NDG National Data Guardian
for health and social care

Who to speak to if you have a concern or complaint about how your health and social care data has been handled

November 2026 v2.0

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1 Introduction

The NDG's role is to provide national-level advice. We offer guidance to government and the health and social care system to help ensure that national policies and plans for the use of healthcare data are trustworthy, transparent and aligned with public expectation.

We cannot respond to people's queries or complaints about the mishandling of their own health or care data as we do not have the power to investigate or enforce sanctions.

While we cannot intervene in individual cases, we believe people should know how to raise concerns and access the right support. Below are the steps you can take if you have a complaint about how your health and care data has been handled:

2 Speak with the organisation first

If you have a question about how your data is being used, or if you are concerned about how an organisation has handled your data, the best first step is to raise your questions and concerns directly with them. The most relevant staff are:

2.1 The Data Protection Officer (DPO)

DPOs ensure that organisations comply with data protection laws (UK GDPR & Data Protection Act 2018). They handle issues related to data security, subject access requests (SARs), and data breaches. All NHS (and many social care) organisations will have a DPO.

Contact the DPO if:

- you suspect a data breach or unauthorised access to your personal data
- you have questions about how your data is being collected, stored, or processed
- you need help with making a subject access request (SAR)
- you would like to exercise your rights to object to the use of your data, to have your data corrected, or to erase your data
- you are concerned about an organisation's privacy policy or its compliance with data protection laws

2.2 The Caldicott Guardian

Caldicott Guardians are senior healthcare professionals (such as doctors, nurses, or social care leads) who focus on ethical and confidentiality issues in health and social care data.

In NHS organisations, the Caldicott Guardian often works closely with the DPO, so you may receive a joint or coordinated response. All organisations that handle confidential patient information and deliver publicly funded care will have a Caldicott Guardian.

Contact the Caldicott Guardian if:

- you are worried about inappropriate data sharing within a healthcare setting
- you want advice on the ethical or legal justification for sharing patient data
- you have concerns about balancing privacy with patient care needs
- you need guidance on safeguarding or public interest disclosures involving health data

2.3 Finding contact details

You can find DPO and Caldicott Guardian contact details by:

- checking the organisation's website (look under sections such as "information governance," "privacy notice," "data protection" or "Caldicott Guardian")
- calling the organisation's main switchboard and asking to be directed to the information governance or data protection team or Caldicott Guardian.
- submitting a Freedom of Information (FOI) request if contact details are not publicly available and switchboard has not been able to help.

3 Making a complaint

If you have contacted with an organisation to discuss the way it has handled your data, but you are not satisfied with their response, you have the right to make a complaint.

How to do this:

3.1 Report data breaches to the Information Commissioner

If your complaint is about a data breach, you can report it to the Information Commissioner's Office (ICO), the UK's data protection regulator. The ICO investigates complaints about data privacy. If you suspect a data breach, either you or the organisation responsible for the breach can report it to the ICO:

The organisation's duty: Under UK GDPR, healthcare organisations (or any data controllers) must report a personal data breach to the ICO within 72 hours if it is likely to pose a risk to individuals' rights and freedoms.

Your right to report: You can report a breach to the ICO yourself if:

- you suspect a data breach has occurred

- you believe the organisation has failed to report it
- the organisation has not provided a satisfactory response

To report a breach, visit ICO Report a Breach or call 0303 123 1113.

3.2 Complain to the service that handled your data

If you're not satisfied after speaking with the DPO, Caldicott Guardian, or other staff at the relevant organisation, you have the right to make a complaint.

The information here applies to England. If you live in Scotland, Wales or Northern Ireland, there are different routes for complaints.

3.2.1 For NHS services

You can either complain directly to:

- the service that provided your care / handled your data
- the organisation that commissioned that service (the body that pays them)

You cannot complain to both.

All organisations that provide an NHS service in England must have their own complaints procedure. Details are usually available in waiting areas, at reception, on the organisation's website, or by asking a member of staff.

If you would prefer not to raise your data handling complaint directly with the service, you can take it to your local integrated care board (ICB). ICBs are responsible for planning and commissioning (buying) healthcare services for their regions.

The NHS provides clear guidance on how to make a complaint about NHS or adult social care services. It explains the support available to help you through the process, including the Patient Advice and Liaison Service (PALS) available in NHS hospitals.

3.2.2 For adult social care services

Privately arranged and funded adult social care

If you are unhappy with how a social care service, care home or home care that you pay for has used or handled your data, it is usually best to raise your concerns with the service provider first. If you wish to make a formal complaint, each organisation will have its own procedure, so ask them directly.

Care arranged by your local council

If your care is funded or arranged by your local council, you should first raise any concerns with your care provider. If you would prefer not to do this, you can contact your local council directly. Every council must publish details of how to complain on its website, or you can ask for this information directly.

4 Taking your complaint further

If you complained formally to an NHS or social care organisation about how your data was handled and the issue was not resolved, or you were unhappy with their reply, you can take your complaint further in the following ways:

4.1 Escalating NHS complaints

If your concern relates to an NHS organisation, you can escalate your complaint through the NHS complaints process. More information is available at NHS Complaints.

If you have followed the NHS complaints process but remain unhappy with the outcome, you can take your complaint to the Public Service Ombudsman (PSO). The PSO is the final stage for unresolved complaints about NHS care. More information is available at www.ombudsman.org.uk.

4.2 Escalating social care complaints

If the council does not resolve your complaint to your satisfaction, you can take the matter to the Local Government and Social Care Ombudsman.

They investigate individual complaints about councils, all adult social care providers (including care homes and care agencies) and some other public service organisations. They explain how to complain on their website.

4.3 Reporting to the Care Quality Commission (CQC)

You can report poor care experiences to the Care Quality Commission for monitoring, but they cannot take up complaints on your behalf. This is because, like the NDG, they do not have the power to investigate or resolve individual complaints.

4.4 Complaints about individual health and care professionals

If you have concerns about how a doctor, nurse, midwife, or other regulated health professional has handled your data and you have not been able to resolve the issue in any of the ways described above, it is possible to take your complaint to the relevant professional

regulator. Professional regulators are independent of the NHS and are responsible for protecting the public by ensuring healthcare staff meet and maintain high standards.

General Medical Council (GMC): for doctors: www.gmc-uk.org

Nursing and Midwifery Council (NMC): for nurses and midwives: www.nmc.org.uk

Health and Care Professions Council (HCPC): for paramedics, physiotherapists, social workers, and other regulated professionals: www.hcpc-uk.org