

# Health Data Compass: Deepening Engagement and Shaping Content

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## Executive summary

The Health Data Compass is a new resource being developed by Understanding Patient Data (UPD) to bring together public insights on health data into one coherent, accessible, and up-to-date evidence hub. It is designed to reduce duplication, connect fragmented work across sectors, and support more consistent, informed decision-making in policy, research, and practice.

From January to March 2026, UPD delivered a series of workshops with cross-sector representatives to co-develop the compass and ensure it reflects the needs of the people who will use and advocate for it. These sessions explored how insights should be presented, what information users need to trust evidence, how the hub should function, and what wrap-around engagement is required to maximise value.

Across the workshops, participants consistently emphasised the need for **transparency and context in the compass**. Users want sight of methodological detail, demographic information, and clear articulation of motivations enabling them to make informed and independent judgements. They also called for **simplicity, clarity, and strong search functionality** at the heart of how the hub functions, supported by layered information and consistent visual design.

Participants saw the Compass as more than a repository. It should be something that supports **action**, including identifying gaps, informing policy, guiding research questions, and improving engagement practice. At the same time, they urged UPD not to create new communities or training programmes, but instead to **align with existing networks** and add value through better recognition, visibility, and strategic communication.

Insights from this co-development phase now underpin key decisions about scope, design, and functionality, guiding the development the Health Data Compass ahead its planned 2026 launch later this year.

## Background

The health data landscape is busy, fast-moving, and often fragmented. Across the NHS, government, research, and civil society, many groups are trying to understand what people think and expect when their health data is used – but too often this work happens in silos, with duplication and missed opportunities.

The **Health Data Compass**, developed by Understanding Patient Data (UPD), will bring this together.

This new initiative will bring together public insights on health data into one shared, live, coherent evidence hub that helps everyone shaping the future of health data draw on the same, up-to-date picture of public attitudes. It's designed to reduce duplication, connect work across sectors, and support more coordinated engagement.

### What the Compass will do:

- Combine insights from PPIE and community engagement, research, surveys, secondary literature, and UPD's own social listening and public sentiment tracking.
- Summarise what we collectively know – and don't yet know – about public attitudes to health data.
- Offer analysis aligned with major policy priorities, including the 10-Year Health Plan.
- Support more coordinated, impactful engagement across the whole health data community.

Launching later in 2026, the Compass will be openly available to policymakers, advocates, researchers, innovators, and others who want to understand and respond to public expectations on health data. To ensure the Health Data Compass is truly additive, valuable and useful for a broad health data community it is important this insight hub is co-developed with the people who would ultimately use and advocate for it, which is what grounds this co-development approach.

## Engagement approach

From January to March 2026 UPD led the delivery of a series of multi-stakeholder workshops to co-develop the Health Data Compass and validate its framing with key audiences. These workshops form part of a multi-stage and phased approach to engaging the health data community with the development of this hub.

Phase 1 engagement achieved initial cross community agreement for the delivery of the Health Data Compass, and an understanding of generic value-add for this resource. This phase involved qualitative interviews which helped to achieve early buy-in from trusted voices across the community, running from October – December 2025.

The second phase of engagement was achieved through the delivery of these dedicated workshops with cross-community representatives, working towards the co-development of the Health Data Compass. Workshops helped answer vital questions about the development and eventual use of this resource to ensure the compass becomes an additive, valuable and insightful asset for a broad health data community.

These workshops convened representatives into structured themed sessions, using breakout rooms to facilitate audience specific discussions to understand where views differ and overlap across PPIE, Policy and Research focussed groups. This approach balanced understanding individual audience needs with the ultimate goal of developing a broadly used tool.

Workshops were structured around 4 key questions for which we felt community insights were integral to answering:

1. How do we transform and present public insights in a way that is actionable?
2. What information do we need to know for insights to be seen as trusted?
3. What is the most important thing you need a platform like this to allow you to do easily?
4. What should this hub enable that doesn't exist today?

Each session lasted around 2 hours and hosted discussions with between 20-40 participants with representation from across sectors and the devolved nations. Insights from each workshop are summarised below, as well as our key takeaways which provide the foundation for the development of the Health Data Compass.

## Summary of Insights

### Workshop 1: Defining how the Health Data Compass adds the most value

*How do we transform and present public insights in a way that is actionable?*

Workshop 1 focused on understanding how people would use the Health Data Compass and how this hub could make public insights more actionable, trustworthy, and usable across policy, research, and engagement contexts.

Through a series of engagement exercises, participants consistently emphasised the importance of transparency, context, and usability as foundations for the hub's **value**. There was strong agreement that clear visibility of who generated an insight, how it was gathered, why the work was done, and when was particularly important. Research and engagement methods were seen as essential data to support comparison across projects. Participants also highlighted the need for structured, layered information, supported by clear and consistent categories and filters across insights held in the hub.

For **presenting insights**, there was widespread support for prioritising accessible communication with requests for plain language summaries and simple visualisations to support users to interpret insights accurately. At the same time, participants cautioned against over-simplifying insights to the point of losing nuance and diversity of opinion, pushing for wider context to be preserved to maintain the richness that makes insights meaningful (e.g. quotes or case studies).

When exploring **how the hub might be used**, groups prioritised understanding public attitudes and applying this to decision making and regulation. This included informed and ethical decision-making through identifying public priorities, informing policy and regulation, improving communication strategies, and reducing duplication of effort. Differences across PPIE, research, and policy groups reflected role-specific needs, but these were complementary and reinforced the hub's potential to act as a shared evidence base. These conversations pushed for the hub to act not just as a repository of public insights but to go further - suggesting functions such as analysing trends, identifying gaps, and building connections.

When **defining scope** for this resource, including what would and wouldn't be included within, discussions highlighted the complexity of building this resource, with no clear consensus on where lines should be drawn. When discussing a definition for health data, groups acknowledged overlaps with adjacent topics such as AI or wearable technology, but with varying views on how much of these topics should be included. These discussions emphasised the need to make decisions based on both use case and community insight.

## Workshop 2: Ensuring insights are reliable and trustworthy

*What information do we need to know for insights to be seen as trusted?*

Workshop 2 explored what users need to know to determine if they *trust* public insights, and balancing this with how the *submission process* should work to encourage submission of insights. Through engagement activities exploring **trust**, participants emphasised two broad categories of information that must be visible to provide a full picture of a project and allow users to assess robustness and rigour:

1. **Logistical and methodological detail** - such as methods, sampling approaches, demographics, recruitment, timeframe, limitations, independence, and funding. This information forms the backbone of projects, and therefore informs the standard comparisons the hub would provide across projects.
2. **Contextual information** - including the justifications behind the work and decisions, who shaped the idea, motivations, how interpretations were formed, and whether communities were involved throughout. This ‘background information’ is crucial in forming the full picture and helping users understand *why* the research was done and how conclusions were reached.

Regarding the **submission process**, participants overwhelmingly called for a simple, intuitive system that does not create additional burden for individuals. This should focus on digital forms with dropdowns and short text fields, supported by resources, feedback loops, and transparent guidance around things like word count and questions. We therefore need to find a way of balancing the almost contrasting desire for a simple submission process, with the high information need for this to be a valuable and trusted resource. Options to ‘save-and-return’ were also seen as important although would present a logistical challenge around data protection that we must consider.

Ensuring contributors receive **recognition** was viewed as essential to incentivise submissions. People want to know their insights are seen, used, and valued. Suggested incentives included providing accessible usage metrics, contributor badges, spotlights in newsletters or webinars, and mechanisms demonstrating how insights inform policy or research impacts. It was noted that different audiences will require different forms of incentive, but all care about visibility and impact.

In this session we also discussed **quality control** and whether we should implement a ‘confidence rating’ of sorts for hosted insights, building on previous discussions. All groups strongly advised against formal ratings, noting the risk of disadvantaging small or local studies and deterring contributions. There was instead a strong consensus that the hub should prioritise clear, transparent information to support user-led interpretation. UPD’s role was seen as enabling transparency, not acting as an evaluator. This should be strengthened with light-touch inclusion/exclusion thresholds for the compass, and clear safeguarding/GDPR assurances to offer protections.

### Workshop 3: Determining the look and feel of the hub

*What is the most important thing you need a platform like this to allow you to do easily?*

Workshop 3 focused on shaping the user experience of the Health Data Compass, exploring what users expect from the homepage, how they want to search and browse insights, and how individual insights should be researched. There was strong alignment around creating a hub that feels intuitive and consistent in its design, and prioritises a high-quality search, with advanced features integrated only where they add value.

Participants emphasised that the **homepage** must quickly communicate ‘what the compass is’ in a way that does not burden regular users. It was suggested hosting high-level information on the homepage, with a separate ‘about the hub’ section which ensures access to additional information like development and governance. The homepage can then focus on rapid access to core functions. Suggested features included recently added insights, trending topics linked to current discussions, and upcoming/in-development research to support strategic planning. There was consistent agreement that the homepage should feel simple and clear, supported by visuals and accessible language that remain consistent across the hub.

**Passive exploration** of the hub was seen as useful but not something that should exist as a standalone section, with most users expecting to use the insight hub with a specific purpose in mind. Instead, there is a want for exploratory features to be embedded throughout the user journey, such as promoting related insights. Passive browsing should be considered in the design but not distract from the hub’s primary purpose which should be helping users find specific insights efficiently. **Search functionality** is therefore the highest priority. Users want a powerful, reliable search supported by filters (i.e. geography, topic, methods, demographics), and sorting options (e.g. publication date, proportionality, relevance). This navigation is supported by layered information: a short top-level summary, a methodological factsheet, a slightly longer description, and ultimately access to full reports. There was broad consensus that full research should remain external to avoid duplicating content or risking promoting outdated versions.

During a prioritisation exercise of **potential functionalities**, participants consistently placed basic functions like a robust search or clear summaries in the “Must Have” category, while placing social-media-style features (likes, comments, in platform sharing) in “Won’t Have”. This was backed up with conversations around risk and need for moderation. Insights on AI implementation were mixed, with a general view that AI tools should be present only for search assistance, not for interpretation or analysis. This will be explored further once we have more tangible ideas for what AI implementation for the compass could look like and will be played back through user testing and co-development before any commitments are made.

## Workshop 4: Designing the wrap-around engagement programme

*What should this hub enable that doesn't exist today?*

Workshop 4 focused on how the Insight Hub can create value *beyond* collating insights. Through a series of exercises, we considered activity that would support the wider health data ecosystem. Participants emphasised that a wrap-around programme should prioritise recognition, strategic partnerships, and meaningful communication, rather than creating new communities or programmes that may duplicate effort. When mapping ideas for a wider engagement programme we explored three main themes:

1. **General promotion and engagement:** Participants strongly favoured regular content that highlights new insights, showcases learning and best practice, and communicates impact. Suggested mechanisms included monthly newsletters, update webinars, annual reports, topic focused events, and short sessions where contributors discuss reflections not included in final reports. The main purpose around this activity was recognising contributors and profiling their work to broader audiences, as well as reinforcing the value of the compass.
2. **Building connections:** Groups were clear that they did *not* want the hub to create new communities of practice, working groups, or networking structures. Instead, they encouraged UPD to align with and amplify existing professional networks, PPIE groups, and cross-government forums. The hub should plug into these spaces through speaking opportunities and strategic partnerships. The emphasis was on avoiding duplication and leveraging established platforms to expand reach.
3. **Promoting culture change and upskilling:** Rather than delivering training or upskilling programmes, participants saw value in the hub supporting the system by helping users interpret insights, identify gaps, and encourage best practice. Suggestions included highlighting gaps to guide future research and drawing together practical lessons on PPIE.

In the final communications campaign activity, we explored promoting and launching the Health Data Compass. Participants pushed for a phased, audience--first approach:

- Pre-launch, groups suggested using teasers and targeted messaging via existing networks and social media to generate interest.
- To launch the compass, there was a suggestion of embedding the announcement within existing conferences and events over time, supported by a shorter “lunch and learn” style event on launch day primarily for contributors and partners rather than a large, one-off event.
- To sustain interest, they advocated for audience-first and ongoing, consistent communication showcasing value over time through case studies, blogs, testimonials, usage stories, and periodic updates.

## Cross Cutting Themes

Across all four workshops, several clear and consistent themes emerged about what users need the Health Data Compass to be, what they value, and how they expect to engage with it. These themes cut across discussions on use cases, trust, design, functionality, and engagement, and together form the principles for the initial development.

### **1. Prioritise transparency:**

Participants repeatedly emphasised the need for transparent, consistent information about how insights were generated, covering methodology, sampling, demographics, funding, independence, limitations, and motivations. These discussions demonstrated that trust is determined by providing access to clear, contextual information that enables users to make their own judgements.

### **2. Focus on simple and clear design:**

Users consistently prioritised a hub that feels simple, intuitive, and easy to navigate. Strong search emerged unequivocally as the core function of the platform, requiring robust filters, relevant results, and short, scannable summaries. Information should be presented in layers, enabling quick scanning with optional deeper exploration.

### **3. Avoid duplication of effort:**

Across workshops, users urged UPD to avoid duplicating effort through creating new communities, networks, or processes. They felt the system is already rich with communities of practice, training opportunities, and events that provide a strategic opportunity to align with, amplify, and connect into.

### **4. Promoting visibility, recognition, and impact:**

Across sessions, users described value in terms of how the hub elevates, evidences, and demonstrates the impact of public insights. They want the compass to elevate and demonstrate how insights inform decision-making- and provide meaningful feedback to contributors to help evidence the impact their work is having.

### **5. The Compass should go beyond just storing insights:**

Across all workshops, participants saw the hub as more than a repository. They want it to enable decision-making, highlight gaps, support coordination, make public attitudes more visible, and ultimately contribute to improving research, policy, and engagement practices. This includes optional wraparound activity that drives use and demonstrates impact.

## Implications

Based on insights we have heard through workshops, we have been able to make some of the following early commitments which have been influenced by this process:

- For the purposes of the hub, health data is defined as any information collected about people combined with their medical history. Only healthcare professionals who are directly involved in a patient's care will be able to access full patient records. But some of the information from these records may also be useful for specific purposes beyond individual care. The Health Data Compass will therefore capture insights on health data for both primary and secondary uses, including views on related topics - but only when they directly intersect with health data.
  - We recognise from feedback that this definition will miss insights on social care data, so we commit to expanding this definition to include health and social care data during the first re-development after launch.
- Insights will be held in the hub for a period of 5 years after publication, moving to a separate legacy or archive section in the compass after those 5 years have elapsed. This informs the evidence synthesis work that [White Tail](#) is leading for us. In that they will collect and synthesis public insights on health data from the previous 5 years to build the foundation of this resource.
  - We recognise from feedback that only looking at the last 5 years would miss out on notable legacy reports that have been influential on current policy and regulation, we will therefore populate the 'archive' within the hub with these notable reports on launch.
- We will develop an initial submission portal that will launch in **April 2026** for the self-submission of insights which will help to test and refine a more permanent portal for launch with the compass later this year. This portal will prioritise simplicity.
- Insights on user journeys and resource functionality will inform a kick off meeting with [Invuse](#) in **March 2026**, the web developers helping us to build this resource as part of a full redevelopment of the Understanding Patient Data website.
  - We are committing to launching a version of the compass that successfully achieves the core functionality, before looking to expand to additional functionality.
- Based on discussions and feedback, we are committing to not including any formal quality control or confidence rating systems, instead developing light touch inclusion/exclusion criteria and prioritising transparency in the hub for the initial version that launches in **Autumn 2026**.

## Final Note

The early development of the Health Data Compass has been shaped first and foremost by the people who have generously contributed their time, insight, experience, and challenge throughout this co-development phase. We want to extend a sincere thank you to everyone who took part in the workshops, interviews, discussions and activities that informed this report. Your open and honest feedback around this complex resource has directly influenced the direction, scope, and ambition of this work.

A consistent message across every session was the importance of building this resource *with* the community it is designed to support. This co-development has allowed us to test our assumptions, confront challenges, and find commonality across very different roles, which helps us understand how the Compass can deliver real value in practice.

As we move from concept into development in the coming weeks, we will continue refining our understanding of what the Health Data Compass is, and equally, what it is not. The workshops have helped us recognise where we are best placed to lead, where we should collaborate, and where other parts of the system are already doing excellent work that we should amplify rather than duplicate. These insights will guide the decisions we make in the coming months on scope, features, governance, and engagement.

Thank you again to everyone who has contributed to shaping this phase. We look forward to continuing this approach of collaboration and co-development as the Compass progresses, and to working with partners across the health data community to ensure this becomes an additive, useful and widely adopted resource.

With thanks,

*The Understanding Patient Data Team.*