

Invitation to Tender

For

Understanding Patient Data: explaining health data security

Date

9th October 2024

Tender Ref: TEN1023



**Understanding
Patient Data**

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1. About the NHS Confederation

The NHS Confederation is the membership body that brings together and speaks on behalf of organisations that plan, commission and provide NHS services in England, Northern Ireland, and Wales. We represent hospitals, community and mental health providers, ambulance trusts, primary care networks, clinical commissioning groups and integrated care systems.

We have three roles:

- to be an influential system leader
- to represent our members with politicians, national bodies, the unions and in Europe
- and to support our members to continually improve care for patients and the public.

All our work is underpinned and driven by our vision of an empowered, healthy population supported by world-class health and care services, and our values of voice, openness, integrity, challenge, empowerment.

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.

About Understanding Patient Data

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.

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. 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.

2. 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).

3. Scope of the work

We are tendering for desk research, deliberation workshops and co-creation workshops relating to public perceptions and explainers on health data security and breaches.

4. Contract period

The contract period for this tender is five months starting in mid-November 2024.

5. Proposal document

Interested parties are asked to submit a proposal document. The deadline for submission is **5pm on Friday 25th October**.

The Proposal document should, as a minimum cover the following areas:

- Demonstrate your understanding of the topic, and outline your proposed methodology and timeline for the project
- Brief outline your values, structure, size and capabilities in general
- Provide 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)
- Complete the equalities questionnaire at schedule 1 (refer to guidance provided) – please highlight or delete as applicable)
- Address how your organisation is aligned with the values of the NHS Confederation – see Appendix 2

Proposal for services

Background

Most people trust the NHS* to keep their health data secure, even amongst those who are less trusting of the NHS more broadly¹. However, many remain concerned about security threats such as cyber-attacks² and there is little awareness or understanding of what is done to keep health data safe³. Research by the University of Manchester Centre for Social Ethics and

¹ NHS Digital. (2024). *Public attitudes to data in the NHS and social care*. Available at: <https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/public-attitudes-to-data-in-the-nhs-and-social-care?key=BHuH6cw7W9513htxNU9BpB8h9BstjG5QhGlF6R993aNbeydxdgcVzH94yVkriKey>. [Accessed 2nd October 2024].

² NHS Digital. (2024). *Public attitudes to data in the NHS and social care*. Available at: <https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/public-attitudes-to-data-in-the-nhs-and-social-care?key=BHuH6cw7W9513htxNU9BpB8h9BstjG5QhGlF6R993aNbeydxdgcVzH94yVkriKey>. [Accessed 2nd October 2024].

³ Understanding Patient Data. (2019). *Understanding public expectations of the use of health and care data*. Available at: <https://understandingpatientdata.org.uk/sites/default/files/2019-07/Understanding%20public%20expectations%20of%20the%20use%20of%20health%20and%20care%20data.pdf>. [Accessed 2nd October 2024].

Policy and The Patients Association found that patients want to be told more about their data is kept safe due to concerns about leaks or misuse, and are keen to understand whether NHS systems are good enough to prevent this⁴. The report recommends more accessible and understandable information about “how the NHS assures the technical quality of its data handling, plus details of its successful track record in minimising breaches” as part of future NHS public awareness and information campaigns on health data. Even in research exploring public attitudes towards other health data topics, such as data linkage, the importance of data security is frequently emphasised by public participants⁵. Despite some attitude shifts towards health data sharing pre- and post-Covid-19, one sentiment that seems to have been consistent is a concern about the strength of the legislation in place to protect individuals from data misuse, with doubts over its enforcement and sufficiency⁶.

With perceptions of health data security inevitably influencing attitudes towards the sharing and use of personal health data for research and planning, there is a risk that without exploring what people want to know, whether and how these needs can be met, and co-creating potential solutions, these concerns, well-founded or not, can undermine trust in the many uses of health data. Providing an opportunity for people to access transparent, accessible and understandable explanations about the genuine practices, risks, and successes or failures of health data security, can help inform better quality conversations and decisions.

NHS communications about data security, which understandably tend to promote positivity and reassurance, can be perceived particularly by those who are more ‘disengaged and health data protective’ as too emotive or pressuring⁷, while media stories which tend to focus on breaches and cyber-attacks in an alarmist way⁸ can spark panic and misunderstandings of risks and consequences⁹. Between these two approaches of *reassure* and *alarm* is one that instead seeks to help people to *understand* the basic facts of health data security, to support them to make more informed choices about their own data, and to take a more critical approach to information given by various organisations.

⁴ The University of Manchester Centre for Social Ethics and Policy & The Patients Association. (2023). *General Practice Data Trust (GPDT) Pilot Study: Report on Patient Focus Groups*. Available at: <https://www.patients-association.org.uk/Handlers/Download.ashx?IDMF=3abe6cd4-1cfe-424e-b658-1d603862c277>. [Accessed on 2nd October 2024].

⁵ Jones, L., Nelder, J., Fryer, J., Alsop, P., Geary, M., Prince, M. & Cardinal, R. (2022). Public opinion on sharing data from health services for clinical and research purposes without explicit consent: an anonymous online survey in the UK. *BMJ Open*, 12, e057579. DOI: 10.1136/bmjopen-2021-057579.

⁶ Summers, C., Griffiths, F., Cave, J. & Panesar, A. (2022). Understanding the security and privacy concerns about the use of identifiable health data in the context of the Covid-19 pandemic: survey study of public attitudes toward Covid-19 and data-sharing. *JMIR Formative Research*, 6(7), e29337. DOI: 10.2196/29337

⁷ NHS Digital. (2024). *Public attitudes to data in the NHS and social care*. Available at: <https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/public-attitudes-to-data-in-the-nhs-and-social-care?key=BHuH6cw7W9513htxNU9BpB8h9BstjG5QhGlf6R993aNbeydxdgcVzH94yVkriKey>. [Accessed 2nd October 2024].

⁸ Understanding Patient Data. (2021). *Analysis of UK reporting on health data*. Available at: [https://understandingpatientdata.org.uk/sites/default/files/2022-01/Analysis%20of%20UK%20reporting%20on%20health%20data\(2\).pdf](https://understandingpatientdata.org.uk/sites/default/files/2022-01/Analysis%20of%20UK%20reporting%20on%20health%20data(2).pdf). [Accessed 2nd October 2024].

⁹ Cowan, D. (2024). *Cyber expert urges against ‘panic’ over NHS data leak*. Available at: <https://www.bbc.co.uk/news/articles/clw08q19n9ro>. [Accessed 2nd October 2024].

Many existing online explainers are directed at organisations, to support them to ensure data and cyber security and to conform to legislation¹⁰¹¹¹². Explainers directed at the public tend to be resources for those who believe their data to have been leaked, shared, misused etc.¹³ or only offer basic explainers in an unengaging way¹⁴. Progress continues to be made on the standards and measures for data security capabilities across health and social care organisations in line with other sectors¹⁵¹⁶, but this is not necessarily always well-communicated with the public. UPD has [a written resource](#) on our website on this topic, but this focuses more on broad concepts and may have gaps in what the public really want to know and how they want to see this information.

Therefore, UPD is commissioning a supplier to undertake desk research, and conduct deliberative engagement and co-creation workshops to develop specifications for resources on this topic. This will form part 1 of a two-part programme, where part 2 will involve producing the resources.

**In referring to the NHS we mean all health services across the UK including for example Northern Ireland's Health and Social Care.*

Scope and outputs

We have based the approach below on a [recent project](#) with similar aims and objectives that worked well, but we are happy to hear alternative suggestions as to the methodology and approach in proposals and will finalise this with the chosen supplier. We tend to arrange an expert project steering group who can support with development of ideas and offer feedback and direction.

Workstream 1: Desk research & report

We expect that this would mostly be a systematic review of public sector resources (academia, research, government, NHS, etc), but the visibility of this topic in media resources may also be interesting to explore how it is presented to the public particularly when things go wrong.

Topics to explore might include:

- Evidence relating to people's understanding of and attitudes toward health data security – this might span topics such as trust, breaches, cyber-attacks, accidents, etc.
- Gaps in public engagement work on health data security

¹⁰ Information Commissioner's Office. (2024). *Data security incident trends*. Available at: <https://ico.org.uk/action-weve-taken/data-security-incident-trends/> [Accessed 2nd October 2024]

¹¹ NHS Health Research Authority. (2024). *Security assurances required for applications to the CAG – update to DSPT assurances in England*. Available at: <https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/guidance-confidentiality-advisory-group-applicants/update-dspt-assurances-england/>. [Accessed 2nd October 2024].

¹² National Cyber Security Centre. (2024). *10 steps to Cyber Security*. Available at: <https://www.ncsc.gov.uk/collection/10-steps>. [Accessed 2nd October 2024].

¹³ Information Commissioner's Office. (2024). *I'm worried my information has been shared*. Available at: <https://ico.org.uk/for-the-public/im-worried-my-information-has-been-shared/> [Accessed 2nd October 2024]

¹⁴ NHS England. (2023). *Personal data breaches*. Available at: https://transform.england.nhs.uk/information-governance/guidance/personal-data-breaches/#service_user. [Accessed 2nd October 2024].

¹⁵ National Data Guardian and NHS England. (2024). *NDG and NHS England issue joint statement about NHS Data Security and Protection Toolkit*. Available at: <https://www.gov.uk/government/news/ndg-and-nhs-england-issue-joint-statement-about-nhs-data-security-and-protection-toolkit>. [Accessed 2nd October 2024].

¹⁶ Department of Health and Social Care. (2023). *Cyber security strategy for health and social care: 2023 to 2030*. Available at: <https://www.gov.uk/government/publications/cyber-security-strategy-for-health-and-social-care-2023-to-2030>. [Accessed 2nd October 2024].

- What public-facing resources, compared to organisation-facing resources, already exist to explain these concepts
- Style of communications across these resources depending on the source
- The resulting report would be used to inform the second workstream. The audience is primarily the UPD team and steering group, but we will also publish the report so it will need to be written in accessible language.

Workstream 2: deliberations and co-creation of specifications for resources

- Plan, prepare and conduct workshops with a nationally representative sample from across the UK, including those from seldom heard groups (e.g. less digitally enabled people, young people, ethnic minorities, those more likely to opt-out etc.).

- We recognise the value and inclusiveness of face-to-face engagement, but we understand this can be challenging financially and geographically, so we are open to suppliers suggesting the most appropriate approach

- We anticipate the sample size being approximately 40-50 people across a number of workshops

- Deliberative engagement workshops to gauge understanding of and attitudes to topics and questions such as:

- How worried are people about health data security, compared to the security of other personal/non-personal data?
- Do they trust that their data is kept safe? If so, why? If not, why not?
- Do they know what current approaches to do this look like?
- What do they want to know about how their data is kept safe?
- How would they like to see this explained?
- Testing responses to existing explainers and ideas for explainers

- Co-creation workshops to develop specifications for a public-facing explainer resource(s), covering topics such as:

- How is health data kept secure?
- What is cyber security?
- What is a health data breach? (mistakes, intentional misuse, cyber/hacking attacks etc)
- How common are they? Most common types / Putting them into context
- How does the NHS respond when breaches happen?
- What are the consequences for the organisation/software company/staff/individual etc.?
- What are the risks to me if there is a breach?
- What is good and bad about the current ways of keeping health data safe?
- What is being done to prevent further breaches?

- Interviews with 6-8 expert stakeholders to provide insight on how it could be used by organisations in their public-facing resources, and to ensure it is accurate and transparent.

These topics and questions can be further developed and shaped through steering group and stakeholder engagement during the project, so this is not a definitive or exhaustive list.

The resource would likely be an animation aimed at a broad public audience so the ultimate output of this workstream would be a draft script and written storyboard. We receive feedback that our [existing animations](#) are widely used because of how accessible they are and can be adapted by multiple organisations. We also feel that this is a gap in the current resource provision in the sector, particularly on this topic. However, if the desk research and co-production workshops highlight a different recommended approach, we would be open to exploring other potential resources.

Milestones:

Workstream 1: mid-November 2024 – January 2025

Workstream 2: January – end of March 2025

Wrap up: beginning-April to mid-April 2024

This can be adjusted slightly if necessary - please provide a timeline in your proposal. More specific milestone and delivery dates will be decided during the contracting phase with the chosen supplier.

Deliverables:

- Desk research written report with executive summary ([example here](#))
- Written outputs from deliberation and co-creation workshops (e.g. methodology, content covered, discussions and decisions made, challenges and learning, conclusions and recommendations, etc.) ([example here](#))
- Specifications for resources to be created, i.e. script, written storyboard, styling suggestions (we do not expect the actual resource to be produced at this stage)
- Debrief presentation with UPD team

Fee proposal

The total budget for this project is approximately £50,000 excluding VAT.

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.

The second phase where the resource is created will come under a separate contract and budget down the line.

6. Proposal scoring

The Proposal documents will be scored based on the criteria and weighting below:

Criteria
Fit to requirements of the brief
Quality and experience of the team
Value for money
Alignment with our values and ethical principles (See Appendix 2 and 3)
Quality of engagement with management and the tender process

7. Access to Management during the preparation of the Proposal document

Please submit any questions to hello@understandingpatientdata.org.uk and we will get back to you as soon as possible.

Please note that due to the expected interest in this project, we will not meet individually with people or teams interested in submitting a proposal, but we welcome any and all questions via email.

8. Tender interview Panel

The formal tender interview panel will consist of individuals from Understanding Patient Data and NHS Confederation.

9. Timetable

Action	Date
Invitation to Tender (ITT) sent out	09/10/2024
Deadline for tender response documents to be submitted	25/10/2024
Shortlist finalised	30/10/2024
Formal tender interviews	04-08/11/2024
Preferred Supplier notified	08/11/2024
Contract negotiation	11-15/11/2024
Work commences	18/11/2024*

*We may be able to have a degree of flexibility with the start date if necessary for the chosen supplier.

10. Instructions for the return of tender submissions

Tenders should be submitted by email to hello@understandingpatientdata.org.uk cc to contracting@nhsconfed.org

Tender ref: TEN1023

Tenders must be received **by 5pm on Friday 25th October 2024**. Tenders received after this date will not be considered. Tenders must include the completed Equalities questionnaire found in Appendix 1.

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

11. Further Information

Further information on about this tender can be obtained from:

Name	Job Title	Email Address
Emma Morgan	Policy & Engagement Manager	Emma.morgan@understandingpatientdata.org.uk

Appendix 1 - Equalities Questionnaire for completion

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

1. 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

Please evidence all questions.

If you answered NO to any part of questions 4 or 5 can you provide (and if so, please do) 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

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

- Legislation prohibiting discrimination; or

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

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

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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 which 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.

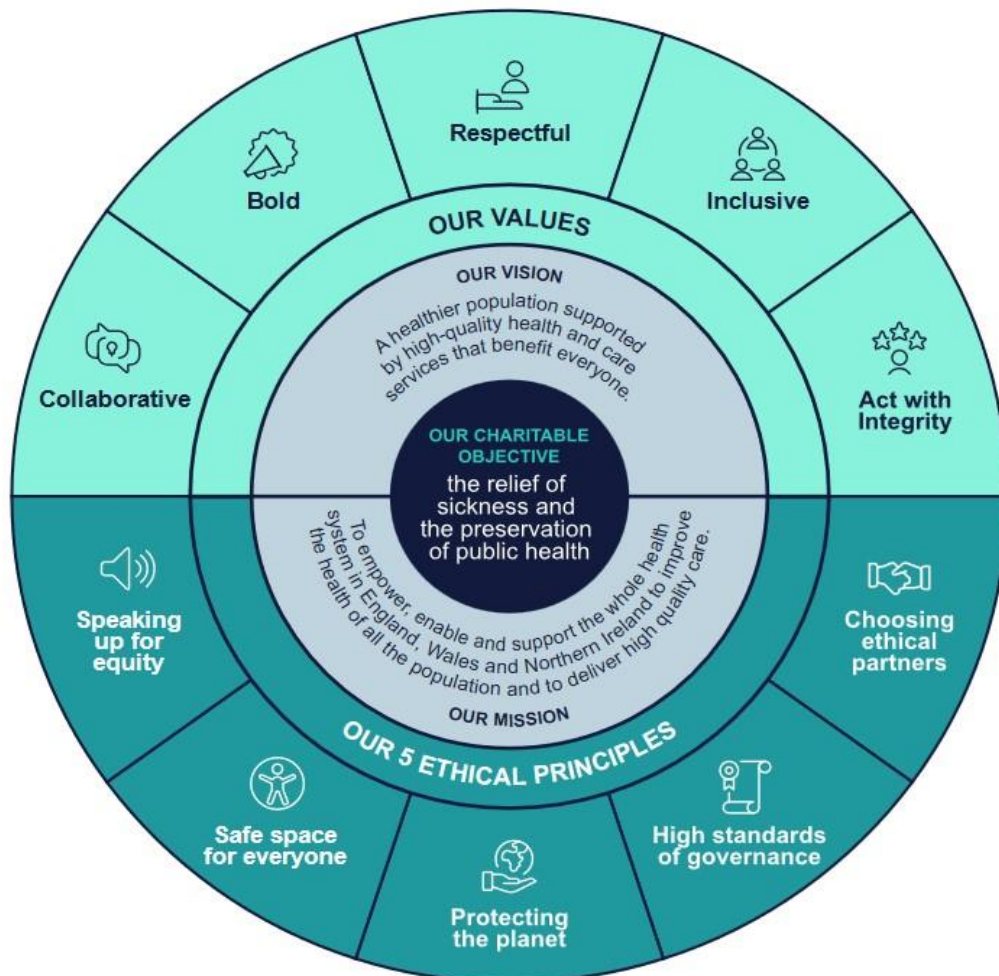
We are a diverse organisation with a diverse membership and recognise and value each other's strengths.

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.

Appendix 3 Our Ethical Principles



As an organisation we often face certain ethical questions in our day-to-day work – from the types of organisations we want to partner with, to the broader impact our decision-making and activity has on the environment and wider society. In making those decisions, we need to have a consistent and logical approach that is directly linked to our organisational purpose.

As a charitable organisation, our purpose is to make a positive impact. Our vision is of a healthier population supported by high-quality health and care services that benefit everyone. To achieve that we need a more equitable and inclusive society and a good quality environment where we are halting the impacts of climate change.

As an organisation we have our own operational impact. Through this ethical framework we proactively champion ethical behaviour in all we do, including how we work with others, how we champion our cause and how we make decisions.

This framework empowers staff to look to achieve a greater positive impact in their work, making decisions that are inclusive, have greater social value and that take us towards our commitment to be carbon neutral. It helps us to be true to our values and charitable objective in everything we do. Our ethical principles are:

Speaking up for equity - We speak up about wider determinants of health and call for an improved and more equitable population health and healthcare for the whole population.

Safe space for everyone – we constantly strive to be an organisation that is always supportive, inclusive, equitable, safe, respectful, and fair for everyone.

Protecting the planet – we are committed to reducing our own impact on the environment, not least our carbon footprint, with our actions and of those we interact with.

Choosing ethical partners – we seek to only work with other individuals and organisations who can demonstrate active and strong alignment with our principles.

High standard of governance - We will hardwire our ethical principles into our decision making, ensure our organisation is run to highest standards of governance, with transparency and accountability.