

Your Data Matters to the NHS

What does this mean for nursing, midwifery and care staff?

Pocket Guide

This guidance is for the nursing, midwifery and care staff that provide care across health and care sectors. The NHS has produced this guidance with the involvement of the Royal College of Nursing, the Royal College of Midwives and service users

This guidance will be reviewed by March 2020

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Further information and support for nursing, midwifery and care staff:

Data Protection Regulations

Go to: digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/information-governance-alliance-iga/general-data-protection-regulation-gdpr-guidance

Contact: The Information Governance Manager or Data Protection Officer at your organisation

National Data Opt-out

Go to: digital.nhs.uk/nationaldataoptout

Call: 0300 303 5678 with specific enquiries

Email: enquiries@nhsdigital.nhs.uk (please include 'National data opt out' within the subject) with queries or to provide feedback on this guidance.

Leading Change, Adding Value

Go to: www.england.nhs.uk/leadingchange/

For nurses, every nurse is an e-nurse

Go to: www.rcn.org.uk/clinical-topics/ehealth/current-work

Guidance on information governance from the Care Providers alliance

Go to: www.careprovideralliance.org.uk/information-governance.html

Who might use health and care data?

Organisations that can request access to data may include:

- NHS organisations
- Local authorities
- University and hospital researchers
- Royal colleges
- Pharmaceutical companies researching new treatments



Confidential patient information will only be released if it is:

- used to support the delivery or improvement of health and care services
- required by law



Access to confidential patient information will not be given to:

- marketing companies*
- insurance companies*

* unless an individual specifically requests this

You can find out here (understandingpatientdata.org.uk/companies) about how the NHS works in partnership with companies in case you are asked about this.

When does the national data opt-out apply?



Data sharing for planning and research purposes

Includes data released under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support'), Find out more here: <https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/why-confidential-patient-information-used/>

This identifies you personally



Data shared for an individual's care & treatment

e.g. Where data is shared between the health and care professionals in a hospital and in a GP practice.

This identifies you personally



Legal requirement / public interest / consent

e.g. There is a mandatory legal requirement such as a court order, to protect the greater interest of the general public or there is explicit consent.

This identifies you personally



Data is anonymised

The data shared is determined to be compliant with the ICO Anonymisation: managing data protection risk code of practice.

This does not identify you personally

Further information about when the national data opt-out does and does not apply is here nhs.uk/your-nhs-data-matters

What's new?

In May 2018:

1. **New data protection regulations** were introduced in the UK. The General Data Protection Regulation (GDPR) is a new set of EU regulations which will replace the existing Data Protection Act.

2. **A national data opt-out** was introduced in England. This provides a secure, accessible way for individuals to opt out of their confidential patient information being used for reasons beyond their individual care and treatment.

What do I need to do?

Nursing, midwifery and care staff have a key role in **helping individuals understand the importance of information** so that they can always be supported to make an informed choice about how confidential patient information is used for research and planning. You can help **signpost individuals to information** about these changes.

Those with senior responsibility for Information Governance within your organisation will be taking steps to ensure compliance with GDPR. It is important that you remain professionally up to date with the ways in which data can be used and also undertake **your Information Governance training** in line with your organisation's approach.

Leading Change, Adding Value includes ten aspirational commitments that enable nursing, midwifery and care staff to address the three

gaps in the Five Year Forward View: health and wellbeing; care and quality; and funding and efficiency. It also helps identify and reduce unwarranted variation in your workplace and deliver the triple aim outcomes of better experiences, outcomes and use of resources. Commitment 10, *'We will champion the use of technology and informatics to improve practice, address unwanted variations and enhance outcomes'* specifically empowers staff, whatever your role, wherever you work, to identify and reduce unwarranted variation so you can quantify your significant contribution across health and care, placing a focus on the importance of data and its use.

For nurses, **every nurse is an e-nurse** also describes how effective use of information is a key enabler in delivering health and social care now and in the future.

What other things might I be asked about?

New data protection regulations - what you need to know:

In May 2018, the strict rules about how data can and cannot be used were strengthened. The NHS is committed to keeping patient information safe and always being clear about how it is used.

Individuals will be able to ask what happens to their data and for access to the records about them.

The national data opt-out - what you need to know:

Individuals can choose whether their confidential patient information is used for research and planning. This will not affect their individual care.

Individuals can find out more about data use, choose to opt out or change their choice at any time at: [nhs.uk/your-nhs-data-matters](https://www.nhs.uk/your-nhs-data-matters).

Individuals do not need to do anything if they are happy about how their information is used.

What are the benefits of sharing data?

Research	 Prevent serious illness	 Develop new treatments	 Learn more about diseases
Planning	 Plan NHS health services	 Make services safer	 Improve individual care

The Understanding Patient Data Initiative ([understandingpatientdata.org.uk](https://www.understandingpatientdata.org.uk)) supports better conversations about the uses of health information. They have published case studies to explain the wide range of ways that data can be used to deliver better care and improve health.

How will data be kept secure?

Individuals are protected in the way information is processed (under the Data Protection Act) and the right to confidentiality (under the common-law duty of confidentiality).

All organisations have a legal duty to protect data and to only share it for specific reasons. Organisations and individuals found in breach of their responsibilities are liable to criminal prosecution and fines of up to £17million.