

KEEPING INFORMATION SAFE

- **Secure data facility to ensure safe environment for analysing information**
- **Strict approvals processes and checks for organisations wanting to access data – backed up by sanctions**
- **Health and Social Care Information Centre operates to international security standards**

The Health and Social Care Information Centre (HSCIC) is the national body appointed by government to collect and analyse data about health and care in England. The HSCIC has responsibilities under the Data Protection Act, and is accountable for the security of personal information.

All HSCIC's systems and services for storing and processing data are designed and operated in accordance with multiple international security standards and best practices. This means that information in IT systems is protected, staff are properly trained, information is managed properly, and the organisation links sensitive information ensuring full compliance with the law.

NHS numbers, dates of birth, postcode and gender are needed to link information to hospital information. As a patient's coded information from their GP reaches the HSCIC and is linked with hospital information, information that could identify them, like their NHS number, will be automatically replaced with a reference number.

During the pathfinder stage of care.data, access to the information collected will only be given to a few approved analysts who will have to travel to a new secure data facility that the HSCIC is setting up. Initially only a very limited number of approved analysts will be able to access the linked data from hospitals and GP practices in the secure data facility. This will allow the HSCIC to assess the quality of the data and provide guidance to organisations to aid understanding and interpretation of the data once it starts to be used more widely.

After this initial restricted period, other approved organisations will be able to apply to access, use and analyse the data in the secure data facility. Approved applicants will only be able to take anonymised data away from the HSCIC.

Eventually organisations will be provided with access outside the secure data facility. Organisations are only approved to receive data if they:

- go through strict approvals processes and checks
- sign a data sharing contract with the HSCIC setting out how the information can be shared, what it can and cannot be used for, security requirements on how it is stored, and restrictions on onward sharing or publication.

Question for discussion:

Having considered these measures, can you suggest anything additional that you would want to see to be assured that your personal information is safe?

ACCESS AND DATA USE

How data can be used

- **Data will never be shared with organisations that wish to use it for purely commercial purposes e.g. insurance or direct marketing**
- **New legislation has tightened controls around what the data can be used for**
- **Data can only be used for health and social care purposes and health promotion**

Commercial organisations will be able to access the data, subject to strict conditions and oversight. The use of patient data by organisations not funded by the NHS has a number of benefits and is responsible for many of the important innovations in healthcare over recent years. For example, one in eight men get prostate cancer. Cancer Research UK discovered a drug which was effective in treating prostate cancer. The charity worked with commercial companies who helped fund expensive clinical trials to ensure that the drug was safe and effective. Cancer Research UK now receives royalties from this drug which are invested back into research into cancer.

An example of unacceptable use would be a large national supermarket chain wanting to link patient health data to their shopping data so that they can target their advertising. For example, they want to send gluten free product discount vouchers to people known to suffer from a gluten allergy. This intended use of the data has no benefit to the health and social care system so would not be permitted.

How you can scrutinise who is using the data

- **New legislation means there will be independent scrutiny of who has access to the data**
- **You can see who has accessed the data because the HSCIC publishes a register of who it has shared information with**

We are committed to transparency and laying a clear audit trail on who is granted access to the information, for what purpose and to what outcome.

The HSCIC will not sell the information. It will only charge a fee to cover its costs (HSCIC is not fully funded by government) and will not profit from providing information to other organisations. An applicant's track record in handling confidential information will influence our decisions to share information with them.

In another legislative change, the Confidentiality Advisory Group has been put on a statutory footing and has an explicit role advising HSCIC on decisions to share information. In addition, the Independent Information Governance Oversight Panel (IIGOP), chaired by Dame Fiona Caldicott, has agreed to advise the care.data Programme Board on the first phase of the implementation of the programme. Dame Fiona has just been appointed National Data Guardian for health and care, a new role in which she will become the patients' champion on security of personal medical information.

Questions for discussion:

1. **What further questions do you have about how data will be used?**
2. **What do you think about the arrangements to allow scrutiny of who is using data – what else, if anything, would you need to see?**

THE APPROACH TO COMMUNICATION AND ENGAGEMENT

Our overall aim is to ensure that members of the public in care.data pathfinder areas can make an informed choice about sharing their data, and that GPs and staff in GP practices feel supported in the process. Communication to patients in pathfinder areas will consist of:

- letter and leaflet mailed to all registered patients in participating GP practices
- Posters available for display in surgeries and other community locations
- Some GP practices in pathfinders will test email or text communication to their registered patients about care.data
- materials currently being tested with a range of stakeholders in pathfinder areas and nationally, so what you see tonight is draft

For patients that want a greater level of detail, there will be more information available:

- Frequently Asked Questions
- case studies of how data can be used, and the benefits of this
- a video
- dedicated information phone line and email for queries
- all information online via NHS Choices website

We are producing materials in a range of accessible formats:

- Easy read
- Audio
- Large print
- BSL
- Braille
- Translations

Standard format materials will include an accessibility message. Accessible materials will be made available to patients needing them via the NHS Choices website or the Information Line. We are working with local Healthwatch and the voluntary sector in the pathfinder areas to help ensure that accessible materials get to patients who need them.

Other community engagement approaches to support communication with patients include:

- Community engagement toolkit to support local and national voluntary sector and patient groups to have conversations with their members and networks about data sharing
- Frequently Asked Questions to respond to the queries that have been raised in relation to diverse groups (for example, homeless and insecurely housed people; gypsy travellers; young people and students; and carers.)
- Working with social enterprise the Helplines Partnership to brief and support health and social care helplines which may receive queries on data sharing
- Briefing meetings for local voluntary and community sector organisations in each pathfinder area, in advance of members of the public receiving their letters

Questions for discussion:

- ***What do you think of the proposed approach to communication in the pathfinder areas?***
 - *Elements that you like?*
 - *Elements that are missing/should be done differently?*
- ***How should we evaluate our communication and engagement approach?***