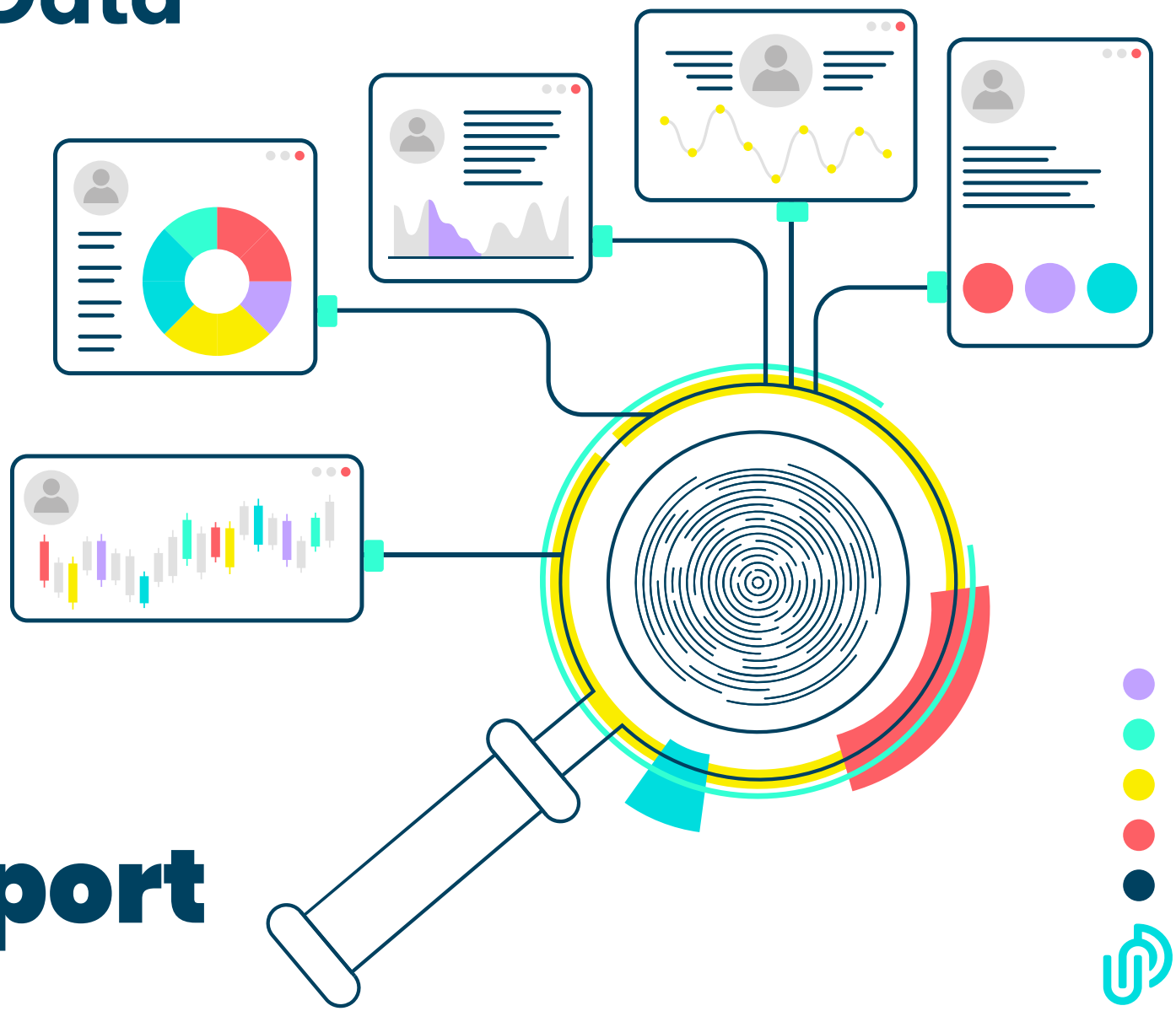
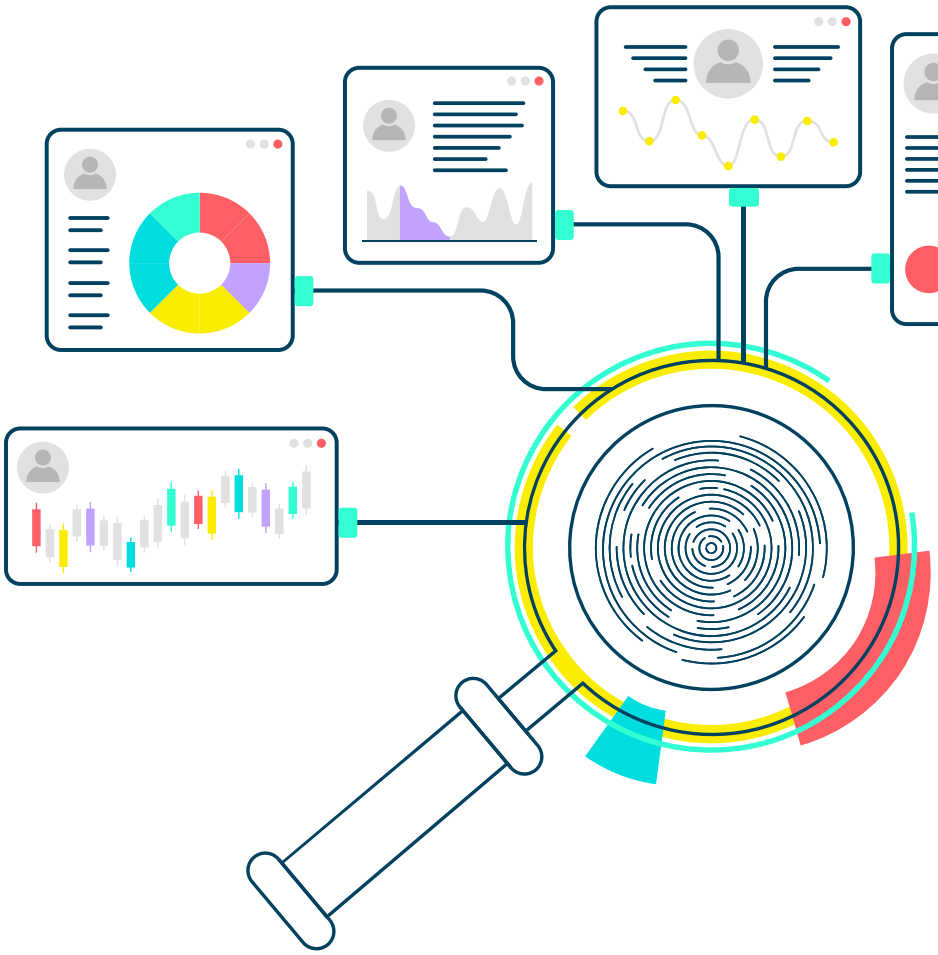
Understanding Patient Data



Annual Report

2025/26



Contents

04 **Introduction**
05 **Theory of Change**

06 **Our Year in Review**
06 **Understanding Public Views: Research and Evidence**
07 Spotlight One: Shaping national debate on GP record data
08 Spotlight Two: Helping explain NHS data security

09 **Making Public Voices Heard: Influence and Advocacy**
10 Spotlight Three: Raising our profile and influencing the health data debate

12 **Meeting the Needs of the Health Data Community: Capacity-Building**
13 Spotlight Four: Making health data information more accessible

14 **Learning and Improvement**
15 **Looking Ahead**

16 **Financial Summary**
16 2025/26 Detailed Financial Summary

Introduction

Over 2025/26, the landscape around health data became faster-moving and more visible. Government plans to modernise the NHS increasingly placed data, digital infrastructure and AI at the centre of reform - creating opportunities to improve care and research, while raising important questions about governance, accountability and public benefit.

The Data (Use and Access) Act, the Government's 10 Year Health Plan and the Life Sciences sector plan all reinforced that the success of these ambitions will depend not just on technology, but on how patient data is accessed, governed and used in practice. At the same time, plans for a Single Patient Record moved closer to delivery, with early procurement and market engagement making change feel more immediate across the system.

As policy has accelerated, so too have public questions. Debates this year have focused on AI, cybersecurity, commercial partnerships, large technology suppliers, and wider concerns about where data sits and who ultimately has influence over its use in an increasingly uncertain global context. While there remains strong support for the responsible use of health data where there is clear public benefit, uncertainty persists around decision-making, accountability and safeguards.

This is the context in which Understanding Patient Data (UPD) has worked over the past year.

Throughout 2025/26, our focus has been twofold: continuing to provide trusted, evidence-based leadership in national conversations about health data, while also strengthening the foundations needed to maximise our long-term impact in a rapidly changing environment.

That has meant expanding the evidence base on public expectations, contributing to policy development and media debate, and becoming a more responsive organisation that can support earlier identification of trust risks, misinformation and emerging public concerns.

Behind the scenes, we have also invested in organisational development - starting a full website and user experience redesign, refreshing our theory of change, commissioning a new monitoring and evaluation framework, and developing a longer-term operating model to support sustainable impact beyond 2030.

Taken together, this has been a year of delivery and preparation: responding to a fast-moving policy environment while building the evidence, tools and partnerships needed for the years ahead.

Anna & Angela

Anna Steere
Head of Understanding Patient Data

Angela Coulter
Chair of Understanding Patient Data

*with special thanks and acknowledgment to **Peta Foxall** who Chaired the Strategic Advisory Group until July 2025

UPD Theory of Change

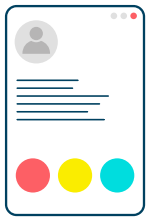
OUR GOAL:

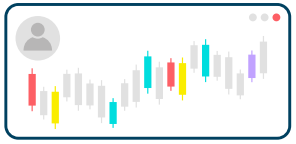
Patient data is used well, responsibly and for public benefit

PUBLIC SUPPORT AND CONFIDENCE DEPENDS ON:

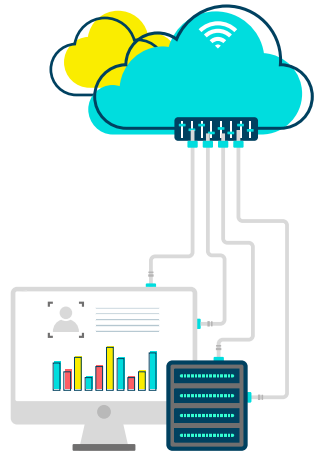
- Awareness of how patient data is used
- Understanding of benefits, risks and safeguards

IF UPD MAKES THE USE OF PATIENT DATA MORE VISIBLE, UNDERSTANDABLE AND TRUSTWORTHY, THROUGH:





- **RESEARCH AND EVIDENCE:** Providing the most credible, cumulative and accessible evidence base on public expectations about patient data use
- **INFLUENCE AND ADVOCACY:** Elevating diverse public voices as an integral, visible force shaping how patient data is used and protected
- **BUILDING CAPACITY:** Supporting the system to anticipate, understand and respond to public expectations so they can act and communicate with clarity and confidence



THEN:

- Decision-makers understand public expectations better
- Public voices are visibly & meaningfully included in debate and decisions
- The health system has the expertise it needs in using public voice to shape services

SO THAT:

- People are at the centre of decisions about their data
- Support and confidence is built and maintained

Our Year in Review

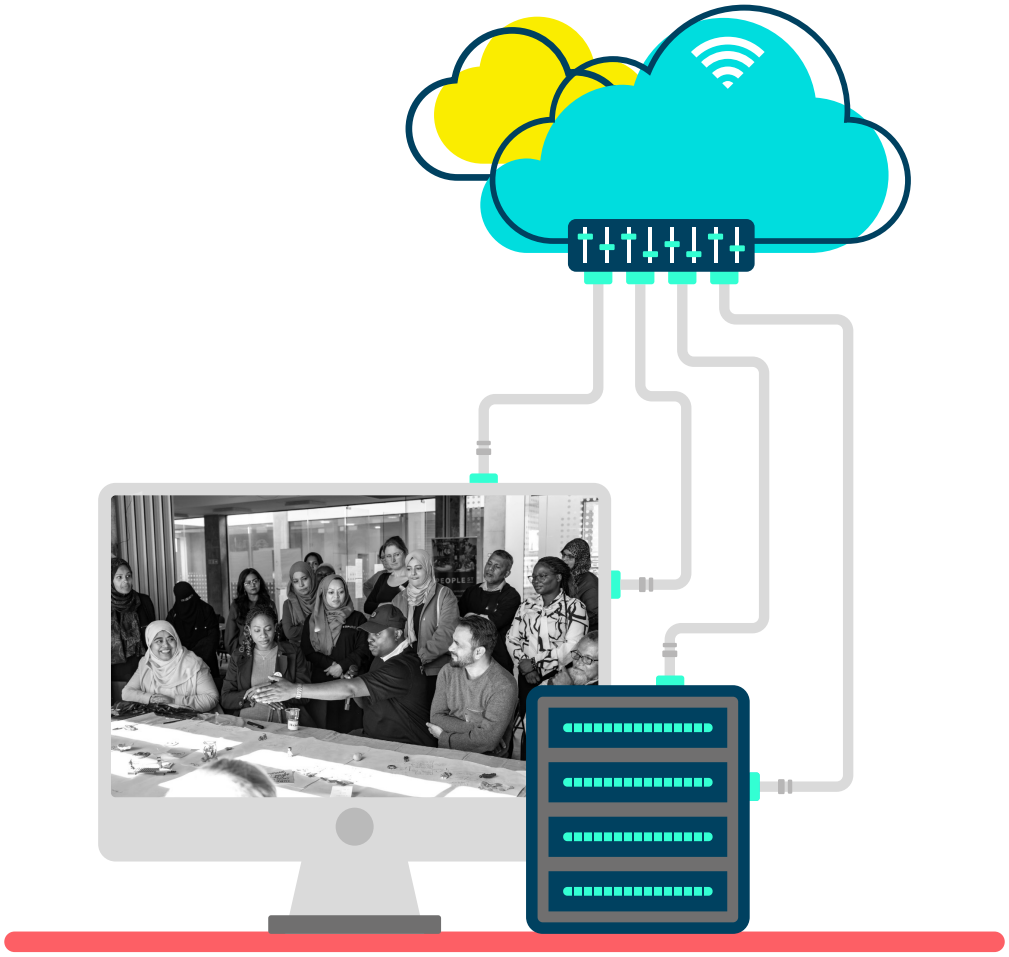


FIGURE 1
Roundtable facilitated by People Street. Source: People Street

UNDERSTANDING PUBLIC VIEWS:

Research & evidence

Over the past year, UPD strengthened its role as a trusted source of evidence on public attitudes towards health data use. We combined polling, qualitative engagement and community-led research to track how understanding, trust and expectations are evolving - and to bring that insight into live policy and communications debates.

We produced new evidence on public awareness and expectations on GP record data, with direct relevance to plans for a Single Patient Record (see Spotlight 1).

We advanced work on public understanding of health data security in direct care, translating evidence and lived experience into practical public-facing animations and explainers (see Spotlight 2).

We continue to invest in more inclusive approaches to engagement. Our UK-wide project with people seeking asylum and refuge is addressing an evidence gap on how marginalised communities experience and understand health data use. Early findings point to language barriers, digital exclusion and low awareness of how information is used across the NHS. The project (due to complete in September 2026) will inform more inclusive policy and engagement approaches.

We also strengthened UPD's longer-term evidence infrastructure. We began a five-year systematic review to underpin a searchable evidence library (the Health Data Compass, launching 2026) and built a more responsive capability for tracking public sentiment in a fast-moving environment.

Shaping national debate on GP record data

MAY 2025

SPOTLIGHT 01.

WHY IT MATTERED

As plans for a Single Patient Record (SPR) moved closer to implementation, UPD produced one of the most detailed recent studies exploring public understanding and expectations around GP record data.

WHAT WE DID

UPD combined a nationally representative online survey with in-depth focus groups and workshops to build a robust evidence base on public awareness, expectations and concerns regarding GP data use. The work determined how to explain GP record data to the public in a transparent and trustworthy way.

WHAT WE FOUND

- **61%** of people believed aN SPR already exists
- **57%** did not recall receiving information about how GP data is used
- People strongly preferred receiving information through trusted local NHS channels, particularly GPs

See the full report here.

REACH AND IMPACT

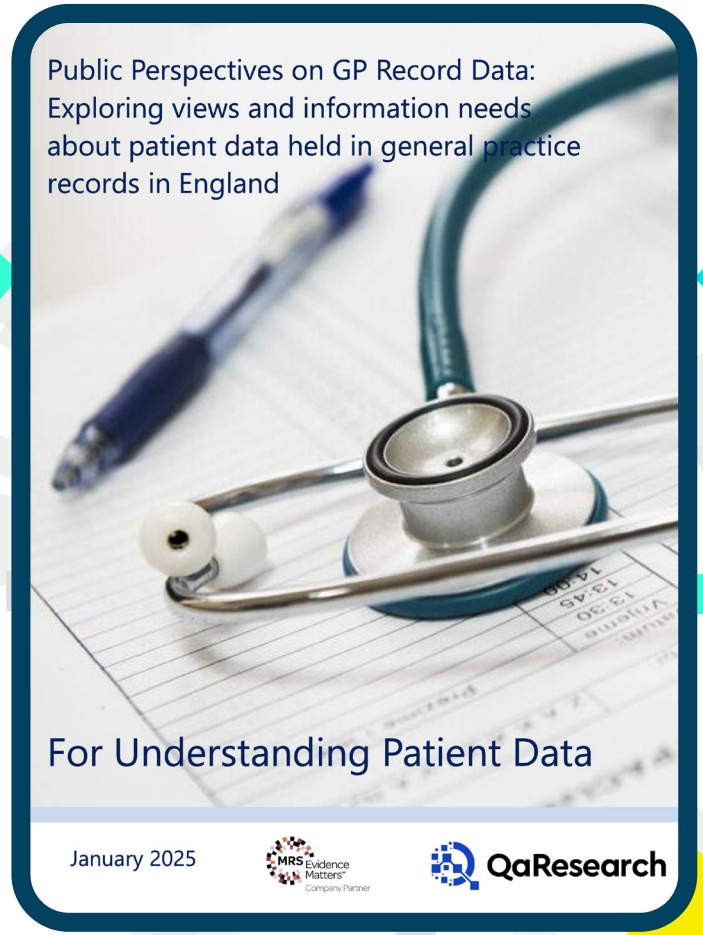
- Findings cited in national sector media coverage, including Digital Health
  - Public attitudes to the SPR and
  - NHS England's approach to data infrastructure
- Used to shape discussions with national teams about how the use of GP data is communicated to the public, particularly on trust, transparency and preferred channels
- **591** people viewed the report on our website (from publication date to the end of March 2026)

WHAT WE LEARNT

The findings highlighted the gap between policy assumptions and public understanding, with clear implications for how the SPR is communicated and implemented.

FIGURE 2

The front page of UPD's Public Perspectives on GP Record Data report



Helping explain NHS data security

MAY 2025

SPOTLIGHT 02.

WHY IT MATTERED

Public concern about cyberattacks, data breaches and commercial misuse continue to shape confidence in health data use.

WHAT WE DID

UPD combined evidence review, public dialogue and co-design workshops to understand what assurances people need around health data security in direct care. This informed the creation of public-facing explainer resources designed to make NHS data security clearer, more relatable and more accessible.

WHAT WE FOUND

- UK public supports health data sharing but fears misuse and breaches.
- Most information is technical, text-heavy, and difficult for general public understanding.
- Critical gaps exist for accessible multimedia resources explaining health data security.

REACH AND IMPACT

- Resources widely shared and disseminated through NHS, Patient safety and engagement networks including Patient Safety Learning
- Resources translated into five additional languages plus Welsh
- **8,818** views of these resources on our website (from publication date to the end of March 2026)

WHAT WE LEARNT

People want visible accountability, plain language and realistic explanations - not simply reassurance that systems are "safe". This work reinforced that people want visible accountability, plain language and realistic explanations - not reassurance alone.

"Health data security is far too important to leave it in the hands of few experts; what is at stake affects us all in different ways. Everyone has something to contribute to the discussion and improve suggested ways of enhancing the security of our health data."

Research participant

FIGURE 3 (ABOVE LEFT)
Understanding Patient Data's Keeping NHS Data Safe animation
FIGURE 4 (ABOVE RIGHT)
Understanding Patient Data's Malicious External Data Breach infographic explainer

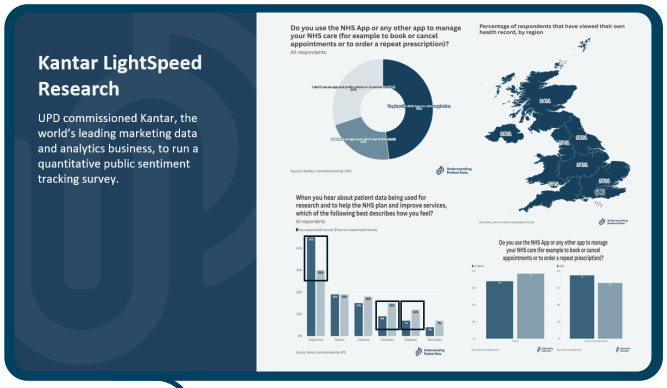


FIGURE 5 (ABOVE LEFT)
Kantar research commissioned by Understanding Patient Data, exploring levels of confidence in NHS protections of health data
FIGURE 6 (ABOVE RIGHT)
Anna Steere, Head of Understanding Patient Data, chairing a main-stage session at the inaugural National Patient Data Day

"UPD provide balanced, constructive, and expert input into policy development processes, helping to guide and support policymakers. Products like the sentiment tracker have also been very insightful, and used across our team to further understand the data landscape."

Joanna Stapley | Senior Policy Lead | Data Opt-Out, Department of Health & Social Care | Data Policy | Joint Digital Policy Unit

MAKING PUBLIC VIEWS HEARD:

Influence & Advocacy

UPD has maintained influence across the sector by shaping key discussions and convening people around priority issues. We chaired, contributed to or shaped workshops, roundtables and public events on AI, synthetic data, public trust, data governance and equity. We also convened stakeholders to discuss the future of public choice (opt-outs), and commissioned new insight work on what the Patient and Public Involvement and Engagement (PPIE) community needs to efficiently engage and involve patients and the public on patient data.

Alongside this, we piloted and refined a sentiment tracker alongside media analysis to capture emerging public and stakeholder views on health data use. This insight has informed briefings and behind-the-scenes influencing, and in 2026/27 we will publish and share the findings more systematically.

We have started developing a resource hub to support journalists and we have used key sector moments – from the Labour Party Conference to National Patient Data Day – to test and strengthen our messages, and to build relationships with decision-makers, communicators and engagement leaders.

Internationally, we deepened partnerships with European and other non EU organisations to advance shared learning on trust, governance and interoperability, including early engagement on the European Health Data Space (EHDS) and the Towards a European Health Data Space 2 (TEHDAS2) programme. We published a comparative analysis of international approaches to single patient records, distilling practical lessons for England on trust, governance and implementation.

In 2026/27, we will expand this work through our EHDS Unpacked webinar series and workshops, and by supporting expert input into live TEHDAS2 consultations.

SPOTLIGHT 03.

Raising our profile and influencing the health data debate

ONGOING

WHY IT MATTERED

Debate on health data is often shaped by risk and controversy, creating challenges for policymakers and the wider system. Trusted, independent insight is essential to support informed discussion.

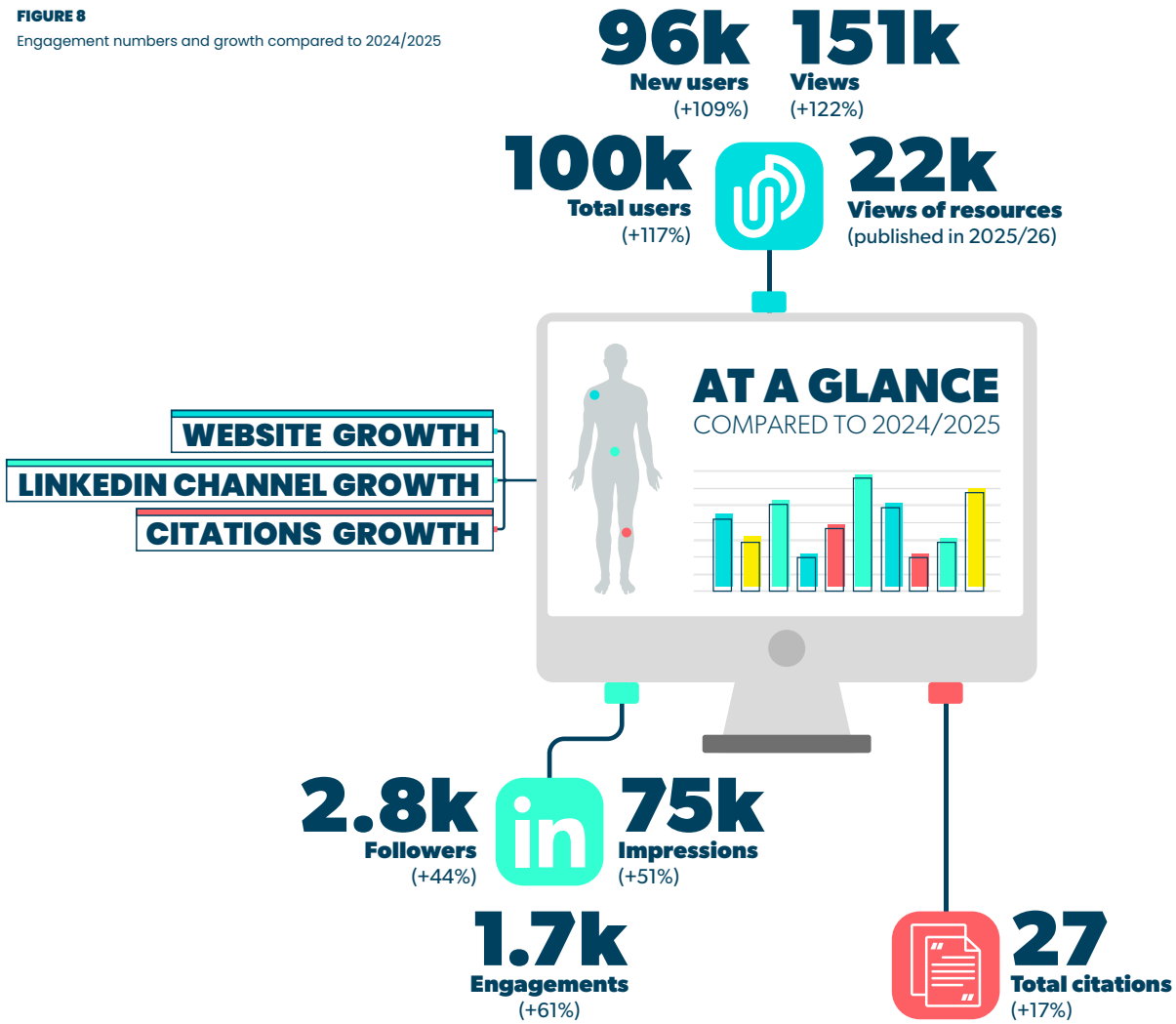
WHAT WE DID

We contributed to early thinking on opt out policy development, shaped narratives around the Single Patient Record, and supported discussions on emerging legislative approaches - alongside wider work on data security, AI and public trust.

While our sentiment tracker and media analysis is not yet published, it is already informing how organisations anticipate and respond to public concern. In particular, we are testing links between digital engagement (for example NHS App use and access to records), trust and likelihood to opt out - insight that is directly relevant to the design and rollout of the Single Patient Record.

FIGURE 7
Engagement trends for Understanding Patient Data's LinkedIn posts, showing peaks aligned with key announcements, policy updates, and resource releases

FIGURE 8
Engagement numbers and growth compared to 2024/2025



UPD's reach and influence have grown significantly over the past year, driven in part by the strong performance of our new policy explainers. On LinkedIn, followers increased by **44%**, with impressions rising by **51%** and engagements by **61%**, indicating a growing and more active audience for our content as we move into a year of reform and change.

This momentum is mirrored on our website, where total users reached **100k**, and views climbed to **151k**, including **22k** views of resources published in 2025/26 alone – demonstrating clear demand for accessible, high-quality information. This expanding reach is translating into greater influence, as wider citations of UPD's work have continued to rise, with **27** recorded in the last financial year against **23** in 2024/2025, and with **12** already in 2026 year to date.

Together, these trends suggest that we are extending our visibility, but also strengthening our position as a trusted and increasingly influential voice in debates on health data and public trust.

WHAT THIS MEANS

Our advocacy work and our channel growth are aligned, but they are not the same thing. Advocacy influence comes through trusted relationships, convening and timely input into policy and practice. Growing reach helps ensure that evidence and public insight are easier to find and share, strengthening UPD's voice in the wider debate and creating demand for clearer explanations. Through our work we hope to shift discussion beyond reactive, risk-led narratives towards more evidence-informed decision-making on health data.

MEETING THE NEEDS OF THE HEALTH DATA COMMUNITY:

Capacity-Building

As policy shifts from strategy to delivery there is growing demand for practical tools, shared evidence and more coordinated approaches that can help organisations communicate, engage and make decisions in ways that are proportionate, transparent and grounded in public expectations.

This year, we expanded practical resources to help organisations communicate and engage on health data in clearer, more inclusive ways. We developed animations and interactive explainers on NHS data protection and cybersecurity, and translated key animation resources into Welsh, Polish, Punjabi, Romanian and Urdu.

We also began developing the Health Data Compass: a searchable hub bringing together public attitudes evidence, engagement insight and practical analysis to support more coordinated, evidence-informed decision-making across the sector.

Early co-development with policymakers, researchers and engagement practitioners highlighted persistent challenges - fragmented evidence, duplicated engagement and uncertainty about what proportionate involvement looks like - which will shape the next phase of the work.

Alongside this, we continued mapping the PPIE landscape around health data to identify what is working, where gaps remain and where more joined-up approaches could reduce duplication.

"UPD resources have been invaluable for us when designing our national deliberations on health and care data. Knowing that we can use trusted resources that have been tested with the public is critical to ensure the public can meaningfully debate and deliberate such a complex policy area"

Ellie Munari | Public Engagement Design Lead | NHS Transformation Directorate

Making health data information more accessible

SPOTLIGHT 04.

ONGOING

WHY IT MATTERED

Access to information about health data use is often limited for people whose first language is not English, creating barriers to more inclusive engagement and informed discussion.

WHAT WE DID

In Spring 2025, UPD worked with Brickwall and GoLocalise to translate our ***Data Saves Lives*** animation series and ***Using Patient Data for Research*** animation into Welsh, Polish, Punjabi, Romanian and Urdu - the most widely spoken languages in the UK after English. The BSL version of our Using Patient Data for Research animation was kindly produced and shared by Health Innovation North East and North Cumbria.

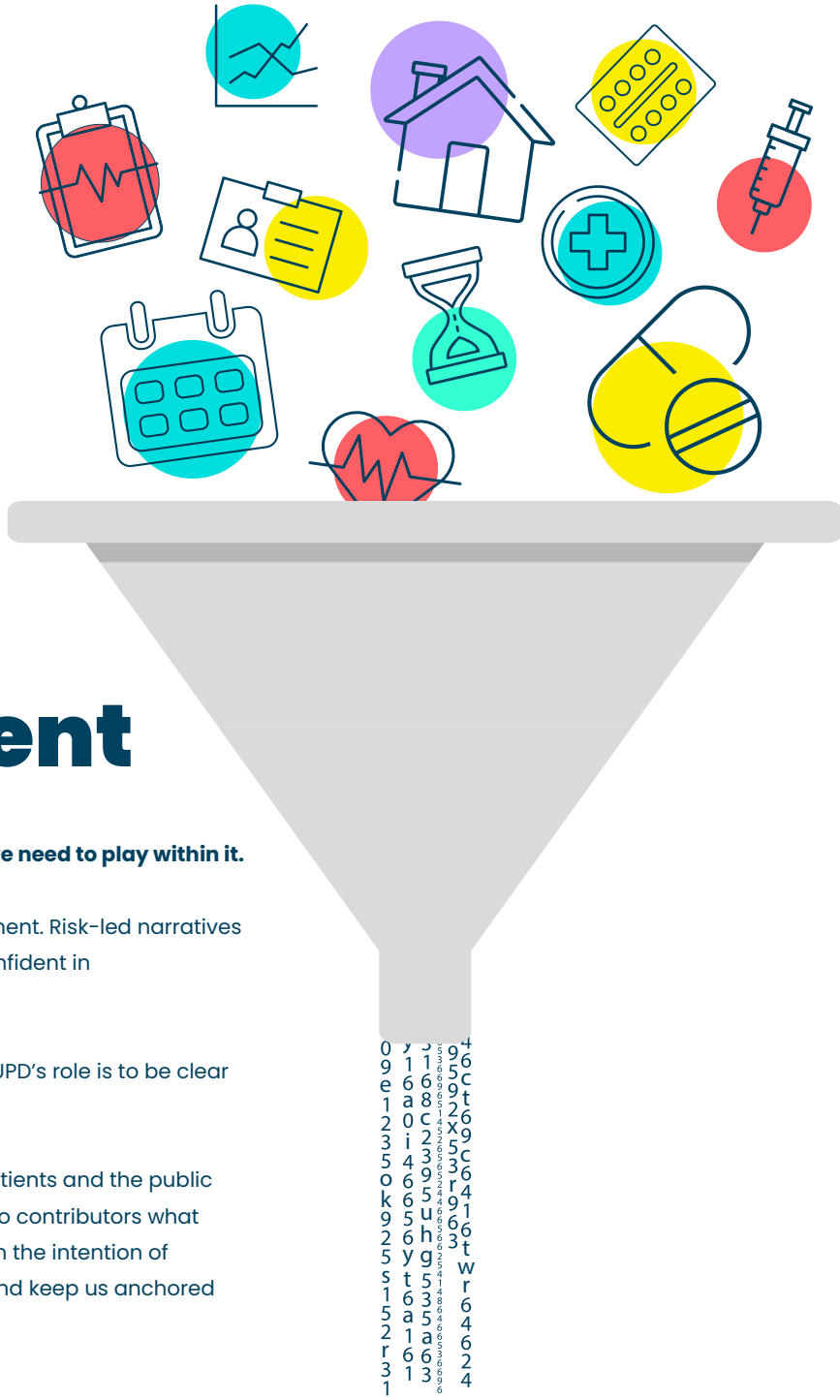
REACH AND IMPACT

- Resources translated into **6 languages**
- **3,326** total animation views across platforms (from date of publication to the end of March 2026)
- Shared across NHS, research and relevant communities to support more inclusive engagement activity including through:
  - Indian Association Manchester
  - Pakistani Resource Centre
  - Welsh NHS Confederation
  - Romanian Culture and Charity Together
  - Norfolk Polonia CIC

WHAT WE LEARNT

Translation alone is not enough – accessible communication also needs trusted channels, culturally-relevant framing and practical reuse by organisations already working directly with communities.

FIGURE 9
Illustrations from the Data Saves Lives animation series



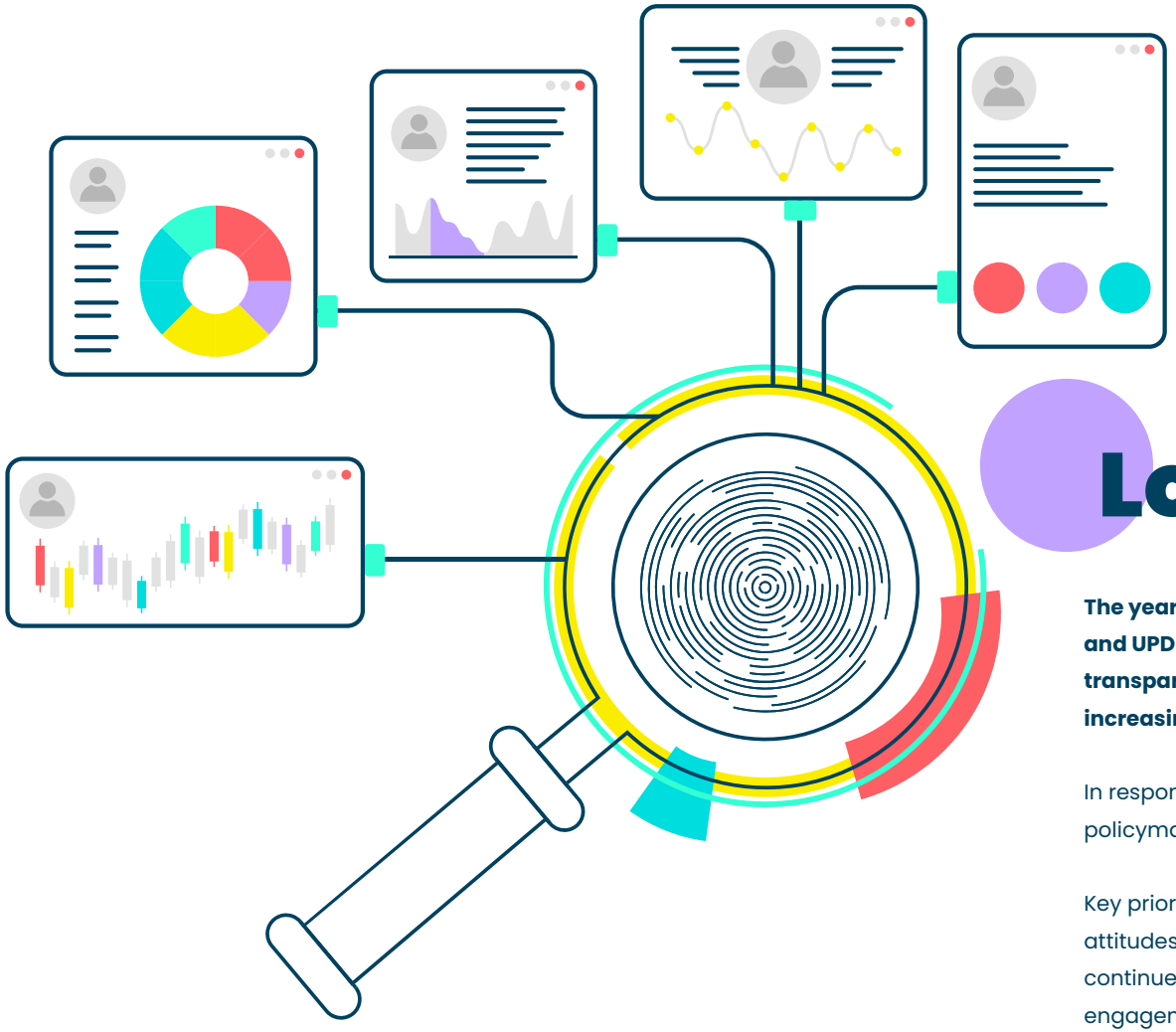
Learning & Improvement

This year sharpened UPD's understanding of the environment we are operating in - and the role we need to play within it.

01. Health data debates are increasingly shaped by a fast-moving, emotionally-driven media environment. Risk-led narratives can spread quickly and outpace nuanced explanation, so UPD needs to be more responsive and confident in communicating evidence and public insight in real time.

02. Objectivity does not mean neutrality. With competing agendas shaping debate about health data, UPD's role is to be clear about what we stand for: patient data used well, responsibly, transparently and for the public good.

03. To ensure we stay on track, UPD needs to build clearer feedback loops so that what we hear from patients and the public consistently shapes our priorities, products and influencing work and so we can demonstrate back to contributors what changed as a result. This means more deliberately embedding PPIE within our own organisation, with the intention of establishing a standing public panel in 2026/27 to help steer our work, challenge our assumptions and keep us anchored in lived experience.



Looking Ahead

The year ahead will be an important period for both the wider health data environment and UPD itself. As national reforms move further into delivery, questions around transparency, legitimacy, public involvement and trust are likely to become increasingly significant.

In response, UPD will continue strengthening its role as a trusted intermediary between policymakers, researchers, practitioners and the public.

Key priorities for 2026/27 include publication of a first State of the Nation report on public attitudes towards health data use, further development of the Health Data Compass, continued work on patient choice and opt-out policy, and expanded international engagement around the European Health Data Space.

We will also continue investing in our organisational foundations, including a refreshed website and communications approach, strengthened monitoring and evaluation frameworks, and development of a longer-term operating model to support sustainable impact beyond 2030.

Across all of this work, our focus remains consistent: **helping ensure that patient data is used well, responsibly and for public benefit**.

Finances

Income & Expenditure Breakdown 2025/26

TOTAL 2025/26 BUDGET	£640,400
INCOME	
NHS England deferred income	£182,190
Quarterly payments from MRC, NIHR, DHSC and OLS	£275,696
Claim against Wellcome Grant	£53,430
TOTAL INCOME	**£511,316**
EXPENDITURE	
In-year project costs	
Health Data Security Research (Kohlrabi)	£10,000
Health Data Security animations (Brickwall)	£24,520
Evidence synthesis (Whitetail)	£21,000
PPIE System analysis (HQIP)	£18,000
Translations of UPD animations (Brickwall)	£8,153.75
Refugees and Asylum Seekers (People Street)	£19,500
Monitoring and evaluation (Apteligen)	£11,800
Sentiment Tracking (Kantar) and Analysis (NHS Alliance)	£11,570
Social listening tool (Pulsar)	£15,000
Website UX, IA, Migration (Invuse)	£30,000
State of the Nation (Amy Darlington)	£2,200
Sub-total (project costs)	**£171,743.75**
Staff Salaries (including on-costs and training)	**£227,833.00**
Staff Travel and Subsistence	**£3,583**
Contribution to NHS Alliance	**£58,368.00**
Apprenticeship Levy Charge	**£982.00**
Overheads (website hosting and maintaince costs, software)	**£34,806**
Irrecoverable VAT	**£14,000**
TOTAL EXPENDITURE	**£511,316.13**

Financial Summary | APRIL 2025 – MARCH 2026

Understanding Patient Data is a hosted organisation of the NHS Alliance. It is 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. UPD operates under a five-year funding arrangement totalling £3,201,990, equating to an average annual budget of approximately £640,400, inclusive of inflation and irrecoverable VAT. The funding provided through the Wellcome grant is not allocated on a fixed annual basis, and expenditure may therefore vary from year to year.

In 2025/26, expenditure was approximately **£65,000** below budget in relation to staffing costs, primarily due to vacancies held during the year and staff time offset through the TEHDAS2 grant (**£22,135**). In addition, some project costs have been deferred into the following financial year. As a result, total expenditure for the year was **£511,316** against a budget of **£640,400**.

The current underspend is expected to be carried forward, with higher project and staffing costs anticipated in the next financial year as the team expands to full capacity and deferred activity is delivered. Overall expenditure across the funding period is therefore expected to remain broadly in balance with the total grant allocation.

Understanding Patient Data also holds an additional grant from Wellcome to support engagement on TEHDAS2 which expires July 2026. Total: **£99,000** (ringfenced).

We are expecting to make use of the full budget provided by Wellcome for TEHDAS2 engagement, reflecting the decision to prioritise international expertise, high quality convening and specialist policy input. The majority of this budget will be spent in May/June 2026, through a number of workshops and high-level convening.

TEHDAS2 grant spend 2025/26

Total: £99,000 (ringfenced)

ITEM	COST
Staff costs (October 25 – April 26)	£22,134.87
TEHDAS2 IP Rights & Trade Secrets workshop travel	£464
TEHDAS2 IP Rights & Trade Secrets workshop accommodation	£329.82
Food reimbursements	£25
Total spend for 25/26	**£22,953.69**
+20% VAT	**£27,544.43**

wellcome
NIHR | National Institute for Health Research
UKRI Medical Research Council
NHS England
Department of Health & Social Care
Office for Life Sciences

www.understandingpatientdata.org.uk