

General Practice Data for Planning & Research

IG Expert Liaison Group

Terms of Reference

V1.0 - approved by ELG membership 23 November 2021

V1.01 – added IGARD deputy – 19 January 2022

V1.02 – updated ahead of publication – 16 February 2022

Background

On 19th July 2021, [ministers wrote to all GPs in England](#) describing changes being made to the General Practice Data for Planning and Research (GDPR) Programme. Data collection will now only begin when the following criteria have been met:

- the ability to delete data if patients choose to opt-out of sharing their GP data with NHS Digital, even if this is after their data has been uploaded
- the backlog of opt-outs has been fully cleared
- a Trusted Research Environment has been developed and implemented in NHS Digital
- patients have been made more aware of the scheme through a campaign of engagement and communication.

These commitments were made to address a number of issues (including the lack of sufficient transparency) that contributed to the delay of the original GDPR collection in the summer of 2021.

In order to offer advice to the Programme in the delivery of these criteria from an Information Governance (IG) perspective, and hence enable the collection to start, an Expert IG Liaison Group is being set up.

Name

The GDPR IG Expert Liaison Group

Purpose

1. To allow the GDPR programme to consider key data protection matters such as transparency, pseudonymisation and reidentification arrangements, data sharing/access, opt-outs (National Data Opt-out and Type 1) and associated documentation, including transparency notices, patient information material and communications and the NHS Digital and Template GP Data Protection Impact Assessments with key IG stakeholders.
2. To provide key IG stakeholders with the opportunity to review and discuss issues and provide advice and feedback to NHS Digital on the IG elements of the GDPR programme.
3. Promote improved engagement and communication with key IG stakeholders, service users and the public.

Membership

The group is attended by representatives from the following organisations

- NHS Digital, Privacy Transparency & Ethics
- NHS England, Data Policy & IG
- Department for Health and Social Care
- Independent Group Advising on Release of Data (IGARD)
- Information Commissioner's Office
- Office of the National Data Guardian (NDG)
- Confidentiality Advisory Group

Transparency

These Terms of Reference will be published as part of the wider description of the GDPR programme governance arrangements.

Action Notes will be published.

Governance Context

The GDPR programme currently maintains three further stakeholder groups in addition to the IG Expert Liaison Group. These are as follows:

- The GP Data for Planning and Research Programme Board
 - The primary forum for programme progress reporting and escalations as well as aligning delivery with the broader internal portfolio delivery across NHS Digital, and NHS England
 - The programme delivery team will present key documentation for review and ratification following reviews and feedback from all other stakeholder groups
 - Board membership consists of the NHS Digital CEO, Directors of Technology/Data/Privacy from NHS Digital, NHS England, and GDPR Programme leadership
 - The board meets monthly
- The Check and Challenge Group
 - The primary aim of this group is to challenge the delivery of the GDPR programme delivery against data expert and general practice profession perspectives
 - The group will be specifically asked to challenge where the programme approach is thought to be diverging from the commitments and conditions made in the Letter to GPs signed by Ministers, or from additional commitments made
 - Group membership consists of representatives of general practice and data profession
 - The panel meets fortnightly in alignment with the Patient and Public Engagement and Communications Advisory Panel
- The Patient & Public Engagement & Communications Advisory Panel
 - The primary aim of this panel is to challenge the delivery of the GDPR programme delivery against patient and general public perspectives
 - The panel will be asked to review documentation considering the engagement and communications approach and delivery, and will guide the implementation of the overall comms and engagement strategy
 - Group membership consists of interested members of the general public and members of specific patient representation groups
 - The panel meets fortnightly in alignment with the Check & Challenge Group

Secretariat

Provided by NHS Digital: set up meetings, develop and distribute agenda and papers, record and distribute minutes (within 3 working days of each meeting).

Papers and documents will be shared through a dedicated MS Teams Site.

Meetings

The group will meet at least monthly via MS Teams. These Terms of Reference (including membership) were agreed in the first meeting and will be reviewed regularly and updated as required.

Ad-hoc meetings may be scheduled as necessary to address urgent issues.

The group will continue to meet until the GDPR collection has been fully implemented.