Stuck on repeat - Appendix 2

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Spotlight on the Ideas Sprint

Introduction

This appendix presents findings from an 'ideas sprint' conducted as part of this research. The Ideas Sprint was a cross-sector, collaborative exercise. It brought people with lived experience together with regulators, service providers and consumer organisations to test emerging thinking about the sharing of support needs in real time.

The purpose of this appendix is to present what was learnt through that process. It sets out why the Ideas Sprint was convened, how it was designed, and the key insights that emerged as participants worked through shared challenges. In particular, it explains how grounding discussions in lived experience helped stress-test ideas and principles against real-world complexity.

Importantly, this appendix also shows how insights from the Ideas Sprint informed and refined the recommendations in the main report. Further details on the methodology and facilitation of the Ideas Sprint is provided in the accompanying methodology note.

1. Designing the Ideas Sprint: purpose and scope

As the main report outlines, many people with mental health problems have had to repeatedly share sensitive information about their needs or circumstances with their essential service providers. This is often at times of distress or periods of poor mental health. While the sharing of support needs already takes place within and across some essential service sectors, existing approaches are fragmented, and vary significantly in how they share data, which organisations the data is shared with and how the system is governed. For many people with mental health problems, this inconsistency in experience can increase cognitive burden, undermine trust, and mean that sharing information does not reliably translate into appropriate support.

To put our research findings and the principles developed with our Research Community into practice, the Ideas Sprint was convened. It tested emerging thinking and tensions around models that share support needs across essential services and explored how data sharing could work better for people with mental health problems.

This included considering the governance arrangements and safeguards needed to make future models acceptable, safe and usable.

A central aim of the Ideas Sprint was to ensure that discussions were grounded in lived experience. Members of Money and Mental Health's Research Community took part alongside representatives from essential service providers, regulators, industry leads and consumer organisations. This was to ensure that the ideas developed were tested not only for technical or operational feasibility, but against the realities of people's lives - including fluctuating mental health problems, varying cognitive load, and differing access needs.

Participants were asked to work through defined challenge areas and to develop potential interventions, reflecting on opportunities and risks. This approach was designed to move the discussion beyond abstract thinking. It aimed to develop a clearer understanding of the conditions under which sharing support needs could reduce harm and improve support, rather than create new barriers or exclusions.

The sections that follow synthesise the key insights that emerged from the Ideas Sprint. These insights informed the development of the report's recommendations. It helped illustrate what would need to be in place for cross-sector data sharing in essential services to work well in practice.

2. How the Ideas Sprint worked

The Ideas Sprint was designed to create a structured but open space for collaboration across sectors. The aim was to bring together a range of perspectives and test ideas in a way that was **grounded, practical and focused on real-world delivery.**

Who took part

Participants comprised essential service providers, regulators, consumer organisations and members of Money and Mental Health's Research Community. This reflected the cross-sector nature of the challenge and the importance of grounding ideas in lived experience.

How it was structured

The Sprint was organised around six challenge areas, each reflecting a core barrier or trade-off. Participants were placed into mixed groups and asked to work on a shared problem statement. Each group was tasked with developing a proposed intervention to respond to their challenge. Participants were encouraged to consider not only what might work, but what could go wrong, what would be required to implement their ideas, and where risks or dependencies might arise.

To support this, we used a shared digital workspace called Padlet to capture ideas, amplify quieter voices, and support accessibility. This created a record of emerging thinking as discussions developed. Further detail on the design and facilitation of the Ideas Sprint is set out in the methodology note.

What made the approach distinctive

Three features of the Ideas Sprint were particularly important:

1. It was cross-sector by design. This allowed ideas to be tested across different regulatory, operational and organisational contexts rather than within a single silo.
2. Lived experience was embedded throughout the process. This helped to ensure that proposed interventions were assessed against the realities of people's lives.
3. The emphasis was on feasibility and risk, not just ambition.

Participants were encouraged to consider how ideas might work in practice, where they might fail, and what safeguards would be needed to prevent harm. Identifying unresolved tensions or dependencies, including the need for legislative or regulatory change, was treated as valuable insight, rather than a limitation.Together, this approach enabled the Ideas Sprint to generate insights that were grounded in both lived experience and practical delivery considerations. As such, the insights meaningfully informed the recommendations set out in the main report.

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3. What participants told us: key insights and ideas

The following section synthesises the key insights that emerged across all six Ideas Sprint groups. While each group worked on a distinct challenge area, there was a high degree of consistency in how participants framed both the problems with current approaches to this type of data sharing and the conditions required for future models to work well. Illustrative examples are drawn from particular groups where they most clearly articulated an idea or intervention, but these insights were reinforced across the Ideas Sprint as a whole.

Together, these insights provide additional context for the recommendations set out in the main report. This section sets out the explicit links between the insights raised in the Ideas Sprint groups and how they are reflected in the final refined recommendations.

Insight 1: Trust depends on visible governance, accountability and alignment

Across the Ideas Sprint, trust was consistently framed as something that must be actively designed into any system that shares support needs, rather than be assumed or built through reassurance alone. This includes the use of clear and consistent standards that people can recognise across sectors. Participants emphasised that people are more likely to trust data sharing systems when they can see clear structures of responsibility, understand who is accountable, and know what will happen if things go wrong.

This was most explicitly articulated by Group 3 whose focus was on security and transparency. They proposed the creation of an independent convening or oversight organisation to operate and govern a shared system for recording and sharing support needs. Participants in this group stressed that transparency must go beyond explaining how data is protected, and instead clearly set out: who oversees the system; who is responsible for decision-making; and what processes are in place if data is misused, breached, or leads to harm. Trust, in this framing, was rooted in preparedness and accountability rather than promises of perfection.

Similar themes were developed by Group 5 whose focus was on connectivity and governance. They emphasised the importance of regulatory alignment and clear accountability. Participants noted that people are more likely to trust a data sharing system when they know that the information they share will be interpreted in the same way, regardless of which sector or service they are engaging with. This can be built through the use of shared support needs codes and terminology, to ensure consistency and confidence across all sectors.

Participants highlighted the risk that, without shared standards and coordination, responsibility for data sharing can fall between organisations or regulators. This can leave people uncertain about where to turn if something goes wrong. Trust was seen as stronger when escalation routes are defined, roles are clear, and accountability does not depend on navigating complex institutional boundaries. In this sense, alignment was seen as a practical condition for trust, reducing uncertainty about how shared information would be used across different services.

These points were reinforced across other groups. Participants working on clarity and comprehension raised questions about who would be responsible for setting and enforcing communication standards, reinforcing the importance of clear accountability. Meanwhile, those focused on consent highlighted accountability gaps when consent changes or is withdrawn.

Across the Ideas Sprint, there was a clear view that trust depends not only on how systems function in ideal conditions, but on how they are governed and managed when things go wrong; and being transparent enough to acknowledge that they will.

How these insights informed our recommendations:

This insight helped shape and sharpen the report's recommendations relating to strong safeguards and accountability.

- This includes proposals for:
- clearer cross-sector governance,
- independent oversight,
- an audit of the existing system
- and redress

It also reinforced the importance of regulatory coordination and alignment as a foundation for trustworthy data sharing across essential services. This includes the development and use of a shared taxonomy of support needs and terminology.

Insight 2: Meaningful control requires consent models that adapt over time

Participants across the Ideas Sprint consistently described consent as an ongoing process rather than a single decision point. There was strong agreement that meaningful control over data must account for fluctuating mental health problems, varying cognitive load, and changing personal circumstances over time.

This was most clearly articulated by Group 2 who focused on facilitating control and consent.[1] Participants in this group explored mechanisms that would allow people to review, update and withdraw consent easily, rather than relying on static or implied consent models.

Participants noted that people may not always know what support is available at the point of disclosure. They developed ideas such as prompts or short "quizzes" to help people identify what support they might want and with whom, giving them greater control over what information is shared.

Related ideas emerged from Group 1 who focused on clarity and comprehension. The group proposed a consent management platform where people could see and control how their data is shared. Participants emphasised the importance of clear roadmaps showing how data is used, alongside different communication formats - including visual and audio options - to support understanding. Confirming choices and outcomes in ways people can easily grasp was seen as essential to building trust and maintaining control.

Other groups reinforced these concerns from different angles. For example, highlighting the risk of consent overwhelm, and warning against rigid or automated consent processes that do not allow for reassessment as circumstances change. Across the Ideas Sprint, there was a shared view that consent must be designed into systems as something people can return to, rather than something they are expected to get "right" once.

How these insights informed our recommendations:

This insight helped position and refine the report's proposal for a future consent dashboard that would give people control of their data across different systems.

It also informed proposals around:

- periodic check-ins,
- clear opt-out processes,
- the ability for people to update, delete or port their information as their circumstances or service providers change.

The insight also supported the development of recommendations on how the principles of informed and dynamic consent, control and choice, and transparency could be put into practice throughout the data sharing journey.

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[1] At the Ideas Sprint, attendees had varying levels of expertise in data protection and likely referred to consent in similar but also different ways. In this appendix, like in the main report, "consent" is used in line with the everyday language used by Research Community members to mean giving permission for information to be shared. This reflects the importance people place on feeling able to give, withhold or withdraw permission in order to feel in control of their data. It is distinct from the more precise legal definition of consent under UK data protection law. A focus on consent still acknowledges that data may be shared appropriately under other lawful bases where permitted.

Insight 3: Inclusion and human support are non-negotiable

Inclusion was consistently framed by participants as a matter of dignity, fairness and choice, rather than simply access to a digital system. There was strong concern across the Ideas Sprint that digital-only data sharing could become a gatekeeper to support if alternatives are not protected and resourced.

This was most clearly articulated by Group 4 who focussed on designing equitable, inclusive and accessible systems. Participants proposed a range of inclusive design standards. This included the use of simple language, avoiding overly granular or medicalised categories, and offering multiple communication channels, such as phone, post and face-to-face alongside digital options. They emphasised that people who cannot or choose not to share their support needs must still be able to access fair support. The group also highlighted how stigma, embarrassment and digital exclusion can be reasons people may disengage from data sharing systems altogether.

Group 6 who focused on balancing automation and human support reinforced this perspective. The group explored models where automation could offer a first tier of support while building in clear hand-off points to trained staff. Participants stressed that empathy and human judgement are essential. This can particularly be where people are distressed or have complex needs, and that automation should support - not replace - meaningful human interaction.

These themes were echoed across other groups. Participants working on clarity raised concerns about communication formats and accessibility, while those focused on consent highlighted barriers faced by people who are unable to engage digitally. Taken together, there was a strong consensus that inclusive design and human support must be treated as foundational requirements, not optional enhancements.

Together, these insights provided a practical lens through which earlier evidence and lived experience findings could be tested and refined.

How these insights informed our recommendations:

This insight helped strengthen the report's recommendations on inclusive design, such as creating a good design blueprint and standards, as well the need for public awareness campaigns.

It also influenced recommendations for:

- putting the principles into practice, like ensuring human support sits alongside automation,
- the need for trusted intermediaries to help people navigate this type of data sharing.

The insight reinforced the importance, and helped shape our recommendation, of embedding digital inclusion within any future cross-sector data sharing framework.

4. Why the Ideas Sprint was integral

The Ideas Sprint played a distinctive role within the project by enabling forms of testing and sense-checking that could not have been achieved through desk research or bilateral engagement alone. While earlier research identified recurring problems with existing approaches to sharing support needs, the Sprint created a space to examine how those problems interact in practice - across sectors, systems and lived experience - and where proposed solutions can begin to break down.

By bringing people with lived experience into the same discussions as regulators, providers and other stakeholders, the Sprint made visible tensions that are often obscured when these perspectives are considered separately. In particular, it showed where core principles need to be translated into practical action, where governance gaps can emerge between organisations, and where assumptions about consent, trust or inclusion do not hold when tested against real-world complexity.

Asking participants to design and stress-test interventions revealed constraints, dependencies and risks which helped bring our principles and high-level models to life. This process helped distinguish issues that could be addressed through better system design from those requiring explicit policy decisions, regulatory alignment or new safeguards. It also clarified where trade-offs are unavoidable and must be acknowledged transparently, rather than remain unresolved through system design.

In this way, the Ideas Sprint was an essential step in moving from diagnosis to actionable insight. The Ideas Sprint ensured that the report's recommendations are grounded in a realistic understanding of what it would take to make sharing support needs work safely and fairly in practice. For many people with mental health problems, data sharing is not neutral: it can either reduce harm or compound it. The Ideas Sprint was essential in understanding the difference and ensuring the former.

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