

Care.data

A Guide for the Voluntary and Community Sector

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Briefing Aim:

This briefing explains what care.data is and how it will impact on individual citizens, when it is introduced nationally (some time in 2015). The briefing has been written to help voluntary and community organisations discuss the issues that care.data raises for citizens.

Regional Voices does not take a position on care.data. We are neither recommending that citizens be involved or suggesting they opt out. We want to provide factual information about the initiative (which has been checked for factual accuracy with the Health and Social Care Information Centre and NHS England), so that individual citizens can make informed decisions about whether to be involved in this programme.

Bev Taylor, October 2014

1. What is care.data?

Care.data is a national programme of work which aims to ensure that more joined up data is made available to clinicians, commissioners, researchers, charities and patients to improve the quality, safety and effectiveness of local care services.

The first phase of the programme will collect data from primary care (from your GP practice) and link this to data from acute care (from hospitals) in order to track diseases, conditions and treatments across the country. In time, it will see data collected and linked from other sources, such as ambulance trusts and community services, so a better picture can be gained of the service and treatment people receive. Data has been gathered from hospitals for some years to produce Hospital Episode Statistics (HES). Collecting primary care data and linking this to hospital data will give the NHS joined up information about care pathways that it has not had access to before.

2. Why is this project happening? What benefits will it bring? What will it enable the NHS to do that it couldn't do before?

Care.data will enable the NHS to compare diseases, conditions and treatment between geographical areas, across the country. It will give the NHS new information, such as how many people visit their GP and why they go there. This data will help to improve treatment by showing where there are problems, such as poorer cancer detection and survival rates in one city compared with another. The data will prompt analysts to ask why there is a problem and to work with local staff to reduce it.

The information will also enable researchers to find good practice across the country where things are working well, such as local GPs supporting people with long-term conditions to avoid them going into hospital. Understanding what works well will encourage service improvement for all.

3. What information will be kept about citizens and by whom?

GPs already use a system of codes to categorise diseases, referrals and prescriptions. This coded information is stored on your personal medical records held by your GP. Your records also include information that identifies you, such as your name, address and date of birth.

The data that will be collected from your GP practice under care.data will include the coded information about diseases, referrals and treatments, together with four identifiers - your NHS number, postcode, gender and date of birth. It's important to note that your full medical records will not be used or sent anywhere. Written notes that your GP makes during conversations with you will not be collected. The information that will leave your GP surgery will be a series of codes about medical conditions, referrals and prescriptions, together with the four identifiers described above. These identifiers are needed so that your GP record and your hospital records can be accurately linked together. Your name, full address, telephone number, and sensitive information will not be collected.

4. What happens to this data? Where does it go? How is it used?

The data will be sent electronically from your GP practice to the Health and Social Care Information Centre (HSCIC). The HSCIC is the national body responsible for collecting, processing and analysing national health and care information in England. At the HSCIC, the identifiers within the record will be replaced by a pseudonym. This pseudonym will help ensure that your records are linked together accurately whilst protecting you from the risk of being identified. The information will then be updated each month, to enable quantitative analysis of health trends and patterns.

5. Are there any exceptions to this use of the data?

Yes, there are exceptional circumstances in which the HSCIC has to release information that can identify a person:

- Where there is a court order (such as in a murder investigation)
- Where there is a major public health outbreak (such as a high incidence of tuberculosis)
- Where a national health research advisory group has agreed to the identifiers being used for confidential research, under strict conditions.

6. Who has access to the data? Will it be given or sold to anyone outside the NHS? Will the database be used to make a profit?

NHS researchers and analysts will be the main users of this data. Universities, charities and private companies will be able to apply to use the data, provided they can show that it will only be used to improve health and social care and not for purely commercial purposes. This safeguard was laid down in the 2014 Care Act, to avoid losing public trust should companies use the data to make a profit. The Act also means that an independent expert advisory group will advise on disclosures by the HSCIC. In addition, the HSCIC will have a secure data facility to support strengthened controls around data access.

7. What are the risks involved in keeping this new data? What about confidentiality?

There are risks associated with data sharing and it is important that individuals decide for themselves whether they want their data to be used, balancing the personal risks against the benefits to society.

There is a slight risk that individuals may be identified and their confidentiality breached, despite identifiers such as your NHS number being removed. As an example, it is theoretically possible that researchers noting a high incidence of road traffic accidents in a local area could match this data with accident reports in local newspapers to find individuals. To protect against this risk, restrictions and strict controls are placed around access to any confidential data including legal, technical and governance controls. For example, data sharing agreements and contracts must

be signed by those receiving the data and legislation is being introduced which will set out new controls to protect the data.

8. Can I see my own personal data?

If you want to view your health records, you can make an informal request during a consultation or by phoning your GP surgery to arrange a time to see them. If you want to get copies of records you will need to make a formal application for access to records in writing to your GP surgery. There may be fees to pay.

In addition, by March 2015 you will be able to access your GP records online. All practices will be offering access to summary information; some may offer access to full records. There is no charge for online access to GP records. However, the data sent to the HSCIC looks different because it is sent in the form of codes.

9. Can I opt-out of this project? What if I am uncomfortable about my GP giving my data to HSCIC, or about HSCIC giving it to researchers?

If you do not want your confidential information to be shared with HSCIC, please contact your general practice and tell them you wish to 'opt-out'. Opting out will not in any way affect the care or treatment you receive. You can opt-out (or opt back in) at any time.

10. When will the care.data project start?

The scheme was due to start in 2013. However, concerns were raised by GPs, professional bodies and patient groups. In response, NHS England paused the care.data programme in early 2014 for a 'listening period' to raise awareness, listen, discuss both the benefits and risks involved with stakeholders and act on their responses. Regional Voices has facilitated two regional events for the voluntary sector as part of this listening process and will organise a further three regional events, from November 2014.

From October 2014, there will be a number of trial 'pathfinder' areas testing the care.data system. These areas will be: Leeds (3 Clinical Commissioning Groups), Somerset CCG, West Hampshire CCG and Blackburn with Darwen CCG. NHS England will work with these 'pathfinders' to find the best ways to inform patients and ensure they can make informed decisions about whether to be involved. These approaches will be tested and measured before patients' coded data is extracted and linked to hospital data.

This trial phase will be overseen by an Independent Information Governance Oversight Panel (IIGOP), chaired by Dame Fiona Caldicott, whose role will be to advise, challenge and report on the state of information governance across the health and care system in England. The decision to proceed to data extraction from the pathfinder areas will be taken by the NHS England Programme Board, based on the evaluation and advice from IIGOP.

11. Further Information

Read more about care.data on:

www.england.nhs.uk/ourwork/tsd/care-data/
www.hscic.gov.uk/article/3525/Caredata
<https://medconfidential.org>

Other briefings and resources for the VCS from Regional Voices about the transition in health and care can be found on www.regionalvoices.org/changes

Regional Who's Who in Health and Care Guides: www.regionalvoices.org/whoswho

To find out more about Regional Voices' work in health, wellbeing and care go to <http://www.regionalvoices.org/developments>



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Regional Voices connects voluntary and community organisations with government, through nine regional networks, to inform and influence policy at local, regional and national levels. Regional Voices is a Strategic Partner to the Department of Health, NHS England and Public Health England.

If you require this information in an alternative format or further information email or call: contact@regionalvoices.org 0113 394 2300

