

National Data Opt-out: Factsheet 1A – Data use and patient choice

This is one of a series of factsheets about data uses and the national data opt-out

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Factsheet 1A - Data use and patient choice

Purpose

This factsheet provides information on how data is used within health and care, why it is provided to other organisations, and the choice patients have.

Data use in health and care

Data is recorded whenever a patient has any contact or interaction with the health and care system – for example, when they receive care, a diagnosis, treatment or services to support their general wellbeing.

Health and care services are delivered by many separate organisations. For example, in England there are around 135 hospital trusts, 35 community providers, 54 mental health trusts as well as over 8,000 GP practices. There is no single universal electronic patient record across the health and care system so, as well as the GP practice record, other organisations will hold separate records for the same patient. Health and care organisations also use a range of electronic and paper systems to record details about the care and treatment that patients receive. In some large organisations, like NHS hospital trusts, there can be many different systems in use to cover the range of care and treatments being delivered.

Data use for individual care and treatment

The data being recorded is used by health and care professionals to help make diagnoses and decisions about a patient's care.

To provide safe and effective care and treatment for a patient it may be necessary for a clinician or professional in one organisation to provide information to a clinician or professional in another organisation; for example, when a patient visits their GP who refers them to a specialist in a hospital for further tests. In some cases, this sharing of information may be quite complex because of the care the patient is receiving. The clinical team responsible for the patient can also use the data to assess the quality and safety of the care being provided for the individual patient.

In these circumstances, the use of patient data is referred to as 'for individual care and treatment'.

Local health and care records

Some areas have put in place local shared care records to make it easier for local health and care organisations to share data with each other. When data is shared for individual care purposes this needs to include information which will uniquely identify the patient. Health and care organisations involved in local care record sharing will have more information available for patients about their local care record and how the data is shared and who with.

Data use for purposes beyond individual care and treatment

The data recorded as part of a patient's individual care and treatment may be used, along with data about other patients, to plan services by:

- understanding what care and treatment patients need and are using;
- predicting what services will be needed in the future so that funding and resources for these services can be put in place; and
- understanding the outcomes of patient care to ensure that safe and effective care is being delivered and the best possible use of health and care resources are being made.

The data recorded may also be used for research purposes, such as to:

- look at diseases and illnesses and their treatments to see whether anything unexpected is happening, such as whether patients on certain medications are at a higher risk of developing other conditions, like heart disease or stroke;
- identify the risk factors for disease and its severity, such as age, gender, ethnicity, where patients live, or another health problem, like high blood pressure or obesity; and
- monitor the outcomes of a new drug or type of treatment to see if it is effective or whether it has side effects.

The use of patient data for these planning and research purposes is referred to as being used 'for purposes beyond individual care and treatment'.

For any data to be used beyond the patient's individual care and treatment there should be a benefit to the health and care system and it must never be used for insurance or marketing purposes without the patient's explicit consent.

When data is used for purposes beyond individual care and treatment it is normally anonymised, which means that information that identifies an individual patient has been removed or pseudonymised. A pseudonym is a unique identifier which does not reveal the patient's 'real world' identity.

Further information about anonymisation can be found in Factsheet 2 – "When it applies" and at: www.understandingpatientdata.org.uk/what-does-anonymised-mean.

When is identifiable data used for purposes beyond individual care and treatment?

Sometimes, to understand and analyse the care and treatment patients are receiving and to undertake research, it is necessary to join data together.

By joining together data from different health and care organisations it is possible to better understand how well something is working. For example, has the expansion of two GP practices led to fewer patients attending the local Accident and Emergency Department, as the managers might have planned? Is a new hospital treatment continuing to keep people well, or have patients been visiting their GP with a return of their symptoms?

To join the data from different health and care organisations a single unique identifier is needed for each patient. This is the individual's NHS number. Occasionally the NHS number may not be available or has been entered inaccurately so other facts about the patient, such as date of birth, may also be used. The more of a patient's details that can be matched together the greater the certainty that the different sets of data relate to the same patient.

In most cases the identifiable data is provided to a national organisation like NHS Digital, which has legal powers under the Health & Social Care Act 2012 allowing it to link the data from multiple sources. NHS Digital can then anonymise the data and provide it to other organisations to carry out their analysis without using any identifiable information. There will also be times when organisations use a different legal basis, such as explicit patient consent or a s251 (NHS Act 2006) approval to provide identifiable data to another organisation that already has some patient data, enabling the receiving organisation to join the data together.

Information about legal bases to use information can be found in Factsheet 1B – "Types of data used and legal protection in place", and for more about data uses within health and care see: www.understandingpatientdata.org.uk.

When and why might other organisations be provided with health and care data?

Many health and care services are delivered by public organisations working in partnership with commercial organisations to ensure effective delivery of those services.

In addition to supporting the direct running and management of services, commercial organisations may also be contracted to help with planning or research. For example:

- Health and care analysis companies can be employed by NHS Trusts and care organisations to use their expertise to help the organisation understand how effectively its services are being run and managed, to compare their performance with others, and identify what could be improved. The NHS organisation providing the data will continue to have all legal responsibility for it and will have a contract that covers the data sharing arrangements in place.
- Pharmaceutical companies and commercially funded research studies investigate diseases and existing treatments to determine if new treatments or better care pathways can be developed to prolong and improve quality of life for patients. These studies also help to reduce costs to the health and care system because of more effective treatment. Most of these studies use explicit consent and the use and sharing of data will be explained clearly to participants before they make their decision.

Data should never be provided from a health or care organisation to another organisation for insurance or marketing purposes without the explicit consent of each individual patient.

For more information about companies using health information see:
<http://understandingpatientdata.org.uk/companies>

The national data opt-out choice

The national data opt-out (offered to the public as '*Your Data Matters to the NHS*') allows a patient to choose that they do not want their confidential patient information to be used for purposes beyond their individual care and treatment. All health and care organisations in England are required to apply the national data opt-out by March 2020.

A patient can change their mind and update their national data opt-out choice at any time. For information about how to do this see Factsheet 5 – "Setting a national data opt-out"

A patient can choose to opt out but still agree to take part in a specific research project or clinical trial.

A patient's national data opt-out will not apply where data is legally required to be shared, or if there is an overriding public interest.

The national data opt-out will not prevent anonymised data from being used for purposes beyond individual care, where it is anonymised in line with the Information Commissioner's Office code of practice on anonymisation.

Further information about when the national data opt-out does or does not apply can be found in Factsheet 2 – "When it applies".