**Better data means better care**

The value of better data for GPs, patients and the NHS

NHS England London region

A large volume of resources has been sent to practices about care.data over the last six months, and available via [http://www.england.nhs.uk/ourwork/tsd/care-data/](http://www.england.nhs.uk/ourwork/tsd/care-data/). This sets out in detail what the programme is and tries to achieve. This notice provides further information about care.data and its purpose, specifically for GPs (and of interest to other healthcare professionals) in London.

1. **What does care.data mean for GPs and their patients?**

NHS England, after consulting widely with external stakeholders involved in commissioning, researching and managing the NHS, are convinced that a better data service will offer real value nationally for a variety of secondary purposes.

GPs will want to know what this means for them and the patients they serve, and how the new system adds value and the national and local benefits it will bring.

2. **The value of this data for you, as a GP, as part of the NHS as a whole**

The NHS is one single system, albeit complex. Care.data is a data system that reflects the NHS’ nature and complexity. It is not possible solely to rely on local data collection and analysis to drive quality of care. This new system will draw a significant body of NHS data together in a safe and secure environment for multiple secondary uses – for you, your patients and those who commission and manage NHS services. It is a large scale, long term programme, the benefits of which, set out below, will build up gradually over time. It builds upon the existing system for hospital data – HES, which has served the NHS very well for many years, but needs improvement and linkage to other data sets.

Individual GP practice data is a crucial part of the wider system of data in the NHS.

Secondary uses of data include quality improvement, national clinical audit, clinical research, commissioning, invoice validation, community profiling, service performance management and much more. Care.data will be the main engine for supply of data to support these crucial and valuable processes.


GP data will be used to assess the quality of care being provided for patients, leading to measurable improvements in quality derived from better and more informed commissioning and research supported by that data. All research for clinical benefit starts with good data, and any researcher knows that linking data improves its quality: it improves accuracy, volume of accurate data, data completeness and much more. Single source data is much weaker and less valuable. This is not to decry the value of single site studies done at practice level, for example. But larger data sets from many similar providers have far greater accuracy and value. All good, clinically managed large data sets link data in the way care.data will do. The best example, the national clinical audit system, which will also supply data into care.data, already uses large volumes of linked data, supplied under
consent or legal exemption, to inform patient care. The national diabetes audit, drawing data in much the same way from GP records as care.data will do, already manages over 3 million linked patient records. Care.data will do much the same, but on a larger scale, for the explicit benefit of improving care.

Clinical research will benefit enormously from care.data. Researchers will be able to interrogate the data for research studies solely based on the data, much as has been done in the past on much weaker HES hospital data, for example; but also to use the large bank of linked data in HES to verify data gathered through other research data flows. This will add quality to research studies, to the benefit and improvement of clinical care and patient outcomes, as well as providing greater opportunities for research.

Care.data is not about bureaucracy, targets and list cleansing: it is about collecting good data for proper clinical improvement purposes. Of course the data will be used to compare performance as part of commissioning, but this will be to improve patient care in a meaningful way. NHS England will only use like for like data to compare performance, and use techniques such as risk adjustment to support such uses.

The cost of care.data will not be borne by local GPs but centrally, and these costs are being carefully controlled. We recognise that some GP time will be spent explaining it to patients, but such explanation of how the NHS uses data is a legitimate part of care and part of the responsibility of GPs as data controllers. We are helping GPs as much as we can with national materials and a helpline so that the burden on GPs is minimised as much as possible.

3. How GPs will be able to use the data

Other NHS England programmes are concerned with enabling interoperability of clinical records and access to data for primary care purposes. Care.data complements these for secondary uses. Increasingly, as the project develops and collects more data from more sources, some of the outputs of care.data will be accessible directly by you as a practice. You will be able to draw down data to inform your clinical work, such as how your performance compares to that of your peers, and the outcomes of your interventions with patients. You will be able to use the data for your own research, and for community profiling and demographics, as well as public health purposes. We will define data outputs of various sorts, including those of specific utility for primary care, which you will be able to draw down.

As local commissioners, involved closely in CCGs, GPs should wish to ensure the data available to them is as good as it needs to be – and this means comprehensive and linked. Care.data is a system designed for good commissioning, and as commissioners GPs will be the primary beneficiaries.

4. Benefits for patients

GPs need to know that their patients will benefit too. They will benefit through their care being understood and improved through analysis and research. In time they will get access to their data and may choose to prevent the release of confidential data about them out if they want to. Transparency about the uses of data about patients will be central to the development of care.data. We are consulting throughout with patients and as the project is launched we are being transparent with patients about what to expect – such as through the leaflet drop to households. You should be reassured that this project is being inspired by patient needs and will provide them with confidence and assurance about its security.
5. **The legal background**

The extraction of the data is mandatory. Under the powers of the Health and Social Care Act 2012 (HSCA), the Health and Social Care Information Centre (HSCIC) can, under circumstances determined by the Secretary of State, and as directed by NHS England, require Personal Confidential Data (PCD) from GP practices without seeking patient consent.

6. **Endorsement by professional bodies**

Much more important than the legal requirement is the belief amongst clinical leaders in the importance of care.data. The BMA and the RCGP both worked on helping NHS England define the dataset and support its introduction. This is because, as professional bodies, they see the importance of flows of data for the purposes intended that derive from GP records. They have set out why they support care.data in a joint statement with NHS England: [http://bma.org.uk/practical-support-at-work/ethics/confidentiality-and-health-records/care-data](http://bma.org.uk/practical-support-at-work/ethics/confidentiality-and-health-records/care-data)

7. **The support available for the practice and the patient**

There is a large volume of support material available on the care.data part of the NHS England Website at [http://www.england.nhs.uk/ourwork/tds/data-info/](http://www.england.nhs.uk/ourwork/tds/data-info/) and this added to regularly, including with a new animation in 2014. Material is also found on the websites of the Information Commissioner (ICO) and the HSCIC.

There is a telephone helpline and email support that is available for practices themselves (Contact Centre on 0845 300 6016 (open from 9 am to 5 pm Monday to Friday) or send an email to: enquiries@hscic.gov.uk (quoting ‘care.data – GP’ in the subject line).

From January 6th until March 31st 2014 a telephone helpline for patients will be open at 0300 456 3531. This, combined with the detail in the leaflet, will reduce the possible burden of patients coming into their surgery to ask for explanation about their right to object and what they need to do if they have concerns.

There is also material available for patients on NHS Choices: [http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx](http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx) and material will be placed on the London specific patient information resource, myhealthLondon: [https://www.myhealth.london.nhs.uk/](https://www.myhealth.london.nhs.uk/). We will also inform and link with Healthwatch groups.

If you have problems with your N3 account, help is available via [http://n3.nhs.uk/CustomerInformation/HowdoI/ContactN3.cfm](http://n3.nhs.uk/CustomerInformation/HowdoI/ContactN3.cfm).

As with any other issue to do with your IT system you should use the system procedures in place that you would use for other IT queries, such as contacting the CSU or other support that has been commissioned for your practice. Nationally NHS England and the HSCIC are working with all the major providers of IT systems to GPs to ensure their systems are able to supply the data.
8. Will the data be given to the private sector?

The data is primarily intended for use, and will be used, by those commissioning and managing NHS services, to improve those services and make sure they meet patient needs more effectively.

Researchers of clinical services, with the purpose of improving them, such as academic and clinical bodies, are likely to be major users of this data.

Some data, in aggregated or anonymised form, will be made available at a later stage to private companies involved in data re-analysis. These organisations have always had a role in re-analysing public data for useful benefit. However this is not the primary purpose of care.data. The system is not being built around their needs nor is their profit the primary purpose. The primary purpose is for improving clinical care by those running the NHS.

We are exploring how data within the programme can be made available to patients. In the future, patients should be able to access their own data through care.data and pass it on to others. They may be able use this as they wish and it will be very useful for all kinds of research purposes, such as by patient representative bodies or charities.

Is it necessary to collect so much data?

For statistical significance and accuracy of conclusions, and for other secondary purposes, the bigger the data set, and the more discrete elements, the better. This richness of linked data vastly improves data quality and reliability of output.

In the initial period at least, some data records are kept outside of the data set. For the GP extract, sensitive areas like the free text are excluded, after detailed discussion with professional groups like the BMA and the RCGP. Data should only be shared that is appropriate for doing so.

The exact volume of data that is most useful for the multiple purposes intended from care.data is a matter of balance, and by agreeing the volume and content with the representatives of clinical professions, and in discussion with patient bodies, we will ensure we get that balance right: an appropriate volume of data but one which reflects sensitivity and risk. The technical guidance referred to sets out what areas are excluded and included. Patients can of course object to the supply of confidential data about them from their records.

The exact volume of data will be reviewed over time and more areas may be extracted in the future, only after discussion with professional bodies.

Will the data be secure? Why are you not removing patient identifiers?

Identifiers in the data are kept separate from other data within the HSCIC environment. There are very strong research reasons why the HSCIC need identifiable data and why pseudonymisation at source, i.e. at the practice, whilst it may be desirable, is not fully achievable at the present time. This may change in the future and we will keep developments in pseudonymisation under review.

The data will be managed to the highest standards of data security. Fully identifiable data will be accessible only by the Health and Social Care Information Centre (HSCIC), and only through the safest channels. Flow outwards will only be within the law and no-one will be able to access identifiable data without legal permission or patient consent.

Some take a default view that all electronic data is fundamentally unsafe, and the recent international cases like Snowden and Wikileaks have increased this feeling for some people.
Anything we say will not change this perception. We are hopeful that you can make a judgement in that, although exceptional data breaches can happen, the level of security being used ensures this is remote and minimised, and that the value of having such linked data is greater than the small risk of security breach. We are committed to specifying the highest standards in data security and we offer this assurance to you in taking your views about the system.

**The burden on the practice**

You may believe that a large number of patients will come into the surgery looking for advice and explanation. In our experience of the pilots, this was not the case. The vast majority of patients do not have concerns about the use of their data in this way, and many assume that it is used in this way already. Some do and some will seek advice. As we detail above, we have commissioned a dedicated patient information line to discuss these issues and provided a large volume of material on-line, in addition to the detailed, clear and comprehensive leaflet to be sent to patients houses, all available in multiple languages. These efforts will reduce the number of people who will come into the surgery seeking information.

The material we provide for you here and on the website should enable GPs and their teams to answer the queries patients may raise.

**Further queries from London GPs**

The vast majority of queries and questions about the introduction of care.data should be answered by reading the various resources named, this note, or using the email helpline or the call line. Patients should be referred to the various named web resources and the new helpline.

If, as a GP, having tried all the resources above, you still want to discuss issues care.data, the Regional Head of Intelligence for London, Robin Burgess, is able to come and discuss the programme at practice level or with groups of GPs, wherever possible.

Contact robin.burgess@nhs.net.