



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

**Stage 2: Qualitative engagement with people working in health care
and**

Stage 3: Quantitative survey 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. [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.

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 explores and is 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 has been 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.

UPD is commissioning a multi-stage public engagement project to learn from members of the public and people working in healthcare about the barriers to health data collection and co-create resources to support improvement. As well as working with expert suppliers, we are taking soundings from an independent advisory group (listed in [this blog](#)) made up of clinicians, service providers, researchers and campaigners.



Project stages and objectives

Stage 1 (started June 2021)

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. [This stage is currently being carried out by ClearView Research](#). Interim insights have already been gathered and Stage 1 is due to complete at the end of February 2022, and the findings will be published.

Stages 2 and 3 (the stages of this RFP) will build on the insights from stage 1:

Stage 2

Qualitative engagement with people who work in healthcare (both in clinical and non-clinical roles), who are responsible for collecting patient health data. In order to hear their insights on: the factors that contribute to limited collection or poor quality data, the good practice that does exist already and ideas for improvements.

Stage 3

Quantitative survey with Black and South Asian members of the public to complement the qualitative engagement work and gain representative insights.

Although we will adapt in response to what we learn in Stages 1-3, we currently envisage the following subsequent stages:

Stage 4

Co-creation of resources to support better conversations between healthcare workers and Black and South Asian members of the public on data collection, underpinned by professional 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.

Overall project objectives

- To understand from both members of the public and people who work in healthcare 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 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.

This RFP is for stages 2 and 3 above (in bold). There will be a separate RFP for later stages.

For stages 2 and 3, we are looking for a supplier with a track record in both qualitative and quantitative health research, with:

- the networks and knowledge relating to health data collection and use to deliver small group engagement workshops with healthcare workers, in both clinical and non-clinical roles
- expertise in quantitative research in this area, in order to devise and deliver a large-scale public survey with Black and South Asian members of the public that builds on existing relevant survey insights.

NB – we are looking for stages 2 and 3 to be delivered in parallel over the same time period.

Objective - stages 2 and 3

To complement the insights gained from Stage 1 and so deepen our understanding of the issues this project is investigating.

Engagement

- To build on the insights from Stage 1 by exploring the perspective of people working in healthcare responsible for collecting and using patient health data: in their experience, how is data collection carried out, why is this data often incomplete or incorrect, how might it be improved and why does it matter.

To get a clear picture of healthcare workers' views on the challenges of collecting health data, how they might be addressed and how to make the best use of this data; as well as capturing examples of existing good practice.

Survey

- To complement the qualitative research with quantitative research that will give us a large, representative sample of the views of Black and South Asian people. The survey will be developed using findings from stage 1.

The supplier will deliver:

Planning

- Kick off meeting between UPD and supplier – to finalise:
 - Engagement - scope, number, geographic locations, formats and participant range. Design and production of stimulus materials for the sessions, to support exploration of issues set out in the section below.
 - Survey - scope, design, methodology, delivery, and reporting on survey.
 - Above to be reviewed by UPD.



Engagement

- Plan and carry out engagement with a diverse range of healthcare workers around the UK.
- Deliver ~ 4 engagement sessions (8-12 participants per session), with those working in primary and hospital care settings who undertake health data collection (e.g. GPs, practice nurses, practice managers and receptionists, hospital admission administrative staff, patient experience leads and analysts). We anticipate that the number of sessions will be split evenly between primary and secondary care staff.
- To explore issues such as:
 - how participants view health data collection and storage; what they understand about its use for research and service design and delivery; their thoughts on interactions with patients about health data collection and use (what are their experiences of these interactions, if any? how do they feel about collecting data? have they received guidance on how to ask patients and answer concerns patients may raise?)
 - their aspirations for how routinely collected health data should be used, (e.g. should it and does it play a role in addressing health inequalities?)
 - reflections on why patient records have missing information; are there root causes that if addressed could lead to improvements; or effective incentives for improvement?
 - awareness and experience of good data collection practices: why are they effective and how might they be replicated?
 - thoughts on support and resources that would help staff complete patient health records and feel equipped to answer patients' questions about why data are collected and used

We envisage the sessions will start with open discussion and then feed in insights from the stage 1 engagement with Black and South Asian patients (which UPD will share with the supplier before the project commences) to guide further exploration.

These stage 1 insights will cover areas such as:

- Levels of trust in the NHS and those working in health care
- Understanding of how and why patient data is collected
- The perceived advantages and disadvantages of your health data being collected
- The perceived benefit that patient data collection and use brings to Black and South Asian people, if any
- Suggestions for improvement.
- Engagement sessions should take place in a range of locations across the UK (or virtually, drawn from a range of locations) and span clinical and non-clinical roles (see some examples above; suppliers are welcome to suggest other/alternative roles they think should be included). There should be diversity among the participants in terms of age, sex, ethnicity, and job role and seniority.
- At least one session should be with Black and South Asian healthcare workers specifically, to enable them to discuss the issue from their perspectives as people both working in healthcare and from Black and South Asian backgrounds.



Survey

- Design and deliver a representative survey of Black and South Asian members of the public in the UK.
- Supplier to propose a methodology for delivering a representative survey of Black and South Asian members of the UK public, across the range of relevant ethnic groups (as in the [2021 Census](#)). Please detail the proposed methodology, including sample size calculations to estimate proportions in the Black and South Asian population (assume 95% confidence, a 50% sample proportion, and report both a 3% and 5% margin of error; please adjust for expected drop-out based on your experience), choice of sampling frame, stratified sampling strategy, and any other issues the UPD team should consider. The survey is intended to explore their views and aspirations on the collection and use of data about them within the health system. Questions can be developed based on the engagement conversation findings from stage 1 which UPD will share with the successful supplier. The intention is to complement the stage 1 qualitative engagement with quantitative research. Areas are likely to include:
 - what is understood by 'patient data' and 'health data'
 - attitudes to health data collection and the consequences of missing data
 - what constitutes trustworthy data collection
 - how people want to have conversations about patient data and when
 - aspirations for how routinely collected health data should be used, including to address health inequalities.
- The survey should allow for comparison with other ethnic groups, including White ethnic groups (either as part of the same survey by oversampling with the general population, or by reference to other, comparable survey data).

Report

- Supplier to produce 2 full reports:
 1. Engagement - a high-level summary setting out the methods used in each engagement 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.
 2. Survey – the methods, analysis and findings from the survey and relevant insights from comparable survey data.
- Review meeting with UPD and other relevant UPD invitees to present and review the reports and take stock of insights and implications for the rest of the UPD project.
- Supply UPD with 2 slide decks of the findings of the engagement with healthcare workers and survey in editable format, which UPD can use to share the work with other stakeholders and partners.
- Support UPD's dissemination of the engagement and survey findings, by sharing them with your relevant networks.



We anticipate the work will take around 4 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 £65,000 excluding VAT.**

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

3. RFP Timetable

#	Activity	Responsibility	Date
1	RFP issue to Suppliers	WT	31 January 2022
2	Submission of Supplier Q&A to Wellcome Contact	Supplier	12:00 GMT, 7 February 2022
3	Return of Supplier Q&A to Suppliers	WT	12:00 GMT, 10 February 2022
4	Submission of RFP Response	Supplier	17:00 GMT, 21 February 2022
5	RFP Evaluation Period	WT	22 to 24 February 2022
6	Short-listed applicants notified and request for Third Party Security Risk Assessment (TPSRA2) forms to be completed	WT	17:00 24 February 2022
7	Supplier Presentations	Supplier	2 March 2022
8	Notification of Contract Award	WT	4 March 2022
9	Contract Negotiation	WT & Supplier	4 March to 1 April
10	Contract Start Date	WT & Supplier	4 April 2022

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 submit any questions they have about the exercise. All questions should be submitted to engagement@understandingpatientdata.org.uk in accordance with the RFP timetable.

*** NEW information added Tuesday 15th February:



We received one question from a potential supplier:

I was hoping I could seek clarification on the ethnic groups that fall under the definition of Black and South Asian.

Answer from UPD:

We are looking for the following ethnicities to be covered, taken from the ONS 2021 census categories:

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed and multiple background, please describe (unless the description accompanying does not include Black or South Asian background(s))
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background, please describe (unless the description accompanying is not a South Asian background)
- Caribbean
- African
- Any other Black, Black British or Caribbean background.

We do not anticipate the scope including people of Chinese heritage given the focus on South Asian (and Black) members of the public.

Any further details regarding ethnicity categories can be finalised with the chosen supplier at kick off.

RFP Proposal

Suppliers are required to submit proposals which respond to the following sections;

RFP Questions

Suppliers are required to submit a concise proposal which responds to the questions below. Please keep your proposal to approximately 5 sides of A4 (11 pt font, 1.5 line spacing) or 14 slides.

	Question
1	Outline your methodology for delivering the key activities and objectives for the two stages in this RFP and the rationale for your chosen approach. Please include your proposed stages and timeframes to meet our requirements
2	Outline the project team and how the team's previous experience, expertise and networks are relevant to all phases of the delivery of the project.
3	Specifically, outline your track record (including links to relevant work), delivering: <ul style="list-style-type: none">• engagement projects using a range of methods with people working in the health sector



	<ul style="list-style-type: none"> • robust, representative surveys on complex health issues.
4.	Outline your approach to working closely with the team at UPD.
5	<p>Outline any major risks and challenges you foresee with:</p> <ul style="list-style-type: none"> • potentially running the engagement element of the project virtually (or a combination of face to face and virtually), depending upon any pandemic restrictions at the time • keeping to the 4 month project timeline • seeking to engage with healthcare workers when there are very many pressures on their time • effectively building the survey questions in response to the findings from the public engagement stage with Black and South Asian members of the public so their contributions are embedded in this next stage of the project. • ensuring the survey design will allow for comparison with other ethnic groups either as part of the same survey by oversampling with the general population, or by reference to other, comparable survey data • ensuring the reports are clear and accessible as well as detailed and robust • ensuring dissemination of the survey reaches influential decision makers in the health policy and service ecosystem • any further risks and challenges you identify with this project and your plans for mitigating them.
6	<p>Describe your methodology for recruitment, engagement and dissemination and how you would deal with the requirements of UK GDPR and PECR.</p> <p>In particular, please describe the strategy for the engagement of networks and recruitment in general and how this will comply with the above legislation.</p> <p>Separately, please confirm the anticipated roles of Wellcome and you from a data protection perspective.</p>
7	Outline your approach to equality, diversity and inclusion as this relates to methodology, practice and your organisation.
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.

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 2 March 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
- 25 minutes for questions and clarifications from the UPD team
- 10 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 incorporated into your proposal as an annex and 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. 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

The joint point of contact for all communications 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