

Patient and Public Involvement and Engagement plans

Introduction and Purpose

Our funding proposal included a clear commitment of PPIE involvement across all elements for DATA-CAN, built on national and international best practice.

Working with an initially small patient panel, we ratified our core PPIE principles within a month, produced a comprehensive PPIE strategy and recruited a diverse (gender, age, ethnicity, geography, gender and experience) 13 member PPIE Group within 3 months with an appointed patient Chair. Our PPIE Coordinator and the PPIE Lead work closely with the PPIE Group Chair to support the Group.

After six months we surveyed our PPIE members to understand how our PPIE approach was working. The results were very positive, though it was clear that a few of the less-experienced PPIE members had struggled in some instances. We have put steps in place to address this and are keeping it under review.

As part of our bid, we committed to implementing the outcomes of the public review undertaken by OneLondon. It was positive to note that the key recommendations and practices in the report were already being adopted within our programme.

Vision and Aims

We already follow best practice described by HDR UK, and from the outset adopted the principles of transparency developed by the use MY data patient movement.

Our vision is to further develop our PPIE members as experts in their field, to become the voice of DATA-CAN and exploiting their documented 'reach', collectively linking to around a hundred other patient, data and research organisations.

Our core PPIE learning materials form the basis from which other Hubs may produce similar disease-specific modules, whilst collectively producing the common core modules, such as Information Governance, data access, commercial links and partnerships.

Approach

Involvement

Our PPIE voice is pervasive across DATA-CAN, with members working alongside our Commercial, Data and Communications functions. We will continue to operate in this way, building on what has already taken place:

- Production of the PPIE Strategy, and Terms of Reference for the Group
- Recruitment of staff, including Chief Operating Officer and Head of Communications roles
- Co-production of the DATA-CAN website content with communications team
- Authorship of blogs, articles, data case studies, plus patient quotations on press releases
- Review of all commercial contracts
- Active participation in Steering Board meetings, including presenting updates from the PPIE Group
- PPIE subgroups including for Data Services, Comms and Commercial teams
- Providing support for other Hubs – Better Care North, Surgery hub
- PPIE Training Programme

- Contributed to CRUK in their future TRE plans.

Engagement

Leveraging the ‘reach’ mentioned earlier and supporting the use MY data movement provides additional networks through which we can conduct our engagement activities and crucially brings external questions and a critical friend view to what we do. We have drafted a ‘Lay briefing pack’ to assist our members in their engagement activities.

Our links to use MY data and the National Data Guardian

We directly support the use MY data movement of patients, relatives and carers who share an interest in how data is used to improve care and outcomes.

- Our PPIE Lead is Expert Data Adviser to use MY data and two members of the DATA-CAN PPIE Advisory Group membership of use MY data and we also provide secretariat support.
- One DATA-CAN PPIE member sits on the National Data Guardian Panel.

UK Standards for Public Involvement

Our PPIE group ensures the HDR UK Involvement and Engagement Guiding Principles are embedded across the work of DATA-CAN. We believe that within this milestone report we have evidenced compliance with the UK Standards for Public Involvement:

1. Inclusive Opportunities – 12 of 13 members involved in additional DATA-CAN activities beyond PPIE Group membership

2. Working Together – through our sub-group structure and embedding within DATA-CAN workstreams
3. Support and Learning - comprehensive set of learning materials, plus 1:1 mentoring available with our PPIE lead, briefing opportunities and drop-in sessions used by members
4. Governance – two patients are members of the Steering Board, two patients on the Management Group, at least one patient on all programme subgroups
5. Communication – our PPIE team are included in design and sign-off for communications materials, including website content, press releases (which have included patient quotations) and reports
6. Impact – Still learning – we document activity which leads to influence via Impact Log.

Two quotes from our members in this regard:

“It is so good that in DATA-CAN we can identify with the National Standards as a reality and not made up for a report!”

PPIE Member1

“When I saw a slide showing the various levels in the DATA-CAN group and how PPIE members were involved at every level of this project, it gave me reassurance that my experience could be used to benefit others and my voice was indeed valuable to the group.”

Measures of Success

A key measure of success will be the ability of DATA-CAN to take innovative decisions, knowing that there is a strong PPIE guidance and support for these. Successful industry partnerships are critical and our PPIE work underpins all

contracts, providing reassurance and transparency, helping to improve openness and trust in an area where the public have yet to feel entirely comfortable.

A joint paper between PPIE members, PPIE Lead and Scientific Lead is currently being written illustrating how we have achieved our current impact.

Additionally, we are developing an Impact Log which we will keep as a running document at each PPIE meeting.

Risks and Mitigation

- Our PPIE function must feel engaged, supported, listened to and trusted. Mitigation is to provide extensive support including training, mentoring and 1:1 support and budget to match.
- The overall risk is in the loss of public trust in how institutions use patient data. Mitigation is to ensure that what we do is clear, open, transparent, has value to patients and has their support.

Supplementary PPIE Strategy Update

Publication of an academic article about practical PPIE and RWD

We will produce an article aimed for publication in a peer reviewed journal, with a focus on how we have taken best practice theory and embedded this as practice throughout our PPIE function. This will have a specific focus on the PPIE role to oversee and steer the use of real-world data and commercial partnerships.

Implementing Equality, Diversity and Inclusion (EDI) across DATA-CAN

Whilst we included an EDI approach into our PPIE recruitment, we will extend this further to ensure EDI best practice across DATA-CAN activities, including working with our partner organisations.

Refine, as necessary, our definition of 'PPI impact' with our PPIE Group and make appropriate changes to our impact recording mechanisms

Reflecting the need to demonstrate impact, we will continuously review and improve our mechanisms to measure impact.

Developing learning materials about commercial uses of data (with one/more commercial partner)

Building upon our existing work, we will work with commercial partners to co-produce learning materials to describe the role of commercial organisations in the use of healthcare data. This will examine the opportunities, risks, safeguards, benefits and realities of the uses of healthcare data.

Thinking about how we could connect with schools/young people

As a direct result of requests from within the PPIE group, we will be looking into partnerships or linkages which we can make to organisations which have existing footholds into communications with schools and younger people about the uses of healthcare data.

Areas of AI and data ethics

We will be exploring the areas of ethics and AI, to equip our PPIE members with information and reference materials to enable them to play an active part in discussions in this area.

Developing and support a wider network of networks

We already have strong links, and provide support to, the use MY data patient movement, and we will seek to build upon these linkages, together with other Hubs, to establish a “network of networks” of PPIE activity, specifically focused on the uses of healthcare data.

As part of the sustainability work, define, develop and deliver a “review/consultative” model for potential commercial users of data

Building on the work we did to review a commercial “fair value” offer from a commercial company (described in one of our case studies), we have already undertaken similar commissioned work for a charity and have several other similar commissioned reviews which have been requested by commercial organisations. This is potentially an opportunity which we will explore further.