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Improving lives through linked data: Views from groups with complex needs

Full report



**Ministry of
JUSTICE**



Department for Levelling Up,
Housing & Communities



Office for Health
Improvement
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Iechyd Cyhoeddus
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Executive summary

The Better Outcomes through Linked Data (BOLD) project is a three-year, cross-Government pilot programme, created to demonstrate how individuals with complex needs can be better supported by the Government through linking and improving data in a safe, secure and ethical way. BOLD is sharing and linking a range of social policy datasets from across government to drive new evidence and insight, and better understand how services delivered in one part of government impact on outcomes in another.

To ensure that BOLD delivers for the individuals with complex needs that it aims to serve, four projects have been identified that could deliver the greatest impact with the highest probability of success. The four key vulnerability projects chosen are: Homelessness, Substance Misuse, Reducing Reoffending and Victim Pathways. In order to demonstrate what BOLD will involve in practice, each project has developed 'use cases' which outline key research questions and the data sets that will be used to investigate these.

As part of a commitment to put data ethics at the heart of its delivery, and to support transparency and public engagement, BOLD and the Centre for Data Ethics and Innovation commissioned this piece of research with the overarching aim of informing how to take the BOLD programme forward, by engaging and consulting with the relevant audiences.

The research has engaged 82 people with lived experience of offending, alongside third sector support services, and the high-level findings are provided below.

The term audience is used throughout this report to describe groups of participants discussing a particular topic, including those with relevant lived experience and the organisations that support them.

Key findings

- 1. Overall, participants across the pilots are receptive to the principle of data sharing, and can easily identify how this could improve public services.** Many participants cite personal experiences of times where sharing information across public services would have improved their support journeys and led to better outcomes, and therefore feel that data linking would be a worthwhile exercise.
- 2. In line with these broader attitudes, participants are generally positive about the BOLD programme itself.** They feel that the programme's ultimate goal of achieving better outcomes for vulnerable people is positive, and that data sharing is 'sensible' in this context.
- 3. Participants often have overlapping experiences across the key pilot areas, and are able to reflect on the relevance of BOLD across a range of audiences.** This is most true for Homelessness, Substance Misuse and Reducing Reoffending, where participants are aware, and have personal experience of, the challenges and stigma faced by all of the pilot groups.
- 4. However, although overlapping experiences are common, it shouldn't be assumed that individuals in specific pilots have experience of other issues covered by BOLD.** Participants are concerned that, by using linked data to identify trends and patterns, BOLD could risk reinforcing stigmatising beliefs about people with certain experiences. They feel that BOLD's aim should instead be to build

understanding of, and empathy for, these audiences in wider society, as well as within public services.

5. **Participants also express concerns about the degree to which BOLD could negatively impact individuals and their outcomes.** Despite this being highlighted as something BOLD will *not* do, participants' heightened sensitivity towards maintaining their anonymity means this continues to be a top-of-mind concern. They are particularly worried about data relating to their past experiences hindering their ability to have a 'fresh start', and access services.
6. **There is also scepticism about the impact that BOLD is likely to have, stemming from broader distrust in Government and poor past experiences.** Participants are doubtful that Government will take action as a result of BOLD's research findings. This inaction is thought to be likely due to perceived system inefficiencies and the prospect of insights coming up against ingrained social and political attitudes or beliefs. Victims feel that systemic failings, such as within the Criminal Justice System and Police, are to blame for poor outcomes, and that addressing this will have the most impact for victims.
7. **To resonate and reassure members of key vulnerability audiences, BOLD use cases should be developed with four key principles in mind:**
 - **Relevance:** Use cases should depict issues that are recognisable and relevant to target audience groups.
 - **Impactful:** Examples of BOLD outcomes should clearly explain the positive impacts that it could have on the target audience groups.
 - **Clear and informative:** Case studies should be explicit in how BOLD will and won't use personal data, including clarifications about anonymisation where necessary and what BOLD is aiming to achieve.
 - **Non-stigmatising:** Care must be taken to avoid any suggestion that BOLD may link negative factors together and increase the stigmatisation that these groups experience on a regular basis.
8. **Intermediary organisations are key gatekeepers for engagement with the target pilot audiences.** Experiences of working alongside these organisations as part of this research reaffirm the need to proactively engage with them and build trust, in order to secure buy-in and support across the target audiences.

Considerations for communicating BOLD

Conducting this research was a learning opportunity in itself, and there are a number of key takeaways for BOLD in conducting stakeholder and public engagement about the programme in the future. These recommendations highlight learnings, and draw out key considerations for communicating about BOLD, as well as ongoing engagement.

1. **Engaging the target audiences requires the trust of bought-in intermediary organisations.**
 - Stakeholder engagement with intermediary organisations is a key part of building trust in BOLD. It is worth taking the time to **proactively engage with these organisations**, explain BOLD and take their feedback on board where possible.

- This research highlighted the importance of involving intermediary organisations early on in the development process, so that they feel consulted, and their input heard.
- Intermediary organisations that are bought into BOLD are often able to facilitate recruitment of end users of their services. However, these organisations are also often over-stretched and time poor, and timescales for recruitment should reflect that these organisations need approximately three to five weeks to recruit end users.
- Furthermore, this research demonstrated the impact that sharing information about BOLD could have in building confidence in the project. Therefore, BOLD should consider longer term engagement with these pilot audiences, as part of building further buy in and confidence in the project.

2. The target audiences often intersect. However, BOLD should be careful not to make assumptions that this is always the case.

- Participants are likely to fall into multiple target audiences, and readily speak about this. These intersecting vulnerabilities help BOLD to present a compelling case for data linking to improve services across these areas of need.
- However, **it cannot be assumed that these individuals within these audiences will *always* have intersecting experiences; BOLD risks reinforcing stereotypes if these assumptions are made.** For example, use cases about substance misuse should ideally not conflate ex-offenders and substance users in every example. While participants with a history of substance misuse acknowledge that this may sometimes be the case, many have never been to prison and resent the implication that they are likely to have offended.
- This is **especially true of the victims' audience.** Participants from the other audiences cite personal or anecdotal examples of people within these groups who have also been victims of violent crime and/or abuse. However, participants within the victims' audience are less likely to reference overlapping experiences with the other audiences.

3. In order to build support for BOLD both among these audiences and intermediary organisations, example use cases should lead with the impact for the target audiences.

- The initial use cases were, understandably, very detailed and focused on *what* would be happening in each example. However, as these underwent testing with the intermediary organisations it became clear that **the use cases need to focus on the *why* for each audience.**
- Leading with the impact for the target audience helps get to this *why* and engages the audience by explaining why this issue is important to look into.
 - Following this with explaining *which* research questions are being asked to resolve this issue, and *how* the data is being linked (e.g., what categories of information is being shared with who), provides a

full picture for those who wish to understand the use case in more detail.

- In developing new use cases, it is important to consider the principles outlined in the previous section of this report. **Assessing use cases against the metrics of relevance, impact, clarity, realism and a lack of stigmatisation** will help to build use cases that have the support of the target audiences and intermediary organisations.
- This also reinforces a broader implication for the pilots, that the interests of **‘end users’ should underpin teams’ work** as much as possible – for example, considering outcomes for end users at the outset when developing research questions and use cases.

4. Communicating about the BOLD project will be key in building support for its aims. Proactively sharing what is new about BOLD, and what BOLD will and won’t do, will help to assuage initial concerns.

- Intermediary organisations and participants readily speak to the challenges they’ve experienced with public services and where data linking between these services could have improved these experiences. While this is a good foundation for BOLD to build on, it is important to acknowledge that many within the target audiences have recognised this issue for many years and feel they have been ignored along the way.
 - **BOLD is in a position to acknowledge that this anecdotal evidence exists**, and to explain that what BOLD can do is analyse linked data to provide hard evidence in support of policy decisions seeking to improve these issues. This avoids presenting the issues being tackled by BOLD as totally new issues or ones that no one has any perspective on already.
- BOLD should also proactively address potential concerns by communicating what it will and won’t do with the data. This worked very well in the research and often headed off concerns that otherwise risked dominating the conversations. **Highlighting anonymity, access permissions to the data and safeguarding measures** is particularly important for the target audiences and intermediary organisations to understand when they first learn about BOLD, and helps to build their confidence in the project.

5. Ongoing engagement and communication about BOLD will be important in ensuring BOLD’s success when it is put into practice.

- Participants had questions about whether or not they, and people like them, would be **contacted to give their consent** to their data being linked in the BOLD project. BOLD should be prepared to answer questions about this and, if not collecting consent, have a strong rationale as to why.
- Ongoing engagement with stakeholders and intermediary organisations will be critical to the success of BOLD. This is not least because these organisations have access to end users, but also **because they will help to shape the narrative around BOLD**.
 - Many of these organisations have been warmed up through this research. Keeping them engaged and updated on the progress of

BOLD will help to strengthen these relationships, as well as cue to others in the sector the value of the BOLD project.

Note: the findings in this report reflect the views expressed by participants who took part in this research. The sample for this research included a total of 82 participants from across the Reducing Reoffending, Substance Misuse, Homelessness and Victims audiences.

Background and methodology

Background and objectives

The Better Outcomes through Linked Data (BOLD) project is a three-year, cross-Government pilot programme, created to demonstrate how individuals with complex needs can be better supported by the Government through linking and improving data in a safe, secure and ethical way. To ensure that BOLD delivers for the individuals with complex needs that it aims to serve, four projects have been identified that could deliver the greatest impact with the highest probability of success. The four key vulnerability projects chosen are:

- Homelessness
- Substance Misuse
- Reducing Reoffending
- Victim Pathways

BOLD and the Centre for Data Ethics and Innovation commissioned this piece research with the overarching aim of informing how to take the BOLD programme forward, by engaging and consulting with the relevant audiences.

Specific aims of the research were to:

- Gain **feedback** to improve and refine **how BOLD delivers** the four pilot projects, in particular in relation to determining acceptable uses and forms of analysis of shared data;
- Inform **how BOLD communicates** about the aims of the programme, and the progress it will make to the relevant audiences, in order to be as **clear and transparent** as possible in what BOLD are doing;
- Understand how the ways in which BOLD manages data **impacts on how much trust there is** in the programme.

Methodology

Our overall approach consisted of the following stages:



Intermediary organisation workshops

We conducted workshops with expert intermediary organisations, such as charities, who have a deep understanding of each of the audiences' attitudes and needs.

The purpose of these sessions was to:

- **Explain the purpose of the project to the intermediary organisations, covering:**
 - The proposed approach for the project
 - The specific methodologies to be used for their audience, including specific groups within this audience
 - Run through the initial draft materials
 - The role we would be asking them to play in the recruitment of participants for fieldwork
- **Gain their feedback on the approach and materials**
 - We built in time for this to ensure that the organisations had an opportunity to have their perspective on this heard, particularly in relation to the BOLD use cases
 - Ensuring that our research approach was ethically informed and considerate of practical considerations relevant for each audience (e.g., setting for fieldwork activities likely to ensure most engagement)

The following organisations participated in the intermediary workshops. Note - three more organisations were engaged but are not mentioned in the report:

Reducing Reoffending	Substance Misuse	Homelessness	Victims
Nacro Unlock	Change, Grow, Live Aspire Drug & Alcohol Services The Well Communities Build on Belief	Crisis St Basils Centrepont Thames Reach	Survivors Trust New Pathways Welsh Government BAWSO Male Survivors Partnership

Fieldwork

We engaged with a total of **82 participants** from across the four key vulnerability audiences over the course of the fieldwork period, using a combination of methods to ensure full participation from a range of individuals with differing levels of need.

The fieldwork activities conducted for each audience is outlined below:

	Reducing Reoffending	Substance Misuse	Homelessness	Victims
Stage 1	2-3hr in-person and online pilot workshops with more confident participants from each audience (either due to having taken on a more public 'advocacy' style role or as			1hr depth interviews to gain detailed feedback

	a result of having recently transitioned out of the audience). This initial phase enabled us to gain feedback in a group setting and ascertain whether our research materials would be suitable for lower confidence participants in each audience. We then had the opportunity to refine our materials before the second stage of fieldwork.	on the BOLD project. This approach was taken to ensure that participants felt comfortable sharing their experiences (rather than in a group setting).
Stage 2	Online community, following the same content as the pilot workshops. Gaining feedback through set tasks and response activities.	

Note on our approach: Based on feedback gained in the pilot workshops, we were not required to adapt our materials for the second stage of research, as all information and activities were clear and useful in the sessions.

Sampling

Given the specialist nature of these audiences, and based on our experience of conducting research with these audiences, it was agreed that we would work with the intermediary organisations to recruit participants for the research. We developed a recruitment screener, which was shared with intermediary organisations, enabling them to reach out to their networks as a trusted voice to find potential participants.

For the Victims audience, we used this approach alongside working with our trusted recruitment partner, 'iThoughts', to free-find participants who fitted the relevant criteria.

Achieved sample

Below is an overview of the achieved sample across the research, with further sample detail provided in the audience specific reports:

	Reducing Reoffending	Substance Misuse	Homelessness	Victims
Stage 1	5	10	5	6
Stage 2	22	9	13	12
Total	27	19	18	18

Note on demographics: The existing UK populations across each of these pilot audiences is noted as being skewed in terms of gender, age and ethnicity. For this research, we have recruited a range of individuals representing different characteristics and experiences. However, this has been naturally impacted by the realities of these audiences, for example, more male prison leavers, and more female victims of crime. We have nonetheless sought to include a mix of ages, genders, ethnicities and regional locations across the total sample for each audience. More detail on the achieved sample can be found in the audience specific reports.

Note on intersecting vulnerabilities: Based on our sessions with the intermediary organisations, we anticipated that it was likely that our participants would have experience of more than one of the four vulnerabilities mentioned. This became apparent during the research as participants, though recruited with a focus on one specific pilot audience, spontaneously shared experiences across multiple vulnerabilities.

Note on sample: Our target sample for each pilot was a total of 18 participants across both stages of fieldwork. We received interest from c.200 participants for the Reducing Reoffending pilot, and it was agreed that we would include additional participants at Stage 2. Full details of participant demographics can be found in the audience reports.

Note on limitations of this research: Several caveats apply to the findings presented in this report. The participants were not randomly selected and are not representative of the whole population of interest. As participation was voluntary, it is likely that participants are more motivated than the general population, and likely to have a stronger interest in the issues being explored. As the evidence draws upon individual past experiences, responses may also be subject to recall bias. This research provides rich insights into the experiences and views of participants, though it should be noted that findings will be influenced by the attitudes, experiences, crimes experienced and inherent individual biases of those providing input. The findings therefore reflect only the views of one sample of individual participants and do not reflect wider experiences of all victims.

How to read this report

This report consists of overarching findings that were broadly consistent across all four key vulnerability audiences, providing overarching feedback on the BOLD project. The individual audience reports will detail findings relevant to each specific audience.

Throughout this report, audience-specific differences will be highlighted with the following colour coding, where relevant:

Reducing Reoffending	Substance Misuse	Homelessness	Victims
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Context

Engagement with participants throughout the research surfaced contextual themes which, while not derived from direct lines of questioning, were influencing participants' responses to data linking and the BOLD programme. This section highlights the most relevant of these contextual themes for all audiences.

Many participants within each audience share a significant amount of overlapping experiences with the other audiences, often spontaneously referencing their experiences in these areas.

- While participants were recruited to have experience of one of the audience focuses, we found during discussions that many also fit within the other audiences. For example, many within the Reducing Reoffending audience spoke about their experiences with homelessness and substance misuse when discussing what could have been improved about their interactions with public services.

"I'd be quite happy if my previous offending history was released to an organisation to whom it was pertinent, but not for instance to my doctor – to whom it's not." (Homelessness)

- However, participants emphasise that while overlapping experiences are common, they should not be **assumed**. For example, those in the Homelessness audience express concerns that they could receive less support from public services, and good will from the public, should it be assumed there is a 'link' between homelessness and substance use.

Audience differences: Victims

Participants from the Victims audience did not reference overlapping experiences with the other pilot areas. However, participants from the other audiences did cite examples (personal and of people they know) of being victims of violent crime. These participants see such crimes as being a common experience for people who are living in vulnerable circumstances, such as rough sleeping.

Participants feel that they, and others in similar circumstances, are often stigmatised by broader society

- Based on their own experiences, and those of others they know, participants are acutely aware of the stigmatising attitudes and beliefs about them that are held across society.
- They also feel stigmatised by 'the system' (i.e., public services, authorities), often reinforced by negative past experiences.
 - Examples cited include difficulties accessing services or employment opportunities.
- This is a key contextual factor that means participants are particularly sensitive to the prospect of pre-judgments or assumptions being made about them.

"When we leave prison, we don't leave wanting to think about it for the rest of our lives. It's just one single experience we've had in life that we tend to want to put behind us. I would prefer being identified by Government

institutions based on what every other British citizen is assessed by. Including information about my conviction will not support me, it will only make things harder in my opinion.” (Reducing Reoffending)

Audience differences: Victims

Participants from the Victims audience note that social stigma plays a significant role in holding victims back from reporting crimes and seeking support in the first place. This is because many victims fear repercussions in terms of being ostracised by their communities, or their reputation being affected.

“Sometimes people are worried about repercussions because of information about them being known. They’re worried about judgement from the people closest to them – let alone what they think would happen if they reported to the authorities.” (Victims)

Many participants within this audience have a lack of trust in Government, largely driven by negative experiences of public services.

- Participants have engaged with a range of public services because of their circumstances. Those experiences have often been negative due to:
 - A lack of consistency and ‘joined up’ working together between services.
 - Frustration when interacting with public services, with information and support they are eligible for being difficult either to access or to understand.
 - A lack of trust in the UK Government to improve these services, with many raising anecdotal conversations or news stories they’ve encountered about a lack of Government investment in public services.

Audience differences: Reducing Reoffending

Ex-offenders are particularly likely to reference negative experiences with public services and a distrust of Government, which they perceive to be a result of a ‘lower’ status as prison leavers in the eyes of the state. Additionally, this audience was particularly likely to feel that those who deal with their cases, especially probation officers, do not care about them or their outcomes. This is seen most notably in participants’ claims that probation officers rarely tell them about the different support services or benefits they are eligible for, and the onus is always on them to find this out.

*“It’s all about ticking boxes. I don’t feel like probation officers’ care.”
(Reducing Reoffending)*

Audience differences: Victims

Victims are more likely to cite a lack of trust in the Police and Criminal Justice System, specifically. This is largely based on their own negative experiences of these organisations when pursuing justice outcomes (e.g., Police not pursuing cases, victims not feeling ‘believed’ or ‘listened to’, and not being referred to the relevant support services). Furthermore, recent high-profile cases of Police Officers committing violent crimes have

reinforced low trust – and even fear – of the Police (e.g., Sarah Everard case and David Carrick).

“I’ve had amicable conversations with Police Officers that have left me feeling hopeful, but hope is always dashed.” (Victims)

“There needs to be an overhaul of the system – what was in the news recently about that police officer committing two decades of rape. This needs to change if they want to build trust.” (Victims)

However, participants are also able to reference positive experiences interacting with public services, with these most often characterised by the empathetic and supportive attitudes of staff with whom they interact.

- Positive experiences interacting with public services highlight the dedication of staff. Staff are felt to go above and beyond when dealing with issues of understaffing and underfunding of their services.

*“The staff usually want to do a good job, which involves helping people. They generally know what they’re doing, and what they need to do.”
(Substance Misuse)*

Participants see public services as having the potential to improve, and generally feel that their experiences of accessing them would improve if they were better ‘joined up’.

- Participants feel that streamlining and joining up services across different areas more effectively would improve their experiences of accessing public services.
- However, some also feel that there are broader social attitudes exist which see them as less deserving of support.
- While data linking could improve public service provision, some participants express concerns that it will be used to evidence links between homelessness and substance use, or substance use and offending, for example.
- Rather than reinforce the stigma that these audiences often already face, participants hope that BOLD can be used to shift assumptions of these audiences as not worthy of support, and that data linking will ultimately be part of a broader shift towards providing more consistent and cohesive support to people like them.

Audience differences: Victims

Participants note that social attitudes and stigma play a significant role in holding victims back from even reporting crimes in the first place. For example, victims do not want to subject themselves to ‘shame’ or ostracisation from their families, communities and society more widely. They therefore feel that there is a need for broader societal and attitudinal changes in order for service improvements to have impact.

“I have friends who haven’t reported crimes to the authorities because they’re scared about the impact on their reputation.” (Victims)

Participants believe there are a number of ‘obvious’ improvements that could be made to the public services they have interacted with.

- Many participants have had significant experience interacting with public services for a complex range of needs and know others in similar situations. As such, they have already thought about how services working together would better support their needs.
- Participants readily point to their intersecting needs. For example, those who have left prison describe the challenge of continuing to access drug and alcohol support upon release. These participants feel there is a very clear pathway between receiving adequate addiction treatment upon release and reducing reoffending. They also feel that those within their circles, including people in similar situations and support workers they interact with, know this as well.

“Access to drug and alcohol support when you’re in prison doesn’t continue on the outside. There needs to be a communication bridge between those support services in prison and those on the outside.”
(Reducing Reoffending)

Implication for BOLD:

It is important that BOLD does not present data linking to improve services across intersecting needs as a totally new idea, and risk appearing naïve to the issues that participants feel are obvious.

Audience differences: Victims

Victims have a different trajectory of interaction with public services compared to the other pilot audiences. In general, victims have fewer interactions with a range of different services as a result of, and in connection with, their experience as a ‘victim’ per se. By comparison, prison leavers carry a ‘label’ for life which factors into the way they access different systems (e.g., housing, benefits).

While victims do feel ‘let down’, they do not always experience the degree of repeated ‘failure’ from the system that is common across the other pilot audiences. Victims taking in this research were less likely to describe ongoing circumstances and experiencing ‘labels’ for life when interacting with public services, when compared with participants from the other pilot audiences. This is likely due to victims having more ‘choice’ than these audiences in reporting their experiences as victims to public services.

“The Criminal Justice System only intervene when it is too late, and you feel like you’re not being heard, and when you build the courage to speak up, it’s just forgotten about until the next incident is reported. I was lucky to have my mum who helped me and put her heart and soul into it. I know other people who have suffered from forms of domestic violence, abuse and online harassment, all of which has not been taken much notice of, again until it is too late... If I’m honest, I suppose not everyone would speak up [about crimes] due to how poor the CJS is.”
(Victims)

Intermediary organisations that support these audiences also begin from a place of strong opinions regarding how public services can be improved to better support their service users.

- These organisations expect their audiences will have mixed attitudes towards data linking, particularly as they often come into contact with the audience members after public services have failed to support them adequately. Thus, levels of distrust are high.
 - Stakeholders emphasise anonymity and consent will be key to building trust among these audiences, many of whom may be suspicious that their data could ‘come back to haunt them’ later on in life. This is particularly true of substance users, who worry they will get a ‘history’ that will link them with substance use later in life.
- However, many of the organisations are willing to see BOLD as an opportunity to improve services and to look in particular for patterns and data on ‘what goes wrong’ before a person experiences hardship. This will help to develop more preventative methods and services, as opposed to always being focused on crisis management.
- It will be important for BOLD to work closely with these organisations to support buy-in to the BOLD project.

Audience differences: Victims

It is particularly important to work closely with intermediary organisations supporting victims, as these organisations were most likely to express scepticism of the BOLD project during initial workshops explaining BOLD and the research. Concerns around how the personal information of victims is shared and who will have access to it are widespread, with stakeholders worrying that this could inhibit victims from approaching support services in the first place.

Additionally, it is important that use cases do not appear to be scrutinising the work of support organisations, many of whom are dealing with huge caseloads on tight budgets, and instead are focused on achieving better outcomes for victims.

Carrying out additional workshops with these organisations and ensuring their perspectives were heard and acted upon – in terms of any information presented to victims and the issue areas BOLD focuses on – was key in building trust in the BOLD project.

Attitudes towards data sharing / linking

During the research, participants were shown information about what data linking involves, to help build their understanding of this topic and explore their initial response to the concept of their data being used in this way. This section highlights key themes relating to their overall attitudes towards data linking. Full stimulus material shown to participants can be found in the Appendix section of each audience specific report.

Participants are cautious about data linking, and seek to understand the security measures that will be put in place to keep their data safe.

- As many participants mistrust the Government, they have concerns about how data linking will be done safely and appropriately.
- While concerns initially centred on data linking being used to track people and make decisions about their situations or what support services they would be eligible for, this eased upon further explanation of BOLD and the anonymisation of personal data. However, some participants remain concerned that the Government could reverse this decision in the future and de-anonymise the data.
- Participants are also concerned that erroneous data entries into their files could be made more difficult to correct if the data was linked. An incorrect data entry has the potential to badly affect this target audience, for example one participant referenced an incorrect entry that he was seen in his exclusion zone (that turned out not to be the case) that almost resulted in him being recalled to prison.

“So many people have had data entered incorrectly, like wrong courses or misquotations. You can have data about you that is wrong. I don’t feel like the data being held about me is necessarily correct.” (Substance Misuse)

- Participants also seek clarity on the following aspects of data linking:
 - Will consent for data linking be collected? If so, how?
 - Can I opt out of my data being linked?
 - What data will be shared and with whom? Will private organisations have access to my data?
 - How can I be sure my data will be kept safe and anonymous?
- These attitudes are broadly reflective of those in the general public, many of whom are concerned about the implications of data being shared and the impacts this could have on their privacy.

However, participants see how data sharing could improve public services and this is felt to be a worthwhile aim.

- Participants spontaneously reference points where the sharing of data has improved their experiences of public services. For example, the Government’s ‘Tell us once’ programme to help with bereavement support is felt to be a really effective use of data linking and evidence that it is possible to join up information across services.
- However, the majority of experiences shared were those in which data sharing was not done effectively, negatively impacting outcomes.

Audience example: Reducing Reoffending

Accessing records from time spent in prison is felt to be extremely difficult and an opportunity for data sharing to improve experiences.

For example, one participant mentioned completing his GCSEs while in prison. Upon leaving prison, this participant was not given any documentation of this and was unable to prove he had taken them when looking to apply for college. Ultimately, he had to re-take his GCSEs and felt that had he not had a strong support network around him, he would have given up on his goal of going to college.

*“I did my GCSEs in prison – but then I had to do them again when I got out. What’s the point of doing them if you can’t access them?”
(Reducing Reoffending)*

Audience example: Homelessness

Those who have or are currently experiencing homelessness raised the difficulty in accessing services due to not having a consistent registered address.

For example, one participant spoke about currently living in his car in a borough in London to which he does not have a registered address, with his registered address being elsewhere in the south of England. When attempting to access a mental health support service in this borough, he was told he could not access the service as he was not a resident. This was a critical time for this participant, shortly after which he attempted suicide.

“It’s difficult to access support when you aren’t consistently registered at one address or under particular details.” (Homelessness)

Audience example: Victims

Participants feel that data linking could play a role in preventing individuals from becoming victims – either in the first instance, or in a recurring context.

For example, one participant spoke about her family suffering domestic abuse from her then partner. While the Police and the children’s schools had been alerted to the incidents that were taking place, this information was not shared with Adult Social Care services. The participant had to spend time in hospital, and a social worker suggested that her ex-partner could be let back into the family home to look after the children during this time – which would have been extremely dangerous, and unacceptable.

“Things like the Police alerting Adult Services would give credence to the stress a family is going through and their need for support.” (Victims)

Responses to the BOLD project

During the research, participants were shown information about the BOLD project, to explain its purpose and objectives. They were also shown information about what BOLD aims to do in the context of their respective pilot. This section highlights key themes relating to their response to the BOLD project overall. Full stimulus material shown to participants can be found in the Appendix section of each audience specific report.

Overall, participants across all audiences are broadly receptive to the BOLD project, and agree with its purpose of achieving better outcomes.

- In line with broader attitudes towards data linking, the majority of participants are positive about the role that BOLD will play in filling knowledge gaps across Government departments and service providers.
- BOLD's focus on better outcomes is compelling, with participants particularly interested in the ways in which BOLD will support outcomes that transition people out of vulnerabilities long-term (e.g., preventing repeat homelessness, substance misuse and reoffending).

"Huge, a potential gamechanger. If it could get to root of the reason so many of us fall back into homelessness, I think it could change the lives of many." (Homelessness)

"I think this would be very useful. When in active addiction I found all departments, especially to do with health, were not connected and did not have the same information, knowledge or even know which services were available to people in my situation." (Substance Misuse)

Many participants are surprised that the data linking that BOLD will conduct is not currently being practised across services.

- Despite participants having various personal experiences of services not being 'joined up', there is a basic assumption that information sharing is currently being practised across Government departments and support services.
- This assumption also exists in relation to the intersection of different vulnerabilities, as this is something participants themselves share anecdotal evidence of (e.g., they know that incidences of substance misuse and homelessness are high amongst prison leavers).

"I think linking data sounds like a good idea and I'm sure it must already be done to an extent as it allows new patterns and insights to be discovered and explored." (Homelessness)

"From the example provided, I feel disappointed that this is not actually how the services are collaborating with each other at the moment." (Victims)

While participants are broadly positive about BOLD, they do caveat this with a belief that data sharing should be selective and purposeful.

- Many express a belief that only ‘relevant’ data should be shared between organisations, and a preference for data not to be shared unnecessarily.
- For example, this could mean only sharing data that is relevant to the work that an organisation does, and that is required to facilitate a shared understanding between two organisations.

“I don’t think it is a good idea for information to be shared across organisations that don’t seem connected. For example, I would be uncomfortable for my health information to be shared with housing services, possibly for fear that it may affect their decision making. I think it may be useful if information were shared between more connected services, however. For example, between health and emergency.”

(Victims)

Participants feel it is particularly important that BOLD actively works against reinforcing prejudices and stereotypes.

- While participants are looking for BOLD to avoid making assumptions about them and furthering the stigma they already often face, they also see BOLD as having potential to take this one step further and to be part of a broader shift in attitudes towards these audiences.
- In identifying patterns in the data and ultimately revisiting the way public services are provided to these audiences, even if this is down the line, participants see an opportunity for BOLD to be part of a wider systemic change in which people in their circumstances are better understood and support is better coordinated.

“Whilst I agree there could be better support, things could always be improved. My firm belief is that what is missing in health is a recollection of the social and society impact on addiction and health conditions. We are a product of our environment and for some reason we can never equate things to needing to change the social structure that creates misery.”

(Substance Misuse)

However, there is some scepticism about the impact that BOLD is likely to have, stemming from broader distrust in Government.

- Across all audiences, participants express doubts over the extent to which Government will actually act on insights gained through BOLD.
- This is often due to broader distrust in Government as a result of past experiences, where they feel that services have not acted sufficiently to support them (or others in a similar situation).

Participants suspect that a lack of action in response to insights from BOLD might occur as a result of:

- **System inefficiencies:** Government might be slow to respond (if at all) to insights from BOLD due to complex bureaucracy or poor organisation. Therefore, insights alone will not lead to better outcomes, and there is a need for effective system-wide processes to implement policy and ‘turn information into action’.

- **Political motivations:** Insights from BOLD might support actions that are politically or socially unpalatable, reducing the motivation of Government departments to act on findings.
 - Examples cited include the perceived prioritisation of specific cohorts for support services (e.g., housing) and an unwillingness of employers to hire those with offending histories.

“I think research has been held back or limited due to limited samples or participants. If this allows us to identify more patterns and, as a result, more areas of support or change then that is a good thing in my mind. However, just because there is data proving a link, doesn’t mean this translates to anything being done about it, as that is down to Government and policy which often ignores science and data.” (Homelessness)

“Employers don’t like unspent convictions. No amount of training and education for prisoners can overcome that, so employment will continue to be a major problem for prison leavers. Accommodation has a similar problem, and many landlords won’t let to the unemployed.” (Reducing Reoffending)

Participants also feel that they already ‘know’ the answers to some of the questions that BOLD is seeking to address, further adding to their scepticism about the programme’s likely impact.

- Based on their own experiences, and ties to specific vulnerable communities, most participants feel that they know what the causes of vulnerability are.
- This means that some of the overarching questions that BOLD is seeking to understand feel ‘obvious’ to participants, and further builds their scepticism about the project’s purpose and likely impact.
- It will therefore be important for BOLD to ensure that the programme is positioned as providing evidence to validate anecdotal understanding, in order to support policy decisions.

Audience differences: Victims

Victims strongly feel that systemic failings (such as within the Criminal Justice System and Police, specifically) are to blame for poor outcomes. Many participants feel that addressing these issues through better funding and development of services and personnel is likely to have more impact than building understanding of the issues through research.

“I just feel that the research is futile, I can tell you the answers you will get from that research! Money, time, manpower needs to be put into our public services, then maybe research wouldn’t be necessary.” (Victims)

Participants have specific concerns about how data used by the BOLD programme will be managed and governed securely, particularly in relation to ensuring anonymity. Specific concerns raised include:

Concern (<i>in order of importance</i>)	Reassurances needed	Most concerned audience(s)
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Acquiring consent	Participants frequently raise the issue of consent upon first hearing about data linking. However, views do change once further information is provided: 1. Participants express a strong interest in opt-in consent for personal data at the point of collection, as well as when data is shared between organisations. 2. However, explanations of how BOLD will anonymise data work well to assuage concerns, and participants feel that opt-in consent at the point of data being shared with BOLD is less important.	Participants generally feel reassured about the need to give repeated consent, once they are offered an explanation of the anonymised nature of the data that BOLD will use. Specific points of reassurance that are helpful include: • Identifying contexts where individuals can opt-in e.g., at the point of data collection, at the point of data sharing agreements being confirmed between organisations • Explaining why consent will or will not be acquired in different contexts • Clarifying legal / data protection policies that will be followed (including reference to familiar terms, such as GDPR)	All audiences
Ensuring anonymity	Strong concern about identifiable personal data being used as part of the BOLD programme.	• Personally identifiable information will be anonymised and used confidentially	Victims
Impact on individuals	Concern that data linking will be used to make decisions about individual cases, and hinder peoples' abilities to access services (e.g., impact on employment or benefits support due to past experiences of substance misuse or offending).	• Data will be used at an aggregate level only • Data will be used for research purposes only • Only relevant data will be shared between different organisations	All audiences (<i>less concern amongst Victims</i>)
	Particular sensitivity towards mention of the Ministry of Justice, due to concerns about data linking impacting individual justice outcomes.	• BOLD will not be used to make decisions about individual cases	Prison leavers

Security and governance	Concern about <u>who</u> has access to data as part of the BOLD programme.	Clarifying policies and requirements on: • BOLD personnel (their qualifications and training) • Access policies (who has access to which information, how is access permitted) • Specific research purposes (what the data will be used for and by whom) • Data will not be 'sold' to third parties or private companies	All audiences
	Concern about what happens in the case of a security breach.	Clarifying policies and processes relating to this scenario, such as: • Security systems in place to prevent breaches from occurring • Process for recovering data in the case of a breach • Process for communicating breaches to those whose data is involved	

Audience differences: Reducing Reoffending

Prison leavers are more likely to be wary of the BOLD project at the outset, with strong concerns about data linking across Government departments and services being used to stigmatise or exclude people with histories of offending. They are also particularly sensitive towards mentions of the Ministry of Justice, given their offending histories, which prompt concerns about justice outcomes based on data about them.

"I strongly disagree with this. I don't see why every single Government department needs to know about my spent conviction. It is hard enough dealing with one body when you have a conviction and being judged on that basis." (Reducing Reoffending)

"When people come out of prison, they want a fresh start. They don't want every arm of public services armed with that information – so that if you ring the council to say your bin hasn't been collected, you get a sarcastic comment from the Council official saying, 'why should we collect your bins when you're a criminal.' Even if that doesn't happen, the suspicion will be there. Private information should stay private." (Reducing Reoffending)

“It opens up the prospect of a Big Brother society, where parents are afraid to take their children to the doctor because they’re concerned information will be passed on to the school.” (Reducing Reoffending)

Audience differences: Victims

Victims are less likely to be concerned that data linking will have a negative impact on the outcomes of individual cases, or hinder peoples’ abilities to access services. This is likely due to the fact that victims generally have fewer interactions with a range of services in connection with their experience as a ‘victim’.

Victims’ concerns lie more in assurances of anonymity and in only relevant data being shared with different organisations on a ‘need-to-know’ basis (e.g., not wanting details of their medical history connected with their case to be shared with adjacent health services, such as pharmacies).

“I think pharmacists should only receive what medication we need and not be able to access our records. I know someone who had a situation before where a pharmacist accessed their medical record data through being a pharmacist. I don’t think someone other than the doctor you see for certain things should see things (e.g., abortions or sexual assault) other than medication you need from that chemist on that day.” (Victims)

“I don’t think I know enough about the project to warrant a smile just yet. However, I do agree it is a good initiative and think it is worth a try at least. I think I feel more comfortable about my privacy after reading the will and will not lists. This confirmed for me that either way you remain anonymous, and data shared is protected. I think I’m worried more about correct procedures taking place (i.e., although they may ask your permission to share data, this is usually in a message that you view once and no one actually reads what they’re saying yes to).” (Victims)

BOLD use cases

During the research, participants were shown three example use cases to demonstrate the types of issues that their respective pilot would seek to address, and how BOLD would do this. This section outlines participants' responses to the use cases overall. Detailed responses to each use case shown to participants can be found in the pilot specific reports. Full stimulus material shown to participants can be found in the Appendix section of each audience specific report.

While specific feedback for the use cases is provided in the specific audience reports, the use case section in this report will draw on findings that are consistent across all audience groups, unless specified. It will provide overarching learnings and principles for future communications development. In addition to the breakdown included in the tables below, this report will also reference the learning process undertaken when developing the use cases with the intermediary organisations.

Note on the development of the use cases:

The use cases were a key area of discussion in the intermediary organisation workshops. The participating organisations across all audiences provided general and consistent feedback on how the use cases should be developed in order to prompt useful discussions with participants. Common themes that were highlighted, and implemented in the refined use cases before starting fieldwork, include:

- *Providing a clear benefit and 'so what' for the audience in question, as well as a personal benefit for participants where possible.*
- *Avoiding stigmatising language (e.g., 'ex-offenders' was changed to 'prison leavers').*
- *Avoiding implications of 'blame' on either support organisations, or participants themselves, for current issues in the provision of services.*
- *Simplifying explanations of which organisations will be involved in the data sharing process, and avoiding technical language about data linking in general.*

What	Why	Evidence
Use cases that are well-received		
The uses cases that are well-received are those that use scenarios that are relevant and realistic to target audience groups. The examples that participants claim they have experienced themselves generally provoke the most positive reactions.	Using relevant case studies appears to help participants understand more clearly why BOLD will be beneficial, as they can imagine how it would have improved their own situation. They also tend to find these case studies more engaging and interesting.	<i>"I think people with similar experience to me would definitely welcome anything that can increase access to relevant education if they want to use it."</i> (Reducing Reoffending)

Participants express fewer doubts or concerns over use cases when it is explicitly clear which services or sectors are going to be sharing data with one another. They then understand why the data sharing is needed and are less worried that their data will be misused.	Many are wary of data sharing between a multitude of different services and organisations. When they know explicitly what data is being shared with whom, they understand why it is necessary or helpful, and are less likely to focus on their concerns. This suggests that when logical benefits of data sharing are apparent, participants are happier to agree with the initiative.	<i>“Access to drug and alcohol support when you’re in prison doesn’t continue on the outside. There needs to be a communication bridge between those support services in prison and those on the outside.”</i> (Substance Misuse)
Participants more readily accept cases studies when the solutions or outcomes they mention are seen to be achievable . When they can understand and believe how BOLD will help in a specific situation, they are more likely to support it.	As already mentioned, participants often approach public service systems with scepticism, based on bad experiences they have had in the past. This is likely why they can react to case studies with a pessimistic outlook, not always believing wider systematic changes are likely. Making case studies and their intended goals achievable and realistic therefore appears to be important.	<i>“There MUST be a joined-up approach to engage mental health services and social care, counselling for people with addiction issues. Sending them off to a useless 12 step group isn’t going to solve the complex problems that cause and maintain addiction.”</i> (Substance Misuse)
Showing the potential positive outcomes and tangible benefits of the BOLD programme appears to increase positive reactions among the target audience groups. The examples that work best spell out how BOLD may improve the systems that are in place.	Despite continued explanations throughout the scenario testing, many are quick to misunderstand the purpose and intended outcome of BOLD. Having clear and tangible outcomes appears to help diffuse many of these misunderstandings.	<i>“These questions are really good to be honest, they’re asking the how and the what. How is it happening, what is the cause, how can we support? Those are really good.”</i> (Homelessness)
Causes for concern		
Participants are wary of stigmatisation , with most	Many are fearful of data linking confirming strong	<i>“If people can access it that shouldn’t be able to, they</i>

having experienced this frequently in their lives to date. Examples should explicitly set out that BOLD will not presuppose target audience behaviours, and rather help increase positive outcomes. This was most relevant for the Homelessness, Substance Misuse and Reducing Reoffending use cases.	links between issues like homelessness, substance abuse, and crime, which they feel may only worsen outcomes for people like them, especially in the areas of housing and employment. Some also believe that BOLD may allow employers, medical professionals or housing officers to see their data, which may harm their chances of receiving extra support.	<i>could share personal details online or with places that then could directly impact your ability to find a job or start fresh.”</i> (Homelessness)
Participants felt that some examples showed a simplified case study that did not take into account certain factors, for example substance abuse users mention that mental health issues are an important factor in many stories of drug abuse, and that it should be referred to. Use cases should, where applicable, ensure that examples are depicted as complex and the result of multiple factors.	Participants feel stigmatised or, in some cases, that the case studies imply blame on the target audience groups when additional factors or circumstances are not mentioned. They respond better when the complexities of these cases are accurately described in the examples.	<i>“Substance use is a result of mental health issues; you have to teach people how to regulate their emotions and find coping mechanisms, rather than treating addiction.”</i> (Homelessness)
Participants are often well aware of the links between issues like homelessness, substance abuse, and crime. In some instances, they felt that the case studies would just be investigations that would find out what they know already, not helping make outcomes better for people like them. Case studies should show how learnings will be applied where possible.	The target audience groups often know better than most what the issues and driving factors are, in making situations worse or missing chances for improvement. Their first-hand experience of the system means they are often frustrated by those in positions of authority telling them what they already know.	<i>“A less naïve, better-informed mindset on the part of support services would be a start – one which understands the severe and very long-lasting pressures experienced by prison leavers of all categories.”</i> (Reducing Reoffending)

Participants are quick to assume BOLD applies to their personal data , even after BOLD's purpose has been explained in full previously. This is why BOLD's function and purpose, especially with the anonymisation of data, needs to be clearly explained and reiterated throughout all communications with the target audience groups.	Participants are repeatedly concerned that their personal data might be compromised as a result of BOLD, either falling into the wrong hands or negatively affecting employer or housing officer views of them. Some even express concerns about data being misused or exploited, by either rogue individuals or an over-controlling Government.	<i>"I don't think it is a good idea for information to be shared across organisations that don't seem connected. For example, I would be uncomfortable for my health information to be shared with housing services, possibly for fear that that may affect their decision making."</i> (Victims)
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Based on this analysis, we recommend using the following overarching principles when designed or editing communications for the BOLD project as whole.

- **Relevance:** Case studies should depict scenarios that are recognisable and relevant to target audience groups.
- **Impactful:** Examples of BOLD outcomes should clearly explain the positive impacts it might have on the target audience groups.
- **Clear and informative:** Case studies should be explicit in how BOLD will and won't use personal data, including clarifications about anonymisation where necessary and what BOLD is aiming to achieve.
- **Non-stigmatising:** Care must be taken to avoid any suggestion that BOLD may link negative factors together and increase the stigmatisation that these groups experience on a regular basis.

Below is an overview of the performance of each use case presented to participants. The ticks and crosses indicate where the use cases did or did not deliver against each respective principle.

Use Cases	Principles			
	Relevant	Impactful	Clear and informative	Non-stigmatising
Substance Misuse				
Use case 1: Treatment for those on probation	✓	✗	✓	✗
Use case 2: Substance use issues after leaving prison	✓	✓	✓	✗

Use case 3: Substance use issues and risk of multiple conditions	✗	✓	✗	✗
Homelessness				
Use case 1: Rough sleeping and substance use issues	✓	✗	✓	✗
Use case 2: Homelessness and spending time in prison	✓	✓	✗	✗
Use case 3: Repeat homelessness	✓	✓	✓	✓
Reducing Reoffending				
Use case 1: Risk of re-offending	✓	✗	✓	✓
Use case 2: Employment after spending time in prison	✓	✓	✓	✓
Use case 3: Children of imprisoned parents	✓	✓	✓	✗
Victims				
Use case 1: Engagement with the Criminal Justice System	✗	✗	✗	✓
Use case 2: Engagement with support services	✓	✗	✗	✓
Use case 3: Accessing support	✓	✓	✗	✓

Further detail on responses to the individual use cases can be found in the audience specific reports.

