

Background

NDG

National

Data Guardian

The National Data Guardian for Health and Adult Social Care in England (NDG) is an independent statutory office holder, occupying a non-regulatory, advice-giving post that was established by the government in 2014 to help build trust in data use across the sector.

The <u>Health and Social Care (National Data Guardian) Act 2018</u> established the NDG as a statutory role, giving them the authority to issue official guidance on the processing of health and adult social care data in England. In addition to formal guidance, the NDG may also offer informal advice, information, and assistance regarding data processing in health and adult social care. However, while formal guidance carries a legal obligation to 'have regard to it', there is no statutory duty to follow informal advice.

The NDG's vision is to improve the quality and sustainability of health and care through the safe, appropriate, and ethical use of people's health and social care information. They contribute to this by providing leadership, expertise and insight on the use of health and social care data, advocating for policies, practices and principles that build and maintain trust in data use and the confidentiality of our health and social care services.

The NDG offers advice and guidance to the government and health and social care system, with a focus on:

- contributing to new data policy and scrutinising proposed policy changes
- reviewing information governance arrangements for data programmes
- promoting the importance of transparency around data use, including around risks, safeguards and public benefits
- fostering open and honest communications and engagement about data use
- ensuring patient and public involvement in the formation of new data policy and in data policy decision-making

The NDG always emphasises the importance of keeping people's information safe and confidential, but also of sharing it when appropriate to achieve better outcomes for patients and service users.

Although the NDG is sponsored by the Department of Health and Social Care, and the NDG's office is hosted by NHS England, the NDG and office operate with independence, autonomy, and freedom to challenge the government on data matters.

Dr Nicola Byrne has held the post since March 2021. She was reappointed in March 2024 for an additional term, which runs to March 2027.

NDG advisors (panel members)

The NDG has the authority to appoint advisors and cover their expenses and allowances. These advisors are referred to as panel members. The NDG also sponsors <u>UK Caldicott</u> <u>Guardian Council (UKCGC</u>) and appoints the Chair of the UKCGC. Within this context the UKCGC Chair is also classed as a panel member. Panel members, together with the NDG, form the National Data Guardian's panel, which convenes every two months to provide formal advice on matters within the NDG's remit.

Panel members are appointed by the NDG based on their relevant skills and experience, ensuring they can effectively support the NDG in fulfilling their statutory responsibilities. Appointments are made following a preliminary discussion with the NDG and are subsequently formalised by the Office of the National Data Guardian (ONDG). The NDG undertakes a separate process with the UKCGC in appointing the UKCGC Chair.

The panel typically consists of twelve to sixteen members, although the exact number may vary depending on the expertise needed to support the NDG's objectives and ongoing work.

A list of panel members is published on the <u>About us</u> section of the NDG website.

General responsibilities of panel members

NDG panel members play a key role in supporting the NDG through a range of responsibilities, including:

- providing advice and expertise to the NDG and ONDG on matters within the NDG remit, both during and outside panel meetings
- raising items or issues relevant to the NDG remit with the NDG and ONDG
- attending panel meetings regularly and actively contributing to discussions
- participating in ad hoc meetings with, or on behalf of, the NDG
- representing the NDG on external boards, panels or other groups
- speaking on behalf of the NDG at events
- assisting the NDG in maintaining key relationships, including those with the Department of Health and Social Care, arm's length bodies, regulators, professional bodies, and patient advocacy groups

Upon appointment, NDG panel members sign a terms of appointment which outlines in more detail the expectations and responsibilities of their role.

Duration of appointment

Panel membership is reviewed annually to account for any changes in individual circumstances or shifts in the NDG's need for a certain expertise. A meeting is held prior to the end of the financial year with each member to review their role, offering an opportunity to decide whether tenure will continue or conclude.

NDG panel meetings

The National Data Guardian's panel comprises all panel members and the NDG, meeting formally every two months, totalling six meetings per year. Panel members support the NDG primarily by contributing to these discussions, and regular attendance is expected. Meetings are held virtually via Microsoft Teams, though a face-to-face meeting is organised each year that members are encouraged to attend in person (although remote participation is available if attending in person is not feasible). The NDG chairs all panel meetings.

The purpose of panel meetings is to enable the NDG to:

- discuss internal and external matters
- invite external stakeholders to encourage, challenge, scrutinise and advise
- review progress against agreed actions, tasks, and published priorities

It is important to note that the panel meeting is not an approvals board.

Papers

The ONDG will circulate an agenda and papers approximately one week prior to each meeting. Panel members are expected to read these materials in advance and prepare for discussions.

Panel observers

In addition to panel members, the meeting is observed by staff in the ONDG (who can contribute to the meeting to support the NDG). On occasion, additional observers may attend by invitation of the NDG.

Record of panel meetings

The ONDG will prepare a summary of each panel meeting, including any actions arising. These minutes will be distributed with the papers for the following meeting, where members will review them for accuracy. Once accepted, minutes are published on the NDG's website.

Support for the NDG Panel

ONDG staff are responsible for supporting panel meetings by:

- scheduling meeting times and locations
- ensuring that agendas and papers are appropriate and circulated on time
- capturing and tracking actions arising from panel meetings
- drafting minutes and issuing them for review at the following meeting
- publishing reviewed and approved minutes on the NDG website.