

Invitation to Tender

For:

Understanding Patient Data: “What words to use when talking about health data”

Date:

4th September 2023

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About the NHS Confederation and Understanding Patient Data

The NHS Confederation is the membership organisation that brings together, supports and speaks for the whole healthcare system in England, Wales and Northern Ireland. The members we represent employ over 1.5 million staff, care for more than 1 million patients a day and control £150 billion of public expenditure.

We support our members in three main ways:

- We represent organisations and sectors, to ensure local organisations and systems work in the best interests of service users, citizens and staff.
- We connect the whole healthcare system, to boost system working and develop solutions to shared challenges.
- We support leaders to develop and hone their leadership skills, equipping leaders with tools, ideas and insights and connecting them with a community of leaders.

Our work is underpinned and driven by our values, which help us to achieve our vision of a healthier population supported by high-quality health and care services that benefit everyone. We are respectful, inclusive, bold, collaborative and we act with integrity.

We represent the NHS as a whole and also have a number of networks to support our members in areas of specific concern to their part of the healthcare system.

We work closely with the Government, Parliament, and national stakeholders.

We provide an independent and robust critique of policy and act as an important conduit between policy makers and NHS leaders – helping to test proposals and assess their impact on front line services.

Understanding Patient Data (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. Our remit is across the UK, and we collaborate internationally too.

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 health and care services as part of providing healthcare, that can be used for research and planning without explicit consent. This data is used for patient benefit by NHS or health and care bodies, academics and sometimes 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.

Legal overview

The charity is a company limited by guarantee and was incorporated on 23 January 2002 (Charity number 1090329, Company Number 04358614).

The charity has a subsidiary called The NHS Confederation (Services) Company Limited incorporated as a company limited by guarantee (Company Number: 05252407).

Scope of work

We are tendering for desk research, co-production workshops, and co-created materials to be produced relating to the use of health data.

Contract period

The contract period for this tender is four months starting in December 2023

Tender submission

Your tender submission should include the following:

Company information

- Brief outline your values, structure, size and capabilities in general
- Examples of similar tenders you have won and delivered
- List two not for profit clients that we can contact for reference purposes (references will be taken up for firms shortlisted)
- Completion of the equalities questionnaire at schedule 1 (refer to guidance provided) – please highlight or delete as applicable)
- How your organisation is aligned with the values of the NHS Confederation – see Appendix 2

Proposal for services

In recent years, particularly following the Covid-19 pandemic, there has been an increase in the use of large-scale datasets for health analysis and research. In addition to this, there has been a drive towards accessing health datasets through specific types of data environments often referred to as Trusted Research Environments (TREs) and Secure Data Environments (SDEs). Some of these environments have already existed for years, for example, the SAIL Databank or the Genomics England Trusted Research Environment, but there is also now a strong governmental commitment to the use of such platforms, following the [Goldacre Review](#), [Data Saves Lives strategy](#), [the policy guidelines for secure data environments for NHS health and social care data](#), and the [draft data access policy](#). These policy commitments have also led to the creation of the [Data for Research and Development Programme in NHS England](#), which is making England-wide investments in Secure Data Environments and has established the NHS Research Secure Data Environment Network. UPD receives some of its funding from this programme.

However, there is currently a lack of clear, factual information on what these environments are, how people feel about them and the language that is used in relation to them (and in relation to the uses of the data), and what can be done to improve public trust. Similarly, there are a lack of independent, non-organisation specific resources that can be used by members of the public, data owners, researchers, healthcare professionals to explain these topics.

This work builds on previous work conducted and commissioned by UPD including:

- What are the best words to use when talking about data
- Quick guide to explaining how patient data is used and resources
- Data saves lives animations
- Large scale datasets guidance
- A guide to co-producing accessible health information

Therefore, UPD is commissioning a supplier to undertake desk research, test language and co-develop proposals for resources in this space. This is part 1 of a two part programme, and the second part will involve producing the resources.

The total budget for this work is around £40,000 - £50,000 excluding VAT.

Aims and objectives:

Business aims:

- Improve UPD's offer of up to date, accessible and balanced information (so people can come to their own informed opinion, rather than seeking to persuade)
- Provide research findings and resources that can be reused by anyone completing a project in a Secure Data Environment or Trusted Research Environment (and therefore reduce unnecessary duplication of time and effort)
- Encourage consistent use of terminology that has been tested with the public

Research aims:

- Improve the publicly accessible knowledge base on the resources that exist relating to key concepts like TREs, SDEs, population health, etc
- Confirm which terms should be used based on what is most understandable to members of the public (e.g. TRE or SDE)
- Co-create proposals for content that should be developed on these topics that are useful to the general public

Research objectives:

- To equip members of the public, organisations and healthcare professionals with research outputs and specifications for resources on key concepts through the completion of desk research and co-creation workshops.

The resources that this work will inform should generally be animated videos (like the data saves live animations linked to above). As these resources 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.

Workstream 1: Desk Research

Workstream 2: Co-developing specifications for resources

Scope and Outputs

Workstream 1: Desk research:

- Desk research (and creation of report) on:
 - o Evidence relating to how do people feel about SDEs/TREs/data environments for health
 - o Where are there gaps in public engagement on SDEs/TREs/data environments for health, and concepts such as “population for health”, data for “planning”
 - o What resources already exist about explaining these concepts
 - o Identifying where jargon or unnecessarily complex words/phrases are routinely used in communications
 - o The report should be able to provide balanced information relating to use of TREs/SDEs as the primary place to do research and analysis with health data going forwards
- The desk research and report would then influence the next stages of the project. The audience of the report is the UPD team and its steering group, but we may publish it so it needs to be written in accessible language.

Workstream 2: Co-developing specifications for resources:

- What do people already know about the changes to using health data
 - o Plus different types of usage (R&D, population health, clinical trials, etc)
 - o What is needed to help people feel satisfied about safety / control of their data
- The resources will likely be videos (like the data saves lives animations) aimed at as broad an audience as possible. This means the focus of this workstream should be on drafting the video brief and script.
- The specifications for the resources should cover these topics, unless the desk research and focus groups suggest otherwise:
 - o What is data access (as opposed to data dissemination) – and pros/cons
 - o What are TREs/SDEs (including which term (TRE, SDE or other) is best to use, and that it's not just one thing) and what does using them enable
 - o Privacy and security of TREs/SDEs (including high level governance/access processes, what ‘suppliers’ can access, and including benefits/risks)
 - o What does data federation mean in health (concepts of local/regional health bodies, primary/secondary/tertiary care)

- What kinds of organisation use their data, and how that type of use should be described (e.g. academic, private sector, etc)
 - General concepts about direct care vs 'secondary uses', 'research', 'analysis'
 - More specific concepts, often relating to data linkage use cases, like population health, health surveillance, etc
- Whilst the exact timing of the video creation phase is unknown, we would like the successful supplier to be available to support and/or advise during this phase.
 - Who we would like you to co-create with:
 - Nationally representative sample with a focus on individuals from seldom heard groups

Out of scope:

- National data opt-out
- Commercial models and procurements
- Specific programmes such as GDPR, Data for R&D, FDP programme, etc as a programme
- Engagement at a local/regional level

Milestones:

Workstream 1: December 2023 – January 2024

Workstream 2: January – mid March 2023

Wrap up: mid March to end of March 2024

This timeline can be pushed back slightly if necessary

Deliverables:

- Desk research written report with executive summary
- Written outputs from co-creation workshops
- Language recommendations for the key concepts, particularly on SDEs/TREs
- Specifications for resources to be created
- Debrief presentation with UPD team

Fee proposal

Your tender should include a detailed cost breakdown, including at least the number and seniority of staff, the number of hours they expect to work, and any outsourced costs. This should be exclusive of VAT.

Proposal scoring

We will rank tenders on the basis of:

Criteria
Fit to requirements of the brief
Quality and experience of the team
Value for money
Alignment with values
Quality of engagement with management and the tender process

Access to Management during the preparation of the Proposal document

Please register your interest and send any questions to hello@understandingpatientdata.org.uk. Questions and answers will be circulated to those who have registered an interest by the deadline.

Tender interview Panel

The formal tender interview panel will consist of three individuals, two from Understanding Patient Data, and one from either the Department for Health and Social Care or NHS England.

Key dates

Action	Date
Invitation to Tender (ITT) sent out	4 th September 2023
Deadline for registering interest	18 th September
Deadline for tender response documents to be submitted	2nd October 2023 midday
Shortlist finalised	9 th October 2023
Formal tender interviews on Microsoft Teams	w/c 23 rd October 2023
Preferred Supplier notified	Beginning of November 2023
Contract negotiation	Mid November 2023
Work commences	1 st December 2023

Instructions for the return of tenders

Tenders should be submitted by email to
Hello@understandingpatientdata.org.uk and copy in
contracting@nhsconfed.org

Tender ref: 2324-74

Tenders must be received by end of Monday 2nd October 2023 midday. Tenders received after this date will not be considered.

It is incumbent on tenders to ensure they have all of the information required for the preparation of their tenders.

For further information about this tender please contact:

Name	Nicola Hamilton
Title	Head of Understanding Patient Data
Phone number	07483075933
Email address	Hello@understandingpatientdata.org.uk

Appendix 1 – NHS Confederation Equalities questionnaire

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 ☐

5. 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 ☐

If the answer is NO to any part of questions 4 or 5, please provide 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 ☐

7. In the last three years, has any contract with your firm been terminated on grounds of your failure to comply with:

- Legislation prohibiting discrimination?

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 ☐

If the answer to question 6 and 7 is YES, or, in relation to question 8, a finding adverse to your firm 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.

- 9. If you are not currently subject to UK employment law, please supply details of your experience in complying with equivalent legislation that is designed to eliminate discrimination and to promote equality of opportunity. List any attached documents.**

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 will 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.