



Understanding Patient Data

Expressions of Interest

Understanding Patient Data: evaluation

Overview

Understanding Patient Data (UPD) intends to carry out an evaluation of the UPD programme, and is seeking to commission an evaluator to undertake relevant activities, including surveys and interviews with our key stakeholders, to better understand and evidence its impact.

Background

About UPD

UPD aims to make the use of patient data in the UK more visible, understandable and trustworthy. We focus on data routinely collected as part of a person's interactions with the health service, that might be used for purposes beyond individual care without explicit consent. This data is highly useful for research and planning purposes, health and care bodies (e.g. the NHS), academics, charities and 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.

We do this by:

1. Creating resources – we produce freely available, engaging, accessible information resources and guidance on how to talk about patient data.
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 minority or marginalized 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 patient data, to promote more balanced reporting.

From 2016 to April 2023, UPD was a programme at Wellcome Trust (with one evaluation of the programme done in [2018](#)). As of April 2023, 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 and NHS England. The current funding for UPD is due to end in April 2025, and the team is currently seeking opportunities for securing future funding.

Purposes and objectives of evaluation

UPD would like to undertake a broad evaluation of the UPD programme, from 2016 to now, as well as some market research-style activities to better understand and evidence the impact of the programme. Ultimately, we would like the evaluation to support our future funding endeavours, serving as compelling evidence of our impact. Furthermore, as UPD is currently working to secure future funding, this evaluation will ideally serve as a baseline measure for future (and more regular) evaluations, and to inform the next programme of work for UPD based on the feedback and results.

We would like to commission an evaluator to support us with some of these activities, namely stakeholder surveys and interviews.

Example topics we may want to explore with stakeholders include:

- Awareness and perceived effectiveness / impact of UPD’s activities in line with the 5 ways of working highlighted in the Background section.
- Use of UPD’s content and estimated reach of that use
- Assess whether specific projects achieved their aims / what impact they had
- Perceptions of UPD’s independence
- Positive and constructive feedback
- Test perceptions / reactions to different operating models and possibility for financial support

We envisage that the internal UPD team will carry out some elements of the evaluation ourselves, such as installing a feedback pop-up on our website, a systematic review of academic uses of our resources, and analysis of our social media and website engagement.

Expected deliverables and outputs

We have some ideas for the activities we would like included as part of this work, which are listed below. That said, we are open to new suggestions and feedback on our approach.

- Survey and interview questions developed in partnership with UPD that align with our Theory of Change and evaluation goals
- Publish stakeholder survey, manage results and analyze responses. Given our extensive network and online following, we estimate that this will likely involve 100-300 responses.
- Organise, conduct and analyze stakeholder interviews. We would support with identifying appropriate and interested stakeholders within our network from a range of organisations and fields. We would suggest approximately 8-10 in-depth interviews, though we're happy to discuss this with the chosen supplier.
- Support the construction of compelling stories of UPD's impact.
- Produce a final report with background, method and findings. We would like this in a format where the additional evaluation work such as engagement analytics and website feedback can be integrated into a single report.
- If any additional evaluation activities (whether mentioned above as something the UPD team could do, or new) are within budget and capacity, we would be happy for this to be delivered by the supplier to support our internal capacity.

Budget & timeline

The total budget we have for this work is £15k excluding VAT, and value for money will be considered as part of the selection process. Your proposal should include a detailed cost breakdown, such as the number and seniority of staff and their day rate. This should be exclusive of VAT.

We expect this project to take about 3 months to complete (not full time), starting in July 2024 and finishing October 2024. Expressions of interest should include a suggested timeline with justification for milestone delivery times.

Selection process

In your expression of interest, please address the following:

- Demonstrate your capacity to deliver with a suggestion of a project timeline
- Outline your experience and provide an example of previous work where you have successfully completed a similar project.
- Provide an appropriate and justified cost proposal

We will rank responses on the basis of:

- Fit to requirements of the brief
- Quality and experience of the individual/team
- Value for money

We don't expect proposals to be more than 2-4 pages of A4.

Key dates:

Action	Date
Deadline for submissions	10am on 17/06/2024
Preferred Supplier notified	01/07/2024
Contract negotiation	01/07/2024-15/07/2024
Work commences	15/07/2024

Expressions of interest should be submitted by email to hello@understandingpatientdata.org.uk by 10am on 17th June 2024. Proposals received after this date will not be considered.

Contact

For further information, please contact:

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