

# PPIE in Health Data: System Analysis

Understanding Patient Data

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## 1. About Understanding Patient Data (UPD)

[Understanding Patient Data \(UPD\)](#) is a hosted organisation of the NHS Confederation in London, UK. It is funded by Wellcome, the Medical Research Council, the National Institute for Health and Care Research, Office for Life Sciences and NHS England. Our remit is across the UK, and we collaborate internationally too.

Understanding Patient Data (UPD) aims to make the use of patient data in the UK more visible, understandable and trustworthy. We focus on data routinely collected by health and care services as part of providing healthcare, that can be used for research and planning. This data is used for patient benefit by NHS or health and care bodies, academics and sometimes commercial organisations, but its use can be controversial.

We provide objective information about how patient data is used and bring the views of patients and the public to policymakers and data holders to ensure data is being managed and used in ways that are worthy of public trust.

UPD's broad strategic objectives are to:

- Amplify the voices of underrepresented groups – the aim is that people should have access to freely available, independent information about health data, understand and exercise their rights and responsibilities, and are able to meaningfully support or oppose initiatives and be (and feel) heard.
- Improve clarity and transparency for health data users to develop and demonstrate trustworthy practices – the aim is that they collect, access and use health data accurately, fairly and safely from an evidence-based position informed by public attitudes
- Influence policy, strategy, and legislation – the aim is to work with policymakers and influencers across the sector to influence decision-making and steer health data policy towards the responsible use of patient data with integrity to improve health outcomes, underpinned by an informed and engaged public.

## 2. Project Background

Public awareness and understanding of how patient data is used remains very low. Many people hold misconceptions about what data is collected, who can access it, and for what purposes. [Low awareness, past controversies, and historically limited national engagement have left trust fragile, contributing to higher opt-out rates and uneven data representation.](#) Against a backdrop of NHS reform, digital transformation, and new government commitments on data, understanding and strengthening the relationship between public involvement, policy decisions and public trust has never been more important.

Patient and public involvement and engagement (PPIE) is an established and growing feature of the UK health data landscape. As the collection, use, and sharing of health data expands to support research, innovation, and improved care, ensuring that the public's voice is meaningfully represented in decision-making has become increasingly important.

PPIE activities are now embedded across health data initiatives, from local committees to national programs shaping health data policies. There are promising examples of PPIE activity shaping priorities, surfacing insights, and fostering public trust in the use of health data. However, the pathways through which these contributions successfully translate into policy impact are not yet fully understood. The community of people and organisations involved in PPIE around health data is complex and evolving - encompassing policy teams, commissioners, practitioners, public contributors and other influential parties working across local and national levels.

While there are many examples of effective and thoughtful PPIE practice, the ecosystem as a whole remains under-defined. The size, composition, motivations and experiences of those involved are not well documented, nor are the practical or policy conditions that enable good involvement to flourish. At the same time, the commissioning environment is shifting - shaped by new funding structures, changing expectations of public participation, and increasing demands for demonstrable outcomes.

This project seeks to build a clearer picture of the PPIE community working on health data: who they are, what drives and supports their work, what challenges they face, and how they connect and collaborate. By doing so, it aims to highlight the needs of three key groups – policymakers, commissioners, and PPIE practitioners - and identify opportunities to strengthen relationships between them. Understanding these dynamics will help ensure that public involvement in health data is not only meaningful and inclusive but also well supported and sustainable within the current and evolving policy context.

The findings of this project will help illuminate the mechanisms that support impactful engagement, celebrate effective practice, and inform future approaches to embedding and evaluating PPIE across the health data landscape. Ultimately, this work seeks to strengthen the evidence base for meaningful public involvement in health data and support policy and practice that aligns with public expectation.

The following links provide examples of guidance developed to support the health data PPIE community, and to illustrate what good practice can look like. They highlight the valuable work already undertaken to inform and strengthen PPIE activities. The focus of this project is not on replicating these initiatives. Instead, it is centred on characterising and strengthening the PPIE community itself to enable meaningful and sustainable participation:

- **UK Health Data Research Alliance – Involving Patients and the Public**  
Guidance on embedding public involvement in governance and commissioning models across health data organisations.  
[Learn more](#)
- **NIHR Imperial Biomedical research Centre – Guidance on Involving the Public in Health Data Research**

Practical resource on ethical and effective public involvement across the research cycle, supporting trust and transparency.

[Access guidance](#)

- **PEDRI – Best Practice Standards for Public Involvement and Engagement**

Draft standards for equity, inclusion, transparency, and needs assessment in data research.

[Download standards](#)

### 3. Objectives

This project seeks to strengthen understanding of the UK's patient and public involvement and engagement (PPIE) ecosystem in relation to health data. Rather than assessing or measuring "impact," the focus is on identifying and characterising the community involved, understanding their motivations and experiences, and examining how policy and commissioning environments enable or constrain meaningful participation.

The insights generated will help policymakers, commissioners, and PPIE practitioners build stronger, more connected, and more effective relationships that support trustworthy and inclusive decision-making around health data. In line with UPD's broader strategic objectives above, the aims of this project are to:

- Map and characterise the UK PPIE community working in the health data space – identifying the influential organisations and individuals involved, their roles, motivations, capacity, and levels of experience, and the structures through which they contribute.
- Understand the needs, incentives and challenges of three key groups – policymakers, commissioners, and PPIE practitioners – to illuminate where relationships are strong, where gaps exist, and what would help improve collaboration and mutual understanding, as well as understanding the impacts of other influential stakeholders in the PPIE community on these groups.
- Explore the commissioning and delivery landscape for PPIE in health data – how priorities are set, how resources are allocated, and how evolving policy and governance reforms are shaping expectations and opportunities.
- Examine how PPIE practitioners and participants experience their work, including what support, training, recognition, and feedback loops they need to feel valued and effective.
- Identify conditions that enable sustainable, inclusive and high-quality involvement, such as supportive commissioning models, clear policy mandates, and networks for shared learning.
- Building on the work of colleagues in the devolved nations, design and deliver quantitative surveys that capture broader experiences of delivering PPIE in health data, providing a more comprehensive understanding of perspectives across the ecosystem. Generate insights and practical recommendations for policymakers, commissioners and PPIE practitioners on how to better connect their efforts and strengthen the overall ecosystem for public involvement in health data.

#### 4. Scope

We would like to appoint a supplier to work with the UPD Community & Partnerships Manager and the wider team to undertake a system wide analysis and review of the health data PPIE community. This analysis is part of a wider programme of work which aims to better support combined impact of public insights on health data, support cross-sector collaboration, and reduce duplication of effort. It will have ongoing links and developments beyond the scope of this individual project. Detail on linked programmes of work and how they relate to this project will be jointly determined and qualified with the successful supplier.

Tenders should provide a detailed breakdown of the budget needed for the deliverables in your proposal, exclusive of VAT, including at least the number and seniority of staff, the number of hours they expect to work, and any outsourced costs. However, to assist with planning and scoping, we expect to receive bids in the region of **£25-£45K**, excluding VAT.

The commissioned supplier will be responsible for designing and delivering research and analysis that deepens understanding of the UK health data PPIE ecosystem and its influence on policy and decision-making. The work should generate clear, evidence-based insights into how PPIE activities, and the individuals and organisations who lead them, shape the policy agenda, and provide practical recommendations for creating environments that enable meaningful and sustainable participation. The approach is expected to combine desk-based research with qualitative and quantitative methods to ensure a robust and comprehensive analysis.

The scope of the work will likely include the following components, although we are flexible to alternative approaches based on the individual supplier's expertise:

1. Project design including refining of research questions and methodology
2. Desk based review of existing literature, evaluations and case studies on PPIE impact in health data to identify gaps and current evidence.
3. Qualitative fieldwork with policymakers, commissioners, and PPIE practitioners through 1:1 interviews and/or focus groups
4. Development and management of quantitative surveys that build on similar work from colleagues across the health data landscape.
5. Analysis and synthesis of findings
6. Reporting of findings, conclusions, recommendations, and insights.

#### 5. Timelines

|                              |                                 |
|------------------------------|---------------------------------|
| Proposals due                | 5pm on 5 <sup>th</sup> December |
| Interviews                   | w/c 15 <sup>th</sup> December   |
| Successful supplier notified | 19 <sup>th</sup> December       |
| Project kick off             | 5 <sup>th</sup> January 2026    |
| Final reporting              | June 2026                       |

## 6. Submission Guidance

Interested parties are asked to submit a proposal document. The deadline for submission is **5pm on the 5<sup>th</sup> December.**

The Proposal document should, as a minimum cover the following areas:

- Demonstrate your understanding of the topic, and outline your proposed methodology and timeline for the project, with justification demonstrating why and how it will be appropriate for approaching this topic.
- Detail your relevant experience of research and analysis, paying particular attention to detailing any expertise in qualitative methodologies.
- Provide a detailed breakdown of the budget needed for the deliverables in your proposal, exclusive of VAT, including at least the number and seniority of staff, the number of hours they expect to work, and any outsourced costs
- Examples of similar projects you have delivered
- Briefly outline your values, structure, size and capabilities in general

In order to assist in the preparation of the Proposal document, applicants are welcome to ask clarifying questions. We will also be happy to organise pre-application calls to talk about the project if capacity allows.

Please email:

Charlie Wilkinson (Community & Partnerships Manager) -  
[charlie.wilkinson@understandingpatientdata.org.uk](mailto:charlie.wilkinson@understandingpatientdata.org.uk)

Proposals should be submitted via email with the subject heading 'PPIE System Analysis: Proposal Application' to

[hello@understandingpatientdata.org.uk](mailto:hello@understandingpatientdata.org.uk)