

Health Data Research UK

STRATEGIC PLAN 2023/24

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1. Welcome from the Director & Chief Scientist

Health Data Research UK (HDR UK) was established in 2018 as the UK's national institute for health data science, with an ambition at launch to:

“Exploit the extraordinary capability of informatics to create a national medical research and innovation Institute that leads the international agenda in health data science.”

In our first five years, HDR UK has already transformed the ability to harness diverse, large-scale data for research that delivers public benefit. We have enabled the application of cutting-edge data science approaches to clinical, biological, genomic, and other multi-dimensional health data to address some of the most pressing health research challenges facing society. Key achievements include:

1. **Assembling key components of a UK-wide data infrastructure and services for health research** – not only the technology platforms, but also the underpinning governance, ethics, standards, public involvement and engagement, and data curation needed to enable health data research. HDR UK has established the [UK Health Data Research Alliance](#) of approaching 80 organisations across the UK, which hold and provide access to health relevant data, and has convened a network of Trusted Research Environments (TREs) across the UK to enable secure, ethical and trustworthy access to de-identified data for research to benefit patients and the public. The [Health Data Research Innovation Gateway](#) has enabled discovery of, and a route to request access to, over 800 UK health datasets held by 60 data custodians.

HDR UK established several health data research hubs, each providing specialist data services required to support researchers and innovators to harness large-scale data for distinct uses. The Institute also leads a fully embedded, highly productive British Heart Foundation (BHF) cardiovascular data science centre.

2. **Accelerating the pace and scale of health and biomedical data science.** Within our first three years, the Institute's UK-wide research community had published >2,300 papers with >65,000 citations, including a wealth of high-profile research that directly informed policy decisions and clinical practice nationwide during the COVID-19 pandemic. **Research is now occurring, for the first time ever, using linked, multi-source, data on a population of more than 65 million people.**
3. **By working in partnership, HDR UK has created a multi-disciplinary, geographically distributed, UK-wide Institute** of over 1500 researchers¹ across >40 organisations². The Institute has also engaged a broader UK and increasingly global community spanning the National Health Service (NHS), research institutes, life sciences and technology companies, charities, government and regulators collaborating on programmes of health data research initiated and enabled by the Institute. Patient and public members have been embedded at the heart of all of our work to ensure transparency and to earn trust. The impact and return on investment from HDR UK's initial £53 million core funding award has been significantly increased through leverage of an additional £200 million during the Institute's first five years.

¹ Institute members are defined in the HDR UK Attribution Policy. As a distributed institute the HDR UK community is defined as people who are in receipt of funds from HDR UK (e.g. salary, research costs), or involved in an HDR UK project (including where salary is provided as an in-kind contribution).

² Includes research organisations that are signatories to the HDR UK Institute Agreement. This does not represent all delivery partners.

Despite great progress during the Institute's first five years, our job is far from done. The transformative potential of health data research is a long way from being realised in full. Only a small proportion of NHS, biomedical and health-relevant data is accessible to inform research. Data is of variable quality. Many datasets are still held, unconnected, in individual institutions or on data platforms that lack the governance infrastructure to support safe and timely researcher access or the computing infrastructure required for advanced analysis. There are major research and technological skills shortages. Public trust and confidence in the use of health data for research remain vulnerable.

As we commence our ambitious programme of work over the next five years (2023-2028), our strategic plan for 2023/24 sets out an ambitious and innovative programme to increase the scale, quality, speed and impact of insights derived from health data research in the UK and internationally. By 2028, the Institute will be well positioned to move forward to the next stage of its >20-year vision 'for large-scale data and advanced analytics to benefit every patient interaction, clinical trial, and biomedical discovery and to enhance public health', and to be at the centre of a global, collaborative network of health data science.

There is much to do, and we look forward to working with all our Institute members and partners to deliver HDR UK's important mission to unite the UK's data to enable discoveries that improve people's lives.



Andrew Morris
HDR UK Director



Cathie Sudlow
HDR UK Chief Scientist &
Deputy Director

2. Health Data Research UK Overview

2.1. HDR UK's Second Five Years

HDR UK's position as the national institute for health data science is underpinned by ongoing core support from the Institute's nine core funders³. Building on this foundational investment, the Institute delivers major programmes in partnership with a wide range of UK and international organisations.

Following completion of an in-depth international review by the core funders in 2022, the Institute was judged as ***internationally competitive and leading edge in most areas***. The International Panel chaired by Dame Muffy Calder concluded that:

- *"HDR UK had made impressive progress, establishing itself as an international leader in the health data research field."*
- *"HDR UK's distinctive success and service to the community, playing a unique convening role was commendable."*
- *"The cohesive interaction of infrastructure and research has enabled significant progress."*
- *"HDR UK has developed a highly successful, world leading national resource, promoting collaborative team science and tackling important challenges in health data science."*

HDR UK's core funding provides a stable foundation for the next five years (2023-2028) and allows the Institute to leverage additional aligned investments to achieve its mission.

HDR UK formally updates its strategic delivery priorities on an annual basis, in response to feedback from partners and stakeholders, as well as to a rapidly moving landscape. Regular interim reviews also ensure the Institute remains agile. This document provides the current strategic delivery plan for 2023/24 and is publicly available on [HDR UK's website](#).

2.2. A UK-wide Institute

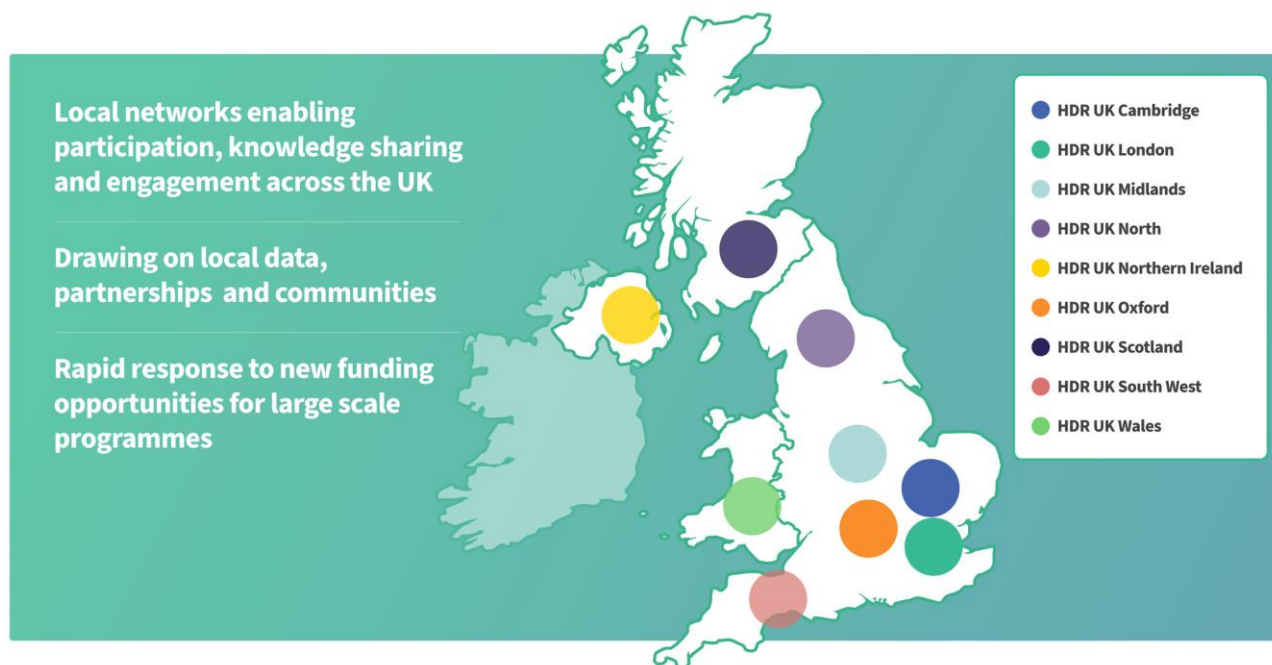
HDR UK delivers through partnership. Members of the Institute are distributed across the UK in 35 leading research organisations. HDR UK's innovative delivery model allows the Institute to harness diverse, interdisciplinary skills and expertise united by shared values and a common commitment to open and team science.

The Institute benefits from the health data science expertise and infrastructure across the UK and globally, working with regional NHS, academic and industrial partners to deliver the Institute's mission.

As an independent charitable company, HDR UK's 'institutionally-agnostic' approach is invaluable, allowing HDR UK to convene, encourage standardisation, and serve a range of partners, while capitalising on the diverse expertise required to generate new research insights from complex and distributed data assets.

³ The Core Funder Consortium, convened by the Medical Research Council, includes the British Heart Foundation, Cancer Research UK, Chief Scientists Office (Scotland), Department of Health and Social Care (National Institute of Health and Care Research), Economic and Social Research Council, Engineering and Physical Sciences Research Council, Health and Care Research Wales and Public Health Agency (Northern Ireland).

Figure 1: HDR UK's Regional Networks



2.3. Organisational Governance

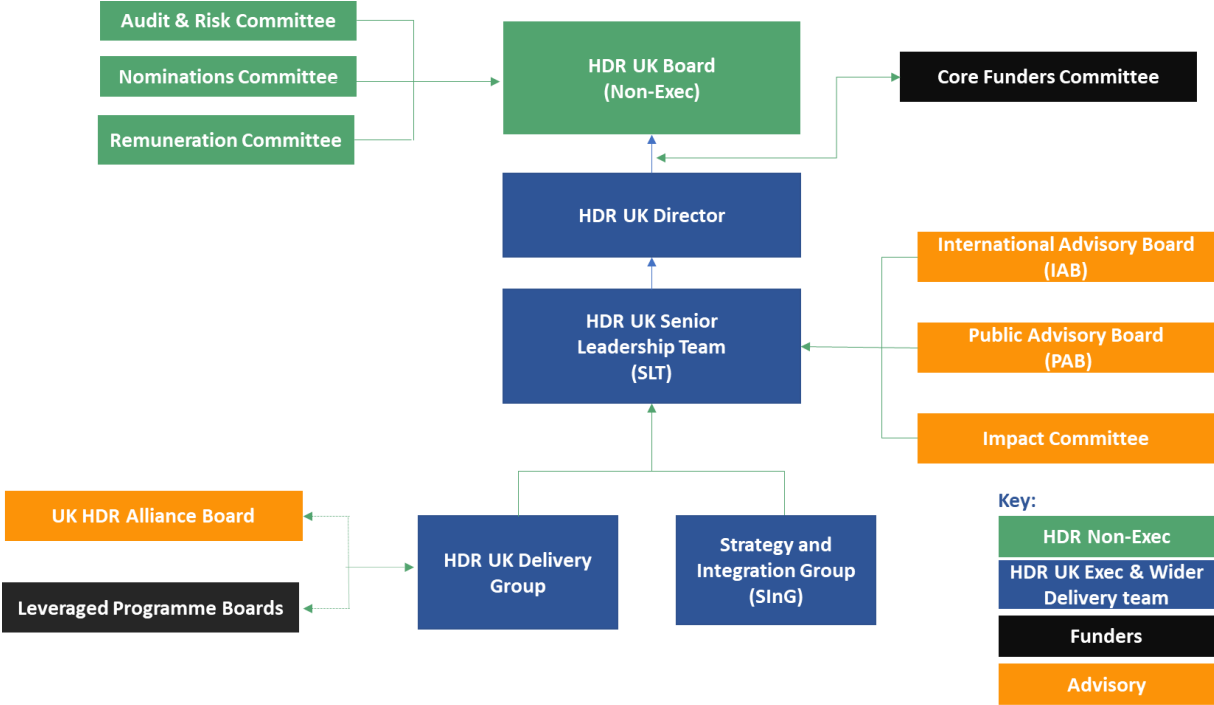
HDR UK's independent [Board of Trustees](#) provides strong and supportive oversight of the Institute. The Board guides HDR UK's vision and strategy and holds the HDR UK Director and [Senior Leadership Team](#) to account.

Three leadership groups support strategic delivery across the Institute:

- **Senior Leadership Team** – responsible for setting (with Board input and approval) and monitoring HDR UK's strategic direction and ensuring that the Institute meets its ambitious goals.
- **Delivery Group** – responsible for ensuring that delivery is on track and supporting integrated research and service provision across a distributed organisation.
- **Strategy & Integration Group** – responsible for maintaining alignment across all HDR UK activities and supporting SLT with strategic direction, horizon scanning and partnership development.

The Institute draws on regular guidance from its [International Advisory Board](#) and [Public Advisory Board](#) to ensure that all its activities align with international best practice and public expectations. The HDR UK [Impact Committee](#), comprised of early career researchers with a diverse range of skills, leads the Institute in the responsible assessment and reward of impact across the HDR UK community.

Figure 2: HDR UK’s Governance Structure



3. Achieving our Vision and Mission

HDR UK makes it easier for researchers to find, access and use diverse, high-quality data to improve health and boost UK science. The Institute provides the leadership to fix difficult technical problems by creating innovative solutions to enable researchers to safely and securely use large-scale data. As a national Institute, HDR UK connects data, people and organisations across the UK and internationally to develop the open collaborations required to accelerate and streamline health data science.

HDR UK's mission and vision drive the priorities and ambitions of the Institute.

Mission

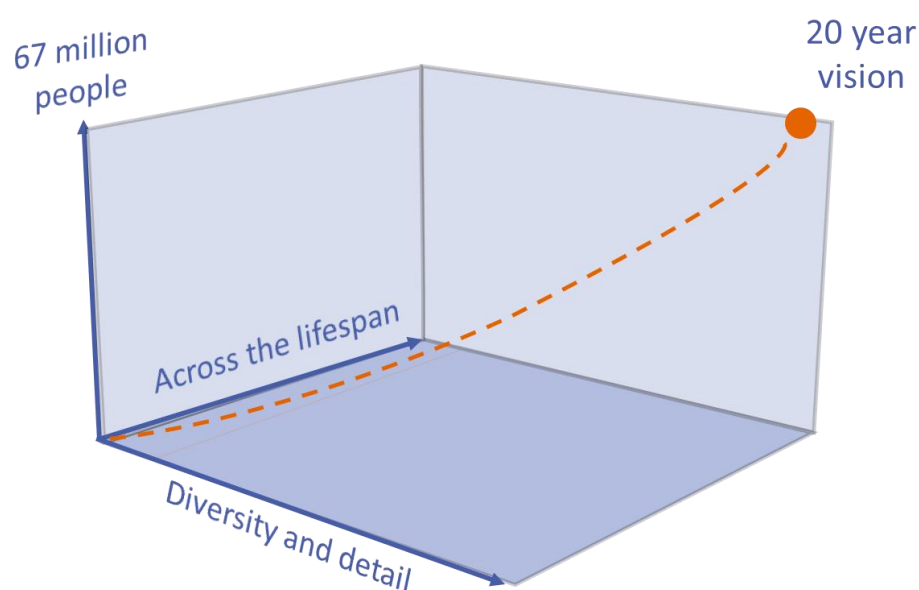
To unite the UK's health data to enable discoveries that improve people's lives.

Vision

For large-scale data and advanced analytics to benefit every patient interaction, clinical trial, and biomedical discovery and to enhance public health.

The Institute's work to accelerate and enable large-scale data use will narrow the gap between new research discoveries and direct impacts for patients and the public. Across pandemics and infectious diseases, non-communicable diseases - including cardiovascular disease, cancer and dementia, as well as rare conditions - patients and the public will have safer, better and faster answers to causes, treatment and prevention of disease to deliver improvement and equality in health outcomes.

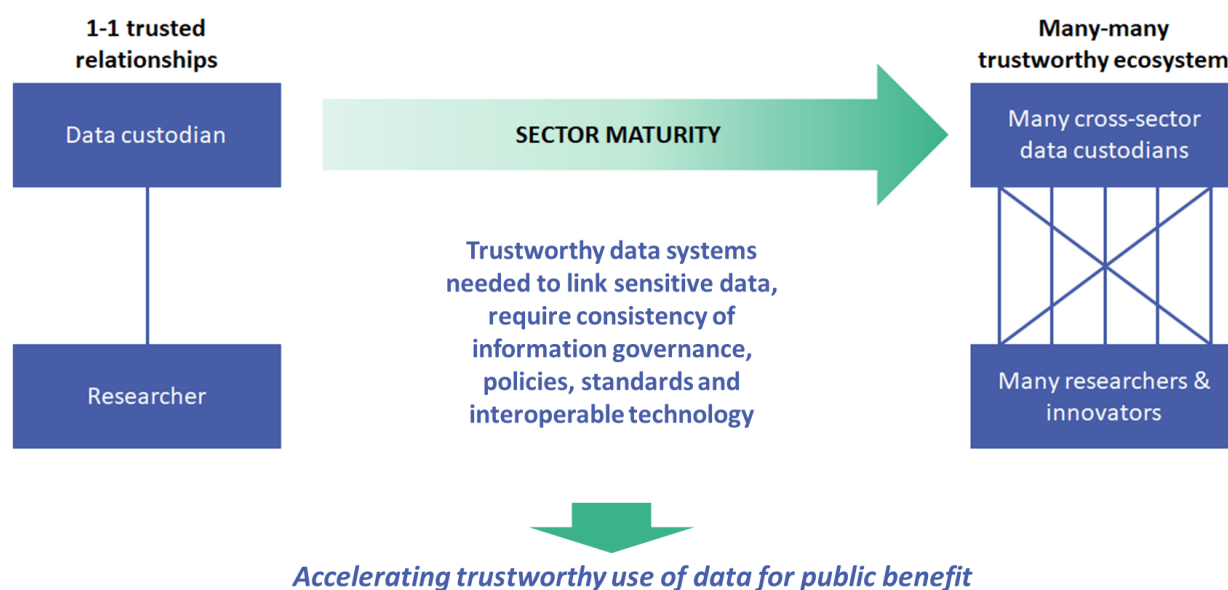
Figure 3: HDR UK enables research at an unprecedented depth, breadth and scale



HDR UK enables researchers to make discoveries, using data across the whole population of the UK, at a greater detail and depth than ever achieved. To fully understand the determinants of health and develop innovations that can improve people’s lives, it is critical that the full range of health-relevant data can be accessed and used safely and securely to deliver public benefit. By developing reliable, safe, and secure approaches, we can assemble the foundations for a new era of health data science to advance the discovery and practice of public health, medicine and care.

To achieve this, HDR UK works with a range of partners, including patients and the public, researchers, innovators and those with responsibility for providing secure access to diverse data resources (data custodians) to establish a trustworthy health data research ecosystem. This will deliver a shift from the current model of one-to-one relationships between researchers and data custodians to a many-to-many approach, increasing the efficiency, reproducibility and robustness of insights generated from previously siloed data resources.

Figure 4: HDR UK connects partners to establish a trustworthy health data research ecosystem required to transform health data research



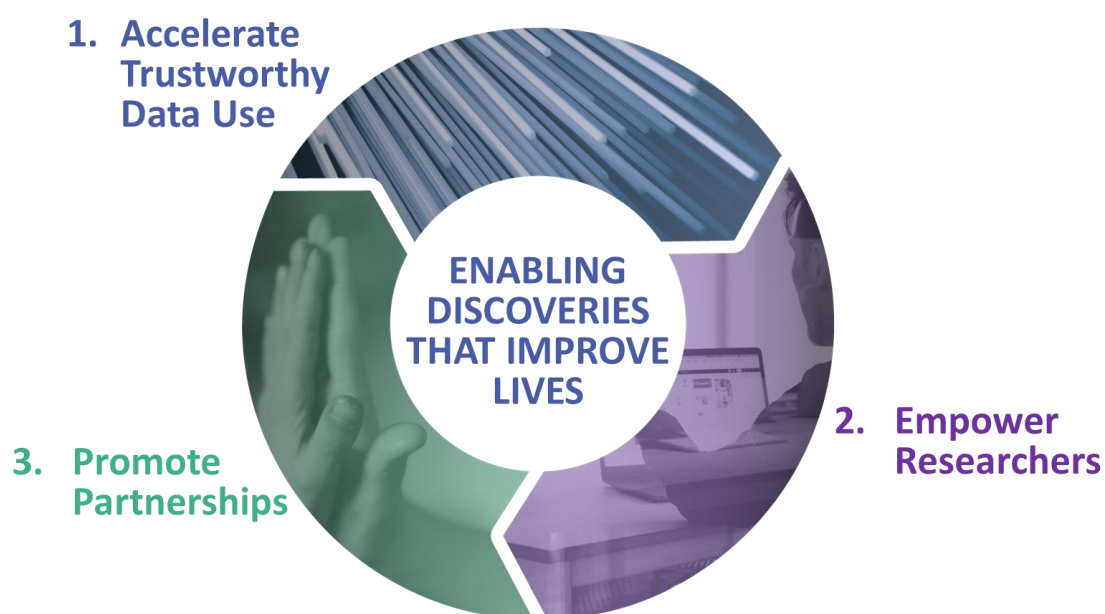
3.1. Long-Term Goals

To achieve the Institute’s mission, HDR UK focuses on three long-term goals:

1. ACCELERATE TRUSTWORTHY DATA USE	By implementing a national research data strategy and assembling infrastructure and services aligned to research and innovation needs
2. EMPOWER RESEARCHERS	By valuing people with diverse perspectives and skills, committed to open and team science to advance scientific discoveries and deliver patient and public benefit
3. PROMOTE PARTNERSHIPS	By building and maintaining critical partnerships, aligning incentives and reducing complexity across a fragmented landscape to streamline health data science

These will be delivered through an integrated approach.

Figure 5: HDR UK’s Integrated Approach



Over the next 5 years, HDR UK will focus on common driving principles with clear success measures to achieve each goal.

	DRIVING PRINCIPLES	5-YEAR SUCCESS MEASURES
1. ACCELERATE TRUSTWORTHY DATA USE	<p>UK-wide scalability with coordinated solutions for economies and efficiencies of scale.</p> <p>Democratised access with no privileged or exclusive access arrangements.</p> <p>Data priorities - generic foundations (data everyone needs) over domain/disease-specific.</p> <p>National data capability over regional and structured data over unstructured. Leveraging the power of multisource data linkage.</p> <p>Embed reproducible data pipelines.</p> <p>User-centred design enhanced by delivery of frictionless services.</p> <p>Open source, interoperable software following a build once and use often principle.</p> <p>Alignment of focus with the UK Health Data Research Alliance.</p>	<p>Increased scale of data use to make high priority datasets available and widely used.</p> <p>New solutions used and adopted broadly, for better access to and use of data.</p> <p>Increased efficiency & productivity for a shorter health data research journey from idea to impact.</p> <p>Advanced data-driven approaches used to deliver research that was not previously possible.</p>
2. EMPOWER RESEARCHERS	<p>Value people with diverse perspectives, interdisciplinary skills and cross-sector expertise.</p> <p>Drive a transformation in research culture underpinned by open and team science.</p> <p>Develop scalable, collaborative endeavours that address the highest priority health challenges.</p> <p>Connect researchers/innovators to policy makers and practitioners to accelerate public benefit.</p> <p>Provide UK-wide training and capacity building initiatives, where a national institute is needed.</p>	<p>People want to work with and for HDR UK because of our positive research culture.</p> <p>Changes in health policy and practice due to use of large-scale data.</p> <p>Delivering benefits to the public and economy locally, regionally, nationally & internationally.</p>
3. PROMOTE PARTNERSHIPS	<p>Partner with public, patients, professionals and policy makers across all activities.</p> <p>Identify and solve critical challenges through aligning incentives.</p> <p>Focus on partners most critical to our mission and vision.</p>	<p>Public trust retained and strengthened.</p> <p>Reduced complexity of fragmented landscape.</p> <p>Growth and sustainability from leveraged funds.</p>

3.2. 2023/24 Integrating Objectives

HDR UK's annual objectives will require an integrated approach across all activities of the Institute for the year ahead. They provide a focus for the Institute to make rapid progress towards achieving its long-term goals, while remaining flexible to respond to emerging needs and opportunities.

By aligning the programmes established through the HDR UK core award, plus those established through partnership funding, the Institute will be able to deliver impact greater than the sum of the individual parts. Each objective will be overseen by a single Senior Responsible Officer (SRO), supported by a cross-Institute delivery group.

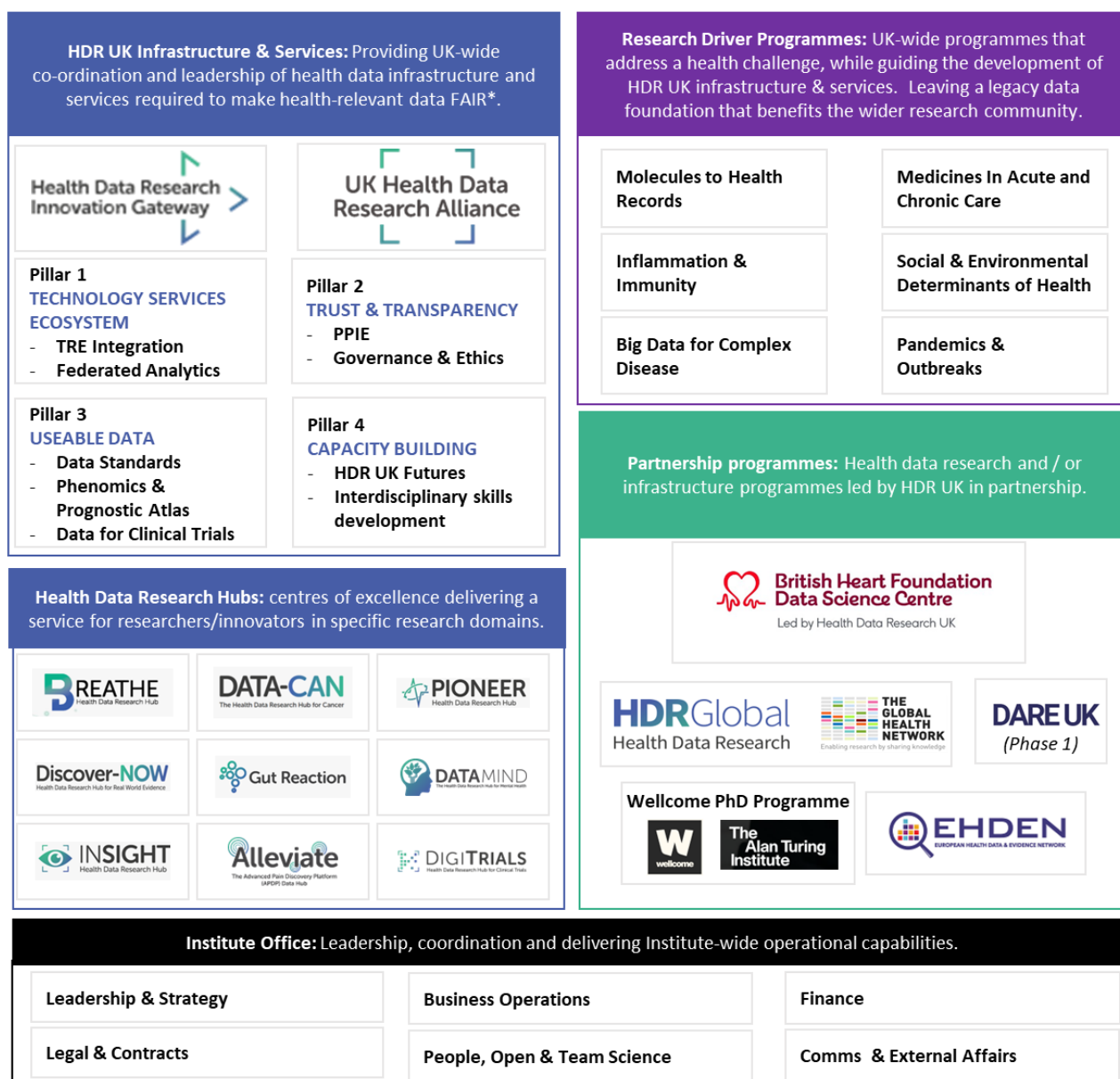
The Institute's 2023/24 objectives are to:

	2023/24 Integrating Objective
1. ACCELERATE TRUSTWORTHY DATA USE	1. Data Strategy Develop & embed a UK-wide strategy to accelerate access and use of data prioritised by research user needs.
	2. Technology & Standards Establish a technology services ecosystem including the development of standards and tools designed to overcome technical and regulatory hurdles to meet emerging researcher needs.
	3. Streamlining Information Governance to accelerate trustworthy data access, working in partnership with UK Health Data Research Alliance members.
2. EMPOWER RESEARCHERS	4. Organisational Effectiveness Attract and develop a diverse workforce, increase maturity of Institute systems, processes and governance, following initial rapid growth, and demonstrate best practice in open and team science.
	5. Impact on Policy and Practice Ensure that HDR UK continues to enable research with rapid impact on policy and practice, with the potential to improve lives.
3. PROMOTE PARTNERSHIPS	6. Alignment & Partnership Ensure that HDR UK maintains and creates strategic partnerships to accelerate delivery of its mission.
	7. Funding Diversification Establish at least one major new partnership programme to further HDR UK's mission, with clear delivery alignment and integration.

4. Delivery Approach

4.1. Current Delivery Mechanisms

HDR UK has evolved a number of different delivery mechanisms during its initial rapid growth over the first five years. The leadership and capabilities established underpin the Institute's long-term goals. Reducing complexity across these delivery mechanisms, while learning from what has and has not worked well, has been incorporated into the Institute's future priorities.



*FAIR: Findable, Accessible, Interoperable and Reusable

4.2. Values

The Institute's **TORCH** values are at the heart of everything we do. They drive the way we work together and create an inclusive and open community that integrates talent across diverse professions, sectors, career stages and geographies.

HDR UK's **TORCH** values act as the foundation of the Institute's strategy, partnerships and delivery approach:

Transparency

Optimism

Respect

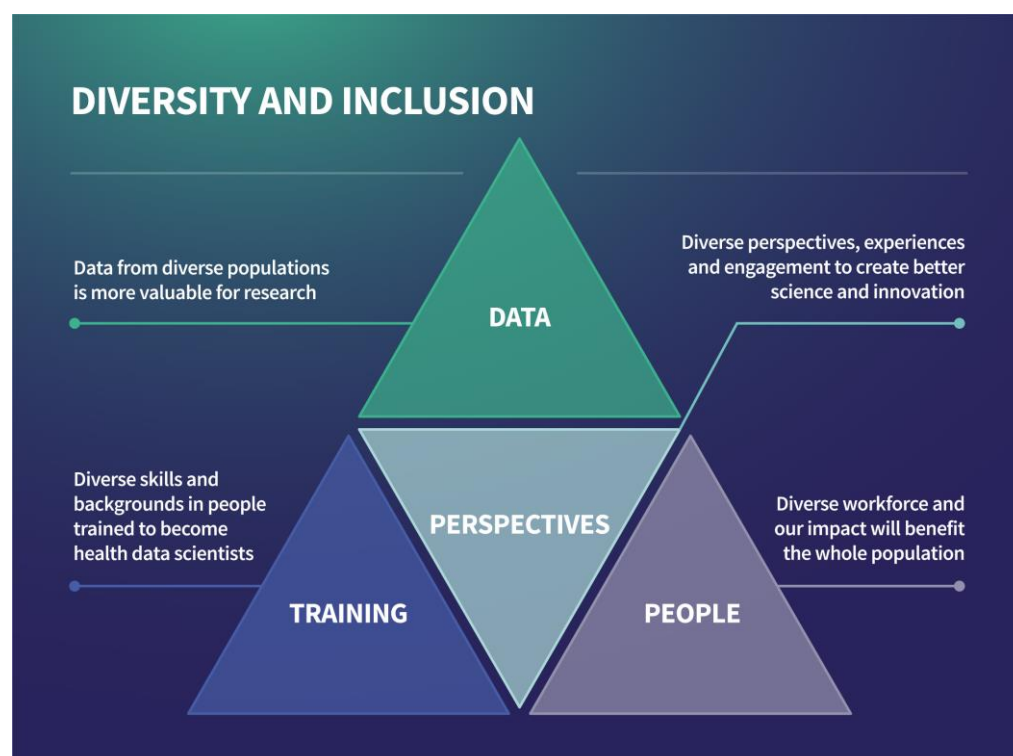
Courage

Humility

4.3. Diversity & Inclusion

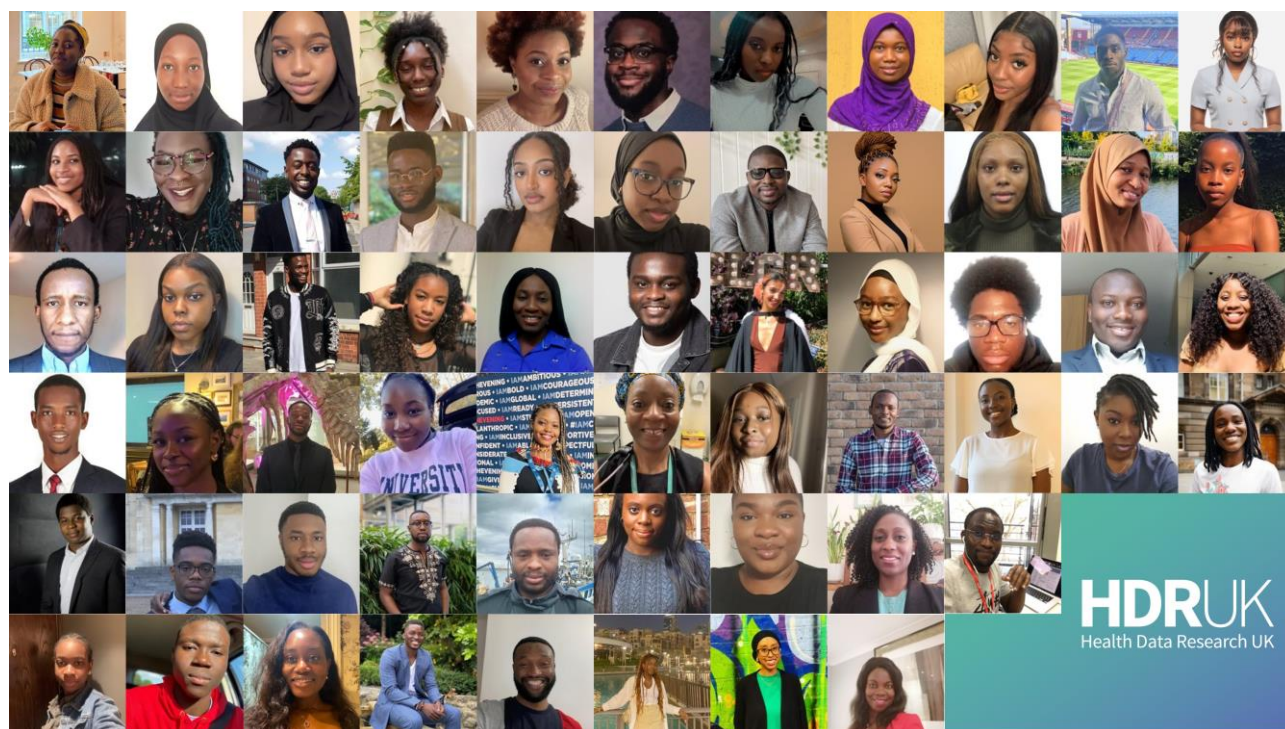
The Institute's commitment to diversity and inclusion, across four domains, is set-out in our [Diversity & Inclusion Policy](#).

Figure 6: Diversity and inclusion at HDR UK



This includes direct interventions such as the ground-breaking Black Internship Programme, and taking action to address a lack of gender diversity across the Institute's senior leaders, through a co-leadership approach in its major programmes.

Figure 7: HDR UK Black Internship Programme cohort 2022



4.4. Public and Patient Involvement and Engagement

The Institute is committed to a relentless focus on patient and public benefit. We can only achieve our vision and strategy if everyone, including patients and the public, has trust and confidence in the safe access to and use of health data for research and innovation. To support this, the HDR UK Public Advisory Board provides strategic advice to the Institute and develops and shares best practice in PPIE across the ecosystem.



4.5. HDR UK's Progress & Impact Framework

HDR UK's 2023/24 Strategic Plan defines a framework that consists of our long-term Strategic Goals aligned to our mission, the driving principles and success measures we hope to achieve in the next 5 years, together with the specific integrated objectives we will focus on as a UK-wide team over the next 12 months. The Institute's Progress and Impact Framework ensures that activities remain aligned, supports flexible and agile delivery and remains focused on delivering impact across all of the Institute's activities to ensure progress towards our mission is achieved.

The Institute's approach to tracking progress and impact emphasises co-creation and focuses on measures of success that are proportional, motivational, easily understood and measured, and agile. We aim to enable effective management decisions with clear delegation of responsibilities that underpin effective delivery across a distributed Institute.

The Progress and Impact Framework has three components:

1. Cross-organisational annual objectives with aligned annual delivery plans – tracked and adjusted each quarter.
2. Progress metrics to ensure delivery remains on track and to identify mitigating actions early – aligned to common milestones and tracked each quarter.
3. Assessment of outcomes and impact on a quarterly and annual basis using an institute-wide Impact Framework and including independent assessment led by the Impact Committee.

HDR UK's impact will be demonstrated through a range of qualitative evidence, including high-impact case studies, stakeholder interviews and an annual impact assessment exercise and will be informed by the needs and priorities of HDR UK's partners, including members of the public.

HDR UK will continue to deliver step changes in the speed and scale of benefits realised from health data research. This will be achieved by providing more robust and insightful research through a distributed data infrastructure. HDR UK will continue to enable research that directly benefits patients and the public, informing clinical decision making and influencing health policy.

By working together, the Institute is able to deliver “more than the sum of its parts” and remain agile to respond to a fast-moving landscape.

HDRUK

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