Care.data: the debate
Summary report

Executive summary

Care.data is a new NHS England scheme aimed at gathering patient data from GP records and merging them with current hospital records. Data will be collated centrally by the Health and Social Care Information Centre (HSCIC) and will provide a picture of care being delivered in different parts of the healthcare system. The data will be used to support research and the development of new services and treatments, as well to assess the performance of NHS services.

Patients, GPs and the media have been critical about this use of personal data and the lack of publicity around care.data. Because of this criticism, the proposed roll out in April 2014 was delayed to ensure the public understand the issues and to clarify certain aspects.

In response to this, Healthwatch Essex held a public debate to highlight and discuss issues of concern. A panel of top experts was joined by around 40 members of the public in a debate held in Chelmsford on 24th June 2014. The debate was chaired by Dr Tom Nutt, Chief Executive Officer of Healthwatch Essex, and a 5 minute film of the debate is available to view here.

The panel consisted of:

- **Marjorie Warnock**, a resident of Chelmsford and an active member of the Patient Reference Group at Sutherland Lodge Surgery;
- **Dr Shane Gordon**, a local GP and Chief Officer of North East Essex Clinical Commissioning Group, based in Colchester;
- **Professor Paul Pharoah**, a cancer epidemiologist from the University of Cambridge, and an expert in dealing with large sets of population-level data;
- **Edward Hockings**, bioethicist and health blogger and founder of the 'EthicsandGenetics' website, who explores the ethical issues of data sharing;
- **Aasiya Moreea**, Regional Head of Intelligence for NHS England, in attendance to clarify factual and technical aspects of the care.data scheme and to listen on behalf of NHS England.

The debate began with the showing of the NHS England care.data public awareness film. At this point, each of the panel had the opportunity to set out their initial point of view, before tackling questions received from the public.

The debate was wide ranging, and a number of important issues were aired:

- The views of panellists and the public were, in many ways, polarised between those who saw clear benefits to care.data, and those who had significant concerns about the practical risks and ethical implications of the scheme;

- The debate showed that public awareness of the 'pros and cons' of the scheme is limited. This is of obvious concern, as the scheme relies on people having sufficient information to allow them to exercise their choice to opt-out of sharing their data, or indeed to agree to the default opt-in position. The debate showed that many people do not feel sufficiently informed to exercise this choice;
- The question of trust was a recurrent theme – this suggests that more work needs to be undertaken to understand and to convey to the public (and professionals) the ethical implications of the scheme and the practical safeguards that would be required to build trust;
- The debate illustrated how the issues surrounding care.data are complex. Despite this, the interaction between the panellists and the public showed that people have an appetite to explore and understand complex issues, as long are they are expressed clearly and simply.

Themes from the debate

In the following section, we have analysed and grouped the main themes to have emerged from the debate. These ranged from the ethics of collecting medical data to the practicalities of how NHS England has approached the implementation of the scheme.

Public awareness

A key theme raised at the outset was the question of public awareness of care.data and, specifically, the information leaflet and the video which were used by NHS England to inform the public. There were concerns raised by panellists and members of the public that many people may still not have even heard of care.data. The leaflet sent out by NHS England was criticised for being sent out alongside junk mail. It was also argued that the public awareness film does not provide patients with enough information to make an informed decision and has been produced for a low level of understanding. At this point, questions of trust were raised — as members of the public may not trust that the scheme will run as claimed if the awareness campaign has been inadequate in setting out all the issues and addressing people's concerns.

NHS England acknowledged that these issues had been raised frequently at public listening events, and that NHS England is aware it has not informed the public as much as it should have done. It was confirmed that new materials will be produced to inform the public.

Members of the panel suggested that a more informative leaflet should be produced alongside more coverage in the national media, including TV. The importance of the awareness campaign was stressed, as everyone should have the opportunity to make an informed choice. For that reason, it was also suggested that there needs to be information for different levels of understanding or interest. It was also suggested that GP surgeries could use more imaginative and comprehensive forms of communication, such as email or text, or write to individual patients.

Commercial use of data

Members of the public and the panel expressed a variety of concerns in relation to the potential commercial uses of data. One panellist described how his 'gut reaction' to the commercial use of the data felt wrong, but that it is difficult to determine why. This theme was echoed by members of the public, who suggested that commercial use of data was instinctively wrong, even though they were happy for data to be used by public and charitable organisations. One argument was that the idea of data being sold creates a fear that it could be misused and potentially re-identified – and then used, for example, for marketing purposes. It was argued that we dislike private companies purely because they are private (and hence not transparent). Although members of the public felt more comfortable about charities or public researchers using data, there was a suggestion that these organisations may not necessarily be as transparent as we think. We must be alert to this complex issue, and there was agreement that the public must have trust in the people who are given ethical approval to use data for research and service improvement purposes.

It was clarified that data will not be sold on to private companies unless they could prove it was for the benefit of the public by improving the quality of NHS services or for clinical research. However, following the release of the Partridge Report (2014), it is in the public domain that the HSCIC has previously sold hospital data to insurance companies. The perception (and reality) of this sort of activity has led to public mistrust and the belief that this could happen in the future with medical and, potentially, genetic records. The transparency of companies that use the data was also questioned. For example, pharmaceutical companies have not always reported all clinical trial data, which meant they could be selective in their use of evidence. There is a need for the processes to be transparent so that people can trust the companies who have been given access to the data.

Ethical issues

Ethical concerns were raised by both the panel and the public, relating to how care.data impacts upon both individuals and society as a whole. There were, for example, worries around confidentiality and changes to the GP patient relationship. The patient member of the panel expressed that she felt uncomfortable with the identifiers (such as NHS number, postcode, and date of birth) being taken from GP records and stored at the HSCIC. Concerns about this extraction focussed on the possibility of data being re-identified. On the other hand, it was argued that with large data sets it is very unlikely data would be re-identified, and no harm has been caused by data held so far. This was challenged on the basis that it depends on your definition of harm and that intrusion and breaking privacy could be seen as harmful. Yet there was no consensus on this, as one member of the public said if that if the data identified that he could be at risk of developing an illness they would like to be informed. On this point, the panel clarified that that data is anonymised and at a population level, so that it cannot get back to an individual and that — if we were to enable researchers or clinicians to contact patients — it would raise new ethical issues.

Members of the public also expressed worries about which diagnosis codes would be extracted. The example raised was that of having a mental health condition and not wishing for that information to be shared. It was confirmed that some 'sensitive' codes, such as termination of pregnancy and mental health conditions, will not be included as part of the extract. However, this raises more questions over what people perceive as sensitive data and who arbitrates on this decision.

The chosen opt-out system was seen by some members of the public as unethical. The default system, which means that data will be extracted unless a patient explicitly rejects, caused much concern. The opt out system relies on everyone knowing about the scheme, being able to make an informed decision and being given the choice to opt-out if they so wish. The GP on the panel expressed concern, suggesting that opt-out may not be the safest default system. He described how the opt-out system for summary care records had been difficult to administer. The example was given of insistent messages on a GP's computer to prompt for these to be uploaded. There was a concern that if an error is made by clicking the wrong button, GPs could inadvertently betray a patient's choice and then not be able to retrieve records.

Queries were raised over the ownership of the data and what happens if there are inaccuracies in patient records. It was pointed out that a patient can mention to their GP if they believe their record is incorrect, and this can be changed if necessary. It was also highlighted that these errors are important for managing an individual's health, but that on a population level these errors are expected and therefore managed as part of the analysis of the data. On the matter of ownership, the patient perspective was that we own our own data and therefore have to give consent for its use. In fact, it was clarified by NHS England that your medical record is about you, but is not owned by you. It was also argued that on some level there is societal ownership of the data, as society through taxes and democratic processes, has paid for the care that makes up that record.

Security

Concerns were expressed around the security of the data collected and how the NHS would ensure this. Members of the public raised questions about the storage of the data, and NHS England provided assurance that the security measures used for Hospital Episode Statistics would be used, and that these had not been compromised previously. Despite this, however, it was argued that it is not systems that fail, but often the humans that manage them, and therefore it is necessary to ensure that the benefits outweigh the risks. It is important that the public are made aware of the safeguards in place to ensure the security of data.

How will care.data benefit patients?

The question of public benefit was considered fundamental by all panellists, but questions were raised by the public and the patient panel member around how care.data would actually help improve the care of individuals. For example, there was agreement amongst panellists and the members of the public that there is a need for health and social care to be more joined up and for GPs to be better

informed about treatment received in hospital — but it was clarified that care.data will not do this for individual patients.

Indeed, there was a relatively poor understanding from the public around how care.data will help improve healthcare. Professor Pharoah set out the case for researchers to be able to access population-level data, not only to advance clinical research but also to plan services. An example around a bowel cancer research project was given to help clarify this matter. This looked at both GP and hospital records for people with bowel cancer, and showed that most people were diagnosed within an emergency setting. These people had a lower chance of survival than those diagnosed earlier. This promoted an awareness campaign informing people to go to their GP if they have any concerns, therefore improving their outcomes.

But the confusion between individual benefit and public benefit illustrated a need to provide distinction around how improvements are on a population rather than an individual level. Whilst for some this overall benefit was instinctively seen as a good thing, it was argued that care.data could be perceived as providing a system that, rather than meeting patient needs, could advance commercial or other 'agendas' — a perception that would further creates public mistrust.

Summary and recommendations

In summary, the debate demonstrated the diversity of views held by professionals and public alike around care.data. The themes that were evident in the debate were public awareness, commercial uses of data, ethical issues, data security and how care.data will meet patient need and provide public benefit. It is evident that NHS England has much more work to do in terms of clarifying and explaining the complexities of care.data — both in principle and practice.

On the evidence this debate, it is recommended that:

- The information provided to patients, professionals and the public should reflect the complexity of the issues at hand, but be able to explain the many aspects of care.data in a way that is straightforward and simple to understand. This will help the public to make an informed choice in respect of opting in or out;
- A more informative public awareness campaign — which better covers areas such as the benefits of care.data, as well as the ethics, data security and safeguards — would help to build trust in the process and the wider healthcare system;
- NHS England considers how it engages the public and professionals, specifically on care.data, and also on similar issues now and in the future. There is a clear need and appetite for an 'honest debate' at a national level, as well as more tailored information to better inform different audiences.