

Stuck on repeat - Appendix 3

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Methodology

This note outlines the methodological approach taken in Money and Mental Health's 2026 report *Stuck on repeat*, by Chris Lees and Kate Wells.

A.1 Research design

This research project consisted of:

- An advisory group made up of experts in data sharing and vulnerability.
- A review of the academic and grey literature, and existing policy relating to the sharing of support needs across essential services.
- Two surveys with Money and Mental Health's Research Community.
- An online focus group with members of Money and Mental Health's Research Community.
- A People's Panel formed of members of Money and Mental Health's Research Community.
- Analysis of nationally representative polling carried out by YouGov.
- A roundtable attended by representatives of consumer organisations, as well as wider discussions with relevant experts in this topic.
- An 'ideas sprint' attended by relevant stakeholders and members of Money and Mental Health's Research Community.

Further details of each component of the research are provided below. We are grateful to all those who supported this research by sharing their personal experience.

A.2 Advisory group

As part of the multi-year project an advisory group made up of experts in data sharing and vulnerability was set up. The aim of this group was to help guide the overall project and provide support and advice on specific elements. The members were chosen because they had experience that was relevant to one or more of the strands of work - the list of members is provided in the main report. The advisory group met several times during the first strand of work to discuss topics such as initial findings from the lived experience research, plans for the Ideas Sprint and draft recommendations. The advisory group will continue to convene for the next strands of work. We are grateful to the members for all their guidance and support.

The report represents the research and views solely of the authors and of the Money and Mental Health Policy Institute and does not represent the views or experiences of the advisory group members.

A.3 Literature review

We conducted a desk-based review of the academic and grey literature published on the concept of the sharing of support needs across essential services. This was conducted alongside a review of the policy context, including the existing systems to share support needs, as well as proposals from previous governments.

A.4 Research Community surveys

We carried out two surveys with Money and Mental Health's Research Community, a group of 5,000 people with lived experience of mental health problems or caring for someone with mental health problems. We received:

- 214 responses from people with lived experience of mental health problems.
- 29 responses from people who have supported someone with mental health problems.

Both of these surveys were carried out between 15 November and 25 November 2024.

In the surveys we asked whether members had used one of the existing systems for sharing support needs and their experiences. We then asked respondents questions about the concept of being able to share support needs across essential services. This included overall views and any benefits and risks, as well as how respondents might want to share data, with which organisations and who should run the system. Finally we asked what should be put in place to make sure this type of data sharing worked for people with mental health problems. For members with caring experience, we asked similar questions with the focus on whether the sharing of support needs would benefit the person they supported and how that person could be assisted to share their needs.

All questions were optional to avoid causing distress to participants, meaning the base size for questions varies. Where necessary, we also routed questions to avoid asking questions that were not relevant to a participant's experiences. Where statistics from this survey are quoted in this report, we also provide sample size and a description of the base.

A.5 Research Community focus group

Using the Research Community surveys as a sampling tool, we held an online focus group in February 2025 with six participants who had lived experience of mental health problems. The focus group was conducted through a video platform.

All focus group participants were offered a £35 voucher as a thank you for taking part. This provided us with the opportunity to dig more deeply into:

- The benefits and risks of a system that shared support needs across essential services.
- The practicalities of how such a system might work.
- What participants felt should be in place in order for the system to best support people with mental health problems.

A written transcript of the focus group was thematically coded. Emerging themes were used to understand people's experiences, and used to inform principles for data sharing and policy recommendations, ensuring our recommendations were grounded in experience and practice.

A.6 People's Panel

In order to co-develop a set of principles that should be applied to this type of data sharing so that it works for people with mental health problems, we convened a People's Panel in April and May 2025. This was made up of twelve members of the Research Community with lived experience of mental health problems who had taken part in the earlier survey, but not the focus group. Twenty members had been originally recruited, however, several dropped out before the main sessions took place. Three members of the People's Panel acted as 'champions' which meant they led smaller group discussions and fed back to the wider group (five had originally been selected).

All sessions of the People's Panel were conducted through a video platform. All People's Panel participants were offered a £60 voucher as a thank you for taking part in the two main sessions.

As a first step members of the People's Panel met with Money and Mental Health staff to introduce each other and to go through how the main sessions would work, both practically and the discussion points. 'Champions' were given additional support to help them prepare for their role, including a guide and a short session.

The People's Panel then met virtually for two longer sessions to discuss the key issues identified in the research up to that point and to co-develop principles for the sharing of support needs across essential services. The sessions were split between Money and Mental Health team members presenting initial findings from the research, smaller group discussion and feedback to the wider team, and interactive elements such as polling. Within the smaller group discussions, members used Google Slides to add thoughts into 'post-it' notes or add their name to sliding scales. 'Champions' then led discussions based on the activities, with support from a Money and Mental Health staff member. The aim of using both interactive activities and smaller group discussions was to allow members to express their views in different ways and to prevent one set of views from dominating. The second session began with a recap of what was discussed in the first.

In the first session, members created a set of principles by considering how the positive outcomes they wanted to see from data sharing could be guaranteed and how the concerns they had could be counteracted. For example, one member's concern was that 'data would be shared without my knowledge' and their corresponding principle was that 'permission would be required each time the data was shared'. Members then had to consider what they would want to prioritise in a system that shared their needs.

In the second session, members were given examples of systems that could share support

needs across essential services. These were based on the systems that currently existed - supplier-to-supplier sharing, portal-based sharing, and a hybrid model. Members then had to consider what principles were in place and how they could be more embedded. Members also discussed which groups of people might struggle or refuse to use the systems, and what could be done to support them.

Alongside the materials created by the interactive activities, a recording was taken of the two main sessions to allow researchers to analyse the smaller group sessions. We then categorised the large amount of principles members had created into a smaller group, which was further refined at the consumer group and charity roundtable.

A.7 Polling

To understand public attitudes towards the sharing of support needs across essential services we commissioned YouGov to conduct an online poll of 2,054 over 18s across the UK. The figures were weighted to be nationally representative of all UK adults (18+). This polling was conducted between 11 December and 12 December 2025. YouGov is a founding member of the British Polling Council and abides by its rules. See <https://yougov.co.uk/> for more detail.

To compare experiences and views between respondents with and without mental health problems, we asked participants “Have you ever experienced a mental health problem?” with the options of “Yes, in the last 2 years”, “Yes, not in the last 2 years, but longer ago” and “No, I have never experienced a mental health problem”. This is the standard question that we have used when surveying people about their mental health in recognition of the fact that a significant proportion of people with symptoms that amount to a mental health problem have not received a diagnosis.¹ Of respondents:

- 26% said they had experienced a mental health problem in the last two years.
- 17% said they had experienced a mental health problem longer ago.
- 44% said they had never experienced a mental health problem.

In our analysis, we focused on those who had more recent experience – which we defined as within the last two years – as we felt this would provide the most relevant results for the experience and views of people with mental health problems.

Additionally, we also wanted to compare the experiences and views of those who have needed support in essential services with those who have never needed this. Respondents were asked “Do you currently need, or have previously needed, extra support to access essential services or interact with any essential service provider(s)?” with the answer options “I currently need...”, “I don’t currently, but have previously needed...” and “I have never needed...”. Of respondents:

- 6% said they currently need extra support.
- 11% said they have previously needed extra support.
- 71% have never needed extra support.

¹ NHS Digital’s Adult Psychiatric Morbidity Survey 2014 shows that 36% of people with a common mental disorder have never received a diagnosis.

In the report we use the term 'support need' to refer to the need for extra support to access essential services or interact with essential service providers. In our analysis, we looked at either the results for just those with a current support need or at the combined results for those with a current or past need.

Participants who had needed support in essential services were asked if they had used a system to share their support needs, and if not, why. All participants were asked a series of close questions about their views on the general idea of the sharing of support needs across essential services, whether they were concerned about certain aspects, and a set of agree/disagree statements related to this area. Finally, participants were asked a set of closed questions about what they would want to share and how.

A.8 Roundtable and expert conversations

We held 29 detailed conversations with experts in this topic. These experts came from data sharing systems, trade bodies, essential service providers, regulators and consumer organisations, data sharing and essential services. These conversations focused on what sharing of support needs currently existed, what the future might look like, as well as the benefits and risks of this type of data sharing.

To test our emerging thinking, as well as initial principles, we held an in-person roundtable on the 2nd June 2025 with representatives from charities and consumer organisations. This roundtable allowed us to consider whether our current principles would also be applicable to wider groups of people or if there would be any unintended consequences. We were also able to understand where there might be gaps in the research we had undertaken so far.

A.9 Ideas Sprint

To explore what the future of the sharing of support needs across essential services could look like and what policy solutions were needed to get there, we held an 'ideas sprint'. This was an in-person event which took place on 6 November 2025. It was attended by experts in data sharing, essential services, vulnerability, regulation and technology, as well as seven members of our Research Community. These Research Community members had either taken part in the focus group or were part of the People's Panel.

The Ideas Sprint followed a similar premise to other 'sprints' or 'hackathons', such as those organised by the FCA. We divided attendees into six groups, with at least one Research Community member in each group. Each group had a different topic based on a challenge we had identified in our research, and they had to come up with an intervention to address a problem statement for that topic. We also gave the groups one of two scenarios based on our research to help them understand the issue and to facilitate their generation of ideas. Additionally, there was a glossary of terms and an outline of existing data sharing systems on each group's table.

The day started with a presentation of our interim research findings and two People's Panel members shared their experiences and thoughts on how a system could be designed to meet their needs. Attendees then split into their groups to first consider the problem statement and to come up with initial ideas, before these were further refined and finalised. Members of the Money and Mental Health team facilitated these group discussions with questions for attendees to consider throughout the day. A digital comments board called Padlet was also used to capture thoughts and questions from attendees throughout the day. The final ideas were captured on a template form and groups then presented their intervention to the rest of the attendees.

The topics and problem statements were:

- Group 1: Providing clarity and aiding comprehension around data sharing
 - How can we design a data-sharing system in essential services that makes it clear, simple, and realistic for people to understand what they are signing up to, and what benefits they can expect - especially for people with mental health problems who may struggle with complex or inconsistent information?
- Group 2: Facilitating control of data and giving consent to share
 - How can we create a data-sharing system in essential services that gives people genuine control over their information - allowing them to choose what to share, when, and with whom - while also making it simple to change or revoke data sharing when their mental health or circumstances change?
- Group 3: Ensuring security and transparency to build confidence and trust
 - How can we ensure that a data-sharing system in essential services is secure, transparent, and trustworthy - so that people with mental health problems feel confident their data will only be used for agreed purposes, and not misused, leaked, or exploited?
- Group 4: Designing equitable, inclusive and accessible data sharing systems
 - How can we design a system that ensures people who can't or don't want to share data - due to digital exclusion, access and language barriers, or personal choice - still get fair and equal access to essential services, without being left behind or disadvantaged?
- Group 5: Connectivity and accountability: Bringing different data sharing systems together
 - How can we avoid multiple, disconnected "tell us once" systems that don't work together - and instead create a consistent, accountable, UK-wide model that sets clear responsibilities and safeguards across sectors?
- Group 6: Balancing automation and innovation with human support
 - How can we balance the efficiency of automated systems with the need for human support - so that people with mental health problems can get help through a data-sharing system in essential services in a way that feels safe, empathetic and appropriate to their situation?

We are grateful to those who shared their knowledge and experience throughout this project.

