NHS Confederation

Invitation to Tender

For GP data public attitudes research

July 2024

Contents

1. About the NHS Confederation and Understanding Patient Data

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.

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.

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 public attitudes research, a series of workshops and the production of a public-facing resource about primary care (GP) data in England:

- Conduct surveys to understand public attitudes on this topic
- Conduct a series of workshops to understand views on the topic with members of the public
- Draft a brief report that sets out the findings of the research, including current understanding of, views on and expectations around data controllership and use
- Co-create a resource – based on workshop findings about how best to convey this information – to help explain how primary care data is collected, stored, used and shared

4. Project background

The data held in a person's general practitioner's (GP) patient record, in comparison with a person's hospital or other health records, is often considered the most extensive source of information about a person's health and is very useful for both individual patient care and secondary purposes. It is used to ensure that a patient's care team has access to as much information as possible about them to help provide the best care, to pay GPs for the services they provide, and can be used for research and analysis within and outside the NHS.

However, not everyone supports sharing their GP data or using GP data for purposes outside of individual care, and for those who do, their support isn't always unconditional. Whilst some may feel this data is more sensitive than, for example, their hospital records, and don't want it shared outside their GP practice, others may disagree and want it to be shared more than it currently is. We are interested in how these expectations match up to reality.

To many people, the NHS is perceived as one entity, but there are over 6,000 GP practices across the country. Each practice is its own legal entity, contracted by NHS England, which means that it is a data controller under GDPR. This makes the GP partners responsible for each of their patients' GP records, making decisions about when to use and share the data they hold, and, as a result of government strategies and developments in research, they are getting more and more requests to do so. As well as these responsibilities, GPs are bound by the duty of confidentiality, and an oath to do no harm, to their patients. This can make data sharing a risky and time-intensive activity, particularly when there are disagreements about the purpose, benefits, and potential problems that might arise. When it's deemed to be too risky, or there are other challenges like technical, regulatory, political or capacity issues, the sharing is either legally mandated or does not happen.

Our recent report on the use of data in Integrated Care Systems (ICSs) found that in all systems we spoke to, use of primary care data was essential to help them achieve their population health management goals, but there remain a handful of GP practices that have not agreed to share data with their ICS. Following negotiations about the 2024-25 GP contract, the British Medical Association (BMA) has announced a series of actions GP practices could take as part of collective action in protest of the contract, which include actions relating to limiting data sharing.[1] Sometimes, when GP data controllership is considered a barrier to national programmes or large scale research, alternative models of data controllership are proposed. For instance, a recent report from the Tony Blair Institute proposed establishing joint controllership of NHS data in England, as is currently established practice in Scotland.[2]

In recent years, high-profile attempts to bring GP data together have been abandoned after being met with pushback from privacy campaigners, parts of the medical profession and some members of the public, such as Care.data and the General Practice Data for Planning and Research (GPDPR) initiative.[3]

Since these projects were halted, others have appeared. NHS England has announced the rollout of the Federated Data Platform (FDP) which, at a national level, will not contain GP data for now, but might at a regional or trust level. The Data for Research and Development programme has been supporting regional teams getting health data into Secure Data Environments. In the last year, the OpenSAFELY platform has been expanded to allow researchers to access de-identified GP data for other research purposes.[4]

Previous research has indicated that GP surgeries are among the organisations most trusted by members of the public with their patient data, with 69% of respondents in a study by the Health Foundation reporting high trust in GP practices with their data, compared to 68% for local hospitals, 64% for national NHS organisations, 44% for pharmaceutical companies and 33% for local government.[5] Another survey, conducted by NHS England, found local NHS services to be the most trusted on patient data, with 73% of respondents reporting they trusted their local NHS services, compared to 62% for national NHS organisations.

Findings from UPD's recent Patient Data for Planning and Population Health suggested some workshop participants perceived that the patient data used by local NHS organisations would be more likely to make them identifiable than data used by national

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[1] "Protect your patients, protect your GP practice", British Medical Association, accessed 21 June 2024, https://www.bma.org.uk/our-campaigns/gp-campaigns/contracts/gp-contract-202425-changes

[2] Benedict Macon-Cooney et al. "A New National Purpose: Harnessing Data for Health," *Tony Blair Institute for Global Change*, 21 May 2024, https://www.institute.global/insights/politics-and-governance/a-new-national-purpose-harnessing-data-for-health

[3] James Temperton, "NHS care.data scheme closed after years of controversy," *Wired*, July 6, 2016, https://www.wired.com/story/care-data-nhs-england-closed/

[4] "NHS expands use of secure COVID-19 research platform to help find new treatments for major killer conditions", NHS England, 17 November 2023, https://www.england.nhs.uk/2023/11/nhs-expands-use-of-secure-covid-19-research-platform-to-help-find-new-treatments-for-major-killer-conditions

[5] Nell Thornton et al. "Exploring public attitudes towards the use of digital health technologies and data", *The Health Foundation*, 24 November 2023, https://www.health.org.uk/publications/long-reads/exploring-public-attitudes-towards-the-use-of-digital-health-technologies

organisations and were less comfortable with local NHS organisations using their data as a result. However, this research did not go into further depth about this perception. There is currently limited in-depth public attitudes research about primary care data specifically. Prior research by healthcare organisations like NHS England have tended to focus on views about specific existing or proposed primary care data initiatives or testing specific models for the use and sharing of GP data. There is also an existing body of research that covers questions relating to views on data sharing, motivations for sharing data, and opting out of data sharing more broadly.

This research will build on existing research by focusing on an in-depth exploration of how people feel about primary care data specifically, how their attitudes about it compare to other health data, and what they think the role of different individuals and organisations should be in accessing, processing and sharing primary care data. Ongoing discussion about the use of GP data presents an opportunity to understand what people think about this topic and how to ensure the system works in a way that engenders public trust.

This project is limited in scope to England.

We will have a project steering group made up of representatives from the various stakeholder organisations involved in primary care data use. They will help shape the topics for exploration and provide advice, but will not be part of the approval chain.

5. Contract period

The contract period for this tender is approximately four months starting September 2024

6. Proposal document

Interested parties are asked to submit a proposal document. The deadline for submission is 10:00 Monday 5th August.

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

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

Overview

UPD would like to undertake a project to explore public understanding, thoughts and expectations about the sharing and use of primary care data. We envisage this will be achieved by undertaking qualitative research focused on a number of online workshops, complemented by a survey, followed by a write-up of the findings of the research.

- Develop research methodology
- Design workshop structure
- Draft workshop stimulus and survey questions
- Source participants for workshops and survey and deliver both
- Run workshops
- Draft write-up of findings (working collaboratively with UPD to develop final outputs)
- Create resource (one page with text and visual elements) to explain the facts about primary care data based on workshop findings

We would also like to develop a poster-style resource for members of the public to explain key concepts about GP data and how it is stored and accessed. We envisage this will be achieved through running a second set of workshops with the same participants in each workshop, focusing on what information about primary care data a resource should include, and how it should be conveyed.

Public attitudes research

We are open to suggestions from the selected supplier on how best to achieve the aims of the project, but envisage the following for the research element of the work:

- **Audience**
  - **Survey -** Nationally representative sample to cover England
  - **Workshops –** A small number of participants (<10) in each workshop. The participants should come from various English regions (though not all workshops need to include participants from each region) and include a range of socioeconomic statuses, ages, genders, ethnic backgrounds, and perspectives on data use
- **Format** – Workshops should generally be online to keep costs down and facilitate equitable access across the country. We would welcome proposals that make provision for involving digitally excluded individuals in the research.
- **Scope** – The final topics and questions will be agreed between the chosen supplier and UPD, but we anticipate this will include participants' perspectives on:
  - Their understanding of the information that is held in their GP record and how this is shared within the NHS and externally with researchers across charities, academia, government/public sector and the private sector
  - What relationship they have with their primary care (GP) record and how this might differ from their relationship with their other health records or other health data
    - E.g. who do they think 'owns' primary care data
    - Are views on GP data affected by the relationship between people and their GP (e.g. does having a named GP increase trust, are GPs seen as 'gatekeepers' of data?)
  - Whether there are any characteristics about primary care data that they perceive to differ from other health data (e.g. sensitivity, identifiability), what drives these perceptions and whether they perceive primary care data should therefore be treated differently
  - Where they think their primary care data is kept and their views on the role of general practice IT providers
  - Who they think has access to their primary care data (NHS/non-NHS organisations and staff roles) and who should have access

- Who they think is/should be responsible for keeping their primary care data safe and making decisions about how their data is used
- What role they think patients and members of the public should have in making decisions about primary care data, and what parts of their own GP data they think people should have access to
- The role of civil society groups and what role they should have (e.g. around advocacy, oversight, challenge)

Development of resource

We are open to suggestions from the selected supplier on how best to develop the resource, but envision this will be achieved by:

- Running a second series of workshops with the same participants, focusing on:
    - What people already know about primary care data (including any misconceptions)
    - What information people would like to know about their primary care data, including the level of detail
    - How best to present information in order to improve understanding
- Writing up recommendations for how to communicate about GP data to members of the public
- Drafting a brief (1-2 page) resource with text and visual elements about key facts relating to what GP data is, how it is stored, who has access, and how it is used, aimed at the general public.

Milestones

We envision this project will commence in September 2024 and meet the following milestones:

September 2024	Project set-up, desk research and development of survey
October 2024	Survey takes place, workshop recruitment and development of workshop stimulus materials
November 2024	Workshops take place, quantitative and qualitative analysis and report writing
December 2024	Report writing and final report delivered, development of resource

Deliverables

The chosen supplier would produce:

1) A written report that sets out the findings of the research. We envision this will include:
    - Executive summary
    - Introduction, context and methodology
    - Key findings: A big-picture overview of people's knowledge of and attitudes towards the collection, storage, usage and sharing of primary care data and the role of different data controllers in the health service and beyond
    - Full breakdown of survey results including graphs as appropriate, including any demographic differences in survey answers and crosstabs showing relationships between different survey answers
    - Discussion about themes arising from workshops and how they relate to the findings of the survey
    - What the findings set out above tell us about the state of the public's understanding and thoughts towards primary care data and its use

We expect the prospective supplier to work with UPD during the drafting process to inform the structure of the report and incorporate comments and edits ahead of finalising the outputs.

2) A 1-2 page factual resource about GP data, and how it is stored, used and shared.

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.

The proposed budget for this work is around £40,000 exc. VAT

7. 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

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

If you have any questions or would like to receive a copy of questions and answers relating to the project, please register your interest and send any questions to hello@understandingpatientdata.org.uk by the deadline below. All questions and answers will be circulated to those who have registered an interest by the deadline.

You do not have to register your interest by the deadline provided to be able to submit a bid, but we will not be able to answer any questions about the tender submitted after this time.

9. Tender interview Panel

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

10. Key dates

Action	Date
Invitation to Tender (ITT) sent out	8th July 2024
Deadline for registering interest/questions	29th July 2024
Deadline for tender response documents to be submitted	5th August 2024

Shortlist finalised	12th August 2024
Formal tender interviews (virtual)	w/c 19th August 2024
Preferred Supplier notified	w/c 22nd August
Contract negotiation	Late August
Work commences	Early September

11. Instructions for the return of tender submissions

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

Tender ref: TEN1017

Tenders must be received by 10:00 5th August 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.

12. Further Information

Further information on about this tender can be obtained from:

Name	Emma Lagerstedt
Title	Policy and Engagement Manager
Email address	Emma.lagerstedt@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.

10. 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

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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.

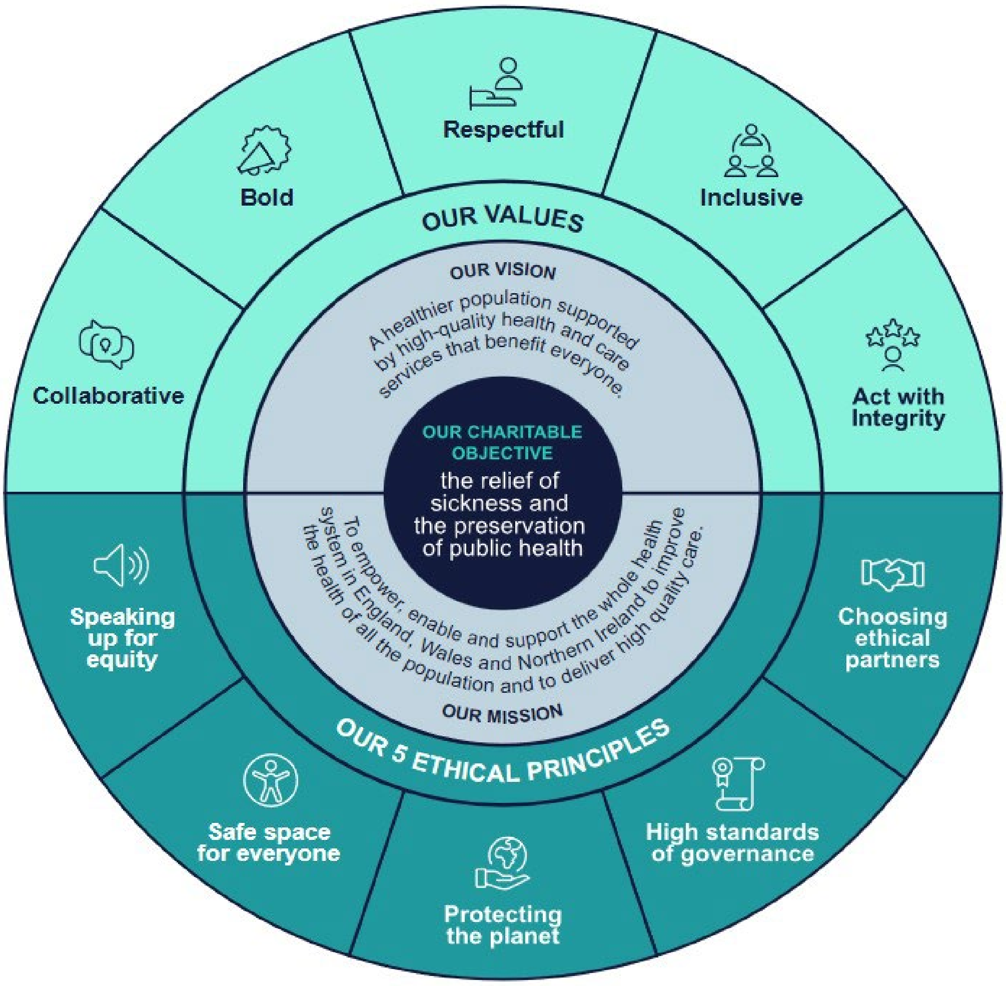
We are a diverse organisation with a diverse membership and recognise and value each other’s strengths.

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.