Care Record). They had separate governance and it was confusing (even for the NHS) and some people think they've signed up for one but it is in fact the other.

Who will data be shared with?

“If health companies make a profit by selling products developed using this research data back to the NHS through the form of medicines, surely we could ask for a discount?”

NHS England – But they also bring their companies over to the UK and improve the economy so there is a wider gain.

“When HIV came along insurance companies used to ask ‘have you been tested?’ They then loaded premiums if people replied they had, even if they weren't HIV positive. Is there risk that this can happen again?”

NHS England – There is no intention to release data for that kind of use. Under the Care Act it will be illegal to make the data available for purely commercial purposes such as setting insurance premiums or direct marketing.

NHS England – Some evidence indicates that people would be more relaxed if they could see and annotate their own data. From April 2015 you can access your own GP records.

Summing up points

Ciarán summarised the morning's discussions then the group were asked to give their main point for the advisory group to take away.

- People need to understand it's a helpful tool for them. If you are new to an area and have, for example, a child with a chronic illness you would want to know if they had the same quality of services there. This can't be done without records like these.
- More effort needs to be made to make it clear what is and isn't shared.
- Some people don't have internet access or don't use the internet. This needs to involve a wider variety of communication approaches and be accessible for all. Communication also needs to be tiered in complexity so people can access the level of detail they want.
- GPs and professionals need education in understanding and explaining the opt-out. Their attitude to the programme could bias someone from opting out. Receptionists need educating as they are the first people patients see.
- Advocacy and voluntary organisations will be useful partners in sharing information as they are trusted organisations.
- The process should avoid placing extra burden on GPs; consider how wider frontline staff could help deliver this.

In closing Ciarán wrapped up by saying this discussion is clearly wider than the care.data project; 'big data' generally needs repositioning at the heart of the debate and understanding by the public needs to be improved.

Note: Thanks to all participants for giving up a Saturday morning. These notes don't capture everything, but hopefully you feel it represents the issues and tone of the conversation well.

For more information about care.data or to get involved please visit the NHS Choices website at www.nhs.uk/caredata

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