Understanding Patient Data

Project Brief: Data for Planning – Views and Expectations (Phase 1)

Understanding Patient Data (UPD), an independent organisation hosted by the NHS Confederation, is seeking support from an external contractor to deliver a project on public views and expectations around the use of data for planning:

- Conduct surveys and interviews/workshops to understand public attitudes on this topic
- Draft a brief report that sets out the findings of the research, including current understanding of and expectations around data use and what examples/use cases resonate with people that can subsequently be developed into co-created resources on the use of data for planning in a future phase of the project

We are inviting quotes based on the outline below.

Background

Project background

"Service planning and improvement" (often shortened to "planning") is one of the four main use cases for health data identified by NHS England[1] and the Government as key to the transformation of the health service in England[2]. In other nations of the UK, health data plans also highlight the importance of data for service planning.[3,4,5]

Health data is used to support planning of many aspects of health and social care services. This can include using data to:

- model and forecast demand for services to ensure hospitals and other providers have the staff and capacity to deliver care
- manage population health by understanding current and future health needs and targeting interventions at the groups that most need them
- improve services through data analysis showing which services are performing well and which ones need additional support

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[1] House of Commons Science and Technology Committee, *Oral evidence: The right to privacy: digital data* (HC 2021 – 22 1000) Q138

[2] Department of Health and Social Care, *Data Saves Lives: Reshaping Health and Social Care with Data*, 2022

[3] Welsh Government, *Digital and data strategy for health and social care in Wales*, 27 July 2023, https://www.gov.wales/digital-and-data-strategy-health-and-social-care-wales-html

[4] Scottish Government, *Health and social care: data strategy*, 22 February 2023, https://www.gov.scot/publications/data-strategy-health-social-care-2/

[5] Health and Social Care Northern Ireland, *Data Strategy HSC Northern Ireland 2022-2030,* 20 October 2022

- support the commissioning of services and allocate resources to appropriate providers and programmes
- predict what health challenges we will face and what services will be needed in the future to respond to national trends and make important policy decisions
- coordinate the provision of health and social care services to ensure each sector has the information they need to help people moving between health and social care providers

This use case for patient data existed long before the Covid-19 pandemic but was particularly important during this period to understand the capacity of UK health services, analyse the spread of the virus and inform service provision on a daily and weekly basis at local, regional and national levels. Since then, there has continued to be a strong interest in planning and the "internal" use of data by health services. This is reflected in the investment in infrastructure such as the Federated Data Platform in England, the GP Intelligence Platform in Northern Ireland, the National Data Resource in Wales and the Discovery platform in Scotland, which aim to facilitate the use of planning for individual care and, importantly, planning.

Despite the importance of using data for planning, it often receives less attention than the use of data for research and individual care and is sometimes used as a catch-all term for any use case that does not fit neatly into either category. This may be because there are assumptions that members of the public are not interested in it, that it is a given that data collected by the health service is used for planning, or because analysts and healthcare leaders fear that fear that increased attention on the many uses for data for planning may result in misunderstanding or increased opt-outs (where relevant).

Whatever the reason, this has resulted in a lack of information and understanding about the use of data for planning, which is three-fold:

- A lack of clarity about when data can be accessed for planning and improvement[6]
- A lack of clarity on public views on using data for planning (including population health and service improvement) beyond occasional high-level polling
- A lack of research on views on data for planning, as most research focuses either only on research use cases, or on secondary uses generally speaking (which does not distinguish between research and planning)

The evidence that does exist shows that whilst members of the public often know or assume that their health data is used for their own care and for research, there is less understanding of the use of data for planning, and that support for these use cases may be lower, or, at best, variable. One study found that whilst the English public are overwhelmingly supportive of sharing personal health data with the NHS, the NHS use cases they are least likely to support relate to service planning.[7]

This means there is an opportunity to undertake research specifically focused on the public's current understanding of how their data is used for planning, what their expectations are in relation to what uses of data are acceptable, what they want to know about the use of data for planning, how they feel about example use cases from current practice, and what language should be used to use to explain data for planning.

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[6] Department of Health and Social Care 2022

[7] Boston Consulting Group Centre for Growth, *Towards a Healthier, Wealthier UK: Unlocking the Value of Healthcare Data*, 2023, 20, 33

In some parts of the UK, a choice is given to the members of the public about whether they allow their data to be used beyond their individual care, such as for planning, e.g. through the National Data Opt-Out in England. In other parts, such as Wales, there is not a choice. However, there has long been debate about whether current opt-out choices are fit for purpose for organisational and individual needs, are well understood, and are well implemented. Whilst opt-out policy is not the focus of this work, and understanding these views better is important regardless of whether there is an opt-out or not, it may help with ongoing or future policy development in this space.

About Understanding Patient Data

Understanding Patient Data (UPD) aims to make the use of patient data more visible, understandable and trustworthy, for patients, the public and health professionals. We work with government, data custodians, health care professionals, patient advocates, researchers, funders and industry to influence policymaking and communication around the use of data to patients and the public.

Data that is routinely collected as part of a person's interactions with the health service is highly useful for purposes beyond individual care, such as for research and planning purposes, 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.

Project specification

Overview

UPD would like to undertake a project to understand public attitudes and expectations toward the use of patient data for planning purposes. We envisage this will be achieved by undertaking qualitative research focused on a number of online workshops, complemented by a survey, followed by a write-up of the findings of the research.

Key activities include:

- Develop research methodology
- Design workshop structure
- Develop a pre-brief for participants to engage with prior to the workshops
- Draft workshop and survey questions
- Source participants for workshops and survey
- Run workshops
- Draft write-up of findings (working collaboratively with UPD to develop final outputs)

Research

We are open to suggestions from the selected supplier on how best to achieve the aims of the project, but envisage the following for the research element of the work:

- **Audience**
    - **Survey -** Nationally representative sample to cover the whole of the UK
    - **Workshops –** A small number of participants (<10) in each workshop. The participants should come from all four UK nations (though not all workshops need to include participants from each nation) and the groups should have diversity in terms of age, gender, ethnicity, disability, and socioeconomic background.

- **Format** – Workshops would likely be held online due to the budget available and to facilitate equitable access across the country. We recognise this might make it more difficult for digitally excluded individuals to participate on this occasion.
- **Scope** – The final topics and questions will be agreed between the chosen supplier and UPD, but we anticipate this will include participants' perspectives on:
    - What do they understand "planning" to mean in the context of using health data and to what extent are they aware of their data being used in this way?
    - Whether the combination of "planning" with "research" as a concept is helpful or not, and why?
    - What do they think the benefits and risks of using data for planning are?
    - Who do they think is involved in using data for planning (e.g. what parts of the health service and what other actors)?
    - When presented with a number of different use cases for health data to support planning, do they:
        - Understand what these mean?
        - Understand how data is used to support these use cases?
        - Support their data being used in this way (why? Why not?)
        - Align with how they thought their data was used (and if not, how do they depart from expectations?)
    - What use cases/examples they find most/least helpful?
    - How does support compare to their support for data for individual care or research?
    - Does support depend on whether their data is identifiable (such as with the use of COPI notices during the pandemic to support planning), de-identified or anonymous?
    - What would help them **a.** understand **b.** feel more comfortable with the use of data for planning? (E.g., examples, information, resources, reports, the role of intermediaries)
    - Do they think people should have a choice about whether their data is used for planning? Are there any exceptions?

Output

The chosen supplier would produce a report that sets out the findings of the engagement exercise. This should include:

- Executive summary
- Introduction, context and methodology
- Key findings: A big-picture overview of people's knowledge of and attitudes toward the use of patient data for planning purposes based on survey and workshops
- Full breakdown of survey results including graphs as appropriate

- Discussion about themes arising from workshops
- What the findings set out above tell us about the state of public understanding and feelings toward data use for planning, and recommendations for how to discuss data for planning with the public

We expect the prospective supplier to work with UPD during the drafting process to inform the structure of the report/deck and incorporate comments and edits ahead of finalising the outputs.

To learn more about the type of projects UPD has commissioned in the past, please refer to previous research published on our website, such as our work on public attitudes to third-party access to data.

Proposed budget: The proposed total budget for this work is £24,000 excl. VAT

Process for award of contract

UPD is looking for proposals which clearly demonstrate capacity to deliver and an appropriate and cost-efficient methodology. Please submit a concise proposal of no more than six pages which addresses the following:

- Outline your understanding of the work required and your methodology for delivering the key activities and objectives of this RFP, with a rationale for your chosen approach.
- Present your timeline for the proposed stages, milestones and actions for the project.
- Provide an example of previous work where you have successfully completed a similar project.
- Outline the skills and experience of your project team and how these will support the project.
- Outline how you would plan to work with the UPD team.
- Outline any risks or challenges you foresee and mitigations to manage this.
- Provide a cost proposal for the project which details and justifies the proposed costs and which deliverables they will help to achieve.
- Give contact information for a named point of contact.

Prior to the submission of your quote, if you have any questions about the project or the selection process, please email us at hello@understandingpatientdata.org.uk. **Please email your completed quote and proposal to this address by 17:00 on 17th November 2023.**

Selection Criteria

The award of the contract will be based on the following selection criteria:

- Experience undertaking attitudes/opinion research including delivering surveys and/or workshops
- Experience and knowledge of patient and public engagement (PPIE) work
- Experience working with clients to deliver research outputs including research reports
- Knowledge of topics related to the use of patient data for secondary purposes
- Value for money

Funding

For the avoidance of doubt, the output of this project brief will be funded as a Contract and not as a Grant.

Costs Incurred by Prospective Suppliers

It should be noted that this document relates to an invitation to quote only and not a firm commitment from Understanding Patient Data nor NHS Confederation to enter into a contractual agreement. In addition, neither Understanding Patient Data nor NHS Confederation will be held responsible for any costs associated with the production of a response to this Request for Proposal.

Contact Details

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Appendix 1 – Indicative timetable for contract award

Date	Activity
30/10/23	Project brief issued
17/11/23 17:00	Deadline for submitting quotes
20/11/23 - 01/12/23	Evaluation period
08/12/23	Notification of contract award
11/12/23 - 22/12/23	Supplier discussions and finalisation of contract
08/01/24	Indicative contract start date
29/03/24	Indicative contract end date

Appendix 2 – Equalities Questionnaire for completion

This questionnaire must be completed satisfactorily in order for any company to be considered to tender for this NHS Confederation contract. The NHS Confederation wants to meet the aims and commitments set out in its equality policy. This includes not discriminating under the Equality Act 2010.

1. Is it your policy as an employer and as a service provider to comply with your statutory obligations under the equality legislation, which applies to Great Britain, or equivalent legislation in the countries in which your firm employs staff?

Yes No

2. Accordingly, is it your practice not to discriminate directly or indirectly in breach of equality legislation which applies in Great Britain and legislation in the countries in which your firm employs staff:

- In relation to decisions to recruit, select, remunerate, train, transfer and promote employees?

  Yes No

- In relation to delivering services?

  Yes No

3. Do you have a written equality policy?

Yes No

4. Does your equality policy cover:

- Recruitment, selection, training, promotion, discipline and dismissal

  Yes No

- Victimisation, discrimination and harassment making it clear that these are disciplinary offences

Yes No

- Identify the senior position for responsibility for the policy and its effective implementation

Yes No

1. Is your policy on equality set out:

- In documents available and communicated to employees, managers, recognised trade unions or other representative groups?

Yes No

- In recruitment advertisements or other literature?

Yes No

- In materials promoting your services?

Yes No

Please evidence all questions.

If you answered NO to any part of questions 4 or 5 can you provide (and if so, please do) other evidence to show how you promote equalities in employment and service delivery.

6. In the last three years, has any findings of unlawful discrimination been made against your firm by the Employment Tribunal, the Employment Appeal Tribunal or any other court or in comparable proceedings in any other jurisdiction?

Yes No

In the last three years, has any contract with your organisation been terminated on grounds of your failure to comply with:

- Legislation prohibiting discrimination; or

Yes No

- Contract conditions relating to equality in the provision of services

Yes No

8. In the last three years, has your firm been the subject of formal investigations by the Commission for Racial Equality, the Disability Rights Commission, The Equal Opportunities Commission or a comparable body, on grounds of alleged unlawful discrimination?

Yes No

9. If the answer to question 6 and 7 is YES, or, in relation to question 8, a finding adverse to your organisation has been made, what steps have you taken as a result of that finding? Please summarise the details below and provide full details as an attachment.

Guidance in answering the equality questionnaire

When completing the questionnaire, all companies must answer each question fully and supply any documentary evidence requested. Failure to fully answer each question or failure to submit any documentary evidence required may lead the NHS Confederation to consider the answer unsatisfactory.

Question 1 and 2

If your firm has implemented an effective equality policy, you will be able to answer yes to these questions. You will be able to confirm your answers by submitting your equality policy and supporting evidence as for as part of this section.

Question 3 and 4

You will need to submit a copy of your firm's equality policy. You will need to ensure that your policy covers:

- Recruitment, selection, training, promotion, discipline and dismissal
- Victimisation, discrimination and harassment
- Identifies the senior position responsibly for the policy

Question 5

Documents available and method of communication to staff. You will be required to submit examples of any documents, which explain your firm's policies in respect of recruitment, selection, remuneration, training and promotion outside of the equality policy asked for in Question 3 and 4.

You will also need evidence of how your firm has communicated this document to staff i.e., notice boards or issue individual employees with a copy. There is no prescribed evidence here. You will need to submit whatever documents your firm uses for these purposes.

In recruitment advertisements or other literature. You will need to submit evidence that makes public your firm's commitment to equality in employment and service delivery.

Small firms may not have detailed procedures, but you must ensure that evidence is provided which demonstrates that personnel operate in accordance with a written equality policy that includes:

- Open recruitment practices such as using job centres and local newspapers

  to advertise vacancies

- Instructions about how the firm ensures that all job applicants are treated fairly.

In material promoting your services This relates to how your firm provides information in materials promoting your services e.g., in different languages, making information accessible to people with hearing and visual impairment and physical access for disabled users.

Question 6

This question's concern is whether any court or industrial tribunal has found your firm guilty of unlawful discrimination in the last three years. It is important to be honest with your answers. The NHS Confederation may check your responses. If the answer is yes, you may wish to insert additional information which details the actions your firm has undertaken to prevent a repeat occurrence.

Answering yes will not automatically mean that you do not get the contract; you need to ensure that the NHS Confederation feels confident that you have sufficient measures put in place to prevent a re-occurrence.

Question 7

This question's concern is whether your firm has ever had a contract terminated for noncompliance with equality legislation or equality contract conditions. If the answer is yes, your firm may wish to submit additional information will details the actions they have taken to prevent a repeat occurrence.

Question 8

This question asks whether your firm has had any investigation carried out, whatever the outcome. The NHS Confederation can check a contractor's answer from lists that the CRE and EOC produce, so please be honest. The NHS Confederation is aware that because a firm has been investigated does not mean that it is guilty of discrimination. The result of the investigation will be taken into account when assessing your firm's answers to the questionnaire.

Question 9

If your firm has been found guilty of unlawful discrimination, you will need to provide evidence that details the steps your firm has taken to correct the situation. The Court, Industrial Tribunal or CRE will have made recommendations about steps your firm should take to eliminate the discrimination. If no action or inadequate action has been taken in this respect, only then will your firm be considered refusal onto the tender list.

Question 10

If your firm is not subject to UK employment law, you must ensure that you supply details of equivalent legislation that you adhere to.

Appendix 3 – NHS Confederation Values and their definitions for reference

Respect

We treat people with respect.

We recognise the diversity of views, and we listen to understand.

We believe in fairness and support one another to achieve our goals.

We demonstrate trust, respect and fairness at all levels of the organisation.

We have fair and respectful employment practices that provide individual support and nurture talent.

Inclusivity

We continuously strive to be a diverse organisation - we encourage different ideas, strengths, interests and experiences.

We have a genuine commitment to being an inclusive and welcoming employer and organisation.

Our staff should represent the NHS and wider population in terms of diversity.

All our staff feel they have a voice, are listened to and valued. We value everyone’s contribution.

We respect different views and show this by listening and being authentic. We respectfully challenge back when needed.

Bold

We are innovative and creative, always striving to be our best.

We are courageous and confident when we need to respectfully challenge.

We are ambitious, aspiring to be the best in our work and encouraging it in others.

We are leading, influencing and represent our stakeholders and the NHS.

We speak for members and lead on their behalf.

Integrity

We are open in everything we do, say and role model.

We are honest with ourselves about where we need to improve.

We have pride in the work that we do, and we are proud to represent the NHS.

We are all accountable for our work and learn from our mistakes.

We have an honest and open culture.

Collaboration

We are all part of one organisation and work collaboratively with other teams.

We are a diverse organisation with a diverse membership and recognise and value each other's strengths.

We encourage internal collaboration to share ideas across teams and external collaboration to have impact across the wider NHS and our stakeholders.

We communicate respectfully and listen to the needs of our members and stakeholders.

We work together with our members and stakeholders to improve patient care.