Better use of Data: Balancing Privacy and Public Benefit

The **Better use of Data: Balancing Privacy and Public Benefit** workshop in Melton Mowbray was one of a series of workshops led by Involve in six local authority areas across England during summer 2017.

These workshops, supported by Understanding Patient Data and the Carnegie UK Trust, aimed to explore how different groups (government, civil society and advocacy groups) make sense of, and balance, the trade-offs inherent in data sharing; specifically between public benefit and privacy.

In a context in which governments and other agencies providing public services increasingly collect, store and use personal data about citizens as part of the business of delivering services there are growing opportunities to use this data to deliver better targeted and more efficient services in ways that stand to benefit the public. However, the sharing of what can sometimes be highly personal data, also raises legitimate concerns about privacy and prompts questions about what are acceptable uses of this type of data. Developing a greater understanding of how stakeholders define and value the public benefits associated with the use of data, and where an acceptable balance between risks and benefits may lie for those involved in the delivery of public services, is therefore at the heart of this project.

This report provides a summary of the views, priorities and concerns of participants at the workshop in Melton Mowbray on the workshop on the 12th July 2017. It is designed to give local stakeholders a record of the debates and deliberations that took place on the day in order to support participants to continue these discussions with colleagues, partners and local policy makers. Similar reports have also been produced for the other five areas.

A full project report, synthesising the findings across the six workshops and proposing a framework for understanding and talking about the potential benefits of data sharing at a local and national level, will be published in September.

Overview of the workshop

The workshop in Melton Mowbray was held on the 12th July 2017 and hosted by Melton Borough Council. It brought together a wide range of professionals from the public and voluntary sectors across the local area to explore the benefits of data sharing for the purpose of delivering better public services.

18 people took part in the workshop, including representatives from the borough and city councils, Leicestershire Police, Leicestershire Fire and Rescue Service, and a range of local third sector organisations working across health, housing, criminal justice, community development and citizen advocacy.

Framing the discussions

The workshop was intended to provide an opportunity for professionals working in the public and voluntary sectors to come together to explore how they collectively understand, define and value the public benefits that may be delivered by the better use of data, and begin to make sense of where an acceptable balance between risks and benefits may lie for data sharing.

There are issues and debates surrounding data sharing that cut across all aspects of public service delivery. This workshop was designed to focus on the sharing of personal information across and between the housing, criminal justice, health and social care and welfare sectors. These sectors were chosen because they are all areas where there is evidence of increasing demand for the sharing of personal data to support more effective multi-agency working at a local level. Further, in all of these fields, decisions about what data to share, when to share it, and who to share it with can not only create ethical dilemmas for professionals but also have potentially significant impacts for individuals.

To help focus discussions during the workshop, a Background Briefing Paper was distributed to attendees in advance. This paper provided:

- Information about the purpose of the workshop and the rationale for the wider project;

- An outline of the policy drivers for the better use of data to support public service delivery;

- A summary of the legal context for data capture and sharing;

- Definitions of 'personal data' and 'sensitive personal data' and the protections afforded to each;

- Information about the legal basis for a 'right to privacy' and the privacy implications of data sharing;

- An overview of the key areas of tension between data sharing, public benefits and individual privacy.

Methodology

The workshops were designed to involve a mixed group of participants, primarily working in small groups (4-6 people) to define, interrogate and problematise the 'public benefits' that could (or could potentially) be achieved by greater data sharing between organisations involved in delivering public services.

In the workshops a series of examples and case studies were used to prompt discussions. These illustrated how data is being shared and used by public service providers across the country for a variety of purposes, but all described as delivering 'public benefit'. These examples were chosen to encourage participants to take a *deep-dive* into their own understanding of the potential benefits and risks of data sharing. As the exercises built on each other throughout the day, participants were also challenged to develop shared criteria to assess the proportionality and relative acceptability of using the different types of data that service providers may have access to for different purposes.

On the day participants also benefited from expert input from:

- Understanding Patient Data's research into the best language to use when discussing the different forms in which personal data can be shared, and explaining anonymisation and the likelihood of re-identification;

- A member of the National Data Guardian's Panel, highlighting how challenges in relation to data sharing, privacy and the public's expectations of how data about them is used are being navigated in a health and social care context;

- Staff from the Open Rights Group, discussing how the legislative context for data sharing is changing and the risks and opportunities these changes bring.

These contributors (alongside an observer from Carnegie UK Trust) 'sat in' on the discussions throughout the day to provide information and respond to questions, but did not actively participate in the deliberations.

A variety of exercises were developed for the series of workshops, and not every exercise was used in each location. Instead the facilitators selected exercises in response to the size of the group, the interests of participants, the local context and the degree to which questions around data sharing were already familiar to participants, in order to prompt increasingly in-depth deliberations about the public benefits associated with data sharing.

In Melton Mowbray the workshop followed the format:

1. Introducing and framing the conversation (including input from Understanding Patient Data about the language that would be used throughout the workshop);

2. Exploring participants initial impressions of the opportunities and challenges associated with data sharing

3. Using two different sets of examples of data sharing practice to identify dimensions of public benefit;

4. Ranking the examples in order of their ability / potential ability to deliver public benefits (negotiating criteria for ranking the examples at each table);

5. Using the alternative set of examples to identify areas of risk and concern, and then ranking them in order of risk (negotiating criteria for ranking the examples at each table);

6. Expert inputs to help frame the next stage of the discussions;

7. Working in small groups to 'define' public benefit;

8. Identifying criteria to rank the relative acceptability of different contexts, forms and purposes of data sharing;

9. Plenary discussion focussing on insights, reflections and 'take-aways' from the workshop.

A summary of participant's feedback after the workshop is included as Appendix A to this report.

Identifying dimensions of Public Benefit

As noted in the Background Briefing Paper circulated to participants, previous research on public attitudes to data sharing tends to suggest that the public are much more likely to accept or support data sharing if there is a public benefit, or at least the potential for public benefit. However, there has to date been little examination of how either the public, or those involved in delivering public services, understand and evaluate the idea of the wider public benefits promised by greater or wider data sharing.

Being able to clearly articulate the wider dimensions of public benefit, in ways that are easily understood and resonate with data controllers, other stakeholders in public service delivery, and ultimately the wider public remains a key challenge for those advocating for greater data sharing for the purpose of delivering better public services.

One of the first tasks participants were asked to do was identify the benefits able to be delivered by a range of examples illustrating how data is being shared and used by public service providers across the country. Two different sets of examples were used during the workshop (identified as examples 1-6 and examples A-F) and these are included in this report as Appendix B. Each set of examples was constructed to stimulate debate and discussion (rather than to illustrate good practice) and cut across a range of sectors (housing, health, welfare, social care and community safety), involved the use of different types of personal data, shared with different types of organisations, and featured a variety of intended outcomes. Half of the tables were asked to consider one set and the remaining tables were given the other.

Working firstly in four small groups, and then in plenary, a range of different types of beneficiaries and benefits were identified, including:

- **Individual service users:**
    - Early identification of needs;
    - Better targeted services;
    - Provision of proactive and preventative services;
    - Safeguarding for vulnerable people;
    - Automatic receipt of services they are entitled to;
    - Improved care pathways;
    - Better outcomes; and
    - Trust that services are being provided with their best interests in mind.

- **The wider public (or sectors of the public):**
    - Delivering social outcomes e.g. community safety or reducing social isolation;
    - Enabling more efficient public services through the better targeting of resources;
    - Ensuring a fair distribution of resources to respond to areas of need;
    - Informing preventative approaches that reduce future demands on scarce resources; and
    - Providing increased accountability to the public for public sector expenditure.

- **Service Providers:**
    - Ability to target resources to prevent need or risk - 'spend to save';
    - Ability to streamline services;
    - Information to enable services to safeguard vulnerable people;
    - Financial benefits e.g. increased revenue by reducing occasions of fraud, debt and waste;
    - Providing information to monitor the impact of services to enable providers to focus on delivering services that have demonstrated they are effective;
    - Providing evidence to help access additional funding;
    - Improving interagency working and collaboration;

- Enabling the creation of shared targets and an integrated approach to delivering them; and
- Having visible impacts/successes that will increased public confidence that data about them is being used with good intent.

- **Staff delivering services:**
    - Improved understanding of individuals and care pathways;
    - Ability to offer a quality service;
    - Reduce time wasted;
    - Greater awareness of the wider sector and their role within it; and
    - Increased job satisfaction through being able to measure the impact they are having.

Establishing criteria for assessing Public Benefit

Having established that there were a wide range of different benefits captured by the term 'public benefit', participants in the workshop were asked to explore criteria for assessing the relative value of different types of benefit. To provoke this discussion each group was challenged to rank the examples they had been presented with in order of their ability (or potential ability) to deliver public benefit.

A range of potential criteria to enable them to rank the examples were identified by participants:

- Scale of the data sharing;
- Number of people that may benefit;
- Quick wins vs long term benefits;
- Broader positive impact vs a very targeted impact;
- Centrality of outcomes;
- Clarity of purpose;
- Ability to measure impacts;
- Strategic value to service providers;
- Social impact of the problem it seeks to address; and
- Potential to deliver efficiency savings.

Despite the range of criteria identified the four groups working on this task however were evenly split in the primary criteria they chose to inform their rankings:

1. the ability to directly deliver wide spread benefits to individuals, the wider public and the public sector i.e. a focus on outcomes; or

2. the ability to address the root causes of problem i.e. a focus on prevention.

This resulted in groups that were looking at the same set of examples ranking them in completely different (and in one case almost opposite) orders, clearly highlighted the complexities and subjective judgements involved in attributing value to an initiative.

1. A focus on Outcomes

When groups focused on the direct delivery of positive outcomes as their principle criteria, they tended to favour examples where there was a clear causal link between the use of data and the benefit delivered. 'Quick wins' were also viewed as important. The use of these criteria led to examples 4: Empty Homes Initiative and C: Tacking Fuel Poverty being ranked as most able to deliver benefits.

In the first case, this was due to the use of data to link addresses erroneously claiming empty homes discounts on their council tax being able to deliver a clear financial benefit to the council for relatively little outlay. In the second case the initiative was described as being one that "sees a need and meets it" by using data to automatically provide a bill rebate to households in fuel poverty. Both initiatives were therefore assessed as being effective and efficient uses of data to deliver a direct and immediate benefit – one to service providers and one to large numbers of the public.

These groups also tended to rank examples higher if they were able to deliver outcomes to multiple beneficiaries – individuals, the wider public and also service providers. Example F: Homeless support in Bristol therefore also ranked highly as it not only enabled the delivery of a better service to individuals, but also had benefits for service providers e.g. by freeing up staff time and enabling them to work more efficiently. Likewise, through this lens, example 6: Information Sharing to Tackle Violence was also identified

as highly beneficial. In this case the data sharing was seen as a proactive way of enabling resources to be effectively targeted to produce clear community safety benefits for the wider public: a 'win-win' situation.

Examples that served simply to provide evidence for future action, or where the link between the use of data and direct impact was less clear tended to be ranked lower by these groups (e.g. 5: Housing Regeneration and Health, A: Kent Integrated Dataset and B: Predicting the Prevalence of Loneliness).

2. A focus on Prevention

Groups taking a focus on prevention tended to rank most highly those examples they perceived as addressing the root causes of a problem, rather than the symptoms. Examples that were intended to identify the underlying causes of social problems and reduce the need for crisis services in the future were therefore ranked as being highly beneficial uses of data (e.g. 5: Housing Regeneration and Health and B: Predicting the Prevalence of Loneliness). As noted by one group: "if you reduce need, you reduce costs!"

Examples that demonstrated that data was being used to take a holistic approach to service provision, through integrated working and sharing information across multiple service providers, were also ranked highly by these groups (e.g. 1: Routes from Diagnosis and A: Kent Integrated Dataset). These were seen as showing data being clearly used to enable services to evolve their delivery patterns through tracking service user's journeys in ways that could inform long term improvements in care.

Examples that were identified as reactive or providing a 'sticking plaster' solution (e.g. 2: Reducing Unnecessary 999 Calls and C: Tacking Fuel Poverty) or which did not embody a long term, strategic approach to service delivery tended to be ranked lowest by these groups (e.g. 4: Empty Homes Initiative).

Identifying and Assessing Risks

Whenever personal data is collected and used there are implications for individual privacy. There are, however, also a range of other risks associated with the use of personal data in the context of public service provision. These too have an impact on how people assess what is acceptable practice i.e. for what purposes service providers should be able to access or disclose personal information and the safeguards necessary to reduce the risks to all parties.

In the second part of the workshop participants were asked to look at a different set of examples, this time focusing on identifying any risks and concerns relating to how data was being used. Here participants had no trouble in identifying a wide range of risks associated with the sharing and use of data in the context of public service delivery. The main risks identified by the group are summarised below:

- **to individuals:**
  - threats to privacy through data being shared about them without their consent;
  - being unintentionally re-identified through data linking;
  - that negative assumptions about a person may occur based on the use of data; and
  - that data about individuals is sold on, or otherwise misused, to target them for unwanted services or offers.

- **to the wider public**:
  - that the use of unreliable data creates an inaccurate picture of the situation in communities;
  - that data analysis leads to the withdrawal of services from communities;
  - that data is used to profile or stigmatise a community, or section of the community; and
  - that over-reliance on quantitative data could result in less qualitative engagement and consultation with the public.

- **to service providers**:
  - that incorrect interpretations or poor quality data lead to poor targeting of resources;
  - loss of trust in service providers if data gathered is not clearly used for public benefit;
  - that different agencies read different information from the data or interpret analysis to suit their own needs / aims; and
  - legal and reputational risks associated with a data breach;

- **to staff providing services**:
  - that clients will withhold information due to worries that it may be shared
  - that the increased bureaucracy involved in collecting and inputting data will take time away from service delivery; and
  - that staff who do not have the skills to interpret data effectively will use it to form harmful conclusions.

Assessing Risk

When the groups were asked to rank the examples, this time in order of the risk this type of data sharing posed, participants worked together at their tables to establish their own criteria to assess and measure potential risk. There were four cross-cutting criteria that appeared to underpin deliberations across the groups.

1. Whether the data used was personally identifiable (including the potential for this information to be used inappropriately);

2. The risk of re-identification (including the sensitivity of the information, the number of people likely to be affected, and the degree of impact this could have on an individual);

3. The quality of the data; and

4. The complexity of the data sharing arrangement.

1. Using personally identifiable information

Groups acknowledged that there were clearly more risks to privacy associated with the use of personally identifiable information, particularly sensitive personal information, than when the information shared was de-personalised or anonymous. This was particularly the case if information appeared to be shared without consent. This resulted in example 2: Reducing Unnecessary 999 Calls being considered a very high risk approach for services, as it proposed directly sharing personally identifiable information about potentially vulnerable people to enable an intervention to be offered that they had not requested. Participants in the workshop also raised concerns that doing this could also have the knock on effect of people no longer accessing necessary services for fear of how their information may be used in the future.

Similar concerns were also expressed in relation to example F: Homeless support in Bristol because it involved the sharing of personally identifiable information of a sensitive nature (including information relating to service users' health and mental health). While the risk of this information being used to stigmatise an individual was acknowledged, the risk of potentially negative impacts on an individual from this model of sharing were generally considered to be less likely to cause harm.

One group also expressed significant concerns about the use of personally identifiable information relating to an individual's financial or benefits status to enable automatic bill rebates in example C: Tacking Fuel Poverty. The perception of risk here was exacerbated by the sensitivity of the data, the high number of people whose data would be used, the fact that the information would be shared for a purpose people may not expect and that it would be shared with private utility companies.

2. Risk of re-identification

Participants also considered the risk of individuals being re-identified through the use of linked data sets held at an individual but de-personalised level. These were identified as a significant risk to individual privacy and as a potential reputational risk to service providers. This resulted in example A: Kent Integrated Dataset being ranked as high risk approach to using data. This was primarily due to the large number of people that data was held about, the number of data sets that were linked and the sensitive nature of the health and social care information that was being used. While participants did acknowledge that the likelihood of re-identification in this case may be low, if it were to happen the impact on an individual was potentially very significant, and this made the example high risk.

Similar concerns were also raised about example 3: Linking data to improve Health and Social Care Outcomes, where the ability to re-identify individuals for the purposes of providing direct care interventions was included in the design of the data sharing model. Here however, the concern focused on the potential for this capacity to be used inappropriately to identify people for other reasons. This reflected fears expressed more widely in the room that, once systems like this existed for data linking, there was the potential for them to be used for purposes other than the initial intent, for example to target people for unrequested services or shared/sold to others (including the private sector)

In groups where the discussions focussed on identifiability or the risk of re-identification as key risks the examples that relied on the use of aggregate data, particularly statistical data that was already in the public

domain, tended to be considered the lowest risk (e.g. 5: Housing Regeneration and Health, D: Funding GP Practices in Socially Deprived Areas and B: Predicting the Prevalence of Loneliness).

3. The quality of the data

The quality and reliability of the data used was also a consideration across a number of the groups, particularly in relation to incomplete or inaccurate data being used to inform service planning or resource allocation. This was particularly highlighted as a risk in relation to example 6: Information Sharing to Tackle Violence, which relies on data being shared from A&E departments on the basis of self-reported details from patients.

In the discussions it was also noted that "any system is only as good as the data you put in". This created an additional risk that if organisations did not have effective and reliable data collection mechanisms, including collecting the right types of information, categorising it consistently and updating it regularly, then services using data to inform decisions might be relying on unreliable or potentially out of date information.

4. The complexity of the data sharing arrangement

Examples that involved the use of multiple data sets shared across a large number of agencies also tended to be ranked as high risk. This was largely because of concerns that, as the number of partners involved in the sharing arrangement increased, there was potential for more people to have access to the data, for access controls to be weakened and thus greater risk of privacy breaches. (e.g. A: Kent Integrated Dataset).

Acceptable uses of data sharing

Determining what constitutes an acceptable balance between the use of data to deliver services that benefit the public and protecting people's privacy, was identified in the framing of this workshop a key challenge for policy makers, frontline staff, advocacy groups and the public at large if the ambitions held for data sharing are to be realised.

The examples used throughout the early stages of this workshop were chosen specifically to highlight the complexity of the considerations involved in determining the acceptability of data sharing across a variety of contexts and sectors. They highlighted that, while the overall goals driving demands for greater data sharing may be arguably beneficial, the realities of practice open up a range of questions about appropriate purposes, the type of data shared and the relative privacy incursions and associated risks that may be need to be acknowledged in order to achieve different types of benefits. Opening up these questions for frank, deliberative discussion and debate between stakeholders was a key purpose of this workshop.

Defining 'Public Benefit'

In the second half of the workshop participants were asked to reflect on the types of benefits they identified that the better use of data could deliver, alongside the insight provided by the expert presenters, to attempt to define the idea of 'Public Benefit'.

The Background Briefing Paper highlighted that, in the review of literature undertaken to prepare for the workshop, the term 'public benefit' was extensively used to describe the purpose of public sector data sharing, yet it was rarely defined. One of the key challenges for public sector providers who want to develop opportunities for the better use of data therefore is to determine a way of clearly articulating what constitutes 'public benefit' and the beneficial uses of data.

The deliberations in this workshop showed that the key elements participants considered necessary for an activity or programme to be described as producing 'public benefit' included:

- That it delivers improved services and better outcomes for people and enhances wellbeing;

- That it represents an effective use of resources (money, time, people);

- That the process and the impacts stand up to scrutiny;

- That it represents value for money;

- That it meets expectations – for individuals and the wider public;

- That the results are actionable;

- That it involves joined up thinking and working;

- That it enables sustainable delivery;

- That it is preventative and able to deliver long term savings;

- That it protects the public – even safeguarding from risks they are unaware of;

- That the benefits are tangible and able to be clearly understood.

Unsurprisingly all of the groups struggled to come up with decisive definitions, particularly given the time allowed during the workshop. Two of the groups however did manage to compose statements that, while still not necessarily encapsulating all of the elements outlined above, do manage to capture both the

complexities of the subject and the spirit of the 'public benefit' service providers are aiming to deliver through the better use of data.

> *"Enabling sustainable, improved outcomes that safeguard individuals and communities through the wise spending of the public purse, in ways that make things better for everyone."*

> *"The measureable advancement of individuals and communities by the effective, timely and efficient use of cross-agency resources (including, but not limited to, time, money and people) which will result in the delivery of identified outcomes."*

Managing the trade-offs

To stimulate the discussion about how the trade-offs between risk and benefit could be managed in practice, participants worked in four new groups to rank the examples in order of the overall acceptability of using data in this way to deliver public benefits. The focus of this section of the report however is not on the order that the examples were ranked, but rather on the compromises and trade-offs the groups made in determining the relative acceptability of the different uses of data.

Key considerations raised in this discussion were:

- **Identifiability** – whether the data used in the process was identifiable, and whether it needed to be to deliver the intended outcomes, was identified as a key consideration in determining acceptability. It was widely agreed that data should be shared anonymously by default unless there was a clear and valid reason for it to be identifiable.

- **Sensitivity of the data** – as many of the examples under discussion rely on the use of sensitive personal data there was some discussion of what types of data are considered most sensitive. Health and care data was seen to be particularly sensitive, as the impacts of it being misused could be very significant for individuals. However it was also noted that most people expect this type of information to be shared between service providers supporting their wider wellbeing. Interactions with the criminal justice system were also identified as particularly sensitive, again because of the potential for this information to be misused or stigmatise a person. Any form of financial information was also highlighted as sensitive because it was considered intrinsically private and it was noted that most people would not expect this type of information about them to be shared without their consent.

- **Security** – these discussions focused primarily on the processes for storing and exchanging information and the access controls and limitations placed on its use. Confidence in these procedures resulted in examples that may otherwise have been considered high risk because of the type of identifiable data that they involved (e.g. C: Tacking Fuel Poverty and E: Justice Data Lab) being assessed as more acceptable by some participants. This was on the basis that compliance with regulation and adherence to good data governance should ensure that security risks are minimised, if not mitigated.

- **Clarity of purpose** – this was seen across all of the groups as vital for generating support for the use of data. When examples were described as vague or 'fishing expeditions' they were generally classed as less acceptable. The importance of clearly defined purposes and parameters for using data was also stressed as being a valuable protection against 'mission creep' and data being used for purposes other than which it was provided or shared.

- **Proportionality** – whether the amount or type of data that was shared was proportional to the outcomes an initiative was able to deliver. This was particularly seen as an issue where large databases, containing multiple data sets were created. For example A: Kent Integrated Dataset received very split reactions from participants in the workshop. While some participants cited it as a very risky and disproportionate use of data linking others argued that if the capacity to do this securely exists then there is value to having access to this type of data for a variety of potentially beneficial purposes.

- **The nature of the problem**– some types of social problems were seen as more important, and more difficult and complex, to address than others e.g. homelessness, violence in communities and social isolation among the elderly. This resulted in some people being prepared to accept a level of risk involved in the use of data if they saw the potential beneficial impacts outweighing the degree of harm that may be caused.

- **Risk vs reward** – discussions in a number of groups acknowledged that the potential to deliver life-changing benefits to individuals would make sharing personally identifiable data acceptable, even if that did entail significant incursions into an individual's privacy and/or the loss of service users trust. The same logic however did not apply if the benefit was only to a service provider, no matter how great that benefit may be.

- **Defensibility -** i.e. is the decision to use data in a particular way defensible. One group in the workshop used this idea as their key criteria for apportioning acceptability: asking "if the data use is susceptible to challenge would we, and could we, make a publically acceptable defence?" These discussions allowed for the fact that while something may be able to be justified legally or procedurally there was also ethical considerations in play in relation to the use of personal data.

What risks are too high to accommodate?

The previous exercise, and the plenary discussions that followed, provided an opportunity for participants to explore some of the trade-offs and compromises that may be needed to allow public service providers greater scope to use data to plan and deliver responsive services. In the workshop there were a number of areas of potential risk, that participants identified as creating 'red lines' for the use of personal data and which should not be crossed, even in the interest of providing better public services:

- When the data may be flawed or incomplete;

- When data is being used in ways that do not deliver demonstrable, measurable impacts;

- When the purpose is unclear, or too open;

- When the proposed use of data is unlikely to achieve the intended objectives; and/or

- When effective security systems are not in place to ensure data is protected from misuse or misappropriation.

Insights and Reflections from the Workshop

Over the course of the day there was time for participants to share and reflect on the opportunities and challenges they saw for data sharing practices in their own work or organisation, and the implications this has for the continued development of data use across the local area. The workshop also closed with a final plenary session which encouraged participants to share any insights or 'take-aways' from the discussions they had been part of.

Opportunities and Challenges

Throughout the workshop participants were generally quite optimistic about the potential of greater data sharing to support the delivery of more efficient, effective and responsive public services. Further, there was a general consensus among participants that services need data, and its collection and use is broadly justified. They were not however, blind to the difficulties and risks involved in delivering these benefits in practice. Key points that emerged from the workshop are presented below.

- The use of data can enable public service providers to develop a wider understanding of social issues and problems and help them see their particular challenges as part of a 'bigger picture'.
    - This was particularly noted as an opportunity in contexts where business objectives cross over and a culture of greater joined up working is developing.
    - Here data can help with identifying, tracking and understanding patterns.
    - Using data effectively in these contexts also provides an opportunity to develop shared targets, and take joint responsibility for them.

- Advancements in digital technology are creating opportunities for data sharing and use that have not been available before.
    - However technology itself is not simply the solution, as the effective use of data still relies of the 'right' data being collected in the first place.
    - The challenge is to ensure organisations have the skills, knowledge in infrastructure in place to effectively use these to their advantage.

- Information sharing between services dealing with vulnerable clients can provide a valuable tool to help support clients who are off the service radar and end up in crisis. However many professionals still 'hide' behind concerns about data protection, even if they are unwarranted and ultimately may not be in their best interest, or the best interest of their clients.
    - Frontline staff need more training to understand what they can / can't share in what contexts. It is not enough for this knowledge just to be held by heads of service or those with a responsibility for data governance.

- The effective collection, linking and analysis of data can be a useful tool to track client journeys and adapt services to improve and capture progress.
    - A key challenge however can be attaining informed consent for data to be used in these types of ways - often the purposes a service wants to use data about individuals for are not the same as what people expect when they provide information to services.

- There are challenges associated with sharing data with partners – including when / when not to co-operate in data sharing, what data to share and also determining what are appropriate uses of another services' data.

- o Participants also acknowledged that there were additional jurisdictional issues in this locality relating to 'cross-border' data sharing between boroughs and with the city council.

- Relying on quantitative data in isolation however should not be seen as 'the' solution for services. The use of data needs to be seen as part of the solution (means to an end, not an end in itself). Otherwise there is a risk of reducing service users and social problems to a collection of recorded facts.
  - o Shared systems cannot replace face to face sharing between professions that can give context and build trust. There is a need to use both hard and soft data to deal with complex problems – the value of 'sharing by talking' should not be lost.

Insights and reflections:

- That taking time out to reflect on the 'public benefits' we claim to be delivering through the use of data has been valuable and encourages us, as service to really ask ourselves – What are the benefits from this approach? Who is benefiting? How are they responding?

- That talking about data sharing is not just relevant to big scale, systematic, digital based systems. The considerations about what we share, with who and why are also relevant to the small scales sharing that we as service providers do, and want to do in the course of our day to day work. These discussion therefore have implications for staff at all levels of service delivery.

- That services need to get better at making the case for public benefit – "we are not very good at telling the stories of what we do well".

- Services need to help the public understand the need for using data – "We need to demonstrate impact rather than just ask for consent". This might be the only way for the culture change needed to deliver public support for the greater and more widespread use of data to happen.

Moving forward with the discussion…

The workshop helped highlight that there are significant differences in the way different stakeholders from the public and voluntary sectors, let alone members of the public, understand and define the concept of public benefit and the impact this has on considerations of acceptable uses of data. Indeed, it was apparent that there is not even a common framework that public service providers seek to drawn upon in order to identify the risks and benefits of data sharing. This seems to suggest that there is a need for more discussion between stakeholders on these matters in order to identify areas of common ground if the ambitions for greater data sharing to improve public service delivery are to be realised.

The workshop also identified that, if public confidence and support for increased data sharing for a greater array of purposes is to be translated into the social licence for organisations to use data more widely, then the public needs to have the opportunity to contribute to discussions about the appropriate uses of data.
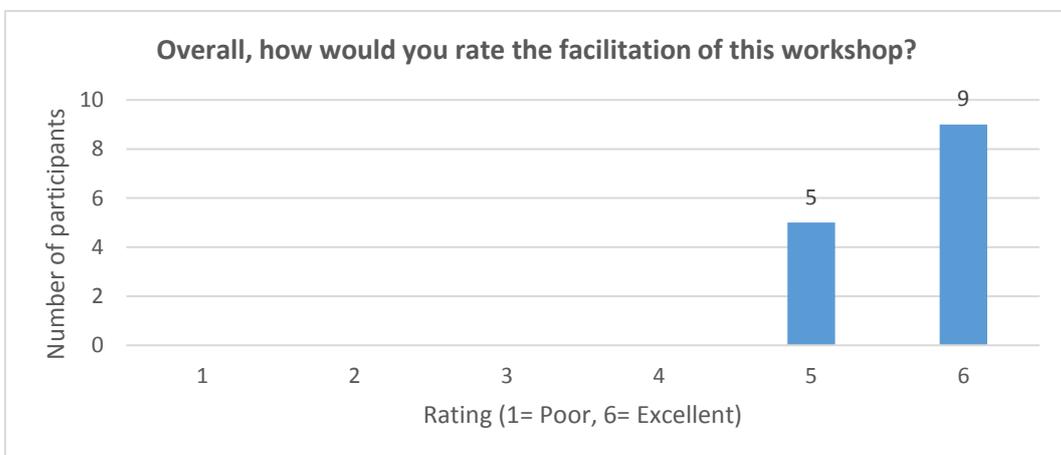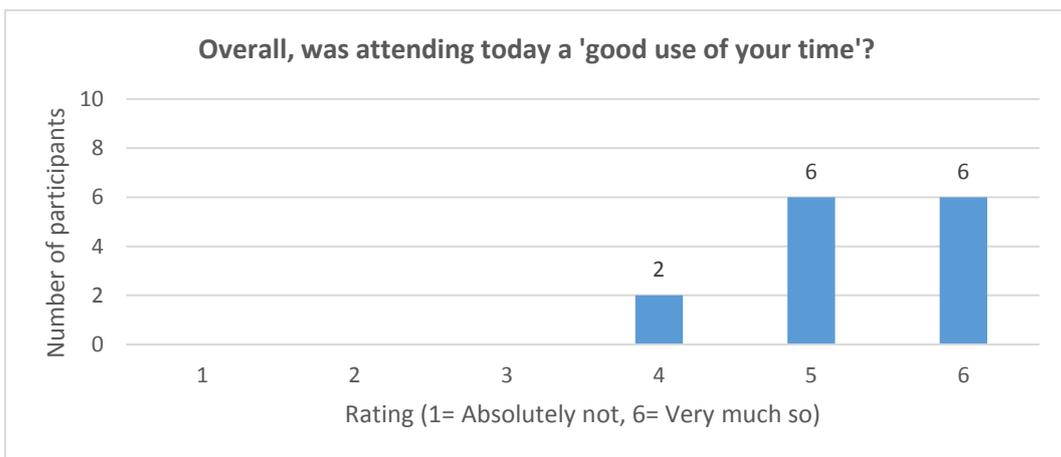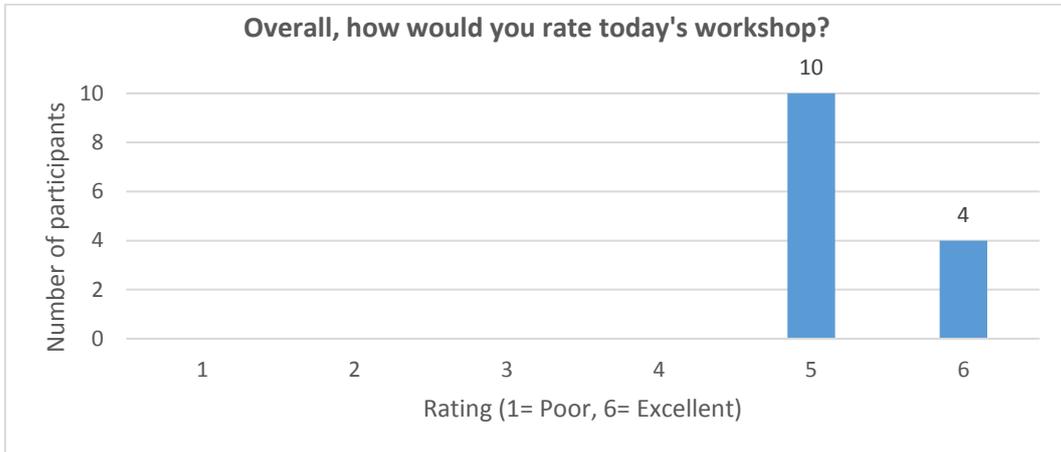
The forthcoming report being produced as an outcome of workshops like this in six local authority areas across England is designed to provide a tool to enable these conversations to take place.

Appendix A: Participants evaluation of the workshop

Number of participants: 18
Responses received: 14
Response rate: 78%

Overall, how would you rate today's workshop?

Rating	Number of participants
5	10
6	4

X-axis: Rating (1= Poor, 6= Excellent)
Y-axis: Number of participants

Overall, was attending today a 'good use of your time'?

Rating	Number of participants
4	2
5	6
6	6

X-axis: Rating (1= Absolutely not, 6= Very much so)
Y-axis: Number of participants

Overall, how would you rate the facilitation of this workshop?

Rating	Number of participants
5	5
6	9

X-axis: Rating (1= Poor, 6= Excellent)
Y-axis: Number of participants

What did you like most, or find most useful, about the workshop, if anything?

"Greater consideration of Public Benefit. Reflection on available data through case studies"

"Lots of information and good interaction between different partners"

"Workshops helped understand subject and encouraged thought process"

"Gave me an overview of larger more strategic data sharing decisions that are being taken"

"Discussions"

"Considering case studies output vs. risk"

"Lots of experience from the facilitators and speakers, encouraged lots of debate – areas of reflection"

"Group work helpful, good mix of talks/workshops"

"Different perspectives from multitude of organisations"

"Positive views of others for sharing data and considering benefits/negatives of case studies"

"Case studies and definitions of public benefit"

"Exploring the justification of data sharing"

"Chance to discuss issues with colleagues"

What did you like least, or find least useful, about the workshop, if anything?

"I found some of the sessions nearly beyond my understanding, but can use it to increase my awareness"

"Didn't talk enough about 'Individual' data – what does an individual want us to do with their data?"

"Nothing – it would be good to see how some of these conversations can be had in local service and with service users – looking forward to reports"

"Benefit/Risk analysis not very productive"

In what ways do you think the workshop could have been improved, if any?

"Very good. Very interesting"

"Refer to the exercise instructions on the projector prior to the exercise"

"Great to hear reports will come out of this"

"I expected more input on "where, when why" which would be useful – even a take-away document"

Do you have any other comments?

"Excellent"

"Great day thanks"

"Thanks for inviting me ☺"

"Very useful and thought provoking"

"Many thanks for an interesting day"

"Interactive, inclusive, participative"

"Very interactive and well structured"

"Very well informed"

"Excellent session"

Example A

Kent integrated dataset (KID)

Kent County Council and Kent's 7 CCGs created the Kent Integrated Dataset (KID) covering the health and care records of 1.5 million people. KID links data from council adult social care, GP practices, mental health services, public health and community health at an individual, but de-personalised level.

This dataset has enabled the public health team to conduct analyses to:

- test 'what works' in the county, for example, evaluating the impact of home safety visits carried out by Kent Fire and Rescue Service on A&E attendances;
- assess the impact of services by comparing outcomes of service recipients with statistically similar people who don't receive the service e.g. falls prevention services;
- calculate average per capita costs for all points of care delivery (adult social care, community care, A&E attendances, non-elective admissions and Out of Hours care) by GP practice area;
- identify gaps in provision for particular client groups, such as a needs assessment for the population of clients with autism spectrum disorders to inform the provision of new services.

Kent Integrated Dataset (KID)

WHO: Kent County Council (KCC) and Kent's seven Clinical Commissioning Groups (CCGs)

WHY: In order to transform public services, KCC needed data analysis that crossed organisational silos. Integrating health and care data created cradle-to-grave health and care records, enabling whole service user journeys to be analysed. Integrated data could inform decisions about which services to provide and how to organise them.

WHAT: The Kent Integrated Dataset (KID). It is one of the largest integrated health and care databases in the UK, covering the health records of 1.5 million people. Data is brought together from council adult social care, GP practices, mental health services, public health and community health. It includes data on activity, cost, service/treatment received, staffing, commissioning and providing organisation, patient diagnosis, demographics and location. Datasets are linked on a common patient identifier (NHS number) and de-personalised.

HOW: The KID was built from existing systems, using a SQL-server data warehouse (The Kent and Medway Health Informatics Services) and a purchased business intelligence tool. KMHIS developed a 'black box algorithm' for data as it enters the KID. This runs an algorithm to check that the information on either side matches up, without the system operators needing to see identifiable data. The programme then creates a de-personalised NHS number - a 64 bit sequence - which is given to each piece of personal data and is applied to all files that come in relating to the same person. The project was assigned an IG expert who advised on the requirements of KID and informed the data sharing agreement for each agency, including the 240 GP surgeries in Kent.

IMPACTS: KCC uses the dataset to inform care, health and public health strategies and decisions. They can test what works and forecast future service pressures and outcomes. It is also being used to help analyse and forecast the impact of change suggested by the Kent Sustainability and Transformation Plan so decision-makers are better informed. It is also possible to run further analysis to test which types of people a programme is most useful for, and for whom it has limited impact, helping prioritise which groups should receive certain interventions or services.

SOURCE: Nesta and LGA (2016) Wise council: insights from the cutting edge of data-driven local government http://www.nesta.org.uk/sites/default/files/wise_council.pdf

Predicting the prevalence of loneliness

Age UK used aggregate statistical data from two different sources (the 2011 Census and the English Longitudinal Study of Aging) to identify areas across England that were likely to be 'hot spots' for loneliness among people aged 65 and over.

They wanted to know what makes older people at risk of being lonely and which neighbourhoods had the highest risk, in order to help them plan their interventions. To achieve this they commissioned a study to isolate the particular characteristics that increase the prevalence of loneliness among older people.

The resulting 'loneliness heat maps', together with local knowledge and an understanding of local neighbourhoods, helped them to plan how they would allocated their resources to tackle this problem: enabling both the development of tailor-made interventions to address loneliness in prioritised areas and an assessment of whether existing services were reaching areas of need.

Predicting the prevalence of loneliness

WHO: Age UK

WHY: Age UK wanted to predict the risk of loneliness among older people across small geographical units in England. The charity wanted to know which neighbourhoods have the highest risk so to better allocate resources to tackle the issue. Better data would also help determine whether existing services are reaching areas of need.

WHAT: The English Longitudinal Study of Ageing (ELSA), is a representative longitudinal survey of people aged 50 or over. It has been used to identify factors associated with an older person being lonely and Age UK developed a model to predict the risk of loneliness based on these factors. However, the sample size of ELSA is too small (6,773) to infer any geographical patterns. Similar factors were also measured in the 2011 Census. The Office of National Statistics National (ONS) Wellbeing Team applied the model, using only those factors for which Census 2011 data exists, on the individual records held in the 2011 Census Microdata files. This produced the relative likelihood of loneliness amongst those aged 65 and over at different geographical locations.

HOW: Census data is held by ONS and the ELSA survey is held by its partners IFS, UCL, Manchester Uni and NatCen Social Research. The ONS National Wellbeing Team applied the model. Both data sets are openly available for research and de-personalised.

IMPACTS: Alongside local knowledge, the loneliness heat map has helped to direct the allocation of resources to reduce loneliness. For example, the heat map predicted Wirral and Rotherham were at high risk of loneliness. As a result, Age UK Wirral identified a gap in provision of social activities in Bromborough and introduced its Friends in Action scheme in the local area. Age UK Rotherham used the map to re-engage local partners with the loneliness issue. Ensuring loneliness was addressed through existing work such as Rotherham Together Partnership, Safer Rotherham Partnership and the Rotherham Health and Well-Being Board.

SOURCE: Age UK (2015) Age UK loneliness maps http://www.ageuk.org.uk/professional-resources-home/research/loneliness/loneliness-maps/

Example C

Tackling Fuel Poverty

The Digital Economy Act 2017 introduced new powers for government to share identifiable information about customers with licensed energy suppliers for the purposes of assisting people living in fuel poverty by—

a) reducing their energy costs,
b) improving efficiency in their use of energy, or
c) improving their health or financial well-being.

The government will link tax credit data held by HMRC with data it holds on property characteristics to identify persons entitled to energy bill discounts and/or help to improve the energy efficiency of their home.

Companies will then receive a yes/no notification for each of their customers so that they can automatically apply a 'Warm Home' rebate or offer support under Energy Company Obligation schemes.

Companies will not be able to use any of the data they receive for any purpose other than those that are outlined in legislation without incurring strict penalties.

Tackling Fuel Poverty

WHO: Government (using information from HMRC and the Valuation Office) sharing with licensed gas or electricity suppliers.

WHY: It is maintained that the best way to guarantee that the government schemes designed to provide energy bill rebates for those in fuel poverty reach those who most need is to provide it automatically. Automatic rebates however can only happen if the state can inform energy companies which of their customers is eligible to receive it.

WHAT: Under new provisions in the Digital Economy Act tax credit (benefits) data held by HMRC will be linked with basic property characteristics data held by the valuation office agency and the Department of Business, Energy and Industrial Strategy (BEIS) ntify citizens living in fuel poverty. Having identified those who would benefit from targeted assistance the government will inform licensed energy providers which of their customers should automatically receive assistance. The only information that energy companies will receive will be a yes/no per customer.

HOW: Clause 30 of the Digital Economy act allow the state to disclose personally identifiable information to licensed gas or electricity suppliers for the purpose of reducing the energy costs, or improving energy efficiency or the health or financial well-being of people living in fuel poverty in connection with an energy supplier obligation scheme. These schemes are the Warm Home Discount (Part 2 of the Energy Act 2010) and the Energy Company Obligation (under the Gas Act 1986 and the Electricity Act 1989). Section 142 of the Pensions Act 2008 already enables the disclosure of social security information about persons in receipt of state pension credit to enable electricity suppliers to automatically provide rebates to customers under the Warm Home Discount scheme. This new clause will enable other datasets to be used for this purpose.

Clause 31 of the act also allows energy companies to share information with those acting on behalf of public authorities to identify customers who are entitled to offers of help to improve the energy efficiency of their home.

IMPACT: While still to be applied the new powers mean that eligible customers will automatically receive a rebate without the need to provide personal information to the energy company to apply for support.

SOURCE: www.gov.uk/government/uploads/system/uploads/attachment_data/file/545213/DigitalGovernment-

Funding GP Practices in Socially Deprived Areas

GPs working in Tower Hamlets and at Queen Mary, University of London (QMUL) used aggregate statistic information from the Index of Multiple Deprivation and consultation rates from GP practices to demonstrate the additional demand per head of population placed on GP surgeries in deprived areas.

This has enabled them to make a case that, in the interests of equality of service provision, levels of social deprivation need to be taken into account when allocating funding to GP practices.

Funding GP Practices in Socially Deprived Areas

WHO: The research was conducted by three GPs working in Tower Hamlets and at Queen Mary, University of London (QMUL).

WHY: GPs in deprived areas argue that funding for GP practices based on the size of the population served actually increase health inequalities by not taking into account the fact that different practice population needs have major implications for practice workload.

WHAT: The researchers examined the 2013 annual GP consultation rates, by age and sex, for the one million GP registered population in east London, and broke this down by the national quintile of Index of Multiple Deprivation (IMD), linking data at their smallest geographical output area. Their analysis showed an excess number of consultations in more socially deprived areas, and illustrated that an individual aged 50 years in the most deprived quintile consults at the same rate as someone aged 70 years in the least deprived quintile.

They were also able to show, by an analysis of consultations which include one or more of a cluster of common investigative blood tests, that these additional consultations were not simply brief encounters for minor illness. Instead the complexity of these consultations showed a similar concentration by deprivation.

HOW: The researchers used publically available, aggregate statistical information about geographic deprivation alongside consultation rates from a nationally representative samples of GP practices.

IMPACTS: The researchers were able to demonstrate that when social deprivation is taken into consideration, some local areas need significantly more GP resources than the current funding formula provides. They developed a new formula to calculate this and found that applying their new formula to Tower Hamlets, one of the most deprived boroughs in England, would indicate 33% more funding was needed to provide a comparable service to other areas.

SOURCES: http://www.bmj.com/content/349/bmj.g6814/rr/808723

Example E

Justice Data Lab

The Justice Data Lab was set up by the Ministry of Justice (MoJ) to give organisations working with offenders, particularly Voluntary, Community and Social Enterprise organisations, access to central re-offending data.

To use it, an organisation needs to provide the MoJ with details of a group of offenders they have worked with, and information about the nature of the intervention. In return the organisation receives a report of the re-offending rate for that group compared to a matched control group of offenders with similar characteristics.

The service provides this information to help organisations to assess the impact of their work on reducing re-offending. It also helps develop a collaborative understanding of effective rehabilitation.

Justice Data Lab

WHO: Ministry of Justice (MoJ) with Voluntary, Community and Social Enterprise organisations working with offenders.

WHY: The Justice Data Lab has been set up by the MoJ to help organisations working with offenders access re-offending data. It is intended for Voluntary, Community and Social Enterprise organisations working with offenders who want to get a better understanding of their impact.

WHAT: To use the Justice Data Lab an organisation needs to provide details of a group of offenders they have worked with including, their name, date of birth, gender and - if possible - Police National Computer Identifier (PNCID) and/or Prison Number, as well as the start and end date for their intervention and whether the work was carried out in the community or custody.

The MoJ then uses this information identify the offenders and track any cases of re-offending. From this they will produce a report for the organisation which shows the re-offending rate for that group compared to a matched control group of offenders with similar characteristics. The difference between the two rates represent the impact of the intervention on the group's re-offending rate. These reports are also published on the MoJ website.

HOW: This dataset used by MoJ is an extract of the Police National Computer, linked to other sources. It contains a wide range of variables relating to criminal history and previous offences, as well as the re-offending outcome. In establishing the Data Lab the MoJ considered confidentiality and data protection and are satisfied that it meets the necessary standards. In particular, they feel that because the purpose of Justice Data Lab is to test the effectiveness of interventions, the consent of individuals is not needed before their data is sent. Further all personally identifiable information about offenders must be sent to the MoJ using a Criminal Justice Secure e-mail address and the MoJ will ensure all individual data sent by organisations is permanently deleted after use.

IMPACTS: The service helps organisations, particularly small voluntary sector organisations, assess and demonstrate the impact of their work. It also helps develop a collaborative understanding of effective rehabilitation.

SOURCE: http://www.clinks.org/sites/default/files/MoJ%20Data%20Lab%20briefing.pdf and
https://www.gov.uk/government/collections/justice-data-lab-pilot-statistics

Homeless Support in Bristol

BrisDoc's Homeless Health Service is working in partnership with homelessness support services, and other agencies who interact with the city's homeless population, to develop a shared data sharing platform that will give a complete picture of the service interactions of clients: pooling information from medical, psychiatric, social agencies, criminal justice and housing services.

This data platform will enable any of the services a homeless client comes in contact with to access their records and ensure a co-ordinated approach to care and support.

In time, analysis of these linked records, will also allow assessments to be made regarding the effectiveness of different approaches to managing and supporting homelessness in the city, informing future service planning and strategic interventions.

Homeless Support in Bristol

WHO: BrisDoc Homeless Health Service and homelessness support services throughout Bristol

WHY: For people experiencing homelessness or prolonged periods of rough sleeping, the rate at which health problems occur increases rapidly: 73% report a physical health problem, and for 41% this is a long term problem; 45% have been diagnosed with a mental health issue. Factors which contribute to unhealthy lifestyles such as smoking, and drug and alcohol use, are also more prevalent than in the general population. However accessing sustained and consistent treatment can be difficult.

WHAT: BrisDoc are developing an electronic data sharing scheme designed to support agencies to deal more effectively with homeless clients. The aim is to pool all available information from medical, psychiatric, social agencies, prisons and housing services into a single electronic platform accessible to a wide range of actors interacting with the city's homeless population. This would mean that, for example, in the case of police or paramedics being called to a street dweller wandering drunk through traffic they would be able to use the data platform to establish whether the person was known to mental health teams, which would lead to a referral there and avoid unnecessary sectioning or a night in police cells.

HOW: Building the data platform has involved combining information from two main systems – the Emis data-sharing platform used by 106 GP practices in Bristol and Connecting Care, a local electronic patient record allowing health and social care professionals in Bristol to access outline NHS patient information. Adult protection information, criminal justice and housing history as well as end of life care plans are now being integrated into the system.

IMPACTS: The system is still under construction however Homeless Services in the city are already seeing the impacts: "Before the introduction of the electronic platform, I have seen support workers spend a day trying to trace a client, only to find out that they are in hospital… Now that link can be made in five minutes."

SOURCE: https://www.theguardian.com/healthcare-network/2017/feb/22/gp-practice-sharing-data-transform-care-homeless-people

Example 1

Routes from Diagnosis

This research, led by charity McMillan Cancer support, linked routinely collected Hospital Episode Statistics (HES) data with cancer waiting times data, data from cancer screening programmes and cancer registry data to map the cancer journey from diagnosis to survival or death.

The information gained from this research has led to a better understanding of cancer patient's clinical journeys and is being used to:

- Enhance clinicians' knowledge of the issues faced by cancer survivors;
- Better understand the patterns of side effects from treatment and which patients are more likely to suffer from them and need support;
- Inform the planning, development and implementation of care pathways for cancer patients.

Routes from diagnosis

WHO: MacMillan Cancer Support in partnership with the National Cancer Intelligence Network and Monitor Deloitte

WHY: More evidence is needed to understand what happens to cancer patients after diagnosis and of the issues cancer survivors face after treatment. Improvements to cancer care are limited because we don't know how many patients are dealing with significant consequences of cancer and its treatments and in particular which patients are affected. More evidence is needed to understand variations in survival outcomes, morbidity and cost between patient groups.

WHAT: Route from Diagnosis is a programme of research performing retrospective analysis of almost 85,000 cancer patients' interactions with the NHS in England over seven years. It linked routinely collected administrative Hospital Episode Statistics (HES) data with cancer waiting times data, data from cancer screening programmes and cancer registry data to map the cancer journey from diagnosis to survival or death.

HOW: The programme used anonymised cancer registry and HES data linked at a patient and episode level. Datasets were linked by an anonymised patient ID.

IMPACTS: The evidence generated can be applied to cancer care commissioning, service and system design, policy formulation, and to inform the direction of academic research. For example, South Yorkshire, Bassetlaw and North Derbyshire Clinical Commissioning Groups have the highest levels of cancer incidence and mortality in England. They used the programme methodology to identify a number of outcome pathways for those diagnosed with colorectal cancer. By matching patient needs to the correct level of support, the CCGs are now designing, testing and evaluating stratified care pathways which provide more individualised care for each outcome group.

SOURCE: Routes from diagnosis, Macmillan http://www.macmillan.org.uk/about-us/what-we-do/evidence/cancer-intelligence/routes-from-diagnosis.html

Example 2

Reducing unnecessary 999 calls

In order to reduce the number of unnecessary calls made to blue light services in Braunstone emergency service providers, the local authority and health services are developing an agreement to share information about repeat callers.

The rationale is that those who repeatedly use emergency services are likely to be facing similar underlying difficulties which may be better served with a social care package or mental health support, freeing up the blue light services to respond to emergency calls instead.

By sharing information about repeat callers between partners the hope is that those identified individuals can be approached and offered alternative support at the earliest opportunity to improve their wellbeing.

Braunstone Blues partnership information sharing agreement – reducing unnecessary 999 calls

WHO: Braunstone Blues is a multi-agency project consisting of Leicester Fire & Rescue, Leicester Police and East Midlands Ambulance Service. It also strategic input from Leicester City Council, Leicester City Clinical Commissioning Group, Leicestershire NHS Partnership Trust, and University Hospitals of Leicester NHS Trust.

WHY: The project partners want to identify underlying causes for increasing calls to the blue light services in Braunstone. Those that repeatedly use emergency services, irrespective of which service it is, may be facing similar difficulties which cannot be dealt satisfactorily by one organisation alone. Many vulnerable households calling the blue light services may be better served with a social care package or mental health support. In order to support an early intervention project and provide the most suitable service, the underlying causes for calling the blue light services needs to be identified and understood.

WHAT: A multi-agency information sharing agreement is being set up to share identifiable data between health and non-health partners for the purposes of early intervention and improving outcomes for vulnerable people.

HOW: There are particular difficulties in sharing health data (particularly around confidentiality and whether data can be shared without consent for interventionist work, or for secondary use purposes if not for individual care). This project would examine solutions in more detail to ensure the resulting agreement is compliant with data protection and human rights laws, as well as the common law duty of confidence.

IMPACTS: By better understanding which households repeatedly call 999, and why, more effective early interventions can be designed across the many agencies. Better data could also show where these vulnerable households would be better served by other specialist services. Ultimately, this would lead to freeing up blue light services to respond to emergency calls.

SOURCE: **LGA data experts grants support better use of local data mini projects** http://about.esd.org.uk/news/lga-data-experts-grants-support-better-use-local-data-mini-projects

Example 3

Linking data to improve health and social care outcomes

De-personalised patient data from health and social care services in East and North Hertfordshire (including hospitals and GPs) was linked to:

- better understand the needs of their local population;
- facilitate data-enabled decisions;
- improve the process of identifying individuals at risk or in need of a specific intervention.

The data is used in an anonymised form to inform service planning and evaluate interventions, however the system is also designed to enable patients to be re-identified and offered services or support.

This is because, in this case, identifiers such as name, NHS number, and full postcode were coded, rather than removed from the dataset altogether. Therefore if an individual is identified as being at risk or in need of a specific intervention, the relevant health and care professional involved in the care of the patient can use the system to re-identify them.

Linking data to improve health and social care outcomes

WHO: Health and social care services in East and North Hertfordshire (including hospitals and GPs)

WHY: The use of linked data was designed to enable health and social care services to:

- better understand the needs of their local population;
- facilitate data-enabled decisions;
- improve the process of identifying individuals at risk or in need of a specific intervention.

WHAT: De-idenified patient data from health and social care services was linked. Identifiers such as name, NHS number, and full postcode were however coded, rather than removed altogether. This meant that where an individual is identified as being at risk or in need of a specific intervention, the relevant health and care professional involved in the care of the patient could use the system to re-identify the individual or individuals and make the necessary intervention.

HOW: The data was linked using the MedeAnalytics' software package (http://medeanalytics.co.uk). The sharing was made lawful by legislation which places a legal duty on health and adult social care organisations to share information when it will facilitate care for an individual. (The Health and Social Care (Safety and Quality) Act 2015, which inserted sections 251A, B and C into the Health and Social Care Act 2012: (http://www.legislation.gov.uk/ukpga/2015/28/contents/enacted)

IMPACTS: Having access to timely, linked data about local patients and service users has enabled East and North Hertfordshire to better understand their patients needs. Specifically it has been used to:

- undertake powerful impact analysis of their re-ablement service (helping people regain their independence);
- set up automated information alerts – for example, advising a GP if one of their patients is making frequent visits to A&E.

SOURCE: National Data Guardian for Health and Care (2016) Review of Data Security, Consent and Opt-Outs https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF

Example 4

Empty Homes Initiative

Empty properties traditionally pay reduced or zero council tax. Sharing council tax information (including property address) between local authority Revenue Services and Empty Homes Teams can be used to help identify empty homes and help prioritise resources to get homes back into use.

Preston and Lancaster shared service have also found that sharing this data not only supports the work of the Empty Homes Team, but has also reduced instances of error and fraud where council tax was not being paid on occupied homes that were incorrectly listed as empty. This generated over £330,000 in additional council tax revenue in the first year.

Empty Homes Initiative

WHO : Preston and Lancaster Shared Service (PALSS - established to enable Preston City Council and Lancaster City Council to deliver Revenues and Benefits services in the most effective, efficient way) and the councils' Empty Homes teams.

WHY: In 2016 there were over 200,000 properties in England that have been empty for six months or longer and getting them back into use is a priority for authorities to address local housing needs, tackle homelessness and regenerate local areas. As empty homes can be exempt from Council tax (or subject to a reduced rate) sharing Council Tax information with Empty Homes Officers enables these officers to have an accurate picture of how many empty properties they have in the area and how long they have been empty.

WHAT: PALSS commissioned a web-based Property Inspection Module to be designed and built for them by performance management company Destin Solutions which proactively tracks all properties in their area.

They also used this information to undertake an Empty Property Review by providing a list of their current empty properties to a private company Equifax, to carry out checks to help identify the likelihood of that property was actually in use. Typical checks looked at whether there was any credit card activity associated with an address or whether any bank accounts had recently been opened listing that address. This information was then shared with revenue and Empty homes teams to decide whether a visit was required to confirm whether the property was still in fact empty

HOW: The Local Government Act 2003 s85 inserted a new section (18A) into Schedule 2 of the LGFA 1992 specifically allowing Local Authorities to disclose personal Council Tax data in the pursuance of empty property work.

IMPACT: By sharing data through the Property Inspection Module the Councils' found that many residents had "forgotten" to inform the authority that they had occupied an empty property, generating over £330,000 in additional council tax revenue in the first year. It also allowed the Empty Homes teams to focus their efforts on bringing genuinely 'empty' and effectively abandoned properties back into use.

SOURCE: http://www.destin.co.uk/casestudy/preston-and-lancaster-shared-service/

Example 5

Housing regeneration and health

This study was designed to examine whether physical improvements in the quality of social care housing had a significant impact on residents' physical and mental health.

Researchers from Swansea University undertook a matched cohort study, using anonymised, routinely collected data from health and social care services in Wales, to compare the health outcomes of those living in regenerated housing with those living in older properties.

The study found that those living in regenerated houses had lower rates of emergency hospital admissions.

The evidence generated by this research is now being used to demonstrate to local Council's that investment in housing improvements not only has a positive impact on residents' health and well-being in the short term, but can deliver long term savings to health and social care budgets.

Housing regeneration and health

WHO: Academic researchers at Swansea University

WHY: Better evidence was needed to determine that improving social care housing does benefit the physical and mental health of residents. Previous studies have been criticised for ignoring the multifactorial nature of causality relating to housing, deprivation and health. Smaller, self-reporting studies also cause stress for participants.

WHAT: A social care housing regeneration programme was being carried out in Carmarthenshire County Council. A cohort study was created by linking routinely collected data in health and social care data sets in Wales. Both housing and health data sets were anonymised (removing names and addresses) and given a unique identifier and anonymous linking fields. They were linked within a trusted third party (NHS Wales Informatics Service).

HOW: Data from the Welsh Demographic Service was used to create the cohort and linked to several datasets held within the SAIL (Secure Anonymised Information Linkage) databank which holds anonymised data about the population of Wales. For example: Patient Episode Dataset for Wales, which includes demographic and clinical data on all inpatient and day case admissions, including emergency admissions; General Practitioner data set, including prescriptions and symptoms; Public Health Mortality records from the Office for National Statistics (ONS)
The SAIL databank has very high data security standards. Individuals are assigned a unique linking field termed an Anonymised Linking Field (ALF), which is operated by the NHS Wales Informatics Service. The ALFs in each data set enables record linkage across data sets at the individual level while retaining anonymity. This cohort study received approval from an independent Information Governance Review Panel. Analyses are carried out within the SAIL Gateway at Swansea University, which is a secure remote access service to the SAIL databank.

IMPACTS: The study found that for those living in regenerated houses there is a reduction in the proportion of residents who have emergency admission to hospital for cardiovascular conditions, respiratory conditions and injuries. The local council is now using this information to consider integrating budgets to focus more funding on interventions in housing in order to deliver long term cost saving effects in health and social care.

SOURCE: Housing regeneration and health study (2012)
https://academic.oup.com/ije/article/43/1/52/730313/Cohort-Profile-The-Housing-Regeneration-and-Health

Example 6

Information Sharing to Tackle Violence (ISTV)

Studies have shown that only 25% to 30% of assaults that lead to medical treatment are reported to the police.

In Hackney, the ISTV programme has seen the A&E department share non-identifiable patient information related to violent crime injuries with the Community Safety Partnerships (CSPs): time and date of the incident; time and date of arrival in A&E; specific location of the incident; primary means of assault (i.e. weapon or body part used).

This has allowed local police to target hot-spots with preventative initiatives designed to reduce knife, gun and other violent forms of crime, for example:

• increasing patrols at key times and locations;

• the creation of dispersal zones;

• providing evidence to licensing reviews.

Information Sharing to Tackle Violence (ISTV)

WHO: Homerton University Hospital A&E, Hackney police licensing, and Hackney Community Safety Partnership [CSP]) as part of the ISTV programme.

WHY: In Hackney, there is a multi-agency approach to violence prevention involving the CSP, police and public health. Although levels of violence have decreased in Hackney in recent years, rates of violent crime, A&E presentations and hospital admissions for assault remain above national averages.

WHAT: All A&Es collect a core dataset on assault patients, such as patient demographics and the time of presentation. As part of the ISTV programme additional data was collected relating to the time and date of incident, time and date of arrival to A&E, specific location of incident and primary means of assault (weapon or body part).

Non-identifiable patient information from A&E admissions was then shared with the CSP in a de-personalised format (however it is acknowledged that there is a risk that individuals could be re-identified when this information is combined with that held by CSP members). CSP analysed the data and subsequently shared it with Hackney police, public health, the Drug and Alcohol Action Team (DAAT), Young Hackney and the Islington Council CCG (Clinical Commissioning Group) so that cross-borough issues could be identified.

HOW: In September 2014 the Health and Social Care Information Centre published an Information Standards Notice for ISTV. This formal standard of information sharing was sponsored by the Department of Health and designed to ensure that the information sharing was fully compliant with the Data Protection Act.

IMPACTS: Examples of how this information has been used include:
- the development of action plans for addressing anti-social behaviour and violence hotspots;
- provide evidence for the creation of dispersal zones (areas where police have the power to disperse groups where the groups' behaviour has [or is likely to] result in harassment, intimidation, or distress to others);
- contributing towards a licensing review after a number of assaults were identified as taking place at a specific venue.

SOURCE: http://www.cph.org.uk/wp-content/uploads/2014/12/Hackney-case-study-health-data-sharing-to-support-violence-prevention.pdf; http://informationsharing.org.uk/reports/egyvresources/