Ref:

GP Data Patient and Public Engagement and Communications Advisory Panel. Also referred to as PPECAP.

Title:

GP Data – Terms of Reference for the Patients and Public Engagement and Communications Advisory Panel

Author:

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Engagement and communications panel sponsor:

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Purpose:

To set out the Terms of Reference for the PPECAP

Background:

In June 2021, the GP Data for Planning and Research (GPDPR) programme and the wider communications team agreed to set up an editorial review panel to oversee and agree the final external communications products to support a public information drive. Since August 2021 the remit and influence of the panel has widened to cover wider engagement, communications, and operational issues related to GPDPR. The panel's work is now firmly part of the communications and engagement strategy and framework for the programme, providing an advisory role on patient and public engagement and communications in particular. NOTE: *Data collected as part of GP data for planning and research for the purposes of this Terms of Reference describes health data of GP practice patients aged over 15.*

In Summer 2022, it was acknowledged that that the technology underpinning the General Practice Extraction Service (GPES) is operating over capacity and is limited in capability due to being ten years old. It was agreed that immediate work was needed to safeguard the provision of existing direct care data collections, and to accommodate future requests.

Due to the urgency of the issues facing GPES, a proposal is being developed to move existing direct care collections onto new, more stable technology which has more capability and capacity to meet requirements. The resources required to resolve these issues are currently aligned to the GPDPR programme, therefore a reprioritisation exercise has taken place.

The commitment to realise the benefits of the using GP data for planning and research purposes remains, and work will continue towards meeting the ministerial commitments for the GPDPR programme, however, the focus for the 2022/23 financial year will shift towards resolving the issues for direct care as a priority.

A project, the Vaccinations, Treatments and Screening project (VTS) has been stood up to deliver this work.

The delivery team remain committed to engagement and transparency in all of their work and are keen to continue with the open work they began for GPDPR. To benefit from existing expertise, whilst being efficient with people's time, it has been proposed that the scope of the terms of reference for the GPDPR programme assurance groups be widened to incorporate discussion about the VTS project. This approach was discussed and ratified with the assurance groups in October 2022.

Key Points:

1. The panel is embedded in the communications and engagement strategy for the GPDPR programme and the VTS project, and as such its findings will be fed into the decision-making process
2. The role of the engagement and communications advisory panel is to:
    - play a consultative and advisory role on the best ways to engage and communicate with patients and carers and the public about GP Data for Planning and Research
    - act as consultants for emerging engagement and communications content for GP data for all four phases of the new communications and engagement plan.
    - make sure that panel findings and recommendations are shared and escalated to board level if appropriate, and that feedback on outcomes is provided back to the panel (you said we did – or in some cases 'we could not because'…)
    - review and contribute to drafts of external content developed to inform patients and the public about GP data.
    - represent the views of their parent organisations (where relevant)
    - act as a senior advisory panel for questions and possible issues raised through the materials drafting and review stages, with response to specific recommendations through the same process as other formal requests and correspondence to the programme.
    - Be involved in the early draft stages of documents to provide feedback and then – as part of feedback loop – where possible review final stage documents to review decisions and changes made based on early-stage panel feedback
    - drive and maximise the effective function of the group by ensuring the agenda, structure, and membership remain under regular review and under the responsibility of all members

Actions required by the engagement and communications panel:

The GP Data Patient and Public Engagement and Communications Advisory Panel is asked to review, comment upon, and approve the draft Terms of Reference for the group in the form of an initial approval, and on an ongoing basis for major updates,

Circulation:

GP Data Patient and Public Engagement and Communications Advisory Panel members

Publication on NHS Digital website 21 February 2022.

Updated version published on NHS Digital website – once approved

Dates considered by panel:

28th October 2021 – Initial Approval

1st February 2022 – Updated following review in January 2022

18th February 2022 – Finalised for publication

13th October 2022 – Updated and approved for publication

1 Purpose

This document sets out the Terms of Reference (ToR) for the Patient and Public Engagement and Communications Advisory Panel (PPECAP). This document defines the panel's role, membership, and operating model. As a living document, it is expected that changes may be required as the GPDPR programme and VTS project progress.

The Terms of Reference will be reviewed on a quarterly basis as a minimum, or as triggered by any major changes.

2 Background

On 19 July 2021, Ministers wrote to GPs in England describing changes being made to the General Practice Data for Planning and Research (GPDPR) Programme. Patient 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 reduced
- a Trusted Research Environment has been developed and implemented in NHS Digital
- patients, carers, and the public have been made more aware of the scheme through a campaign of engagement and communication.

The GP data patient and public engagement and communications advisory panel was established in August 2021 to support the GPDPR programme to meet the ministerial commitments and enable the collection of data for planning and research to begin.

In Summer 2022, it was acknowledged that that the technology underpinning the General Practice Extraction Service (GPES) is operating over capacity and is limited in capability due to being ten years old. It was agreed that immediate work was needed to safeguard the provision of existing direct care data collections, and to accommodate future requests.

Due to the urgency of the issues facing GPES, a proposal has been made to aim to move existing direct care collections onto new, more stable technology which has more capability and capacity to meet requirements. The resources required to resolve these issues are currently aligned to the GPDPR programme, therefore a reprioritisation exercise has taken place.

In October 2022, it was proposed that the scope of the terms of reference for all of the GPDPR programme assurance groups be widened to incorporate discussion about the VTS project.

The role of the GP Data Patient and Public Engagement and Communications Advisory Panel

Overall aims and objectives

1. to act as advisors and consultants on the development and implementation of:
    a. the four phases of the communication and engagement strategy for GPDPR
    b. Communications and engagement activity supporting data collection for the vaccinations, treatment, and screening project.
2. to advise on who, how and when to engage patients and the public, to help shape the emerging communications content.
3. to ensure that all communications content, materials, and activities are informed by patient and public views during development, in order to build trust in the use of patient data

The panel will play a vital role in all editorial activities necessary to support both the GPDPR programme and the data collection for vaccinations, treatment, and screening project. It will support the development of credible and accessible materials, for the programme and project by:

- co-creating, reviewing, and providing patient and public perspective to all content produced by the wider NHS and NHS Digital
- giving guidance to those teams developing the materials, and advising where additional content and/or materials may be necessary
- representing the views as patients and members of the public, as well as parent organisations (where relevant) in providing assurance and approval of materials
- being confident that the content provided in materials has been through sufficient review and rigour, to ensure the content is accurate and responds to concerns and challenges raised during testing, by wider stakeholders and by the panel
- ensuring that approved policy and programme decisions are incorporated clearly and accurately into the materials
- challenging where specific content is thought to be inaccurate or misleading
- reviewing the materials for plain English, checking for consistency in language, clarity, and ease of understanding for external lay/non-expert audiences
- ensuring that materials comply with accessible formats, in line with the approach agreed with accessibility groups
- acting as an escalation route, for questions and possible issues raised through the materials drafting and review stages.

The panel will review a range of materials and collateral from different sources to include:

- communications content to support engagement activities
- communications content to support the public information drive
- accessibility materials to support the public information campaign including information in different formats and languages.

All group members will have authority and responsibility to suggest topics for discussion, changes to group membership, and or any area of improvement. The group structures and processes will be kept under regular review, and amended through group consensus to maximise the effective functioning of the group.

3 Membership

The GP Data Public and Patient Engagement and Communications Advisory Panel includes representation from a diverse range of patient and public representatives (known as lay members), supported by organisations who champion the voice of the public and patients. These organisations are:

- Office of the National Data Guardian
- Understanding Patient Data (until end October 2021)
- UseMYData
- Healthwatch
- Association of Medical Research Charities (AMRC)

In addition to the above members, the panel will be supported by NHS Digital's GPDPR programme team, the VTS project team and attended by representatives from NHS Digital and NHS England as required.

If a panel member from a listed organisation is unable to attend a meeting but they wish to be represented, they may nominate a deputy who is authorised to contribute on their behalf. Patient and public representatives are not permitted to send deputies in their absence.

4 Method of Operation

4.1 Meetings

Chair	The role of chair is rotated between the professional representatives from Healthwatch, The Office of the National Data Guardian and the Association of Medical Research Charities. The position rotates every four months.
Quorum	Chair and five other patient and public representatives members (or alternative representatives) must be present.

	Members must give a minimum of 48 hours notice if they can not attend (except in unavoidable circumstances), to ensure the meeting quorum can be met.
Frequency	Meetings will take place bi-weekly as required. A minimum of 2-weeks notice will be provided ahead of any change in frequency.
Format	The meetings will usually be held via Teams or Zoom. There may also be requests for members to review materials offline or out of the regular meetings and to meet deadlines i.e., for web content or campaign content review. The Terms of Reference, agendas and action notes will be published on the NHS Digital website.
Standing Agenda	Apologies. Actions and review from previous meeting. Materials/presentations/agenda items for review. Any other business.
Governance	The PPECAP are accountable to the GP data programme and the vaccinations, treatment and screening project.

4.2 Inputs

The following inputs will be provided to each Panel meeting:

- minutes and actions from the previous meeting
- programme/project updates

When required the panel will also be provided with:
- materials for review by panel
- papers, , and other materials for discussion

4.3 Escalation Process

Any serious issues or problems to be reported to the Head of Communications and Engagement, GP Data, NHS Digital, and if not resolved, to the GP Data for Planning and Research Programme Board or The Vaccinations, Treatment, and Screening Strategic Delivery Board. Outputs and publication of information about the panel to include:

- minutes and actions arising
- within these, an update on progress on materials submitted for review
- decisions on questions/issues escalated to the panel
- this terms of reference, agendas, high level minutes and documents produced as outputs from meetings will be published on the NHS Digital website
- outputs of meetings will also be shared with NHS partners and colleagues, to inform the communications and engagement planning for GP Data for Planning and Research programme, and the Vaccinations, and Treatment and Screening project,

4.4 Expected behaviours and conduct

Trust and respect is at the heart of this work and members are expected to take part in line with the Nolan Principles. patient and public representatives must also behave in line with NHS Digital's Code of Business Conduct.

Panel members should feel they are in a safe place and are free to express views and concerns, confident that they will be listened to and without fear of reprisal.

There may be times when new public or patient representatives join the Panel. New members will be offered the opportunity to 'buddy' with an existing Panel member to support them whilst they settle in.

Given the online nature of meetings, it is important that all members are able to speak without interruption and also feel free to use other methods of communication available during the sessions.

NHS Digital can ask members to leave the group if their behaviour is deemed inappropriate, such as displaying repeated intolerance of other's views, being aggressive or threatening, bullying, being repeatedly rude or deliberately offensive or breaching confidentiality (see below). This includes during meetings or in correspondence.

4.5 Declaration of interests

At the start of each meeting, the Chair will ask Panel members for Declarations of Interest, in relation to GPDPR programme, VTS project, or any specific item on the agenda. Any interests must be declared and will be recorded and included in the published action notes.

Members of the Panel who have declared an interest will also need to consider any potential or perceived conflict of interest in their contributions to the discussions as a matter of good governance during the meeting and if they feel they are potentially conflicted at any point due to the nature of the discussion, declare this and abstain from the remainder of the discussion.

4.6 Confidentiality

We want all members to feel confident that the views they express in the meeting are confidential and will not be shared by other members either verbally or by other means without permission. Views may be shared confidentially between the Chair, business support staff, or the project or programme team and wider engagement and communications workstream.

- All panel members are expected to maintain confidentiality in order to promote honest, frank discussion during group meetings. Comments and views will not be attributed to individual panel members, without the prior agreement of that member. This includes meeting notes.
- Panel members will be made aware of the NHS Digital Privacy Policy which describes how we collect and use personal data. Personal details of panel members will be processed in accordance with this notice.
- Members may be privy to information that is not yet in the public domain.
- Members will be informed about what is, and what is not, confidential and asked to maintain absolute confidentiality. Any breaches will be taken seriously, with the panel member concerned asked to leave. Members will be told when previously confidential information is ready to be in the public domain.
- The action notes from meetings are published, however this is only done once the Panel have reviewed and approved the content for publication. It is the responsibility of Panel Members to review the action notes and provide feedback if they are not going to be present at the following meeting.

4.7 Parallel Stakeholder Groups

The Patient and Public Engagement and Communications Advisory Panel will be conducted in parallel to a number of other stakeholder groups covering specific elements of programme design and delivery for the GPDPR programme and the VTS project. 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 and Improvement.
    - 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, DHSC, NHS Transformation Directorate, and GPDPR Programme leadership
    - The board meets monthly
    - The dedicated ToR for this group will be published alongside this ToR on the NHS Digital website

- The Check and Challenge Group
    - The primary aim of this group is to challenge the delivery of the GPDPR 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 currently meets fortnightly in alignment with the Patient and Public Engagement and Communications Advisory Panel
  - The dedicated ToR for this group will be published alongside this ToR on the NHS Digital website

- The IG Expert Liaison Group
  - The primary aim of this group is to provide specialist technical advice and guidance into the IG and Legal approach and deliverables of the GPDPR programme
  - The group will be asked to review documentation and approaches covering the legal obligations of the programme such as the DPIA, DPN, EQIA and supporting materials
  - Group membership consists of expert data protection and information groups, regulatory representation, and internal NHS IG & Legal experts
  - The group meets monthly
  - The dedicated ToR for this group will be published alongside this ToR on the NHS Digital website

- **VTS Strategic Delivery Board – details to be added once the Terms of Reference have been agreed.**

As the Patient and Public Engagement and Communications Advisory Panel is designed to review and challenge all communications and engagement elements of the GPDPR programme and VTS project, there will be significant cross-over between the documentation under review at these forums. As such, the interaction between these groups will need to be managed to maximise transparency and alignment.

This will be managed with full oversight and input from Patient and Public Engagement and Communications Advisory Panel members and members will be asked to review options regarding the approach to stakeholder group alignment as and when required.

Where advice, feedback, or guidance from stakeholder groups directly conflict, the GPDPR programme or VTS project will review the feedback and request confirmation from the Programme Board of decisions related to these conflicts. Stakeholder groups will be fully informed of the decisions made and the rationale regarding the decisions prior to any related programme delivery action. Any further challenges beyond this point will be dealt with on an individual basis.