



Request for Proposals (RFP) for Black and South Asian public-led change: equitable data collection

Stage 1: Qualitative engagement with Black and South Asian members of the public.

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.

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.

Based at the Wellcome Trust, we work with patient groups, charities, NHS organisations and policymakers to bring transparency, accountability and public involvement to the way patient data is used.

Understanding Patient Data prioritises public engagement with people whose voices have previously gone unheard when it comes to shaping how health data is collected and used. This project will explore and be led by the views and aspirations of people from Black and South Asian backgrounds on the collection and use of data about them within the health system.

The Covid pandemic has seen [stark inequalities in health outcomes for Black and South Asian people](#), drawing attention to existing health inequalities. It has also exposed the frequent gaps in patient health records on ethnicity, as well as on clinical information and social determinants of health, such as blood pressure and smoking status. As a result, there is now a policy focus on [collecting more](#) and better patient ethnicity data in a bid to deliver more equitable outcomes and vaccination coverage during the pandemic. This also has the potential to improve future health research and planning for conditions that disproportionately affect Black and/or South Asian people. But it is unrealistic to expect lasting change without examining the reasons behind data inaccuracy and incompleteness for Black and South Asian people. These reasons are likely to include structural racism, lack of training, mistrust and the perception that data collection doesn't have a clear benefit. These issues - and how to address them - can only be meaningfully explored through public engagement, led by people with strong connections within Black and South Asian communities.

UPD is commissioning a multi-stage public engagement project to learn from members of the public and healthcare professionals about the barriers to health data collection and co-create resources to support improvement.



Project stages

Stage 1 - Engagement with Black and South Asian members of the public across the UK to understand their perspective on what leads to incomplete data collection and capture peoples' views of data collection and use.

Although we will adapt in response to what we learn in Stage 1, we currently envisage the following subsequent stages:

- Stage 2 – Qualitative engagement with healthcare professionals who are responsible for collecting patient health data, in order to also hear their insights on the factors that contribute to limited collection or poor quality data.
- Stage 3 – Quantitative survey with Black and South Asian members of the public to complement the qualitative engagement work and gain representative insights.
- Stage 4 - Co-creation of resources to support better conversations between professionals and Black and South Asian people on data collection underpinned by professionals' cultural competency in asking for information and discussing why and how data are used.
- Stage 5 - User-testing in health care settings, evaluation and review.
- Stage 6 – Dissemination.

This RFP is for Stage 1; there will be separate RFPs for subsequent stages.

Objectives

Stage 1

- To explore Black and South Asian peoples' thoughts on health data collection and use, why health records are often incomplete or incorrect and what aspects of data collection and use matter to them.
- To understand what it means to be represented: peoples' perceptions of benefits or risks when it comes to being included or not included in health data collection.
- To gain insight into the particular questions, concerns and sensitivities but also aspirations that people from Black and South Asian backgrounds have in relation to the collection and use of data in their health records.

It is very important that the supplier has long-standing and deep connections with the range of communities that we want to engage. This is so that participants feel comfortable taking part in the conversation, express their honest views and are reassured that their insights will be valued and contribute to shaping practical resources to improve health data available for research and service provision to address health inequalities.



Overall project objectives

- To understand from both members of the public and professionals what is needed to support the collection and use of health data in a way that people understand and is trustworthy
- To produce practical resources to provide that support
- To disseminate those resources so they are widely used in health care settings
- To support the sustained collection and use of high quality data, for research into health inequalities and to improve service design.

We also hope that this project will reveal concerns, questions and insights about what it means to be represented, or not represented, in health data and the structural and cultural context to data use. This will inform our own understanding of the patient experience and future UPD work, beyond the lifetime of this project.

2. RFP Specification

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

The supplier will:

Create and deliver a project to understand Black and South Asian peoples' experiences, concerns and aspirations when it comes to data collection and use.

Through:

- planning and carrying out public engagement with people from Black and South Asian backgrounds around the UK
- producing a report setting out the methods used and key themes, narratives and insights and meeting with UPD to present and discuss the findings.

We anticipate the work will take around 6 to 9 months to complete, although we understand there may need to be some flexibility due to the pandemic. 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 £65,000 excluding VAT.

We are open to receiving collaborative bids, in which organisations would partner with each other to deliver this work.

Planning

- Kick off meeting between UPD and supplier – to finalise scope, number, geographic locations, formats and participant range of sessions.



- Engagement sessions design: we want to include creative and innovative engagement approaches in this project alongside more standard formats, so the design of the sessions should demonstrate this mixed approach. Peer engagement should also feature in the range of proposed methods. We are keen to see applicants' ideas and are open to suggestions on the methods and approaches used, to enable genuine, open and rich conversation.
- Design and production of stimulus materials for the sessions, to support exploration of issues set out in the section below. To be reviewed by UPD.

Public engagement

- Approximately 8-10 engagement sessions, with people from Black and South Asian backgrounds (applicants to suggest how to include the range of different individual ethnicities within these two broad groups, including mixed and multiple ethnicities, across the sessions, along with the rationale for number and sizes of groups). The focus is on routinely collected data for health, which includes clinical data (e.g. on mental health issues) or social determinants of health (e.g. smoking status).
- Sessions to explore the following issues:
 - participants' views on health data collection, governance and use (including where data is not used), their questions and concerns
 - their experiences (if any) of being asked for health data about them, and their responses to those experiences
 - what participants think the consequences might be of some types of data being missing or incomplete in health records, for example, on ethnicity
 - what the idea of 'inclusion' in data and data collection means to them (this could include both advantages and disadvantages – when it comes to ethnicity or other routinely collected patient data)
 - what it would take to have a conversation with a health care professional in which they feel comfortable about sharing data and the ways in which it will be stored and used
 - their aspirations for how routinely collected health data should be used in future, including expectations in relation to health inequalities.

We envisage these sessions will provide insight into people's conceptualisation, expectations and concerns rather than produce a neat 'answer' to the problem.

- Engagement sessions should take place in a range of locations across the UK (or virtually draw from a range of locations) and there should be diversity among the participants in terms of socioeconomic background, age, sex, education.

Report

- Once the engagement sessions have taken place, supplier to produce a full report, including a high-level summary setting out the methods used in each session, the range of participants included (non-identifiable), key themes, insights and narratives to emerge from each session and overall, illustrated by non-attributed quotes.
- Meeting between UPD, supplier and other relevant UPD invitees to present and review the report, and how the findings inform the future stages of the project.



- Supply UPD with a slide deck of the findings in editable format which UPD can use to share the work with other stakeholders and partners.

3. RFP Timetable

#	Activity	Responsibility	Date
1	RFP issued to suppliers	WT	23 Feb 2021
2	Submission of expression of interest to RFP	Supplier	1pm, 9 March 2021
3	Supplier event with Q&A on Zoom. This will be an opportunity to ask UPD questions about the project and meet other suppliers with a view to potentially forming collaborations for the proposal.	WT & Supplier	1pm, 10 March 2021
4	Answers to any unresolved questions from Supplier Q&A to suppliers	WT	16 March 2021
5	Submission of RFP response	Supplier	5pm 23 March 2021
6	RFP evaluation period	WT	24 March–31 March 2021
7	Short-listed applicants notified and request for Third Party Security Risk Assessment (TPSRA2) forms to be completed	WT	31 March 2021
<i>Easter break</i>			
8	Shortlisted supplier presentations and forms submitted.	WT & Supplier	28 and 29 April 2021
9	Notification of contract award	WT	4 May 2021
10	Contract negotiation and start date	WT & Supplier	May 2021

4. Response Format

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

Expression of Interest

Suppliers are asked to submit a short expression of interest by e-mail to the Wellcome contacts (Rebecca Asher and Emily Jesper-Mir: engagement@understandingpatientdata.org.uk) by the submission deadline, containing the following:

- A high-level summary of how you would approach completing the project (Max 300 words)



- An outline of how your previous experience and networks are relevant to delivery of the project (Max 300 words)
- Your full company name and number (if you have one)
- A non-binding cost estimate as a single figure, excluding VAT, and an indication of whether you are eligible for VAT.

Suppliers who submit an expression of interest will be invited to a supplier Q&A at 1pm 10th March 2021.

Supplier Q&A

Prior to the submission of your RFP response, suppliers can ask any questions they have about the exercise. All questions should be asked at the supplier Q&A or by email by 5pm on the day of the supplier Q&A (10th March 2021). The supplier Q&A is also an opportunity to meet other suppliers as **we are open to receiving collaborative bids**.

If you submit a question via email, all questions will be collated, answered and returned to all suppliers who have submitted an expression of interest to the RFP process.

RFP Proposal

Having submitted an expression of interest, suppliers are required to submit a full proposal which responds to the following questions.

RFP Questions

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

	Question	Max Words
1	Outline your methodology for delivering the key activities and objectives of this RFP. Please include: <ul style="list-style-type: none">• Your proposed stages and timeframes to meet our requirement.• How you will approach recruitment• Your approach to working closely with the team at UPD	800
2	Outline how your previous experience and networks are relevant to the delivery of the project, including your experience of delivering engagement projects using a range of methods, including peer engagement, with Black and/or South Asian communities	500
3	Outline the project team, including a brief description of their experience	300
4	Outline any major risks and challenges you foresee with: <ul style="list-style-type: none">• ensuring this is meaningful engagement and not extractive	300



	<ul style="list-style-type: none">• potentially running this project virtually (or a combination of face to face and virtually), depending upon pandemic restrictions at the time• adapting to any new pandemic restrictions, as they arise during the project• any further risks and challenges you identify with this project. Please include your mitigation strategies	
5	Please describe your approach to GDPR obligations and use of special category data (We recognise that Wellcome's information governance requirements may be a challenge to smaller organisations and so are able to provide support.)	300
7	Outline your approach to equality, diversity and inclusion as this relates to methodology, practice and your organisation	300
8	Provide a cost proposal which details and justifies the proposed costs to meet our requirements	
9	Give contact information for a named point of contact	

Contract Review

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.



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