



Understanding Patient Data

Request for Proposals

Understanding Patient Data: income generation strategy

Background & objectives

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.

We do this by:

1. **Creating resources** – we produce engaging, accessible information resources and guidance on how to talk about patient data that are freely available.
2. **Understanding people's views** – we commission and undertake attitudes research to understand people's views, expectations and concerns about data use, with a particular focus on minoritized or marginalised voices.
3. **Developing the community** – we support those who work with or care about patient data through convening and partnership projects, building a network of advocates and disseminating good practice.
4. **Influencing and advocating** – we translate attitudes and engagement research into insights for policy and practice at both local and national levels. We provide advice and consultancy to those who are making decisions about data use, encouraging them to take on board people's questions and concerns to build more trustworthy systems for managing and using data.
5. **Communications and media** – we provide advice and commentary to journalists and others seeking to understand the key issues about data, to promote more balanced reporting.



How is UPD funded?

Previously, UPD was an initiative hosted by the Wellcome Trust, beginning in 2016 with a two-year programme. Funding was later extended and UPD continued to be hosted at Wellcome until April 2023 when it moved to the NHS Confederation.

It is currently funded by Wellcome, the Medical Research Council, the National Institute for Health and Care Research and NHS England (although it has an independent Steering Group and is operationally independent). The current funding is secured for two years, until April 2025. Funding beyond this point is not confirmed and this presents an opportunity to consider UPD's options as it continues to grow and develop.

What needs to change?

The current two-year funding is greatly appreciated and enables UPD to continue its important work for the time being. However, we also need to think about the future now to put ourselves in the best possible position, which includes considering a range of funding opportunities. Many of our stakeholders have expressed their desire for UPD to exist, and grow, in the longer term. UPD is well-known amongst many prominent health care and research organisations, consistently receiving positive feedback and support for its contributions as well as requests for more collaborative projects that we don't currently have capacity to take on. There is appetite and opportunity for UPD to expand and develop both its team and its workstreams to ensure the longevity of this important initiative, if it had more reliable funding sources.

Why is the source of our funding important?

UPD's objectivity and independence are important to the organisation's mission and its relationship with its stakeholders. It is a trusted, neutral party. Therefore, who funds us, how much, why and what for are crucial questions that need to be answerable so that we can be transparent with our stakeholders, our work is trustworthy, and we can be held to account.

The total budget for this work is £15,000 excluding VAT, and value for money will be considered as part of the selection process.

Specification

UPD is commissioning a supplier to undertake a review into the potential income generation opportunities at our disposal, and determine the strengths, weaknesses, opportunities and threats of the options available. The UPD team, its Steering Group, and the NHS Confederation will then analyse this information further and take appropriate decisions.

The aim of this work is to explore the options for securing funding for UPD past the end of April 2025, and what UPD could look like under such funding models. We would like at least the following options to be considered:

- Continuing to fund in the same way, either with the same or other public sector organisations.



- Combining this with or solely seeking funding from the private sector, such as pharmaceutical industry partners, including general consideration of the ethical issues that may arise from this
- International funding avenues and how UPD could improve its chances of accessing these.
- Income-generating activities, such as donation-based public funding similar to typical third-sector charities, or professionalising resources such that they become pay-to-access as opposed to our current open-access policy.
- Other appropriate funding models that we have not considered here.

Incorporated into this would also be a consideration of scalability of the UPD team under each funding model. UPD is currently a three-person team, but the demand for work is such that it would be preferable to increase the size of the team. Therefore, each model should be considered according to the current three-person team but also the possibility and consequences of scaling this number up to around 6-8 people.

Output

The supplier would provide a written report that would combine the factual information relevant to the practicalities of each funding model, as well as an advisory element about the suitability of each model for UPD according to the supplier's expertise. We are open to suggestions from applicants as to how this report should be best formatted to meet our needs.

UPD would present the findings of the report to their Steering Group to understand their preference for a future funding model, before presenting its decision to the NHS Confederation board who will ultimately determine the model chosen. UPD will need to present the findings of this report to its Steering Group no later than the end of March 2024 to allow time for decision-making about which funding option to pursue.

RFP Process

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 10 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 RFP response, if you have any questions about the RFP process or the project, please email us at hello@understandingpatientdata.org.uk . **Please email your completed RFP to this address by 17:00 on 29th September 2023.**

RFP Discussions

Based on the proposal submissions, up to three suppliers will be invited to a second stage, where they will be able to discuss their proposal in more detail with the UPD team.

Selection Criteria

Ideally, we are seeking support from an individual or agency with the following experience, skills and track record:

- Knowledge and understanding of the statutory and voluntary sector in the UK
- Experience of developing or managing financial planning for organisations with the statutory or voluntary sector
- Experience of delivering reports to and engaging with teams to support their financial strategy planning and development
- Knowledge and understanding of the issues that can impact on the financial growth and stability of an early-stage organisation
- Value for money



Timetable

	Activity	Date (GMT times)
1	RFP issued to suppliers	04/09/2023
2	Opportunity to ask UPD questions via email: hello@understandingpatientdata.org.uk	05/09/2023- 28/09/2023
4	Submission of RPF response	29/09/2023 17:00
5	RFP evaluation period by UPD	02/10/2023 - 15/10/2023
6	Advice to suppliers as to whether they have been invited to present and discuss their proposal further.	16/10/2023
7	Supplier discussions with UPD	W/c 23/10/2023
8	Notification of contract award	W/c 30/10/2023
9	Follow-up and planning discussions	W/c 30/10/2023
10	Contract start date	13/11/2023

Funding

For the avoidance of doubt, the output of this RFP exercise 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 a Request for Proposal only and not a firm commitment from UPD nor NHS Confederation to enter into a contractual agreement. In addition, neither UPD nor NHS Confederation will be held responsible for any costs associated with the production of a response to this Request for Proposal.

Contact Details

Nicola Hamilton (Head of UPD) & Emma Morgan (Policy & Engagement Manager)

Email: hello@understandingpatientdata.org.uk



Appendix 1 - 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 which 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 2 – 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.

