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

Substance Misuse Pilot

Audience summary report

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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 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 19 people with lived experience of substance use, alongside 4 third sector support services, and the high-level findings are provided below.

This report focusses specifically on the research with the group of participants discussing substance misuse, including those with lived experience and the organisations that support them, henceforth shortened to substance misuse audience in this report.

Key findings

- 1. Overall, participants in the substance misuse audience are receptive to the principle of data sharing and can easily identify how this could improve public services.** Many participants reflect on personal experiences where sharing information would have led to better outcomes, for example between health and care services and addiction treatment services (though it is important to note the data sharing BOLD is undertaking is to inform national policy rather than support management of individual cases).
- 2. Participants are generally positive about the BOLD programme.** Participants are often surprised that their data is not currently being linked in this way, and are largely open to this idea. This audience is particularly interested in the ways in which BOLD will support outcomes that transition people out of substance misuse long-term, for example supporting people not to re-lapse into addiction after receiving treatment, by more joined up working between after-care support services.
- 3. However, some are sceptical about the impact BOLD is likely to have.** Experiences of inefficiencies in public services leads some to feel that while BOLD may identify patterns that could support better outcomes, public services may not have the financial backing or support from Government to implement these changes. Sharing further information about BOLD and the use cases does help to build some

confidence in the project, and indicates the benefit of continued engagement with the pilot audiences going forward.

- 4. While participants feel the use cases raised by BOLD are important and relevant, including to people they know if not themselves, they are surprised to see all three use cases focus on prison leavers or those on probation.**

Participants acknowledge this audience is likely to face additional challenges, but this risks feeling stigmatising to this audience, many of whom have no experience within the criminal justice system.

- 5. Participants expand on the use cases, suggesting that the issues can be applied beyond prison leavers to those experiencing substance misuse more generally.** Participants also suggest better coordination of mental health and addiction treatment services as an area BOLD may wish to explore further, as this is felt to be key to supporting better outcomes in this audience.

Considerations for communicating BOLD with the substance misuse audience

- 1. Proactively communicating that BOLD will anonymise personal data, where feasible, is key in encouraging support from the substance misuse audience.** This audience express concern that their experiences with addiction will be used against them and could impact their access to housing, benefits and employment. Proactively addressing this concern by highlighting anonymity, access permissions to the data and safeguarding measures will help to offset these concerns.
- 2. BOLD should highlight use cases that focus on areas other than the intersection between substance misuse and prison leavers.** This will ensure BOLD does not appear to be making assumptions about intersecting vulnerabilities with this audience and acknowledge the wide variety of people who experience substance misuse.
- 3. Example use cases should clarify how improvement to public services overall will help people like them in the future.** Some participants struggled to see how the use cases could have an impact for them personally, if the data shared is anonymous. Explaining how BOLD aims to improve the provision of public services overall was key in building understanding and eventual support for the use cases.
- 4. Participants highlight the coordination of mental health services and addiction treatment support as a key area in which they feel BOLD could focus on in a use case.** Speaking from experiences, participants feel more joined up working between these types of support would have led to better outcomes in their personal recovery journeys.

Note: the findings in this report reflect the views expressed by participants who took part in this research.

Background and methodology

Background and objectives

The BOLD project is a three-year cross government pilot programme, created to demonstrate how individuals, and particularly those with complex needs, can be better supported by removing barriers across government and linking and improving data in a safe, secure and ethical way. To ensure that BOLD delivers for the individuals with complex needs 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 of research with the overarching aim of engaging and consulting with the relevant audiences for the BOLD project to help inform how we take the programme forward.

Specific aims of the research were to:

- Gain **feedback** to improve and refine **how BOLD delivers** the four pilot projects, particularly 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 up fieldwork activities to ensure engagement with each audience)

The following organisations participated in the intermediary workshop for the substance misuse audience:

- Change, Grow, Live
- Aspire Drug & Alcohol Services
- The Well Communities
- Build on Belief

Fieldwork

We engaged with a total of **19 participants** across the substance misuse audience 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 the substance misuse audience are outlined below:

	Substance Misuse
Stage 1	<p>3-hour online pilot workshop with 10 participants with lived experience of substance misuse, including a variety of alcohol and drug use. Participants were all engaged with support services through an intermediary organisation. Our sample included participants who are currently actively using drugs and/or alcohol.</p> <p>This initial phase enabled us to gain feedback in a group setting and to 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</p>
Stage 2	<p>Online community with 9 participants, following the same content as the pilot workshops.</p> <p>Gaining feedback through set tasks and response activities.</p>

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.

Achieved sample

Below is an overview of the achieved sample across the substance misuse audience:

	Substance Misuse
Stage 1	10 x participants with lived experience of substance misuse, including a variety of alcohol and drug use. <ul style="list-style-type: none">● 6 x men and 4 x women● Range of ages and ethnicities● All located in the Greater London area
Stage 2	9 x participants with lived experience of substance misuse, including a variety of alcohol and drug use. <ul style="list-style-type: none">● 9 x men● Range of ages● Mix of ethnicities● Mix of locations in England and Wales

Note on intersecting vulnerabilities: based on our sessions with the intermediary organisations, we anticipated that it would be very likely that our participants would have experience of more than one of the four vulnerabilities mentioned. This did become apparent during the research as participants, though recruited with a focus on one specific vulnerability project, spontaneously shared experiences across multiple vulnerabilities.

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 the substance misuse audience.

Those experiencing substance misuse share a significant amount of overlapping experiences with the other audiences, often spontaneously referencing their experiences in these areas.

- While participants were recruited on the basis of their experiences with substance misuse, we found during discussion that many also shared experiences with the other audiences. For example, participants reference experiencing homelessness while using substances, receiving substance misuse treatment while in prison and then being left without treatment on release and falling back into substance misuse, and having been victims of crime, including domestic violence and assault and battery.

“It would help women who have experienced domestic violence if information was shared between support services for substance misuse and domestic violence to streamline the process [or engaging with both of these services].”

- There were also participants in both stages 1 and 2 that only had experience of substance misuse and did not share experiences with the other three areas. However, participants in the substance misuse audience were likely to know of others with overlapping experiences, even if this did not apply to them. This audience felt referencing these overlapping experiences was less controversial than the other three audiences. For example, while substance misusers spontaneously discussed experiences with homelessness, those in the homelessness audience perceived use cases referencing substance misuse as potentially stigmatising.
- However, as with the other three audiences, it is important not to **assume** overlapping experiences across the audiences, but substance misuse participants were open to discussing how these experiences intersect when discussed sensitively and without presupposing their own experiences.

Those experiencing substance misuse are likely to have engaged with many different public services to meet their needs.

- Interactions with public services are largely described as a pain point for participants, who find navigating the different support services available difficult and at times, triggering. Negative experiences for this audience are characterised by:
 - Difficulties accessing information and understanding what substance misuse treatment or support services they are eligible for
 - Difficulties getting referrals to the treatment services they are eligible for
 - Incorrect information on their records being challenging to amend
 - Triggering recounting experiences that contributed to substance misuse when interacting with a new treatment or support service

Audience example: Substance Misuse

Participants described difficulties with navigating the support services they are eligible for, while also going through substance misuse treatment.

For example, one participant reflected on his experience of applying for Universal Credit, while also in treatment for a drug addiction. Although he explained his situation when applying, DWP frequently got in touch with him to try and get him into work programmes through the job centre. The participant found this stressful as he needed to focus on recovery from his addiction and was concerned that turning down these work programmes could impact his benefits claim.

“It can be very awkward and frustrating when you have to keep recounting your story to other organisations. For example, the DWP when I had to apply for universal credit. I had to go in and tell them about my drug addiction which was very stressful because I’m not ready to be put through the work programmes they have available through the job centre. They were constantly calling and trying to get me into various work programmes”

- As with the other audiences, participants have also had positive experiences interacting with public services, largely due to the empathetic and supportive attitudes of staff with whom they interact. For example, one participant was in considerable debt and was unable to manage this due to his addiction. He felt staff at DWP were extremely patient with him and understanding of his situation, rather than judging him as he expected. Together, they were able to work out a plan for him to deal with his debt.

“DWP helped me through the debt process and helped me to understand the legalities of everything. They were really understanding of my situation, and it felt like they were on my side.”

Participants feel there are clear improvements to be made in the streamlining and joining up of services, particularly across health and benefits services, that would improve their experiences.

- Participants describe providing the same information about their addiction ‘over and over again.’ This is felt to be particularly true when interacting with health services and the benefits system.
- Participants are very aware of how substance misuse impacts their health and find it frustrating that the different departments within the NHS (most notably when participants interact with physical versus mental health services) do not seem to share information between them. For many, this results in having to re-disclose their addiction when interacting with a new department and having to start assessment processes from the beginning in order to receive appropriate care.
- Participants also express that the lack of joined up working between the health system and the benefits system often leads to them having to provide a great deal of information about their situation to ‘prove’ they are receiving treatment and therefore are not required to be looking for or in work to receive Universal Credit. This is felt to

be a stressful process which would benefit from the sharing of information between health services and DWP.

- Participants readily refer to these examples and the idea of sharing data between relevant services feels 'obvious' to participants and a step in the right direction to accommodate intersecting needs.

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.

[N.B. Much of the participant discussion below is to do with how data about individuals could be shared between organisations to improve the join up of services. This is likely due to this being the form of data sharing participants best understand or are familiar with. However, it is important to note that this kind of data sharing is not in scope for the BOLD Substance Misuse Pilot, who are only using anonymised or pseudonymised versions of data to aid national policy development and research]

Participants in the substance misuse audience initially express concerns that data linking will be used to make decisions about the types of support they are eligible for now and in the future.

- This is a particularly prevalent concern for this audience, who are concerned that their histories of addiction could be used against them. For example, some express concern that they would be placed 'at the bottom of the list' for any social housing, if their substance misuse were disclosed. Additionally, participants express concern that their substance misuse could prevent them from finding work in the future.
- Upon further explanation of BOLD and the anonymisation of personal data, where feasible (i.e. excluding datasets such as the homicide index) these concerns are largely eased. However, along with the reducing reoffending audience, the substance misuse audience remains concerned that government could reverse this decision in the future and de-anonymise data.
- Participants seek clarity on the following aspect of data linking:
 - Can I opt out of my data being linked?
 - What data will be shared and with who? *Participants emphasise that data should only be shared with relevant organisations, rather than a large database being built that all public services have access to*
 - How can I be sure my data will be kept safe and anonymous, now and in the future?

"It sounds good but if you have substance abuse and the data is shared then it could be used against you by employers or housing benefit services."

However, participants see how data sharing could improve public services, particularly in accessing support they are eligible for more easily.

- Participants focus on the personal benefits of data linking, such as:
 - Not having to repeat yourself to the different services you interact with
 - Ensuring the type of support you receive takes into account the variety of needs one has
 - The potential to be able to be referred to and access different support services more easily across the UK

“The benefits of data linking could be huge. It would be helpful when you’re attending an appointment and they have already read up on your data from [their service] and other services. It can relax you because you might not be having a good day. It would also show that you’re being treated as an individual rather than just another appointment.”

Audience example: Substance Misuse

Participants readily make the link between substance misuse treatment services and health services joining together to provide better quality of care.

For example, one participant discussed being prescribed a medication to help treat her addiction. At this time, she was also having some health difficulties and was put on additional medication to help treat these difficulties. She was unaware she needed to disclose the medication she had been prescribed as part of her addiction treatment, which led to complications with other medications she was prescribed. This participant became ill and it wasn’t until she went to the emergency department that she felt health services built a complete picture of all of the medications she was taking.

“Failures in data sharing led to unnecessary medical procedures and a lack of clarity over what medication I should be taking.”

Audience example: Substance Misuse

While participants are overall cautious about the sharing of information with police services, some did identify instances where data linking could be beneficial.

For example, one participant was arrested by the police whilst having an episode related to their addiction. She was taken to the police station and explained her difficulties with addiction to the police. She was surprised at how kind and respectful the police were during this conversation. The police ultimately released her and referred her to a local addiction treatment centre, facilitating her receiving support immediately upon release.

In this instance, the participant felt the sharing of information (between her and the police and then between the police and the treatment centre) made this a positive experience. She reflected on experiences of friends where police did not deal with those experiencing addiction in the same manner and felt that where the police and treatment services could share information, this could help others in a similar situation receive appropriate care.

“The police were incredible. They spoke to me with a respect and were caring, speaking very kindly. They referred me to [an addiction treatment centre] where I then got further support.”

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 the Substance Misuse pilot, specifically. 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.

Overall, participants in the substance misuse audience are receptive to the BOLD project and agree with its purpose of achieving better outcomes for people in similar situations to their own.

- Participants welcome BOLD’s focus on achieving better outcomes. As with the homelessness and offender audiences, the substance misuse audience is particularly interested in the ways in which BOLD will support outcomes that transition people out of re-lapsing or staying in vulnerable situations long-term (for example, re-lapsing into addiction after receiving treatment).

“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.”

- Participants hope to see BOLD streamlining the process of accessing appropriate treatment earlier on when experiencing addiction, as the process for doing so is felt to be overwhelming and difficult for someone in addiction to coordinate across services.

“I feel that if data was shared, then a lot more people would be getting the help they need, rather than giving up and losing hope due to paperwork.”

“I think this will help people have more confidence and seek help earlier as it does away with the stress of facing someone brand new and having to repeat your problems all over again... When you have to repeat your personal information over and over again it feels like you are on a conveyor belt system. It is very stressful and leads to people like myself cancelling appointments or not turning up.”

Audience example: Substance Misuse

Participants can readily see how the BOLD project can be applied. Looking for patterns between addiction treatment and health services and lining up appropriate after care services is felt to be a particularly important application.

For example, one participant is concerned about the impact of coming off the medication they have been receiving while they are in addiction treatment. They feel they are likely to need access to mental health support services as they wean off the medication, to prevent a relapse. They felt BOLD could be applied to see if there was a pattern in coming out of addiction treatment and receiving mental health support in leading to better outcomes. If so, this is something that could pre-emptively be organised for people in a similar situation.

“If information was linked, I might be able to better access services I need. For example, I am worried about my mental health when I come off my addiction medication in January. If services were linked, they would know that people in my situation need mental health support after coming off the medication and it would be there available and waiting for me so I don’t have to stress about trying to line these important services up myself.”

However, there is some scepticism about the impact BOLD is likely to have, stemming from previous negative experiences with public services and broader distrust in Government.

- While participants are bought in to the idea that BOLD can identify instances where data linking could improve services, some express doubts over the extent to which Government will act on these insights.
- For those in the substance misuse audience, experiences of inefficiencies in public services feeds into the perception that Government may be slow to respond (if at all) to insights from BOLD due to complex bureaucracy or poor organisation.
- Some participants also feel 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. For example, the link between having access to stable housing and successfully entering addiction recovery is felt to be obvious to participants.

Implication for BOLD:

It will be important for BOLD to acknowledge that 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 use cases

The BOLD programme and the Substance Misuse pilot have been designed to deliver on 'use-cases'. A use-case is a process, decision, research question or policy that could be improved by evidence derived from linked data. During the inception of the BOLD programme, use-cases were developed and prioritised based on extensive engagement with stakeholders from across government.

During the research, participants were shown three example use cases to demonstrate the types of issues that the Substance Misuse pilot would seek to address, and how BOLD would do this. This section outlines participants' responses to the use cases overall, as well as detailed responses to each use case shown. Full stimulus material shown to participants can be found in the Appendix.

Overall, participants are surprised to see all three use cases focus on prison leavers or those on probation. While some participants have been in prison and others know those in similar situations, this is felt to be stigmatising,

- Some participants mention dealing with substance misuse prior to entering prison and are looking for BOLD to address root causes of addiction and getting support to people early, rather than what appears to be waiting until after they have entered the prison system.
- However, overall, participants feel the issues BOLD raises are important and relevant, including to people they know if not to themselves. Some participants are surprised to learn that data is not already shared in these instances.

"I'm shocked to see so many gaps in data [sharing between relevant organisations]. If they all shared with each other it would be easier for them to give correct information [to service users]."

Across all audiences, we have used the following overarching principles to analyse the performance of the BOLD use cases.

- **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 in the substance misuse audience. The ticks and crosses indicate where the use cases did or did not deliver against each respective principle.

Use Cases	Principles
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	Relevant	Impactful	Clear and informative	Non-stigmatising
Substance Misuse				
Use case 1: Treatment for those on probation	✓	✗	✓	✗
Use case 2: Substance misuse issues after leaving prison	✓	✓	✓	✗
Use case 3: Substance misuse issues and risk of multiple conditions	✗	✓	✗	✗

Use case 1: Those who are on probation who access drug and/or alcohol treatments are likely to need support from multiple services. It can be difficult to coordinate and deliver support services to meet these different needs.

- Participants feel this is uncontroversial and recognise the challenges in being on probation and accessing drug and alcohol treatment.
- Participants with experience of this situation reflect on feeling that there was no continuity between the treatment services they received while in prison and accessing these on release. This is felt to be a particularly difficult time in someone's life, when they may also be trying to navigate the housing and benefits systems and secure employment. Having to also take the initiative to access drug and alcohol treatment is felt to be very stressful at a time when participants described feeling overwhelmed.

“There is no strong continuity between treatment in prison and when someone leaves.”

- Participants feel that creating more joined up working between the probation system and drug and alcohol treatment services is very important, as there can often be a delay in accessing treatment on release. For the person on probation, accessing this treatment in a timely manner is extremely important in supporting their re-entry into society. However, some find that treatment services are not able to provide support in a timely manner and wonder if more joined up working with probation services could ensure people are getting the support that they need, when they need it.

“This is good because treatment services often don't have the same urgency that someone on probation has.”

USE CASE 1: Treatment for those on probation		
	Worked well	Areas for improvement
Relevant	Many are able to relate this to their personal experiences or experiences of those they know and feel this is a sensible issue for BOLD to focus on, as there should be a clear link between the probation system and provision of addiction treatment.	Some have never been on probation and so this did not feel relevant to them. However, most felt it could be relevant for others.
Impactful	Participants feel the link between probation and needing access to adequate addiction treatment is clear and if rectified, would be impactful. However, previous poor experiences with the probation system cause some to feel this issue will not be resolved.	However, there is scepticism that proving this link will result in better outcomes , as participants feel this is obvious and something that staff and those in their situation already know.
Clear and informative	This use case is felt to be clear and the link between probation and treatment is sensible to participants. The parties involved in data sharing also feel appropriate for this issue.	Some wonder what, if any, other support services could also be coordinated to better support those on probation, who are accessing treatment, such as housing services.
Non-stigmatising	Participants acknowledge that probation and substance misuse are sometimes linked and that individuals in this situation are likely to experience additional challenges.	Including this use case among others that do not focus on prison leavers would help BOLD avoid being seen as assuming substance misuse is always linked with offending.

Use case 2: Those who leave prison and who are dependent on drugs and/or alcohol are more likely to be at risk of death from substance misuse when leaving prison. This suggests that public services are potentially not always being delivered to the right people at the right times to prevent this from happening.

- Participants feel this is a really important issue, with some reflecting on their own experiences of leaving prison and having little access to support services for

substance misuse. For some, this meant they lost the progress they had made in overcoming their addiction while in prison, after coming out of prison and having no fixed abode or access to treatment services.

- Some participants also spoke of people they knew who had been in prison and overdosed on release. There is a perception that the drugs one can access in prison tend to be weaker than those they can access outside, leading to some overestimating their tolerance on release and being at increased risk of overdose.

“From talking to people, I know that the drugs available in prison are not very strong ones... When they came out they went back to their old ways but as their body had come down from what they used to have, many overdosed.”

- Participants feel that focusing this use case on how to better support people who have left prison to continue to receive drug and/or alcohol treatments is the most important part of this use case, as articulated in one of the questions.

“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”

- Others look for this use case to go further and address why people are leaving prison addicted to substances and how to improve treatment in prisons to improve outcomes for people upon release.

“It feels like this is missing a massive question. Why are people leaving prison addicted to drugs and alcohol?”

USE CASE 2: Substance misuse issues after leaving prison		
	Worked well	Areas for improvement
Relevant	Nearly all participants are able to reflect on their own experiences or experiences of people they know and feel that leaving prison while dependent on drugs and/or alcohol is a very salient issue among their peer group.	Some have never been in prison and so this did not feel relevant to them. However, most felt it could be relevant for others.
Impactful	Participants feel that public services have the potential to facilitate more timely addiction treatment to those who have left prison and if done, would reduce the risk of death from substance abuse when leaving prison.	Some participants wonder why people are leaving prison still dependent on drugs and/or alcohol and feel this use case has the potential to go further in providing more effective addiction treatment while people are in prison.

<p>Clear and informative</p>	<p>Participants feel this use case is looking into an issue where there is a clear link and potential for a better outcome.</p>	<p>Some are unsure why the ONS holds the records for all-cause mortality rather than DHSC. However, this is a minor point and not distracting to participants.</p>
<p>Non-stigmatising</p>	<p>Participants acknowledge that substance misusers may be more likely to go to prison and that individuals in this situation are likely to experience additional challenges.</p>	<p>As with the other use cases, this use case presupposes a link between substance misusers and prison leavers. While participants accept that some are in this situation, it would be better presented alongside use cases that do not exclusively focus on the link between substance misusers and prison leavers.</p>

Use case 3: Those who leave prison and who are dependent on drugs and/or alcohol are more likely to be hospitalised after they are released from prison. This suggests that prison leavers who are dependent on drugs and/or alcohol may have multiple health conditions and/or risk factors which may be difficult to support over multiple health and care services.

- Participants feel this use case takes a narrow view of a broader issue. They suggest broadening out the issue to look at how public services can better support *anyone* who is dependent on drugs and/or alcohol in the health and care system, rather than solely focusing on prison leavers.
 - Reflecting on their own experiences, participants recall feeling reluctant to engage with the health and care system while using substances, for fear of judgment and concerns they would not be able to access care. This lack of engagement, alongside active substance misuse, often led to multiple health conditions which participants described putting off until the point of hospitalisation.

“It’s highly likely [you’ll have multiple health conditions]. With alcohol you can get liver and kidney diseases. With drugs you can get lung and heart problems and many others.”

- Participants see this use case as an opportunity to look at how substance misuse can be taken into account when in care. Some reflect on their own experiences of being in hospital and not receiving the appropriate medication or information that also considered their substance misuse and any medication they were already taking for addiction treatment.
 - While this is seen as a worthwhile goal, participants seek to apply this to their own situations and therefore struggle to understand how BOLD can work towards this outcome if all the data linked remains anonymous.

“I’m just not clear how this would actually help individuals.”

- However, some do see the utility of focusing on the prison leavers audience, as they are seen as particularly at risk. These participants feel that having a thorough assessment of any health risks prior to leaving prison is important in lining up the appropriate after care on release.

“They need to have a good idea [of any health conditions present in prison leavers]. People should have a comprehensive health report on their condition before leaving prison.”

USE CASE 3: Substance misuse issues and risk of multiple conditions		
	Worked well	Areas for improvement
Relevant	Participants relate to having multiple health conditions , in large part resulting from their addictions, and having difficulty coordinating care across these needs.	Participants feel this use case would be made much more relevant if it focused on the multiple health and care needs across substance misusers , rather than solely on prison leavers.
Impactful	Participants feel that better coordination of health and care services across those with multiple needs , such as substance misuse, leaving prison and having multiple health conditions, is very important for supporting this specific audience and that this use case has the potential to have an impact for this group.	Participants feel this use case could be made more impactful if it focused on all substance misusers , rather than just prison leavers.
Clear and informative	Participants see a clear link between substance misuse and having multiple health conditions.	It feels less clear to participants how health and care services will better coordinate to support these multiple needs, while all the data being shared remains anonymous .
Non-stigmatising	Participants acknowledge that prison leavers and substance misuse are sometimes linked and that individuals in this situation are likely to experience additional challenges .	As with the other use cases, this use case presupposes a link between substance misusers and prison leavers . While participants accept that some are in this situation, it would be better

		presented alongside use cases that do not exclusively focus on the link between substance misusers and prison leavers.
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Participants also mention the following areas as those they feel BOLD should look into:

- **Better coordination between addiction treatment and mental health services.** Participants across audiences discuss the importance of mental health services in supporting them to overcome hurdles in their life. Participants feel this is often difficult to access and requires proactivity from them and acknowledge this can be overwhelming to try and figure out when in recovery.

“There MUST be a joined up approach to engage mental health services, social care and 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.”

- **Readily available information regarding support one is eligible for.** Participants discuss having difficulty finding out what treatment is available to them. For some, this meant they gave up in finding treatment for a period of time, before they were ready to try and access support again. Having readily available information about addiction support across the public services substance misusers are likely to interact with (e.g. health and care, housing, benefits) is likely to help this audience access support earlier.

“When I was ready to be helped, I needed to know what help was available and most places I approached did not have the answer to this.”

Audience detail: Intermediary organisations supporting substance misusers

Intermediary organisations were key in the re-framing of the use cases. Feedback from these organisations focused on ensuring the use cases focus on the benefit to the end user and/or services. For example, detail was added to use case one to more strongly draw out the challenges in accessing drug and/or alcohol treatments while on probation and how services can better support people to access these treatments.

Feedback also flagged a potential issue with a use case focusing on reducing homicide rates relating to substance misuse, as having the potential to be stigmatising and not having a clear benefit to the target audience. As a result, this use case was replaced with use case three, exploring the links between substance misuse and the provision of care for multiple conditions.

Considerations for communicating BOLD with the substance misuse audience

- 1. Proactively communicating that BOLD will anonymise any personal data is key in encouraging support from the substance misuse audience.** This audience express concern that their experiences with addiction will be used against them and could impact their access to housing, benefits and employment. Proactively addressing this concern by highlighting anonymity, access permissions to the data and safeguarding measures will help to offset these concerns.
- 2. BOLD should highlight use cases that focus on areas other than the intersection between substance misuse and prison leavers.** This will ensure BOLD does not appear to be making assumptions about intersecting vulnerabilities with this audience and acknowledge the wide variety of people who experience substance misuse.
- 3. Example use cases should clarify how improvement to public services overall will help people like them in the future.** Some participants struggled to see how the use cases could have an impact for them personally, if the data shared is anonymous. Explaining how BOLD aims to improve the provision of public services overall was key in building understanding and eventual support for the use cases.
- 4. Participants highlight the coordination of mental health services and addiction treatment support as a key area in which they feel BOLD could focus on in a use case.** Speaking from experiences, participants feel more joined up working between these types of support would have led to better outcomes in their personal recovery journeys.

Appendix

Stimulus material showed to participants

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What is data linking?

Data linking is the process of joining different sets of information together so that we can make as much use as possible of the information that each of them holds.

Data linking may include many different types of information and does not necessarily include personally identifiable information.

Linking different sets of data, rather than treating them individually, means that we can draw insights from across the data.

Often, linked data helps us to find new patterns and insights that we would not see if we only considered the sets of data in isolation.

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Better Outcomes through Linked Data (BOLD)

A **public service** is a service **provided by the government** that aims to **address the needs** of the public. They aim to **benefit all people in society**, and include things like health and social care, public transport and waste collection.

Public services are responsible for supporting people. However, people often need to **access multiple public services for support** across different needs, such as housing, employment and health.

Currently, data is often not shared between all the relevant support services, even when the individual is the same. The Government has created the **BOLD project** to see how **linking data** across services can improve them.

This will give services a much broader **understanding of someone's journey** so that they can better assess the **full range of someone's needs**, rather than looking at each need separately. Ultimately, this will enable services to make **better informed decisions** about which support they should provide.

BOLD is initially looking at how linking data can help reduce homelessness, reduce substance use issues, support victims of crime and reduce reoffending.

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Better Outcomes through Linked Data (BOLD)

WILL do

- ✓ Share data through a secure internet-based data sharing platform
- ✓ Follow stringent legal processes to gain approval for data to be shared
- ✓ Keep personally identifiable information separate across sets of data to ensure confidentiality e.g. one person working with a linked data set might know your name and nothing else about you, whereas another person working a linked data set might know some information about you, but not your name.
- ✓ Only use data for the purposes of research and improving services

WON'T do

- Collect new data about individuals
- Use your data to make decisions about you or your case
- Share your data with anyone outside of government or the criminal justice system
- Use any kind of predictive technology to make decisions
- Use your data for any purpose that falls outside of those that have been authorised through data sharing agreements

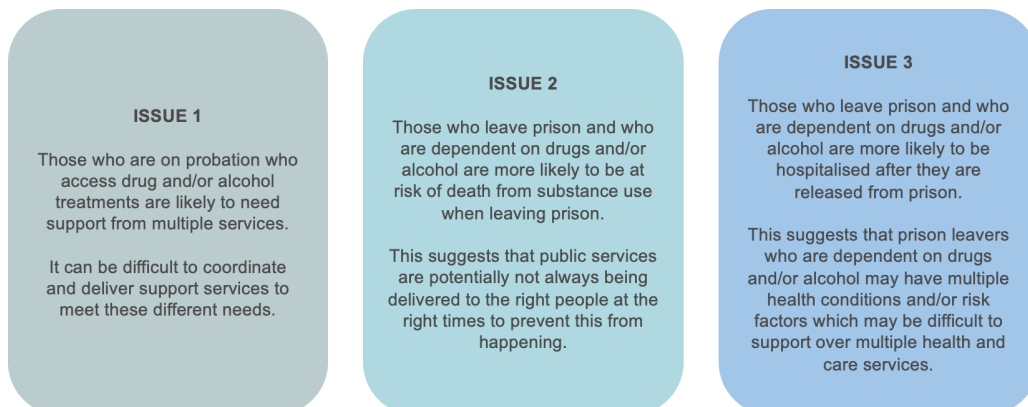
What BOLD could mean for people who use substances

Reducing Substance Use issues

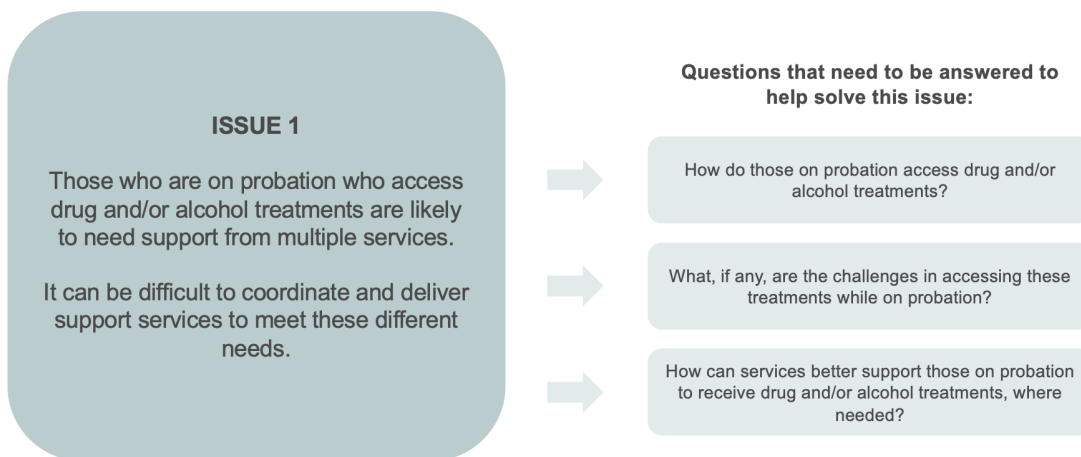
We know that those who use substances often have a variety of support needs and may have to interact with many different public services to access and stay in safe accommodation and treatment.

The BOLD project aims to better understand what makes services effective for people (including those such as prison leavers or rough sleepers) who may have additional support needs.

*The ultimate **goal is to improve services by understanding any additional needs** people may have when receiving substance use treatment.*



Issue 1: Treatment for those on probation



Data from the following organisations will be linked:

	Basic demographic information (e.g. name, age, location)	Probation records (including community orders, such as a drug rehabilitation requirement)	History of engagement with drug and/or alcohol treatments
Ministry of Justice	✓	✓	
Department for Health	✓		✓

ISSUE 2

Those who leave prison and who are dependent on drugs and/or alcohol are more likely to be at risk of death from substance use when leaving prison.

This suggests that public services are potentially not always being delivered to the right people at the right times to prevent this from happening.

Questions that need to be answered to help solve this issue:

How do those currently in prison access drug and/or alcohol treatments? How does this change when leaving prison?

What are the challenges in accessing drug and/or alcohol treatments once having left prison?

How can services better support those who have left prison to receive drug and/or alcohol treatments, where needed?

Issue 2: Substance use issues after leaving prison

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Data from the following organisations will be linked:

	Demographic information (e.g. name, age, location)	History of engagement with drug and/or alcohol treatments	Records of all-cause mortality	Records of when offenders entered and left prison	Risk assessment of drug and/or alcohol issues of offenders
Department for Health	✓	✓			
Office for National Statistics	✓		✓		
Ministry of Justice	✓			✓	✓

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Issue 3: Substance use issues and risk of multiple conditions

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ISSUE 3

Those who leave prison and who are dependent on drugs and/or alcohol are more likely to be hospitalised after they are released from prison.

This suggests that prison leavers who are dependent on drugs and/or alcohol may have multiple health conditions and/or risk factors which may be difficult to support over multiple health and care services.

Questions that need to be answered to help solve this issue:

To what extent, if at all, is dependence on drugs and/or alcohol associated with the risk of developing multiple health conditions?

Which health conditions are present in hospitalisation of prison leavers?

How can drug and/or alcohol treatment services ensure continuity of care to reduce hospitalisations?

Which drug and/or alcohol treatment services can help prevent hospitalisations?

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Data from the following organisations will be linked:

	Demographic information (e.g. name, age, location)	History of engagement with drug and/or alcohol treatments	Records of Hospitalisation	Records of when offenders entered and left prison	Risk assessment of drug and/or alcohol issues of offenders
Department for Health	✓	✓			
NHS Digital	✓		✓		
Ministry of Justice	✓			✓	✓