

National Data Guardian's Panel Terms of Reference

Background

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

The NDG encourages the building and maintenance of trustworthy systems and practices by providing advice, guidance, and challenge on the use of health and adult social care data. Emphasising 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, they advise on matters such as confidentiality; security; effective use of data; communicating with the public; and individual choice.

The NDG is regarded as an independent champion for the public when it comes to matters of their confidential health and care information.

It is a statutory post, and its powers and responsibilities are laid out in the Health and Social Care (National Data Guardian) Act 2018¹. The formal powers associated with the role enable the NDG to give advice to the health and adult social care system. But they can also give advice more generally to non-health and care system bodies, providing it is about health and adult social care data.

The post has been held by Dr Nicola Byrne since March 2021 and her term runs to March 2024. Dr Byrne succeeded Dame Fiona Caldicott, the first statutory postholder.

The National Data Guardian role is sponsored by the Department of Health and Social Care. However, the role operates with independence and autonomy and has the freedom to challenge government on data matters.

Panel membership

Panel membership is by invitation from the NDG, who is empowered by the Act to appoint advisors. Individuals are invited to join the panel based upon the relevance

¹ http://www.legislation.gov.uk/ukpga/2018/31/contents

of their personal knowledge and experience to the NDG's strategic objectives, rather than as representatives of their organisations.

The panel will range from between approximately twelve and sixteen members. The number will vary depending on the knowledge and expertise required by the NDG to support their objectives, and other work they are undertaking.

A list of panel members is published on the *About us* section of the NDG website.

General responsibilities of the panel

The NDG panel members are responsible for:

- providing advice and expertise both in and outside of panel meetings to the NDG and their office on a wide range of matters related to the NDG remit
- raising any items or issues relevant to the NDG remit with the NDG and the panel
- contributing to monthly panel meetings
- attending ad hoc meetings with, or on behalf of, the NDG
- representing the NDG on boards, panels or other groups
- speaking on behalf of the NDG at events
- helping the NDG to maintain their key relationships, such as those with the Department of Health and Social Care, arm's length bodies, regulators, professional bodies, and patient advocacy groups
- completing actions or agreed tasks on time

Duration of appointment

Panel membership is subject to an annual review. An individual's circumstances may change, as may the NDG's need for a certain expertise, therefore a meeting will be held prior to the end of the financial year, providing a sensible checkpoint at which it may be decided to continue or conclude tenure.

Meetings

Meeting frequency

NDG panel meetings are held monthly, with twelve per year.

Meeting purpose

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

- discuss internal and external matters with all panellists simultaneously
- welcome external stakeholders to encourage, challenge, scrutinise and advise
- assess progress against agreed actions, tasks, and published priorities

The panel meeting is not an approvals board.

Papers

The Office of the National Data Guardian (ONDG) will issue an agenda and papers to all panel members around a week before the meeting. Members are expected to read papers and consider any key questions in advance, so that they are prepared for each discussion.

Panel observers

In addition to panel members, the meeting is observed by:

- staff in the ONDG
- Chair of the UK Caldicott Guardian Council (a sub-group of the NDG's panel)
- infrequently, additional observers will attend by invitation from the chair

Record of panel meetings

The ONDG will capture a summary of the panel meeting and arising actions. These minutes will be issued to panel members as part of the papers for the following meeting, where they will be reviewed for accuracy and accepted.

Once reviewed and accepted, minutes are published on the NDG's website.

Support for the NDG Panel

In relation to panel meetings, staff in the Office of the National Data Guardian are responsible for:

- arranging panel meeting times and locations
- ensuring that agendas and papers are appropriate and circulated on time
- capturing and tracking actions arising in panel meetings
- drafting minutes and issuing for review at the following meeting

• publishing reviewed and approved minutes online