



## Request for Proposals (RFP) for Understanding Patient Data: public resources on 'Why large-scale datasets?' and 'What is pseudonymised data?'

### 1. RFP background & objectives

#### Background

Understanding Patient Data (UPD) aims to make the use of patient data in the UK more visible, understandable and trustworthy. [UPD is a programme that will be based at the Wellcome Trust until the end of 2022.](#) Its resources will continue to be used by a wide range of stakeholders beyond this date.

We focus on data routinely collected by the NHS as part of providing health care, that can be used for research and planning without explicit consent. This data is used for patient benefit by NHS bodies, academics and sometimes commercial organisations, but its use can be controversial.

Large-scale data sets are increasingly used to develop new treatments and diagnostics, and for other research and health service design. During the Covid-19 pandemic rapid research using the [OpenSAFELY platform](#) provided specific insights to improve healthcare decisions nationally, based on data from over 17 million primary care records. In addition there are many other initiatives that seek to use data at scale.

But there has been concern from the public and privacy groups about the use of data about people, particularly in relation to [General Practice Data for Planning and Research](#). To ensure a well-informed public debate among patients, opinion formers and policy makers – as well as health care staff and researchers themselves - we need high-quality, accessible guides. We know that members of the public ask thoughtful questions about how large-scale data hubs operate, what risks and safeguards are in place and the nature of the trade offs. We want to meet this need.

The idea for this project originated and developed in partnership with the OpenSAFELY team, who are grantees of our wider department in Wellcome: Data for Science and Health. We then explored the idea further at a scoping workshop with a wider group of experts – researchers, clinicians, policy and engagement specialists and campaigners. Collectively, we identified the need for public resources that provide an open, accurate and engaging explanation of large-scale patient data sets. Although stemming from discussions with OpenSAFELY specifically, these resources would be generally applicable to all large-scale health data sets. A particular point of confusion concerns how data is processed and stored as 'pseudonymised' data. 'Pseudonymisation' is a technical, unclear and off-putting term. We want to produce a straightforward, engaging explanation that helps people gain a clearer picture of how data about them is processed and stored.

So UPD is commissioning a supplier to create two accessible and concise public guides:

1) A guide to the value and limitations of large-scale health data sets, for health research and planning.

To include:



- why we need large health data sets (eg what do they provide that smaller data sets cannot, including improving understanding of rare diseases and application of machine learning)
- public concerns and potential harms (eg relating to identifiability; or incomplete datasets exacerbating health inequalities)
- safeguards (including the different ways of de-identifying data, and the layering of safeguards)
- the trade-off between anonymity and useability
- useful questions to ask about large data sets in research
- key organisations with a place in the data governance landscape
- links to further information.

2) A guide to pseudonymised patient data. To include:

- a clear, brief explanation of pseudonymisation, its purposes (eg for security but also to allow reidentification for clinical use), and the different forms it can take
- how it differs from other privacy-enhancing techniques
- its strengths and weaknesses
- links to further information.

### Objectives of the two guides

- To equip members of the public with
  - an understanding of what large-scale datasets are, their value and risks and how the risks are handled
  - an understanding of pseudonymised data
  - scrutinising questions to ask in order to assess whether the use and management of a large-scale data set is being carried out in a responsible way.

As these guides are for the general public rather than technical resources for experts, it is important that the supplier has a track record in tackling complex or contentious issues, and communicating them accurately, clearly and engagingly.

UPD's role as ever is to give accessible, balanced information - so people can come to their own, informed opinion – rather than seeking to persuade.

The deadline to respond to this RFP is 5pm on Tuesday 16 Nov.

## 2. RFP Specification

This section sets out the specification of services for this RFP. Suppliers should use this section to fully understand Wellcome's requirements and to inform their response.

The supplier will:

Create, deliver and disseminate two public guides:

- A guide to the value and limitations of large-scale health data sets, for health research and planning.



- A guide to pseudonymised patient data, giving a clear, brief explanation of pseudonymisation, including its strengths and weaknesses.

Through:

Stage 1 – **Scoping**: desk research and discussion with the UPD team to agree the key concepts for each guide (optionally: also engage with professionals and patients)

Stage 2 – Producing **prototype draft materials** for user testing.

Stage 3 – **Co-design**: user testing with small, diverse groups of people to inform language, test understanding and direct design, look and feel

Stage 4 – **Redrafting and final design of a range of formats** (multiple formats/suite including e.g infographics, video clips, PDF guide, social media graphics)

Stage 5 – Launch including **dissemination** within relevant professional communities and networks as well as across social media, in partnership with UPD and OpenSafely; and embedding the resources within medical charities and the NHS at a regional level.

We anticipate the work will take around 6 months to complete. This is an outcome specification and suppliers should request the budget needed to deliver the required outputs. However, to assist with planning and scoping, we expect to receive bids in the region of £40,000-50,000 excluding VAT.

### 3. RFP Timetable

#	Activity	Responsibility	Date (all times are GMT)
1	RFP issued to suppliers	WT	Mon 1 Nov 2021
2	Deadline for requests to join the supplier event (below). Also deadline for submission of questions from suppliers by email, to be covered at supplier event.	Supplier	12 noon, Wed 10 Nov
3	Supplier event with Q&A on Teams. This will be an opportunity to ask UPD questions about the project. Please let us know if you would like to attend in advance (by 12 noon on 10 Nov). We will then send you a link to the meeting. <a href="mailto:engagement@understandingpatientdata.org.uk">engagement@understandingpatientdata.org.uk</a>	WT	12 noon-1pm, Thurs 11 Nov
4	<b>Submission of RFP response</b>	<b>Supplier</b>	<b>5pm, Tues 16 Nov</b>
5	RFP evaluation period (& preparation of responses to any outstanding queries following supplier event)	WT	Wed 17 Nov to Fri 19 Nov
6	Advice to suppliers as to whether they have been invited to present their full proposal. Return of response to any outstanding queries to shortlisted suppliers (collated response to all at the same time).	WT	5pm, Tues 23 Nov



	Request for <a href="#">Third Party Security Risk Assessment</a> (TPSRA2) forms and any contract feedback (see below) to be completed		
7	Supplier presentations and TPSRA2 forms and any contract feedback (see below) submitted	WT & Supplier	Wednesday 1 Dec
8	Notification of contract award	WT	Monday 6 Dec
9	Contract negotiation	WT & Supplier	Tuesday 7 Dec to Friday 18 December
10	Contract start date	WT & Supplier	Mon 10 Jan

#### 4. Response Format

The following headers support the timetable by providing further detail of the key steps.

##### Supplier Q&A

Prior to the submission of your RFP response, suppliers can ask any questions they have about the RFP process and project. Queries should be emailed to us ([engagement@understandingpatientdata.org.uk](mailto:engagement@understandingpatientdata.org.uk)) in advance of the supplier event, where they will be answered together with any queries that come up during the event itself. Responses to any outstanding questions will be collated and circulated to all shortlisted suppliers ahead of their presentations.

The supplier event will be held on Thurs 11 November 2021, 12-1pm.  
Please let us know that you would like to attend by 5pm the previous day:  
[engagement@understandingpatientdata.org.uk](mailto:engagement@understandingpatientdata.org.uk)  
We will then send you a link to the meeting.

##### RFP Proposal

Suppliers are required to submit a concise proposal which responds to the questions below. Please keep your proposal to approximately 4 sides of A4 (11 pt font, 1.5 line spacing) or 12 slides.

##### RFP Questions

This section requests responses from suppliers to specific questions in relation to this RFP exercise.



	<b>Question</b>
1	Outline your approach for delivering the key activities and objectives of this RFP. Please include: <ul style="list-style-type: none"><li>• Your proposed stages with descriptions; and timeframes to meet our requirement</li><li>• How you will deliver the co-design</li><li>• How you will quality check to ensure reliable, clear and engaging resources are produced</li><li>• How you will contribute to effective dissemination and embedding of the resources</li></ul>
2	Please provide an example of previous work where you have successfully completed a similar project: using co-creation to produce a high quality, well designed output on a complex subject for a public audience
3	Outline the project team, including a brief description of their experience
4	Outline any major risks and challenges you foresee with: <ul style="list-style-type: none"><li>• ensuring the tone of voice is clear and the resources are accessible without being patronising or overly simplistic</li><li>• ensuring a diverse range of people are involved in user testing sessions at the co-design stage</li><li>• any further risks and challenges you identify with this project.</li></ul> Please include your mitigation strategies
5	Please describe your approach to GDPR obligations. (We recognise that Wellcome's information governance requirements may be a challenge to smaller organisations and so are able to provide support.)
6	Outline your approach to equality, diversity and inclusion as this relates to methodology, practice and your organisation.
7	Provide a brief outline and justification of the proposed costs to meet our requirements. Ideally this would take the form of line items and which deliverables they will achieve.
8	Give contact information for a named point of contact

Based on these responses up to three suppliers will be invited to a second stage, where they will be given a one-hour slot on Wednesday 1 Dec to present a more detailed proposal to the UPD team, via Microsoft Teams.

### RFP Presentations

The presentation sessions will comprise the following segments:

- 5 mins for introductions
- 15 mins supplier presentation or structured discussion.
- 30 minutes for questions and clarifications from the UPD team
- 5 minutes for questions and clarification from the suppliers

If invited to the presentation stage, suppliers will also be asked to complete the tasks described below under 'Contract Feedback' and 'Information Governance'.

### Contract Feedback



This section allows suppliers to provide specific feedback to the contractual agreement which will be used should their proposal be successful. Contract feedback is to be submitted by shortlisted suppliers by the day of supplier presentations in the following format:

Clause #	Issue	Proposed Solution/Comment

Suppliers submitting proposals as a registered company should review this [document](#). Individuals submitting proposals as a sole trader (not registered) should review this [document](#).

Individuals submitting proposals through their own personal services company please highlight this to the Wellcome contact immediately (see point 7 below).

### Information Governance

Shortlisted suppliers are asked to complete the [TPSRA2](#) assessment by the day of the supplier presentation, for Wellcome to assess how you handle data.

As noted above, we can provide support on information governance. Please email in any questions you have in advance of the deadline and we can provide support to help you complete the form.

## **5. About Wellcome**

Wellcome exists to improve health by helping great ideas to thrive. We support researchers, we take on big health challenges, we campaign for better science, and we help everyone get involved with science and health research. We are a politically and financially independent foundation. Find out more about Wellcome and our work: [wellcome.org](http://wellcome.org).

## **6. Non-Disclosure and Confidentiality**

Prospective suppliers should be aware that inappropriate publicity could have a serious effect upon Wellcome's business. The information contained within this document or subsequently made available to prospective suppliers is deemed confidential and must not be disclosed without the prior written consent of Wellcome unless required by law.

## **7. Prospective Suppliers Personnel - IR35 and Off Payroll Working Rules**

Before the RFP response deadline, prospective suppliers must make the Wellcome contact aware if they are intending to submit a proposal where the services will be provided by any individuals who are engaged by the prospective supplier via an intermediary i.e.

- Where the prospective supplier is an individual contracting through their own personal services company; or



- The prospective supplier is providing individuals engaged through intermediaries, for the purposes of the IR35 off-payroll working rules.

## **8. Independent Proposal**

By submission of a proposal, prospective suppliers warrant that the prices in the proposal have been arrived at independently, without consultation, communication, agreement or understanding for the purpose of restricting competition, as to any matter relating to such prices, with any other potential supplier or with any competitor.

## **9. Funding**

For the avoidance of doubt, the output of this RFP exercise will be funded as a **Contract** and not as a Grant.

## **10. 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 Wellcome to enter into a contractual agreement. In addition, Wellcome will not be held responsible for any costs associated with the production of a response to this Request for Proposal.

## **11. Sustainability**

Wellcome is committed to procuring sustainable, ethical and responsibly sourced materials, goods and services. This means Wellcome seeks to purchase goods and services that minimise negative and enhance positive impacts on the environment and society locally, regionally and globally. To ensure Wellcome's business is conducted ethically and sustainably, we expect our suppliers, and their supply chains, to adhere to these principles in a responsible manner.

## **12. Accessibility**

Wellcome is committed to ensuring that our RFP exercises are accessible to everyone. If you have a disability or a chronic health condition, we can offer adjustments to the response format e.g. submitting your response in an alternate format. For support during the RFP exercise, contact the Wellcome Contact.

If, within the proposed outputs of this RFP exercise, specific adjustments are required by you or your team which incur additional cost then outline them clearly within your commercial response. Wellcome is committed to evaluating all proposals fairly and will ensure any proposed adjustment costs sit outside the commercial evaluation.

## **13. Diversity & Inclusion**



Embracing [diversity and inclusion](#) is fundamental to delivering our mission to improve health, and we are committed to cultivating a fair and healthy environment for the people who work here and those we work with. As we learn more about barriers that disadvantage certain groups from progressing in our workplace, we will remove them.

Wellcome takes diversity and inclusion seriously, and we want to partner with suppliers who share our commitment. We may ask you questions related to D&I as part of our RFP processes.

#### **14. Wellcome Contact Details**

Joint point of contact for all communication about this RFP:

Name: Rebecca Asher and Emily Jesper-Mir  
Role: Strategy and engagement managers,  
Understanding Patient Data (job share)  
Email: [engagement@understandingpatientdata.org.uk](mailto:engagement@understandingpatientdata.org.uk)