Glasgow TRE – PPIE

How secure, anonymised NHS data is used to improve health and care across Scotland

University of Glasgow

NHS Greater Glasgow and Clyde

Centre of Excellence for Trials Collaboration

GLASGOW LAB FOR HEALTH DATA SCIENCE AND AI

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Acknowledgements

Participants

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Hypertension

David Gordon

Shindo Kaur

Rheumatology

Sinead Cadger

Gillian Carroll

Stroke

Stuart Bunton

Tom McCrory

Diabetes

Lucy Kennedy

Caroline McGregor

Maciazek Patryk

John Pritchard

Kit Renard

Gustavo Shintate

Cancer

Jim Watson

Other

Edmond Shu Lim Ho

Christine Milligan

We are also grateful to colleagues, collaborators, and partners who contributed their expertise and support throughout.

Glasgow TRE Team

Ms Lauren Blackman

Mr Peter Mclaughlin

Prof Sandosh Padmanabhan

Prof Honghan Wu

School of Cardiovascular & Metabolic Health

Ms Lilou Cluseau

Dr Iain Frater

Mr Tran QB Tran

Dr Aleksandra Radjenovic

Mr Archie Wallace

School of Health and Wellbeing

Prof Jill Pell

School of Cancer Sciences

Mr Luke McNickle

Glasgow Lab for Health Data Science & AI

Dr Jocelyn Friday

Dr Clarisse de Vries

Research Computing as a Service (RCaaS)

Dr Andrew McHugh

The Centre of Excellence for Trials Collaboration

Ms Anna Morris

NHS Greater Glasgow and Clyde - Safe Haven

Dr Alison Hamilton

Summary

May 23rd, 2025, the University of Glasgow and NHS Greater Glasgow and Clyde hosted a Public and Patient Involvement and Engagement (PPIE) event to inform the development of a modernised Trusted Research Environment (TRE). This secure data platform will support responsible, high-impact health research using anonymised NHS data - while maintaining the highest standards of privacy, transparency, and public trust.

This event brought together a diverse group of participants, including stroke survivors, rare disease advocates, public contributors, and experienced clinical trial participants. The aim was not simply to explain what a TRE is, but to listen and gather meaningful insight into what matters most to people when it comes to the use of their health data for research.

This report summarizes the key themes, concerns, opportunities, and recommendations that emerged from those discussions. It includes direct quotes, illustrative graphics, and practical proposals to shape the design, governance, consent model, and public communications of the Glasgow TRE.

Throughout the PPIE, participants made it clear:

They are not opposed to data use, but they want to be respected, informed, and shown how their data helps others.

This report captures their voices and will directly inform ethics applications, public materials, and the operational design of the Glasgow TRE.

Key Themes

Commercial Access

Views were mixed. Participants supported industry involvement only if it clearly benefited patients, and revenues are reinvested in the NHS or TRE infrastructure.

Value of Research

There was strong support for using data to improve NHS care, especially for underserved conditions or populations. Scottish data should be used to answer Scottish questions, but a global comparison was also welcomed.

Inclusion & Representation

People emphasised the importance of engaging underrepresented groups and ensuring that all populations are fairly represented in research.

Consent & Control

Most participants supported an opt-out approach if accompanied by education, choice, and the ability to limit use in sensitive cases.

Trust & Transparency

Participants welcome the TRE's security and safeguards but emphasised the need for clear, ongoing communication about how data is used and what benefits it delivers.

AI & Innovation

Participants were broadly supportive of AI, but wanted reassurance that human oversight, fairness, and accountability would remain central.

INTRODUCTION

What is a Trusted Research Environment and Why Should You Care?

Imagine if your data held in your NHS medical records – test results, diagnoses, prescriptions, and hospital visits – could be safely used to help improve healthcare for everyone. To allow the safe use of your data, we need to develop a Trusted Research Environment, or TRE.

A TRE is a highly secure digital workspace where approved researchers can analyse health data that's been carefully stripped of all identifying information. They do this to uncover disease or health risk patterns, answer important medical questions, and improve services – all without ever knowing who the patients are.

Let's say a researcher is trying to understand why some people recover better from heart surgery than others. With access to de-identified hospital and medication records from thousands of patients, they might spot useful trends that lead to better care pathways – and even save lives. But it must be done safely, securely, and ethically. That's where the Safe Haven comes in.

What's a Safe Haven?

A Safe Haven is like a secure vault for sensitive health data – a protected space where researchers can study health information without ever seeing names, addresses, or anything that could identify a person.

Scotland has five NHS Safe Havens – based in Glasgow, Edinburgh, Dundee, Aberdeen, and a national service – all designed to meet the highest standards of privacy, security, and data governance.

Why are they needed? Because people are right to worry about how their health data is used. No one wants their personal information falling into the wrong hands or being used in ways they didn't expect. Safe Havens exist to reassure the public that data used for research stays secure, private, and purposeful. They ensure that access is strictly controlled, only approved projects are allowed in, and nothing leaves the environment unless it passes rigorous checks.

Think of it as a "reading room for data" – researchers can come in and work, but they can't take the data out.

The Safe Haven Charter, agreed across Scotland, ensures that:

- Your identity is protected
- Research must benefit the public
- Only approved researchers get access
- Data never leaves the secure system

FIVE SAFE HAVEN PROMISES

Our TRE will adhere to the five safes framework, protecting the privacy and security of people's data.

Safe Data

Researchers only use data that has been de-identified to protect privacy. Safe Haven will pull and provision data from patient records and securely transfer it to the TRE. All analysis will happen inside the workspaces.

Safe People

Only trained and accredited researchers can access the data. Researchers must apply for access and will go through a strict approval process.

Safe Setting

Access to data is only possible using secure systems; the data doesn't leave the TRE. Our TRE includes secure, user-specific workspaces that allow researchers to analyse data safely using approved tools.

Safe Outputs

All research outputs cannot be released until they have undergone a disclosure review.

Safe Research

Data must be used ethically, for research that delivers a clear public benefit.

HOW IT ALL COMES TOGETHER

Think of the TRE and Safe Haven as a team

Safe Haven

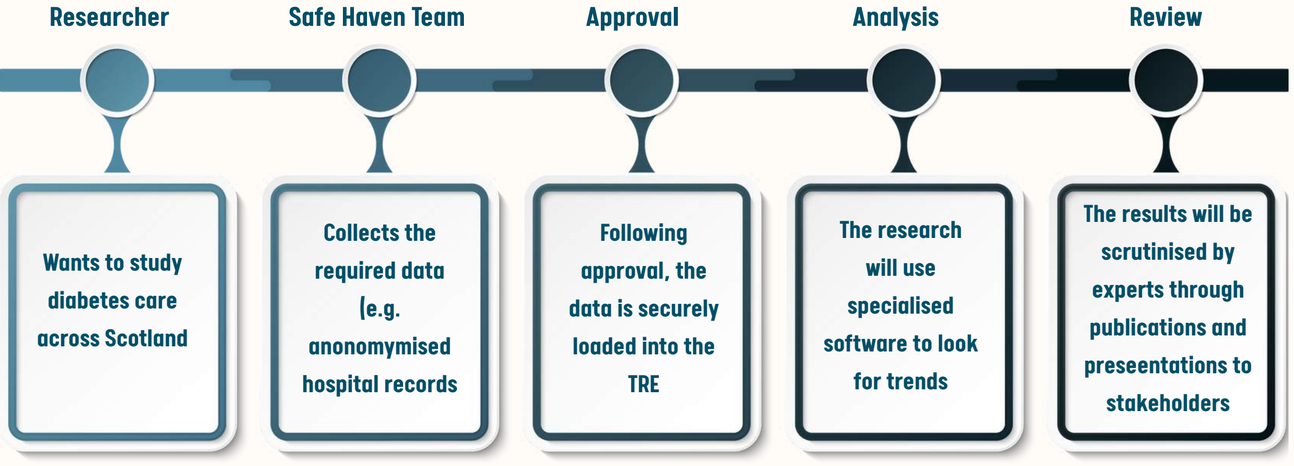
Ensures that only the right people can access data, that the data is anonymised, and that every step follows ethical rules.

TRE

The workspace where those researchers securely carry out data analysis.

Both are governed by strict data security, governance, and ethical standards set by the NHS Safe Haven framework

Example in Action: From Hospital Record to Discovery



PUBLIC VOICES MATTER

As Trusted Research Environments evolve, ensuring transparency and trust in how patient data is accessed and used is critical. Public confidence cannot be assumed–it must be earned.

Participants strongly supported the use of data to improve early diagnosis, treatment, and quality of life. There was recognition that research should balance common and rare conditions, acknowledging the unique value TREs offer to both.

> *"The TRE might find correlations quicker, especially for rarer conditions that aren't as looked into."*

Patients value shorter diagnostic timelines and more effective treatments. AI and data analytics offer opportunities to improve early detection and reduce long-term harm.

> *"It would be good if it brings down the duration of diagnosis, that's what blew up my life and affected my exams, and career. I never got back on track."*

> *"I couldn't get the doctors to treat me as a whole person and look at my entire medical history. It impacted my employment, and I was fired. It has a snowball effect."*

Participants expressed frustration with fragmented care and advocated for the TRE to support more integrated person-centred models.

- Systems currently silo care into specialties that overlook the patient's broader needs.
- Participants shared how delays and a lack of joined-up thinking worsened their health outcomes.
- Analytics offer opportunities to improve detection and reduce long-term harm.

BUILDING TRUST

WHY SHOULD YOU TRUST THIS?

Because your data stays protected at every step. And more importantly, it's being used for something that matters – making healthcare better, safer, and fairer for everyone in Scotland.

That's the mission of TREs and Safe Havens. You won't find your name in the data. But you'll find your experience – as a patient, a family member, a citizen – quietly powering the next generation of lifesaving discoveries.

BUT WHAT ABOUT MY PRIVACY?

> ***"Your data is just a string of numbers to us. We can't see your name, address, or anything personal – and we don't want to. What matters is the patterns, not the person."***

UNDERSTANDING THE TRE
DATA, SAFEGUARDS AND ACCESS

Health data is one of the most powerful tools we have to improve care, speed up diagnoses, and discover better treatments. But using that data responsibly requires the highest standards of safety and transparency.

That's where Trusted Research Environments come in. TREs are secure spaces where approved researchers can study health data without compromising patient privacy. Think of it like a high-security reading room – researchers can examine the books, but they can't take them home.

But how does it actually work? What kinds of data are involved? Who gets access, and how is that access controlled? And what makes it truly safe?

To build public confidence, it's crucial that people understand not just the benefits of data use – but also the safeguards in place to protect them.

PROBLEM

Many participants were unclear on how data enters the TRE, how personal identifiers are removed, and how access is controlled. Key concerns and reflections included:

- **Interest in data protection**, especially anonymisation and read-only access ('dumb terminals').
- **Uncertainty** about who can **access data**, what they see, and what they can take.
- **Concern** that sensitive details in free-text notes may **bypass de-identification**.
- **Fear** of **misidentification,** exclusion, or **stigma** based on **personal data.**

- **Desire for transparency:** What projects use the data, who is involved, and outcomes.
- **Trust in safeguards** increases when systems (like Safe Haven IDs) are clearly explained.
- Acknowledgement that while hacking is a risk, **transparency** and **accountability are key**.
- Preference for **NHS-led TREs** due to **trust,** but support for university research when safeguards exist.

"It's like the Titanic, they said it would never sink - that kind of certainty would make me not believe them. Whereas, if a doctor admits they're unsure and will check, trust is built immediately. It's better to say if you don't know

What has been done: NHS Safe Havens

- Unique Safe Haven IDs instead of names or personal details.
- Pseudonymisation to keep records linkable but de-identified.
- Secure portals for analysis with no data download or external access.
- Disclosure checks before any results leave the TRE.
- Researchers are trained, audited, and only given access to the specific data they need – and only if it's approved.
- Ensure only data required for analysis is provided and all required regulatory permissions are in place.

Mitigation Strategies

To help build public understanding and confidence:

- Use simple metaphors like
  → "Secure reading rooms" - researchers can read, but not remove data.
  → "ID number trials" - data follows a patient, but not their name.
- Develop public-friendly explanation videos and graphics.
- Maintain a public-facing website that shows:
  → Who accesses data and why
  → What studies have been done
  → What benefits have resulted

SAFE HAVEN PRACTICES & LESSONS

Currently, the NHS Greater Glasgow and Clyde Safe Haven operates under a non-consented model for data access, which is legally permitted for research use under specific governance frameworks (e.g., Section 251 support, Caldicott approval, and public benefit review).

Safe Haven Consent & Control in Practice

No identifiable data leaves the NHS firewall - all data is de-identified and pseudonymised before use.

Public awareness materials (e.g., posters in clinics, Safe Haven websites) are used to inform patients that their anonymised data may be used for research.

Patient and Public Involvement (PPI) is increasingly embedded into the development and approval of data projects, especially those using sensitive novel data types.

Local privacy advisory committee (which includes lay members) reviews whether data access requests are justified and align with public benefit principles.

Data is only accessed by accredited researchers in secure environments, and projects are audited and tracked throughout.

Lessons Learned

- **Transparency Builds Trust:** While current legal frameworks allow for non-consented data use, Safe Haven teams have found that proactive communication -not just legal compliance- is key to maintaining public support.
- **Terminology Matters:** Terms like ‘consent’, ‘opt-out’, and ‘control’ are often misunderstood. Safe Havens have learned to use clearer analogies (e.g., ‘reading room’, ‘data trails’) and layered explanations.
- **Opt-out Challenges:** Scotland currently lacks a formal national data opt-out mechanism, unlike England. This creates challenges in aligning patient expectations with what is possible.
- **Access ≠ Openness:** Safe Haven experience shows that simply ‘informing’ people is not enough. People want agency, feedback, and visible impact of their data’s use.

Implications for the Glasgow TRE

- The Glasgow TRE will build on the Safe Haven model but go further in public communication, layered consent options, and involvement.
- We will co-develop plain-language onboarding, opt-out mechanisms, and data use summaries that close the visibility gap.
- We recognise the tension between scalability (needed for AI/ML) and individual control, and will work to balance these through ongoing PPIE and governance oversight.

> ***“Make people proud, not scared, about their data being used.”***

CONSENT, OPT-OUT, & PATIENT CONTROL

Health data can do powerful things – but people want a say in how it's used. During our discussions, participants returned again and again to the same core issue: control.

Who should decide if your health data is used for research? Should people be asked in advance? Should they be told afterwards? Should the system assume you're in – unless you say otherwise?

> ***"The patient should have consent over sharing their health data; it shouldn't be an automatic subscription."***

While there was no single answer, most agreed: whatever the model, it has to be clear, fair, and easy to understand. People want choices – and they want those choices respected.

> ***"If there's an opt-out system, it has to be widely advertised because it's extremely personal, even though it's anonymised. People should have a very clear and easy option to opt-out."***

Observations Elsewhere

England's National Data Opt-Out offers a model – people can opt out of research use of their NHS data. But:

- Uptake is relatively low, possibly due to a lack of awareness.
- Many people aren't clear about what opting out means.
- It's a good foundation, but it needs stronger communication and transparency to be truly effective.

> ***"You may have difficulties with patients who haven't educated themselves and opt-in, potentially causing issues for them. Give people enough information to decide."***

Mitigation Strategies

To build a consent system that works for everyone, participants suggested:

- Combine opt-out models with clear, proactive public education.
- Use natural touchpoints for information: GP registration, hospital admission, and appointment letters.
- Highlight the benefits of data use – real research, real results, real lives changed.
- Make opting out (or back in) simple and accessible, especially offline.
- Regularly show "what your data has helped achieve" – and how people can stay informed.

> ***"Make people aware of how beneficial it has been to use their data. I think that would speak to people, particularly if it's specific to their condition."***

PUBLIC PRIORITIES & DATA GAPS

VISIBILITY & PUBLIC AWARENESS

> ***"I'm hearing impaired and have participated in studies, but I never hear about the outcome. I want to know what they found and what they did with the information."***

When people contribute their data for research, they're not just a statistic – they're partners in progress. But many don't hear back. What happened with their data? Was it useful? Did it make a difference?

While researchers are hard at work inside secure Trusted Research Environments (TREs), the flow of information often stops there. This disconnect can create confusion, suspicion, or simple disengagement. If people don't see the benefits of data use, trust may erode – and opportunities for impact are lost.

"Be upfront about data collection from the beginning. The more information, the more likely a person is to trust you and be put at ease."

That's why visibility isn't just a "nice to have" – it's essential for building trust, encouraging participation, and ensuring research is accountable to the people it aims to help.

> ***The University should share what projects they've carried out using our data."***

PROBLEM

There is a significant disconnect between what researchers do and what the public sees. While the TRE enables secure data use, participants are often unaware of how and why data is used.

- Participants wanted to see more public-facing updates on research, benefits, and opportunities to get involved.
- Emphasis on partnerships with community organisations to improve reach.

> ***One way to disseminate information is by involving disability-led organisations to work with researchers and raise awareness of ongoing research."***

Participants wanted clearer routes for involvement and updates.

- Calls for a more visible and formal system of patient approval.
- PPIE should play a bigger role in deciding which studies are allowed and prioritised.
- Participants want visibility on which projects are approved and why.
- Frustration about the lack of feedback in past research participation.
- Desire for public-friendly communication on what data was used and what it achieved.
- Jargon is alienating–use plain, understandable language.

Models to Emulate

- Clarice Pears community events.
- Learning Disabilities Observatory co-production.
- PhD and policy impact statements.

Mitigation Strategies

- Create 'You Said, We Did' feedback loops.
- Develop a public-facing dashboard showing ongoing studies.
- Integrate project updates into NHS patient portals.
- Provide digestible research summaries through TV, social media, and community centres.
- Host bi-annual public forums to showcase results.
- Build standing PPIE panels across disease areas.

PRIMARY CARE DATA GAPS

Most people assume that all their NHS health information – from GP visits to hospital stays – is stored in one connected system. But that's not the case.

> ***"I think we all assumed that all of your records from primary care will be there when you need a secondary."***

In reality, primary care data (your GP records) is often not linked to hospital data or included in Trusted Research Environments (TREs). This surprised many participants at our engagement events, who expected their full health journey to be available for research and care improvement.

Understanding this gap is crucial – because GP records often contain early symptoms, long-term conditions, and details that hospital records miss. Without it, the picture is incomplete.

PROBLEM

> ***"I think that's a gap, but the public doesn't understand."***

Participants were surprised and concerned to learn that GP data is not routinely included in Safe Havens or TREs.

- People assumed all NHS data was already connected – learning it wasn't caused concern and confusion.
- The absence of GP data was seen as a major limitation on research accuracy and completeness.
- There was frustration about fragmented data across different services and Health Boards.
- Primary care data was widely viewed as essential to make research meaningful and fully representative.

Systemic Barrier

The main challenge is not technical – it's legal and structural.

- General Practitioners are independent contractors, not NHS employees.
- Each GP is the legal data controller of their patient records.
- There is no current national agreement in Scotland to extract and link GP data for research by default.

What Can Be Done

Solving this will require national leadership, GP engagement, and public support.

- Advocate for national solutions to integrate primary care data.
- Engage GPs and professional bodies to co-develop trust-based frameworks for safe sharing.
- Design consent options for patients to opt-in or opt-out of including their GP data in research.
- Raise public awareness of the issue to inform expectations and encourage participation.

WHAT DOES PUBLIC BENEFIT MEAN?

The idea of "public benefit" is at the heart of health data research. But what that means isn't always clear – and depends on who you ask.

Is it about saving NHS money? Helping the most people? Solving rare diseases? Improving quality of life? The truth is: it can be all of these – and more.

During our conversations, participants offered thoughtful reflections on what counts as a good use of health data. They recognised that public benefit is not one-size-fits-all.

> ***The reason I started sharing my life experience for research was to help others so that they don't have to go through everything I did. It might not help my generation, or myself, but it makes some of the pain worthwhile if I know the research is trying to help others."***

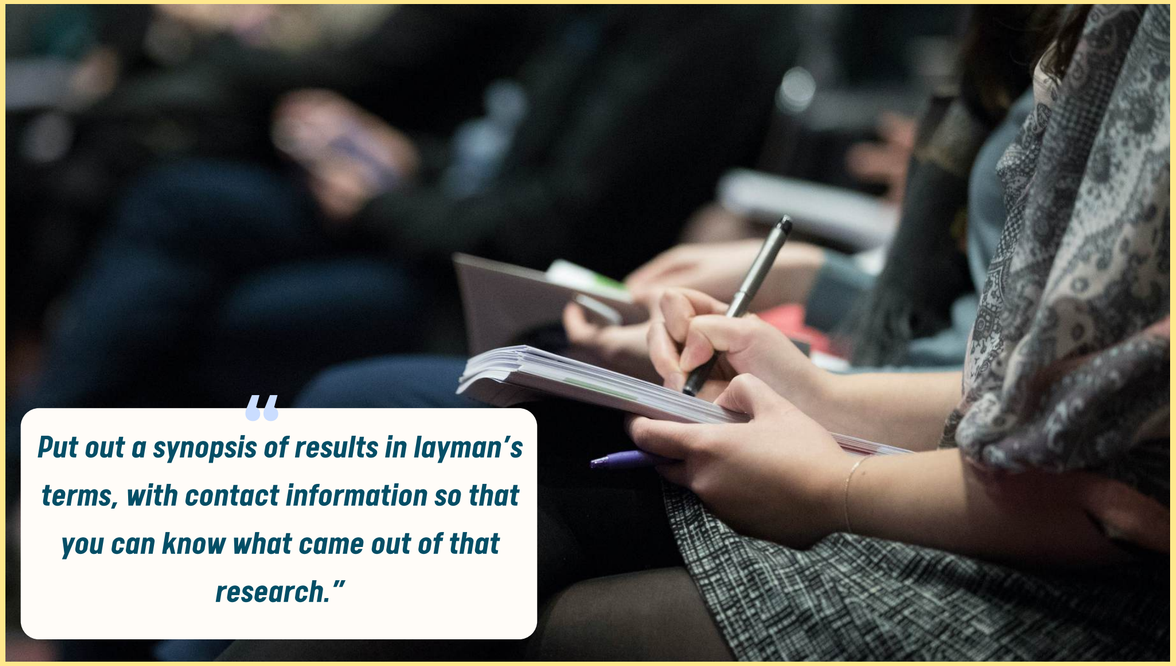
PROBLEM

Participants had varied views on what makes a project worthwhile:

- Some valued broad population benefits, like **improving early diagnosis** or **cutting waiting times**.
- Others prioritised **innovation for rare or overlooked conditions** that may not affect many people but deeply impact those who are affected.

> **"My condition is rare, and there's a small percentage of people who have it, so people aren't researching it. But it would make a world of difference to the small percentage of people with this condition."**

- There was strong support for reducing delays in diagnosis and catching disease earlier – especially where it could improve life expectancy or quality of life.
- Many acknowledged that tools like AI and secure TREs can reveal patterns that were previously invisible.



> ***Put out a synopsis of results in layman's terms, with contact information so that you can know what came out of that research."***

Balanced Perspective

Participants agreed that true public benefit can take many forms, including:

- Improving care and quality of life for patients and carers.
- Saving costs to the NHS, freeing up resources.
- Driving innovation – especially in areas with unmet need.
- Better planning for services through a clearer understanding of population health.

Mitigation Strategies

To ensure public benefit is understood, visible, and balanced across different needs:

- Classify projects clearly – public health, service improvement, innovation, and rare disease.
- Prioritise a diverse portfolio that reflects the needs of the many and the few.
- Track and report outcomes – not just what was studied, but how it helped.

> ***"It's better for researchers to use our data to help other people's health."***

VALUE OF RESEARCH & THE SCOTTISH FOCUS

Scotland is uniquely positioned to lead health research that delivers real public value.

With a population of 5.5 million, a devolved health service, and most healthcare delivered through the NHS, we benefit from a rich, comprehensive dataset. People wanted to know: why use health data? The answer lies in the unmatched value of real-world, routinely collected information–and the opportunity to answer questions that truly matter to Scotland.

Scotland's longstanding data linkage capability and public sector-led research culture make it possible to study real-world health issues at both the national and local levels.

Participants told us they want research that reflects their communities – especially rural areas, underserved groups, and conditions often left out of big studies.

At the same time, participants saw the value of Scotland working in collaboration with the rest of the UK and beyond.

PROBLEM

Participants strongly supported using Scottish health data to answer local questions, but were unsure whether this happened in practice. There was concern that too much focus might shift to international research at the cost of local priorities.

- Support for health research focused on the **Scottish population, health inequalities**, and **rural access.**
- Interest in **rare diseases**, social and geographic **inequalities**, and **local outcomes**.
- Some uncertainty over whether Scottish data is used for Scotland.
- Also, strong support for research that compares Scotland with the wider UK or globally.

> ***"If the money is coming from Scottish funding, it should be put towards helping Scottish people. However, there should be an understanding of how this could impact the wider population."***

The Power of Scotland's Data

Scotland offers a world-class setting for research:

- Comprehensive NHS coverage - most healthcare is delivered by one provider.
- High-quality, population-wide data - from birth to death.
- Stable population - supports long-term follow-up.
- Vast investment in infrastructure - including Safe Havens, the Urban Big Data Centre, HDR-UK, ADRC, and the new TREs.
- Because healthcare data is collected routinely:
  - Everyone is included, not just clinical trial participants.
  - Results are more representative of real patients.
  - There's no need to wait decades for follow-up–it already exists.
  - Costs are far lower than setting up bespoke studies.

Scotland has used this capability to:

- Evaluate the "Back to Sleep" cot death campaign.
- Study whole-population medication outcomes.
- Track COVID-19 progression and vaccine effectiveness rapidly.
- Link multiple sources of data including maternity, GP, prescribing, hospital admissions, and cause of death.

What's Been Done

Significant investment has gone into building the Scottish data ecosystem:

- Regional Safe Havens support secure research access.
- Cross-sector projects supported by HDR-UK and the Scottish Government use data to address health inequality.
- The Glasgow TRE is enabling studies on stroke, colorectal cancer, rheumatoid arthritis, and pharmacogenomics.

Mitigation Strategies

Co-design a PPIE Framework for the Glasgow TRE:

- A clear process map of how public input will shape strategic research priorities (e.g., through advisory panels, consultation sessions, community forums).
- Defined entry points for involvement at each stage, from data access requests to ethics, outputs, and oversight.
- An evolving PPIE participation ladder, allowing for different levels of engagement (inform, consult, co-produce).
- Make Scotland-focused research more visible through events and communications, demonstrate how Scottish data improves care, and support comparisons that bring local benefits.

INNOVATION & EMERGING ISSUES

AI DATA SCIENCE, AND FAIR USE INNOVATION WITH INTEGRITY

Artificial Intelligence (AI) is already transforming healthcare – from helping doctors diagnose diseases faster to analysing huge volumes of patient data for new insights.

At our public engagement events, most participants were open to the use of AI in research. But they also asked important questions: Who checks what the AI is doing? Does it replace doctors? Is it fair? And how is sensitive data – like free-text notes or letters – handled safely?

Understanding and addressing these questions is critical for building a health data system that is both cutting-edge and trustworthy.

> ***" I think the majority of people would like to see their data put to good use in a safe way."***
>
> ***"I'm fine with AI if it helps get through data quicker."***
>
> ***"I think as long as it's clinical, if it's for research, medical stuff, I don't really see a problem."***

> ***I think free-text is more personal, especially when you've been seeing the same doctor for years. My doctor knows me well and writes personal notes. For example, I once wore heels to get a knee injection."***

PROBLEM

While there was general support for AI and data science, participants raised key concerns and expectations:

- **Fairness and representation**: If certain groups are more likely to opt out, they could be left out of research, reinforcing health inequalities.
- **AI as a helper, not a replacement**: People wanted to know that clinicians remain in charge, using AI to support, not override, decisions.
- **Free-text worries**: Clinical letters, discharge notes, and progress reports contain valuable information, but also personal details.
- **Privacy risks**: Participants were uneasy about AI combing through unstructured text without clear safeguards.
- **Transparency and validation**: Participants wanted to know how AI tools are tested, and how errors are caught and corrected.

System Development

AI for Text Data:

- Researchers in Glasgow and Edinburgh are working to make AI safer and more reliable through innovations in Natural Language Processing (NLP) – tools that help analyse free text while protecting privacy.
- Human-in-the-loop systems ensure that AI results are always checked by clinical experts.

Federated models are being explored, allowing joint research across sites without moving or sharing data, thereby enhancing data privacy and security.

Mitigation Strategies

To ensure AI is used safely, fairly, and for public benefit:

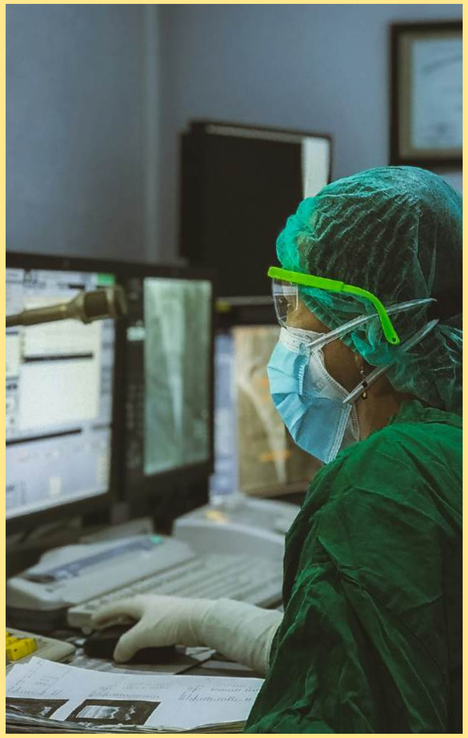
- Showcase examples where AI has made clinical care better and faster.
- Visualise the process – what AI sees, what it ignores, and where humans step in.
- Enforce access limits – researchers only see what they need.
- Promote equity – monitor who's included in the data and adjust recruitment to fill the gaps.
- Involve diverse voices early in designing tools and datasets.

WHEN IS COMMERCIAL ACCESS OKAY?

The question of whether private companies should be allowed to access NHS health data sparked strong feelings.

Some participants were firmly opposed. Others were open – if there were safeguards, clear benefits to patients, and transparency about how profits are handled.

The conversations showed that people aren't against commercial involvement in principle – they're against unfairness, secrecy, or data being used just to make money.



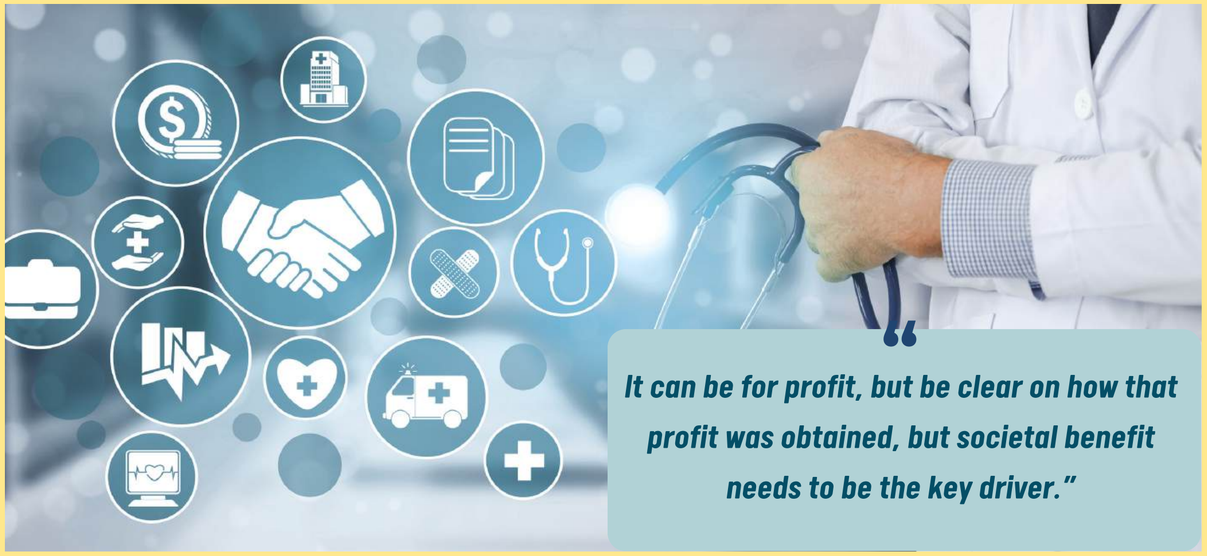
PROBLEM

Participants expressed concern about commercial access to NHS data:

- Mistrust of companies making a profit from public data without public say.
- Unease about "selling" data – even when it's just cost recovery.
- Strong feeling that any revenue from data access should flow back to the NHS or improve the TRE.
- Apprehension about companies using data for advertising or non-healthcare purposes.

> *"I'm completely against companies making money off of people."*

> *"There has to be a tangible societal benefit that you otherwise would not have. For example, taking some of the profits and giving them to a charity is not a tangible societal benefit that you otherwise would not have."*



> *"It can be for profit, but be clear on how that profit was obtained, but societal benefit needs to be the key driver."*

Balanced View

Commercial access was seen as acceptable by many participants when certain principles are met:

- There is a clear public or patient benefit (e.g., new medicines, diagnostics, or faster care).
- Revenue is reinvested – either into the TRE, the NHS, or patient services.
- Terms of access are transparent, and contracts enforce accountability.

What's Been Done

Across the UK – and especially in Scotland – strong rules are already in place:

- Tiered pricing models: Commercial users often pay more, covering both costs and investment.
- Benefit-sharing contracts: Access is granted only if there's a documented public or patient impact.
- NHS Scotland's data access policies explicitly require evidence of public benefit before commercial use is approved.

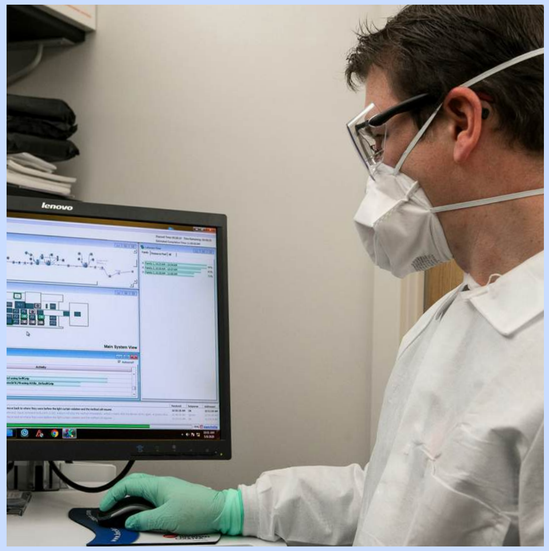
Mitigation Strategies

To make commercial access feel safer and fairer:

- Explain what companies are doing with the data and why.
- Publish revenue use, show how funds are reinvested into patient-facing services.
- Let the public help shape the rules for commercial access through PPIE involvement.

SUSTAINABLE, NOT FOR SALE: CLARIFYING COST RECOVERY

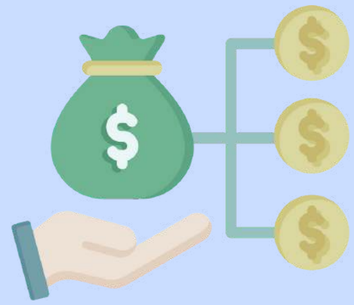
One concern that frequently arises in public discussions is whether health data is being sold. Participants were clear: they supported research and even commercial involvement only when it was in the public interest - but they wanted assurances that data use was ethical, transparent, and not profit-driven.



PROBLEM

- Confusion persists between legitimate cost recovery for services (staff time, data preparation, secure access) and perceived data monetisation.
- Some media headlines have framed NHS data access as "selling," fuelling public distrust.
- Participants expressed discomfort about commercial companies paying to use data, unless it was clearly reinvested in public benefit.
- Lack of clarity on how funds from data access are used, especially when it comes to private sector applicants.

> *"It will always need to be improved. For me, the only issue is when it becomes surplus to that need, because it then becomes a profitable business as opposed to reinvestment."*



Clarifying Cost Recovery

It takes real work–and people–to prepare data for secure, ethical research. Safe Havens and TREs do not simply "hand over" data. Instead, they invest significant time and care to:

- De-identify and pseudonymise records.
- Link datasets from multiple sources (e.g., hospital, GP, pharmacy).
- Check that researchers only access what they need.
- Monitor what goes in–and out–of the secure environment.
- These processes require data scientists, governance officers, IT specialists, and support staff. The fees charged to researchers cover these operational costs, not the data itself.

> *"Everyone thinks that you just press a button and get a spreadsheet, but it takes days of staff work to prep a dataset.*

What Has Been Done

- All Scottish Safe Havens operate on a cost-recovery basis, not for profit.
- Commercial organisations pay higher fees, aligned with their resources and expected benefit.
- Some contracts include benefit-sharing clauses, such as NHS access to tools developed with data.
- Public sector projects (e.g., PhD studies, NHS audits) often access data at reduced or no cost.

Mitigation Strategies

To build public trust in the sustainability model:

- Improve public-facing communications: e.g., "What You Pay For" breakdowns.
- Use plain language to explain staffing, secure environments, and why access isn't free.
- Be transparent about commercial engagement, including how income is reinvested.
- Distinguish between profit-making and enabling research.

LOOKING AHEAD

TRUST, TRANSPARENCY & TANGIBLE IMPACT: WHAT WE HEARD

Across all breakout discussions, one message came through clearly: **the public is not opposed to health data being used for research.** In fact, many are supportive–proud even–of the potential to help others. But that support depends on how data is handled, who is involved, and what comes back to the public.

Participants shared thoughtful, grounded expectations for the future of trusted research. Their feedback forms the basis for action–not just ideals, but practical next steps.

PROBLEM

- There's broad support for ethical data use, but people need proof of safety, benefit, and inclusion.
- Participants want to help, even if they may not personally benefit.
- Many spoke from lived experience–of rare diseases, diagnostic delays, or institutional betrayal–and want future patients to have it better.
- Yet, fears remain: "Don't let this be used against us", "We want to see the results", and "Don't just take–report back."
- Mistrust often comes from being left out of the loop–not just from the data being used, but from not knowing why, how, or what it led to.

What Participants Said

- Prioritise transparency: Clearly state the purpose, who's involved, and how long data will be used.
- Consent must be accessible: Allow simple opt-out with layered choices where feasible.
- Show impact: Provide lay summaries, public updates, and community-level outcomes.
- Make participation inclusive: Design with disabled, rural, older, and ethnically diverse groups in mind.
- Be honest about risks: Don't promise perfection–own mistakes, explain safeguards, and show accountability.
- Limit commercial use: Only allow access where the public clearly benefits, and where funds are used to support the system.
- Invest in trust: Good governance, ethical training, and co-designed projects build legitimacy.
- Recognise different comfort levels: Some will always opt out–that must be respected. But fear should not freeze progress for all.

What We Will Do Next

Our commitments based on what we heard:

- Publish lay summaries for ongoing and completed projects.
- Build co-design panels to involve participants from the start.
- Create clear, layered opt-out options with accessible onboarding.
- Expand visual and plain-language materials about AI, data use, and privacy.
- Highlight impact stories–real-world benefits from research using TRE data.
- Prioritise public benefit in all project approvals, from local to the national level.
- Amplify rural, disabled, and ethnic minority voices across all engagement.
- Reinforce governance structures with clear accountability for researchers and institutions.
- Address the primary care data gap through policy, advocacy, and community support.
- Ensure commercial access to high-impact, transparent, and accountable partnerships.

Final Reflections from Participants

The public is not asking for perfection. They are asking for honesty, visibility, and meaningful involvement. The TRE and NHS Safe Haven system already provides a strong foundation. **But long-term trust will be built by what happens next:**

- **Ongoing dialogue**, not one-off consultations.
- **Proven benefit**, not just potential.
- **Responsiveness**, not silence.

> ***"I think our job is to make you proud that you're not opting out. To make your contribution to society a question of personal pride."***

GET INVOLVED

HELP SHAPE THE FUTURE OF SAFE DATA RESEARCH

We want to continue involving patients, carers, and members of the public as the Glasgow TRE grows. Your voice matters at every stage, from shaping policies to reviewing projects and helping researchers stay connected to real-world impact.

Why Get Involved

- Help make sure public benefit stays at the heart of research.
- Influence how privacy, consent, and security are handled.
- Ensure that diverse voices -including rural, ethnic, disabled, and marginalised groups - are included in decision-making.
- See how your insights contribute to better research, care, and trust.

Who Can Join?

Everyone is welcome - especially people who:

- Have lived experience of using the NHS
- Come from underrepresented communities
- Want to help ensure health research works for everyone

You don't need to be a data expert, just curious, thoughtful, and willing to share your views.

What Support Will Be Provided?

- Briefing and training tailored to your role
- Reimbursement for your time and travel, where applicable
- Flexible participation options (in person or online)
- A named contact for ongoing support and questions

Ways You Can Get Involved

1. Join a Co-design Panel

Work with researchers, governance staff, and other public contributors to:

- Review and comment on proposed research projects
- Help define what 'public benefit' means
- Shape communication and consent approaches

2. Become a Public Reviewer

Help assess TRE policies, public-facing materials, or data access proposals from a lay perspective.

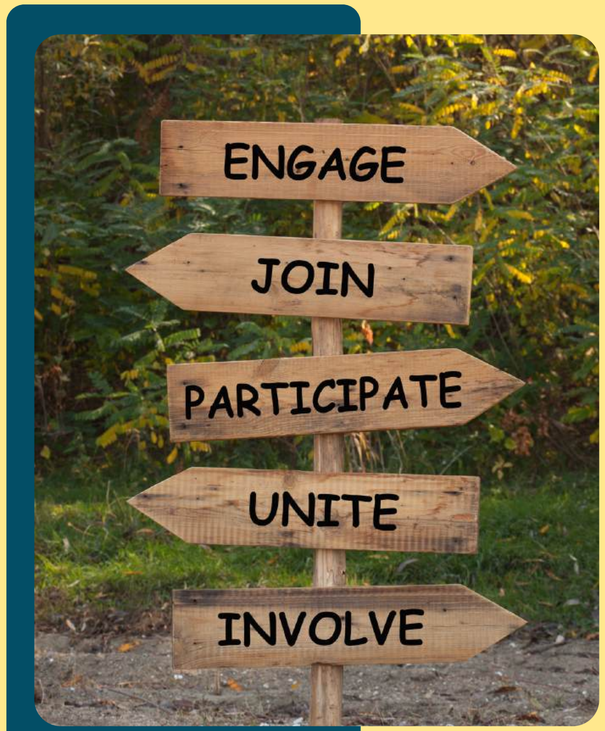
3. Participate in Workshops or Focus Groups

Be part of discussions on topics like:

- Artificial intelligence in healthcare
- Consent and control models
- Representing diverse data needs

4. Help Build Awareness

- Speak at future events
- Share your story about data use
- Collaborate on plain-language summaries and educational materials



How to Register Interest

You can express interest or ask questions by emailing: **info@glasgowtre.ac.uk**

Let us know:

- What type of involvement you're interested in
- Any accessibility or support needs
- If you'd prefer to be kept informed without active involvement

VISUAL APPENDIX: BRINGING IT TO LIFE

What the public values in health data research

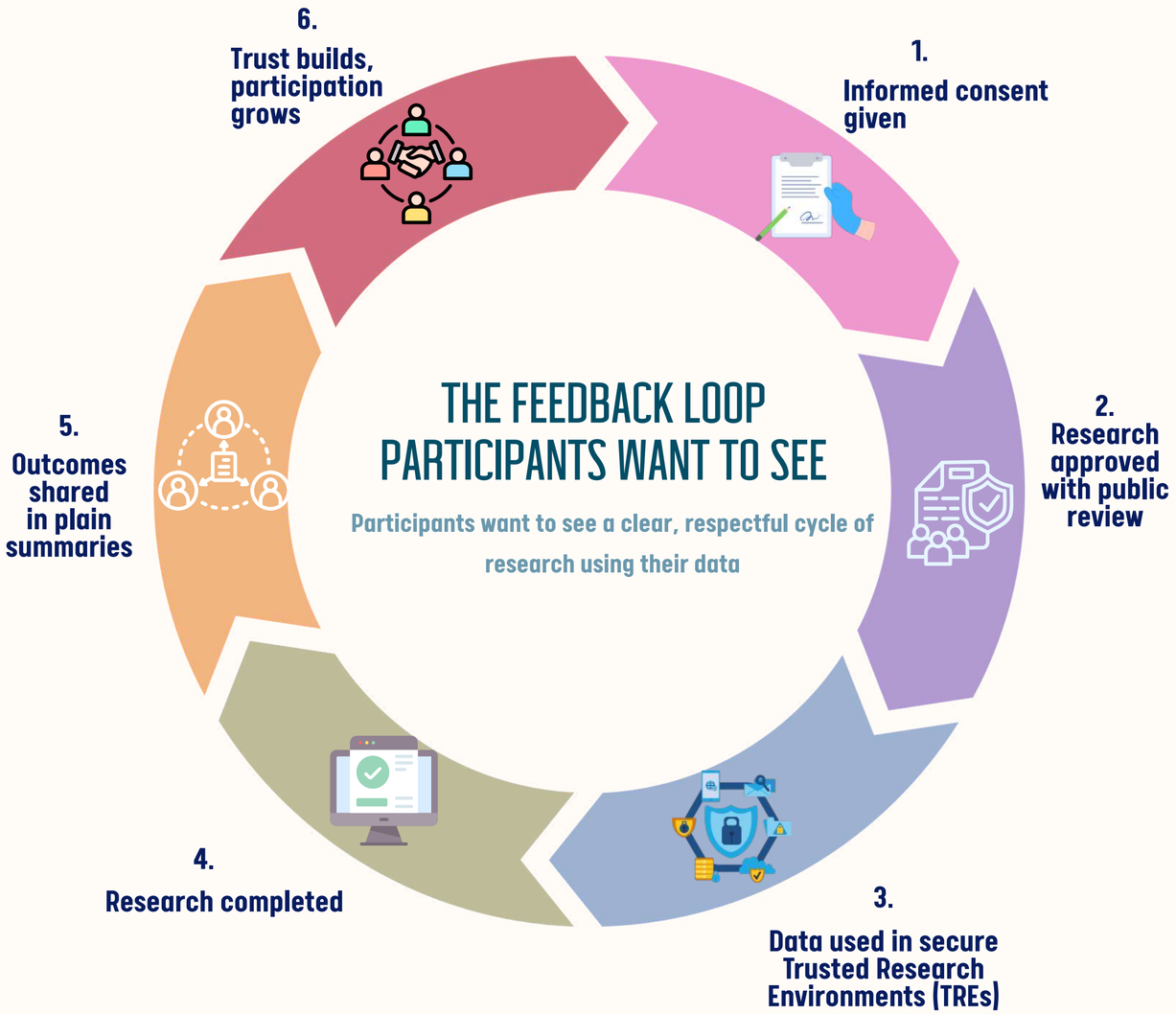
Public Benefit
- Early diagnosis
- Equitable access
- Rare conditions

Safety
- Trusted environments
- Minimal data sharing
- NHS accountability

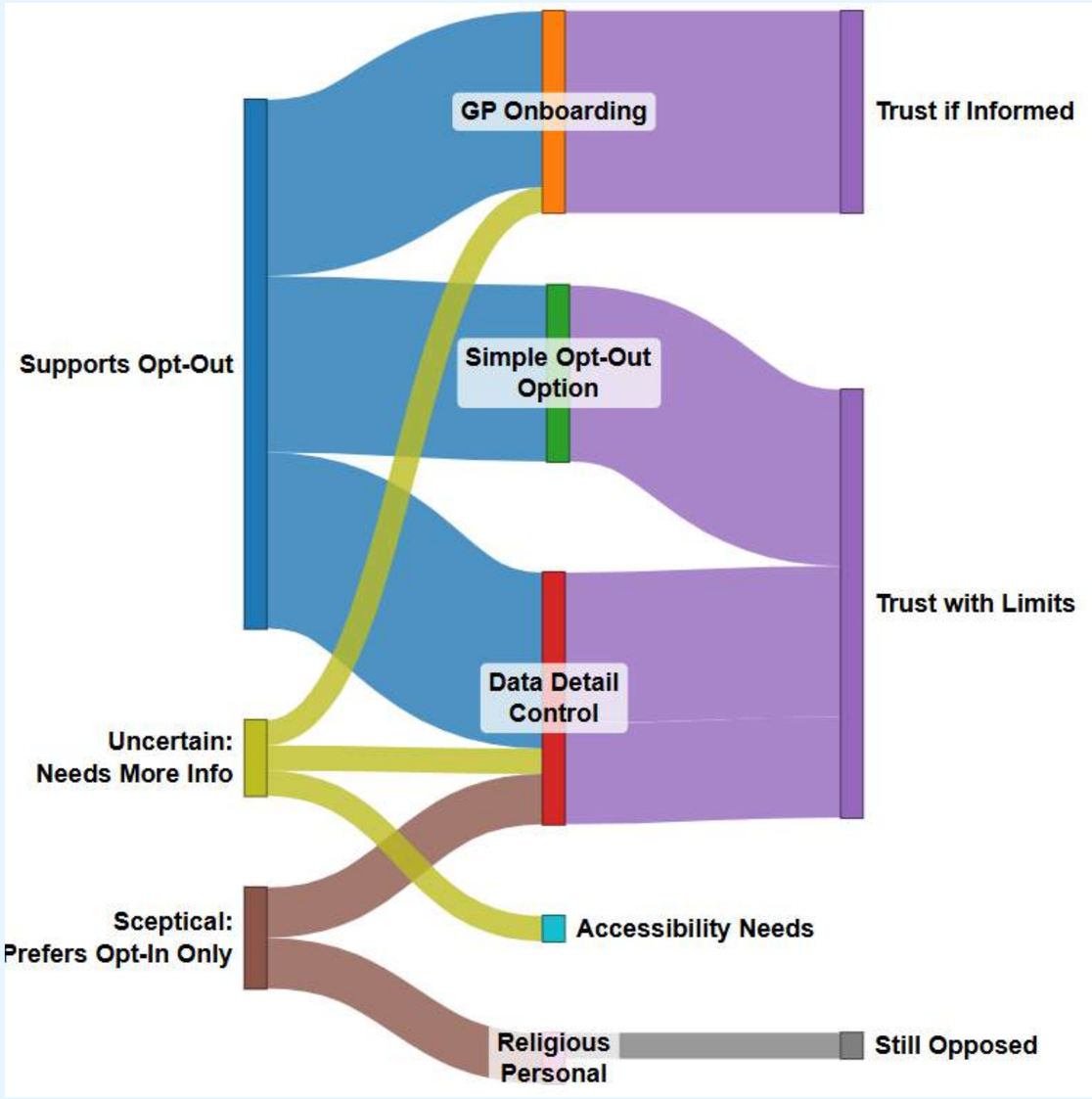
Transparency
- Clear Consent
- Feedback loops
- Plain language

WHAT BUILDS OR BREAKS TRUST

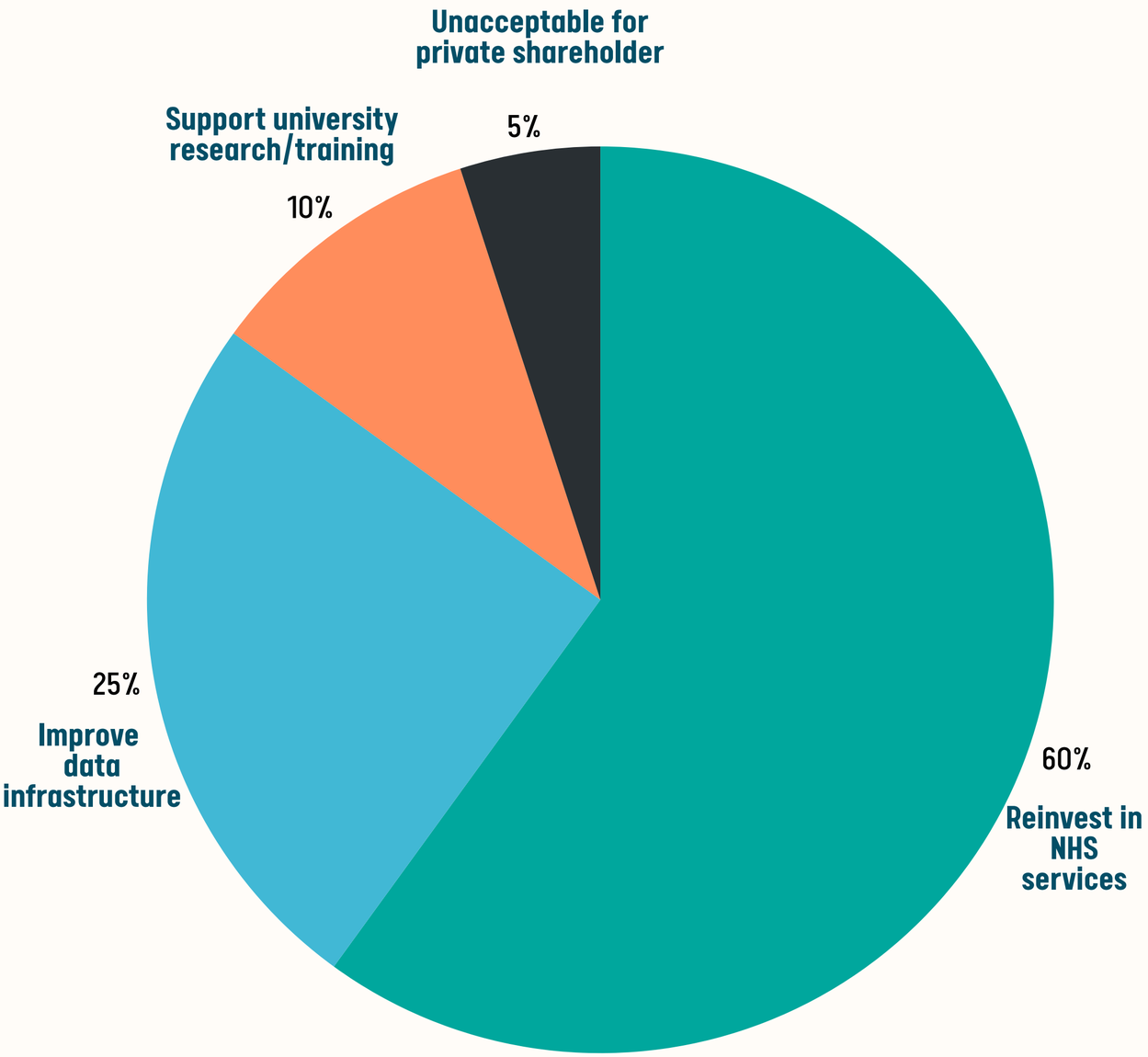
Trust Builders	Trust Breakers
☑ NHS Control	✗ Data leaks
☑ Clear opt-out	✗ Over-commercialisation
☑ Public and patient involvement (PPIE)	✗ Vague consent forms
☑ Feedback on research outcomes	✗ No feedback or visibility
☑ Transparent commercial rules	✗ Use by unregulated third parties



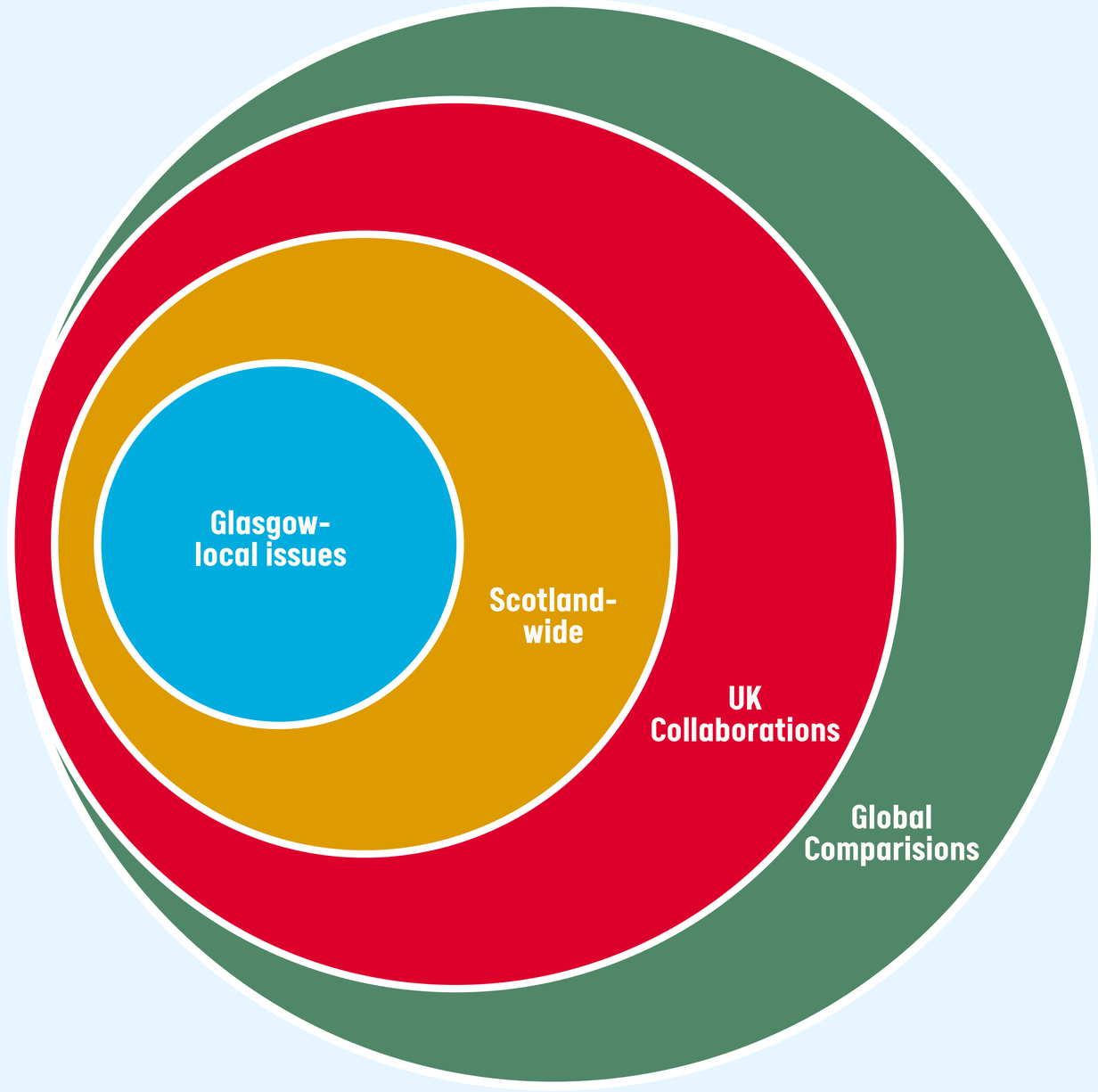
PARTICIPANT CONSENT PREFERENCES



REINVESTING IN WHAT MATTERS



FROM LOCAL TO GLOBAL: RESEARCH SCOPE



Diabetes care gaps

Rare disease registries

Rural access & health inequalities

US/Scandinavian models

VISIBILITY GAPS

How People Think About Consent and Trust in Health Data Use

Inputs

NHS records

Academic work

Research Processes

Secure Access

Ethics Review

Public Facing Output

Missing

Unclear

PATIENT VOICES ON DATA USE

"I wouldn't want this data to be commercialised and sold to places that materially benefit from it (like insurance companies or Amazon)."

"The vast majority of people would like to see their data put to good use in a safe way."

"The main thing is that people can't profit from our data, and the University of Glasgow guarantees the data doesn't get sold.

"You don't want to become targeted as part of the data that you surrendered, you don't want to become a victim of that data."

GLOSSARY

A

Anonymisation
The process of removing or disguising personal details from data (like names, dates of birth, or addresses) so that individuals can no longer be identified.

Artificial Intelligence (AI)
Computer systems that can identify patterns and make predictions by learning from data. In healthcare, AI can be used to help with diagnosis, risk prediction, and making services more efficient - always under human supervision.

C

Consent (Opt-in / Opt-out)

- Opt-in means people must actively agree for their data to be used in research.
- Opt-out means people are included by default, but can choose to say no. Most research using anonymised data in Scotland is currently done without individual consent (non-consented) under strict governance.

F

Free Text
Unstructured written information in health records, such as letters from doctors, clinic notes, or discharge summaries. These can be rich in detail but harder to anonymise because they may include personal stories or identifying facts.

Federated Data Model
A system where data stays in its original location (e.g., different NHS regions), but researchers can analyse it across systems without moving it to one place. This allows for collaboration while protecting privacy.

N

Natural Language Processing (NLP)
A type of artificial intelligence that helps computers read and understand human language. It can be used to safely extract useful information from free-text health records while removing private details.

NHS Safe Haven
A special NHS-approved team and process for handling sensitive health data safely and securely. They manage access to patient data, strip out identifying details, and make sure only authorised people can use it for approved research.

P

Primary Care Data
Primary care data consists of anonymised health information from GPs and other care providers, including demographics, diagnoses, symptoms, prescriptions, and lifestyle factors.

Pseudonymisation
A method of replacing personal information with codes (such as a study ID) that allows data to be analysed without revealing identities. The code can be linked back only by the Safe Haven if needed for updates, not by the researchers.

Public Benefit
The positive impact research should have on patients and society, like improving treatments, preventing illness, or making NHS care more efficient. Public benefit is a legal requirement for most health data research in Scotland.

T

Trusted Research Environment (TRE)
A secure, access-controlled digital workspace where approved researchers can analyse health data. TREs follow strict privacy, security, and governance rules so that personal information is protected at all times. Think of it like a digital ‘reading room’; researchers can use the data inside, but they can’t take it away.

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