Understanding Patient Data Annual Report

2024-25

Understanding
Patient Data

Chair and Head of UPD's Foreword

Over the past year, Understanding Patient Data (UPD) has continued to champion transparency and public engagement to build trust and shape policy and practice in line with public expectations around how health data is used across the UK. The work covered in this report was guided by the leadership of Nicola Hamilton, who stepped down as Head of UPD in early 2025. Nicola led UPD since its move to NHS Confederation in 2023, and we are hugely grateful for her thoughtful and values-driven leadership during this pivotal period.

In 2024 –25, we published research highlighting stark variations in data infrastructure and capability across Integrated Care Systems in England—demonstrating how these differences risk reinforcing inequalities in care. We explored public attitudes to the use of patient data for planning and population health, offering insights into where people see value, and where they expect greater safeguards or transparency. We responded to the government's proposed Data (Use and Access) Bill, assessing its implications for trust, transparency, and responsible governance. Alongside this, we developed practical resources to support better communication with the public, including an animation explaining Trusted Research Environments and new work on how to talk about health data security in a clear and relatable way. Through partnerships such as NHS England's Patient and Public Engagement Advisory Panel and contributions to international initiatives like the European Health Data Space, we've helped shape both national and global conversations about trustworthy data use.

Looking to the future, UPD has secured a new five-year funding agreement —providing a stable foundation for the next phase of our work. We have also welcomed a new Head of UPD, Anna Steere, who brings renewed leadership and vision to our mission.

Dr Peta Foxall CBE –
Chair of UPD Steering Group

Nicola Hamilton –
Former Head of UPD 2023-4

Anna Steere –
Head of UPD

Understanding
Patient Data

Understanding Patient Data

UPD Vision:

Health outcomes for all are improved through the responsible and trustworthy use of patient data

UPD Mission:

To bring together diverse voices, research and resources to create a trustworthy system for the use of health data

UPD Aims:

Patients & publics are empowered to make informed choices about use of their health data

Health data users and custodians handle data in a trustworthy way to improve health and support innovation

Policy makers recognise the importance of patient data and support the environment around its use

Policymaking reflects the latest evidence about data use and public attitudes, and invest into building the evidence base

How we work

We do this through...

Producing **resources** to demystify uses of routinely collected health data

Understanding views through **engagement** and **research**

Convening and supporting patient data communities and advocates

We advocate and influence health data **policy** and practices

We provide commentary to the **media** and create content for online channels

Visibility

Understandability

Trustworthiness

All our work is underpinned by three key principles

History and period of report

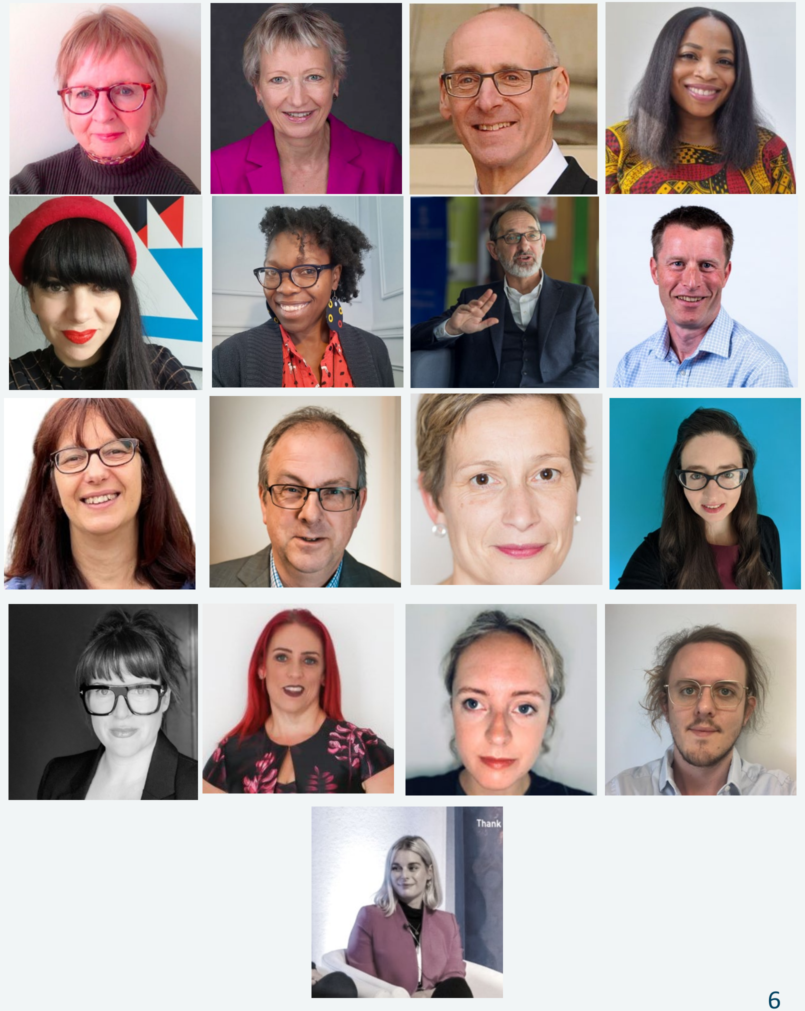
- Understanding Patient Data was set up in 2016 to support conversations with the public, patients and healthcare professionals about uses of health and care data. It was originally a two-year initiative, supported by Wellcome, the Medical Research Council, the Economic and Social Research Council, the Department of Health and Social Care, and Public Health England. The programme was then extended, continuing to be hosted at Wellcome until the end of September 2021. Previous annual reports until September 2021 can be found here.

- In April 2023, UPD moved to a new hosting organisation, the NHS Confederation, the membership organisation that brings together, supports and speaks for the whole healthcare system in England, Wales and Northern Ireland. The relationship of UPD to the NHS Confederation is similar to that of UPD and Wellcome; it remains an operationally independent initiative. UPD's 2023-24 annual report can be found here.

- In April 2025, UPD announced a five-year funding settlement to remain hosted at NHS Confederation, funded by Wellcome, the Medical Research Council, the National Institute for Health and Care Research, NHS England, the Department of Health and Social Care, and the Office for Life Sciences. This report covers the period of UPD’s second year at the NHS Confederation, April 2024 to April 2025.

Our Steering Group

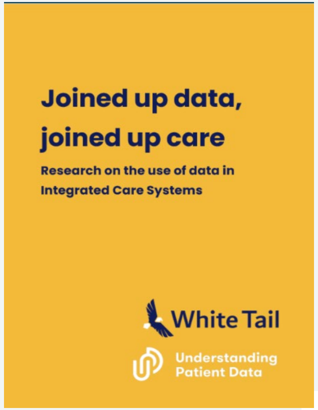
- We are grateful to our Steering Group for continuing to support us in our work over the last year. Current members are listed here, and the minutes are published here.
- We are especially grateful to our Chair, Peta Foxall, for going beyond her two-year term to support the recruitment and transition of a new Head of UPD.
- In 2024, we said goodbye to Rebecca Cosgriff from NHS England due to her changing roles, and welcomed Emma Harris in her place.
- From April 2025, membership of the group will evolve in line with new funding arrangements and the strategic direction of UPD. We will also be looking to recruit a new Chair for the group.



Activity types and work programmes

	Developing the health data community	Commissioning research	Influencing and advocating	Communications and media	Creating resources
Health data policy and legislation	Event speaking, panels Co-hosting discussions, e.g. with Connected By Data Welsh government health data deliberation	What Are the Best Words to Use Commissioning of Health Data Security project	Data Bill influencing and collaboration Data Strategy Advisory Panel Consultation responses 10YHP working group Ministerial letters	Blogs e.g. on AI, research Quotes to the media and editorials (BMJ) Response to Sudlow Review, single care record, HDRS etc.	Health data policy explainers Easy Read Guide comms campaign
Health data infrastructure	Involvement in the NHS England's Patient and Public Engagement and Communications working groups and various NHSE and Government steering groups.	Publication of Integrated Care Systems (ICS) Data project Commissioning of GP data research	Steering group and 1:1 engagement on: Federated Data Platform (C&C group), Data for R&D Programme , NHSE large scale public engagement programme, GP data, data controllership	Quotes to the media around high-profile cases/data uses	What Are the Best Words to Use (SDE/TRE) content & animation production
Population health data, management and use	Supported Welsh govt's public dialogue around using health data to identify and approach people about health and care research	Publication of Data for Planning and Population Health and Equitable data collection for Gypsy, Roma & Traveller communities	Publication of Health Data Alliance ethnicity report Stakeholder engagement re ethnicity data e.g. Runnymede Trust, DHSC	Blogs on opt out and impacts on diversity of data and linked data	Updating and highlighting case studies tackling health inequalities
Sustainability and international reach of UPD	Contributing to the Global Partnership for Sustainable Development Data's Citizen Data: At the Center of Addressing Infectious Diseases	Publication of Wellcome/NHS Confed report on EHDS UPD Evaluation	Commissioning and collating input on TEHDAS2 consultations Securing new funding	Representing UPD at international events (e.g. TEHAS2 annual summit, EU Data Saves Lives)	Shaping Data Saves Lives' information toolkit on the European Health Data Space and translating animation resources

Examples of new publications and research



Joined up data, joined up care

Research on the use of data in Integrated Care Systems

White Tail

Understanding Patient Data

Use of data by Integrated Care Systems

Understanding Patient Data

UNIVERSITY of WORCESTER

GATE HERTS

EQUITABLE DATA COLLECTION FOR GYPSY, ROMA AND TRAVELLER COMMUNITIES IN HEALTH SERVICES

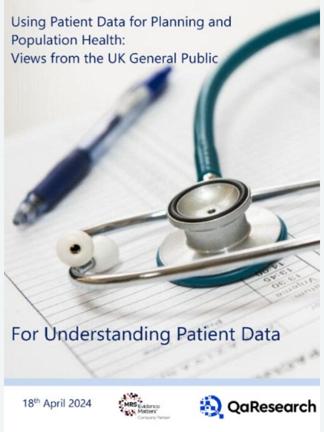
Community-centred and-informed ethnicity data categorisation

January 2025

Prepared By

Dr Peter Unwin, Josie O'Driscoll, Allison Hulmes, Stacey Hodgkins, Shamus McPhee, Dr Rosa Cisneros, Jackie Bolton and Prof. Győző Molnár

Equitable data collection for Gypsy, Roma, and Traveller communities in health services



Using Patient Data for Planning and Population Health: Views from the UK General Public

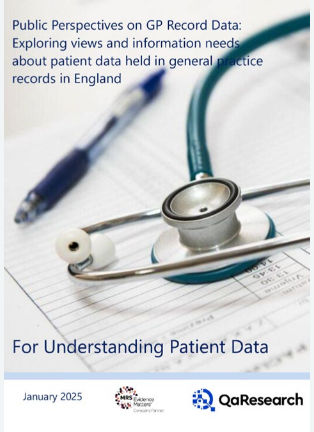
For Understanding Patient Data

18th April 2024

MRS Evidence Matters Company Partner

QaResearch

Public attitudes about patient data for planning and population health



Public Perspectives on GP Record Data: Exploring views and information needs about patient data held in general practice records in England

For Understanding Patient Data

January 2025

MRS Evidence Matters Company Partner

QaResearch

Public perspectives on GP record data

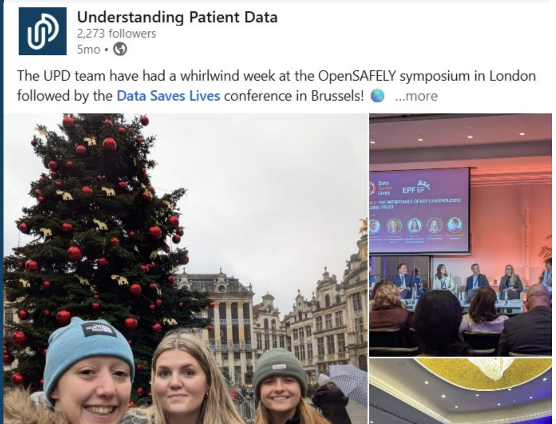
Using Patient Data for Research - What is a Secure Data Environment/Trusted Researc...

SDE/TRE Explainer Animation

Communications and engagement

- In 2024, we nearly doubled our LinkedIn following to 2,277 (up 97.5%) and maintained strong engagement (8.67% vs a 3.5% benchmark). With declining activity and changing perceptions around X (formerly Twitter), we've stopped posting there. Our website continues to perform well, with increased traffic and growing referrals from search, social, and email—even if year-on-year comparisons are tricky due to changes in analytics. The most visited pages include our homepage, patient data explainers, and resources hub.

- The team had a visible presence across the sector—attending major events like the Nuffield Summit and HETT, and contributing to key national groups and initiatives, from the FDP Check & Challenge group to NHSE's AI, comms and PPIE working groups.



Understanding Patient Data
2,273 followers
5mo •

The UPD team have had a whirlwind week at the OpenSAFELY symposium in London followed by the Data Saves Lives conference in Brussels! 🌍 ...more

Understanding Patient Data
2,273 followers
6mo •

📰 It was great to see our joint evidence with NHS Confederation used in the inquiry into UK-EU data adequacy. ...more

HOUSE OF LORDS
European Affairs Committee

House of Lords
London
SW1A 0PW

Tel: 020 7219 6083
hleuroaffairs@parliame

Rt Hon Peter Kyle MP
Secretary of State for Science, Innovation and Technology,
Department for Science, Innovation and Technology,
100 Parliament Street,
London,
SW1A 2BQ

22 October 20

Understanding Patient Data
2,273 followers
11mo •

📰 Today UPD have published a new report in collaboration with NHS Confederation and Wellcome Sanger Institute exploring UK citizens' attitudes toward the future use of their data within the European Health Data Space.

🔗 Learn more and read the report here:
https://lnkd.in/etqpH54D

Sharing health data – Lessons for the UK from the EHD
understandingpatientdata.org.uk

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Project Deep Dive: UPD Evaluation

Led by Emma Morgan

Background / aims:

- With the only evaluation of UPD done in 2018, it was important to undertake a broad evaluation of the UPD programme from its 2016 inception to 2024, as well as some market research style activities to better understand and evidence the impact of the programme.
- As UPD was working to secure future funding, it was hoped that an evaluation would ideally serve as a baseline measure for future and more regular evaluations, and to inform the next programme of work based on the feedback and results.
- We commissioned Apteligen to support us with this evaluation.

What happened:

- A mixed-method, summative evaluation of UPD's importance and impact across the UK's patient data landscape in relation to its five key strands of work (convening the community, producing resources, research and engagement, advocating and influencing, and content/media commentary).
- 1:1 semi-structured interviews with 17 external stakeholders; online survey completed by 40 external stakeholders; feedback from media journalists; review of website and social media analytics; rapid review of citations and references in published literature; review of key organisational documents such as progress reports, strategy documents, and the 2018 evaluation.
- 4 case studies detailing UPD's impact on specific projects, programmes and policies.

Key take-away findings:

- UPD is highly regarded and trusted by a wide range of individuals and organisations from across the patient and health data ecosystem.
- UPD occupies a distinct and important insider-outsider position, while maintaining independence and neutrality.
- Much of UPD's impact comes from its position as a 'boundary spanning' organisation across the patient and health data ecosystem.
- UPD's work leads to patients, clinical practitioners and policy professionals being better informed about how patient data is used, increasing the trustworthiness of organisations.
- UPD's work is perceived to 'save' money elsewhere in the system and increase the impact of strategic investments.

Next steps:

- This evaluation played a valuable role in helping UPD to demonstrate its impact and secure a further 5 years of funding, including from new funders.
- UPD is now designing a more long-term monitoring and evaluation programme with consultancy support, to better embed a continuous learning and development framework over the next strategy period that more comprehensively captures our social, systemic, and financial value.

Led by Nicola Hamilton and Emma Morgan

Project Deep Dive: Gypsy, Roma, & Traveller ethnicity data

Background / aims:

- The Gypsy, Roma and Traveller communities are known to face some of the most severe health inequalities in the UK.
- Ethnicity data captured for these groups in health services is consistently poor, with community members often having to choose inaccurate ethnicity categories. There are also issues around social exclusion and barriers to access which affect ethnicity data collection and accuracy.
- This project sought to understand the attitudes and perspectives of Gypsy, Roma and Traveller communities on the collection of ethnicity data in health services and develop recommendations to ensure these groups are better represented in healthcare data. We commissioned researchers at University of Worcester to support us with this project.

What happened:

- A desk review exploring: what research has been conducted that has examined the importance of ethnic categorisation in demographic data; what are the main approaches to determining ethnic categories; and what research has specifically focused on the ethnic categorisations of Gypsy, Roma, and Traveller populations.
- Surveys and focus groups with Gypsy, Roma, and Traveller communities to explore community members' perspectives on ethnic categories, ethnic data collection, and management, and co-produce suggestions for new ethnicity categories in UK health services.
- A project steering group consisting of community representatives alongside key professional stakeholders such as data analysts and researchers.
- A co-created video with project researchers and community members discussing the project's importance, findings, recommendations, and next steps.

Key take-away findings:

- Most participants reported never being asked about their ethnicity and, when asked to specify, their ethnicity was often not listed, despite the majority recognising the importance of recording ethnicity.
- This omission was generally perceived as meaning: 'You are not known here' and 'You are not welcome / do not belong here'. Members in every focus group expressed some degree of reluctance to declare their ethnicity.
- Other main concerns identified by participants included limited availability of interpreters; not feeling listened to; lack of staff understanding of cultural needs; ineffective communication, and past discriminatory experiences impacting trust.

Next steps:

- Ongoing conversations with policy and decision-making organisations to drive changes to how we collect ethnicity data.
- Exploring opportunities for co-creating community-facing resources that explain the importance of accurate ethnicity data.

Led by Emma Morgan

Project Deep Dive: Explaining health data security

Background / aims:

- Public concerns about health data security are a regular theme in broader public engagement work, but this issue has rarely been explored in depth, despite having implications for public understanding, attitudes and trust.
- In turn, providing the opportunity for people to access transparent, accessible, and understandable explanations about the genuine practices, risks, successes and failures of health data security, without being overly reassuring or alarming, could help inform better quality conversations and decisions.
- We commissioned Kohlrabi to undertake desk research, and conduct deliberative engagement and co-creation workshops to develop specifications for resources on this topic.

What happened:

- A rapid systematic review of peer-reviewed and grey literature as well as the media landscape to appraise existing public-facing communication around health data security, establishing understanding of current public attitudes and knowledge gaps in this area.
- Face-to-face and virtual deliberative dialogues with 47 members of the public across the UK exploring their awareness, understanding, and concerns related to health data security.
- Virtual co-creation dialogues with 15 members of the existing sample, working in small groups to develop resource specifications on the topic of health data security, interspersed and shaped by interviews with experts in data security, governance, and communication.

Key take-away findings:

- The systematic review established that little is known about the UK public's understanding of health data security, but they commonly have concerns about it, and existing communications are overwhelmingly complex and inaccessible and swing between too reassuring or alarming.
- The public dialogues ultimately recommended that: explainer resources should be relatable, ensure transparency in acknowledging concerns without creating fear, provide assurance of accountability and action, and offer various accessible formats for people to choose from.

Next steps:

- Work with a design agency to further shape and develop the specifications and ultimately produce public-facing resources under a CC-BY license so that they can be used by anyone.
- Incorporate public views and recommendations into UPD's broader policy messaging around data security and beyond.

Led by Emma Morgan

Project Deep Dive: Public attitudes on primary care (GP) data

Background / aims:

- Recent attempts to bring GP data in England together in one place have been abandoned following pushack from privacy campaigners, parts of the medical profession and some members of the public. GP data is often considered more sensitive than other types of health data.
- We wanted to explore what people actually think about the information held in their record, how it's used and how it's accessed – as well as their current levels of understanding and what they would like to learn more about – to support communication on this topic to preface the introduction of a single patient record.

What happened:

- We commissioned QA research to conduct to conduct a three-phased research project:
  - Phase one consisted of a nationally representative (England) online survey of 1,004 people.
  - Phase two consisted of six semi-structured focus groups and five telephone interviews.
  - Phase three consisted of three co-design workshops and three in-person interviews.
- Following these three phases, QA developed a report which sets out the findings of the research and recommendations for communicating about this topic to members of the public.

Key findings:

- The research demonstrated that current awareness and understanding of how NHS records are managed is low, with few being able to recall receiving any information about their data.
- There were mixed views about decision-making (data controllership) over data, with members of the public simultaneously preferring a (national) single patient record but trusting GPs more with their data.
- A majority would prefer information about their GP record to come from GPs, and whilst people value transparency about how GP data is collectively used and having information available upon request, most think information about their own records is the most important.

Next steps:

- We will continue to share the findings of our research widely with Government and other policy stakeholders, particularly ahead of changes to how records are managed with the roll-out of a single patient record and to inform debates about data controllership.
- The findings show clearly the need for more and clearer information and engagement about GP record data, and we will be taking the findings from the research forward when designing future resources about how data is used.

Led by Emma Lagerstedt

Financial Summary

The financial summary covers April 2024 – March 2025 only.

*** UPD income was provided over a two-year period from April 2023 - April 2025 totaling £950,232.00 from the following contributors:**

- Wellcome: £299,816.00
- MRC: £197,878.56
- NIHR / DHSC: £101,937.44
- NHS England: £300,000.00**
- 22/23 income brought forward £50,600.00

TOTAL EXPENDITURE IN 23/24 was £332,632.13, leaving £617,599.87 for 24/25.

**** Income from NHS England covers December 2023 - December 2025.**

Income & Expenditure Breakdown 2024-25	
TOTAL 24-25 INCOME*	**£617,599.87**
EXPENDITURE	
Project costs	
• **What Words to Use (Research Works)**	£13,626.60
• **ICS Data (White Tail consulting)**	£11,914
• **UPD Evaluation (Apteligen)**	£15,587.52
• **Gypsy, Roma, Traveller Ethnicity Data Collection (University of Worcester)**	£35,158.24
• **GP Data (Qa)**	£40,507.60
• **Health Data Security (Kohlrabi)**	£41,141.53
• **SDE Animation (Brickwall)**	£9,089.60
• **Translations of UPD animations**	£8,479.90
Sub-total (project costs)	**£175,504.99**
Staffing	
• **Salaries (including on-costs, training, subscriptions)**	£197,581.80
• **Travel and subsistence (staff and steering group)**	£2783.15
Contribution to host organisation (NHS Confederation)	£35,978
Overheads (website running costs, software and organisational development)	£23,563.93
TOTAL EXPENDITURE	**£435,411.87**
Income carry forward **	**£182,190**

23-25 detailed financial summary

	NHS England			MRC/DHSC/NIHR			Wellcome Trust			All Funders		
Costs	**23/24**	**24/25**	**Total**	**23/24**	**24/25**	**Total**	**23/24**	**24/25**	**Total**	**23/24**	**24/25**	**Total**
Staff Costs	48,544	51,038	**99,582**	68,954	73,038	**141,992**	70,504	73,038	**143,542**	188,001	197,114	**385,115**
Overheads			-	21,439	17,989	**39,428**	14,539	17,989	**32,528**	35,978	35,978	**71,956**
Travel & Subsistence			-	332	1,626	**1,958**	1,394	1,626	**3,020**	1,726	3,252	**4,978**
Consultancy	16,019	52,809	**68,828**	35,170	57,053	**92,222**	35,170	66,033	**101,202**	86,358	175,895	**262,253**
Development and website costs			-	12,629	11,587	**24,216**	7,938	11,587	**19,525**	20,567	23,174	**43,740**
TOTALS	**64,562**	**103,847**	**168,410**	**138,524**	**161,292**	**299,816**	**129,544**	**170,272**	**299,816**	**332,630**	**435,412**	**768,042**
Remaining	**£182,190 of 350,600**			**£0 of £299,816**			**£0 of £299,816**			**£182,190 of £950,232**		

NHS England funding covers December 2023 - December 2025 and therefore applies beyond 2023-2025 financial years. £182,190 of this funding is included as part of UPD's new funding arrangements.

Looking ahead

- **Understanding Patient Data (UPD) has secured a new five-year funding settlement from April 2025**, thanks to the generous support of Wellcome, the Medical Research Council, the National Institute for Health and Care Research, NHS England, the Department of Health and Social Care and the Office for Life Sciences. This funding provides much-needed stability, allowing us to deepen our impact and strengthen our role in supporting the health data community at a critical time.
- **While our core mission remains the same, the health data landscape is evolving rapidly**, with major developments in legislation, technology, and policy fuelling debates on initiatives such as a single patient record, AI in healthcare, a national data library, and patient choice in sharing their data. Plans for a new Health Data Research Service are also set to transform access to NHS data. With so much at stake, the need for open, transparent, and informed deliberation has never been more crucial—and UPD aims to play a vital role in shaping policy and practice to align it to public expectations.
- **With long-term funding in place, we will be expanding our team and impact**—with two new posts from April 2025—and strengthening our support for the health data community. We'll be taking a **more collaborative leadership role**, working with partners to empower people and communities, help data custodians and data users develop, use and demonstrate trustworthy practices and guide policy development to create a fair future that reflects and respects public expectations.
- **Over 2025-26, we will be reviewing our website and existing resources to ensure they meet the needs of our core audiences**, while new projects are likely to focus on topics that include AI, linking health and non-health data, alongside research to support understanding of collective changes to policy and practice.