Better use of Data: Balancing Privacy and Public Benefit

Workshop Report – Sheffield

The **Better use of Data: Balancing Privacy and Public Benefit** workshop in Sheffield 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 Sheffield on the 11th 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 Sheffield was held on the 11th July 2017 and hosted by Sheffield City Council. It brought together a wide range of professionals from the public and voluntary sectors and across the city region to explore the benefits of data sharing for the purpose of delivering better public services.

14 people took part in the workshop, including representatives from Sheffield City Council, the NHS, South Yorkshire Fire and Rescue and local third sector organisations working across the fields of health, housing, 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. 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 problematize 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 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 the 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 Sheffield the workshop followed the following 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 an Appendix 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. To date however, there has 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 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, 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 in the workshop were therefore 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.

Working firstly in three small groups, and then in plenary, a range of different types of benefits to the public and service providers were identified. These are summarised below.

For individuals:

- Services that are more personally targeted;
- Coordinated service provision – so that individuals are referred to the right services at the right time;
- Earlier intervention;
- People can provide their information only once (rather than repeatedly to different organisations or departments), give consent for it to be shared, and be assured about privacy concerns;
- Improved outcomes e.g. improved well-being, reduced social isolation;

For the wider public:

- Fairer access to services;
- Better value public services provided;
- Needs are met through service innovation;
- Improved community outcomes e.g. increased community safety or reduced inequalities.

For service providers and staff:

- More effective targeting of resources and service combinations;
- Financial savings;
- Better understanding of clients;
- Enable proactive responses;
- Move towards more preventative public services;
- Can identify opportunities for early intervention;
- Enable risk analysis;
- Inform cost benefit analyses;
- Deliver a more rigorous, evidence based process for funding/spending allocations;
- Informed commissioning;

- Intelligence on unreported issues / or to identify hidden issues;
- Ability to design new, innovative services based on a better understanding of based on needs and demand;
- Staff can do their job better through service coordination;
- Would mean collecting data only once (if we get the consent right);
- Better understanding of the nuances of service delivery across services, making 'transformation' easier;
- Provide evidence of impact / change;
- Allow for better evaluation and monitoring to inform future planning.

"Using data well now can mean future service users get a better service – or even don't need the service."
Workshop Participant

Establishing criteria for assessing Public Benefit

Having established that there were a wide range of benefits that could be captured under 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 were identified by participants:

- Number of people affected;
- Ability to help the most vulnerable;
- Breadth of impact – on the public and service providers;
- If it supports service evaluation and improvement;
- Whether it addresses multiple problems;
- Immediate impact vs. long term impact;
- Costs savings now vs. the cost of doing nothing i.e. preventative impact;
- The needs of future service users vs. current service users;
- Replicability;
- Cost of implementation vs. potential benefits;
- Scale of the problem;
- Likely public support for the initiative;
- Severity of the problem addressed;
- Availability/reliability of the data.

> *"Respect for the individual – both in the methods we use and in the reasons behind the data sharing - means that the public is more likely to 'buy in'."*
> Participant in the Sheffield Workshop

While each group selected a different set of stated criteria to determine how to they would rank the examples, there were four considerations that appear to have recurred across the groups' deliberations:

1. The number of people potentially able to benefit;

2. The ability of the approach to effectively target the most vulnerable and/or the most severe social problem;

3. The tangibility of the outcomes and the probability of success i.e. would it make a real difference;

4. The 'ripple effects' from delivering the benefits – across service providers and the wider public.

1. The number of people potentially able to benefit

Across the groups' discussions there was a clear sense that participants were drawn to examples that had the potential to benefit the most people, either directly or indirectly, and ranking them most highly (e.g. A: Kent Integrated Dataset, 3: Linking data to improve Health and Social Care Outcomes and 1: Routes from Diagnosis). Although providing a direct and immediate benefit to individuals was not the primary purpose of these models of data use, participants felt that these largescale uses of linked data to monitor and analyse service performance could enable significant improvements in how health and care services were provided, which would ultimately benefit large numbers of people.

Examples that used large aggregate data sets to identify trends, and provide evidence for targeting resources differently, were also seen as able to provide benefits to large number of people (e.g. B: Predicting the Prevalence of Loneliness and D: Funding GP Practices in Socially Deprived Areas). Although at least one group did include the caveat that this high ranking relied on trust that the information would actually be used effectively to inform service design.

2. Targeting the most vulnerable people and/or the most severe social problem

The perceived level of need was also a significant factor for participants in determining which examples had the potential to deliver the greatest pubic benefits. Examples that sought to have direct impacts on particularly vulnerable groups and/or which set out to address key social problems were therefore also ranked highly (e.g. F: Homeless support in Bristol and 2: Reducing Unnecessary 999 Calls).

3. The tangibility of the outcomes and the probability of success

Discussions in some of the groups also focussed quite strongly on how tangible the benefits were for individuals and communities, and how directly these benefits were attributable to the way data was used. This was another reason given for why examples F: Homeless support in Bristol and 2: Reducing Unnecessary 999 Calls were ranked highly by some of the groups.

4. The 'ripple effects'

The ability to identify multiple types of beneficiaries from an example also tended to lead to it be ranked very highly. Two of the examples were ranked as most beneficial across all groups (A: Kent Integrated Dataset and 3: Linking data to improve Health and Social Care Outcomes) because they were seen as providing benefits not just to patients through the provision of better care, but also to staff, by enabling more efficient and co-ordinated working, and to services as a whole through the ability to monitor performance and evaluate impact. Examples that showed evidence of promoting partnership working and using data to address multiple issues were also ranked highly, based on the potential for cumulative impacts across services and wider society.

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.

Risks to individuals:

- That information about a person is used without their knowledge or consent;
- The accidental disclosure of identity when data is intended to be anonymised;
- That the data could be misused / misappropriated to re-identify individuals;
- The risk of being profiled / stigmatised by the use of data;
- That a reliance on data is not able to really identify an individual's service needs, resulting in inappropriate or wasted referrals or interventions;
- Being targeted wrongly due to a 'false positive identification' through data sharing or linking;
- That individuals may be deterred from seeking help if they feel that information about them has been, or may be, disclosed in ways they do not choose.

> *"I worry that there is no 'human side' to the story in pure data analysis and it may not actually capture a person's real needs."*
> Workshop Participant

Risks to the wider public:

- That policy decisions are made based on incomplete data, or data analysis based on coincidence or concurrence rather than causality, leading to wrong interventions being created or needed services withdrawn;
- That an over-reliance on data means that important social issues, or problems in specific communities, are missed or ignored;
- That data profiling leads to the ghettoisation or stigmatisation of different communities or sections of the community;
- That using data to identify areas in which to target resources, means less resources available for other uses.

Risks to service providers and staff:

- Loss of confidence in service providers from the public when something goes wrong, either from a data breach or unintended consequences from the use of data;
- That data analysis undertaken without a full understanding of the context, or when used in isolation, is used to validate false assumptions or draw the wrong conclusions;
- That the subjective analysis of data makes causal links that are not necessarily there;

- That data analysis allows for the assumption that a service is consistently delivered and/or experienced by all users;
- That the process of collecting, processing and using data creates more work for staff, but that there are no additional resources available to support this;
- That data is used for oblique purposes i.e. 'mission creep'.

Assessing Risk

When the groups were again asked to rank the examples they were considering, 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 however three key cross-cutting criteria that underpinned deliberations across the different groups.

1. Whether the use damages trust in public services by going beyond what people might expect their data to be used for, or for purposes that they might object to.

2. The data control procedures in place and the vulnerability of the data to misuse or misappropriation.

3. The identifiability of the data used and the type of harm, and the severity of the negative impact, that the use of this data could cause - for organisations, local communities and individuals.

1. Expectation and trust

Across all of the groups where was a consistent focus on the reputational damage to service providers caused by ill-conceived or badly managed uses of data – particularly if data about individuals was being used in ways that the data subject may not have given consent for and/or may not expect. Example 4: Empty Homes Initiative, where datasets held by the local authority were shared with a private company to identify instances of council tax fraud, was particularly highlighted by one group as exemplifying this risk. This example also raised additional concerns because of the punitive outcomes that the data use could produce for individuals.

The use of personally identifiable data by services without the informed consent of the individual was also seen as very high risk and as something with the potential to significantly undermine trust the public sector. This resulted in example 2: Reducing Unnecessary 999 Calls being considered by one of the groups as a very high risk approach for services. This was primarily because it proposed sharing personally identifiable information about potentially vulnerable people to create an intervention that they had not requested.

Example C: Tacking Fuel Poverty was also identified as a very high risk activity for public service providers, as it involved the use of personally identifiable financial information for purposes members of the public might not expect. This risk was considered to be heightened by the fact that government was sharing this information with a private company.

Even when the data used was de-personalised, participants in the workshop still expressed significant reservations about the data being used for purposes that the individual supplying the information may not expect. Thus the example that involved A&E departments sharing anonymised data about people presenting to the department after a violent incident was considered particularly inappropriate by one group (6: Information Sharing to Tackle Violence).

2. Data Security

The way that data is collected, stored, shared and controlled can also create risks, both to an individual's privacy and the organisations using or sharing the data. Thus some of the groups considered the data control and governance involved in the examples (e.g. technical storage and sharing procedures as well as access, monitoring and audit controls) as key criteria for assigning risk.

While acknowledging that there was limited information about these factors provided in some cases, they did highlight a number of examples as appearing to be particularly vulnerable to a data breach or the misuse of data. These concerns were primarily based around the belief that the creation of any large database, linking multiple data sets at an individual level, has an inherent risk of being breached. This risk increases in direct relation to the number of agencies and/or individuals who have access to the data (e.g. 3: Linking data to improve Health and Social Care Outcomes). Similar concerns were also raised in relation to example F: Homeless support in Bristol, where it appeared that frontline workers from a wide range of agencies would be able to access identifiable information about the individual's health, mental health and housing status.

3. Identifiability and the type, and degree, of potential harm

Across all of the groups there was agreement that using personally identifiable data was far riskier, for individuals and service provers, than the use of anonymised, aggregated data. This was particularly the case if information was shared without the consent of the data subject. Additional concerns were also raised if the type of data used was considered especially private and sensitive, for example, information about mental health, criminal history and personal finances. The impact on an individual, from negative stereotyping, stigma or inappropriate targeting if this type of information was misused were considered to be particularly damaging. There was also concern expressed about whether data subjects had to opportunity to 'opt-out' of their data being included within the some of the examples under discussion, and whether there were clear and accessible routes for redress if individuals believed the way data was being used had caused them harm.

Participants also considered the risk of people being re-identified, through the use of linked data sets held at an individual but de-personalised level, as a significant risk to individual privacy and as a potential reputational risk to service providers (e.g. 3: Linking data to improve Health and Social Care Outcomes). This high risk ranking 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 accidental re-identification in this case may be low, the impact of it happening both to an individual's privacy and the standing of the organisations involved, was potentially very high.

Acceptable uses of data sharing to deliver public benefits

Determining what constitutes an acceptable settlement 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 to highlight the complexity of the considerations involved in determining the acceptability of data sharing across a variety of contexts and sectors. They highlight that, while the arguments driving the demand for greater data sharing may be to provide 'benefit', the realities of practice present 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 stakeholder groups was a key purpose of this workshop.

Defining 'Public Benefit'

In the second half of the workshop participants were asked to reflect back on the types of benefits they identified that the 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 a data sharing activity or programme to be described as producing 'public benefit' included:

- Efficacy i.e. that it is an effective and efficient use of public money;

- That it enables high quality service delivery and quality outcomes for service users;

- That is has wider impacts i.e. the 'ripple effect';

- That it is 'forward focused' - delivering long term benefits in a sustainable way;

- That it support contributes to early intervention and prevention;

- That it provides benefit to the majority;

- That it enables the delivery of what people need/want from public services;

- That it uses data in ways that respect the individual, not just in the method of sharing but also in principle;

- That it leads to initiatives and interventions that are evidence based, not just popular;

- That it delivers clear, measurable benefits;

- That the benefits are visible, recognised and valued by service providers and the wider public.

Managing the trade-offs

To stimulate the discussion about how the trade-offs between risk and benefit could be managed in practice participants were asked to work in two groups (each looking at one set of the examples) and now rank them in order of the overall acceptability of using and sharing 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.

While there was genuine concern raised by participants about the negative impacts that data sharing could have on an individuals' privacy and their overall wellbeing, the main focus of the discussion in this workshop was on the risks, benefits and impacts to service providers. Points raised during the deliberations about acceptability tended to focus on:

- **Clarity of purpose** – this was seen by both groups as vital for generating support for the use of data. When examples were described as vague or 'woolly' they were generally classed as less acceptable. Having clearly defined purposes and parameters for using data was also stressed as being a valuable protection against 'mission creep' and reducing the likelihood of data being used for purposes that the public might not expect.

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

- **Sustainability** - if the potential benefits able to be delivered by an activity were sustainable, and had a long term impact, then assessments of acceptability increased.

- **Multi-agency involvement** - while increasing the number of partners involved in the data sharing was considered to be a key way of expanding the potential benefits an initiative could deliver, and enabling a 'ripple effect', the wider a multi-agency sharing agreement became was also seen to be a factor in increasing risk. This was largely because of concerns that, as the number of partners grew, there was potential for more people to have access to the data, for access controls to be weakened and thus a greater risk of privacy breaches.

- **Tackling the 'root causes'** – when data sharing initiatives were seen to actually address the root causes of problems (for individuals or wider social issues) then their acceptability increased, regardless of the potential risks. There was also a sense in the room that unintended negative consequences were more likely to occur when initiatives were reactive or simply attempted to 'plaster over' symptoms of a bigger issue.

- **Likelihood of risk** – while a number of potentially significant risks (for both individuals and service providers) were acknowledged in the discussions, workshop participants felt it was important to balance the severity of the impact with the likelihood of it happening. There was a general sense across both groups that a well-conceived, well designed and well governed data sharing initiative should be able to mitigate against vulnerability to unintended consequences and opportunities for data to be misused.

- **Reputational risk** – one group's discussion focussed very strongly on the reputational risks to service providers from how they used personal data collected from service users. They initially concluded that, if the reputational risk to a council or other public sector provider was too high, then that could not (and should not) be traded for any potential benefit. Throughout the course of the discussion

however opinions within the group changed, due to the recognition that public agencies have to "make tough decisions all the time" regarding how they deploy their resources i.e. public monies. The challenge this group acknowledged however, was how they communicate and 'sell' to the wider public that using data to deliver outcomes, even if the use may be uncomfortable or different to what the public may expect, is acceptable.

"We identified criteria, but kept being drawn back to the examples that would be easier to sell to the public."
Workshop Participant

- **Justifiability** – across both groups, a recurring themes was whether the risks that a particular use of data may pose were outweighed by the benefits. The ability for a service to justify that they had considered the balance (done whatever they could to mitigate negative consequences) and ultimately determined that the benefits – to service providers, individuals and the wider public – outweighed the potential harm, was a key factor in determining whether a use of data was deemed acceptable or not.

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. The discussions however identified three boundaries that participants felt should be considered as 'red lines' for the use of personal data which should not be crossed, even in the interest of providing better public services:

- When there is a lack of public awareness and consent about how data about the public may be used – even if there is a legal gateway to do so;

- When the sharing is not for a defined and clearly articulated purpose, but instead allows for speculative analysis and opportunistic results;

- When delivering on outcomes involves sharing personally identifiable information collected by public service providers with commercial companies – unless there is informed consent and a clear opt-out route available.

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 there was a general consensus among participants that services need data, and that both its collection and use is broadly justified. There was however, considerable focus on the difficulties and risks involved in delivering these benefits in practice. Key points that emerged during the workshop are presented below.

- The increased ability to share data between public service providers (technically and legally) provides an opportunity to move towards being able to provide more responsive and preventative public services.
    - But there remains trust issues between organisations in relation to the willingness to share data, and faith that the agencies they share with will use the data appropriately.
    - There are also problems with the practical realities of sharing data due to incompatible systems, even if the willingness is there.

- The better use of data between and across public service providers is a simple, but powerful tool for gaining a shared insight into the challenges public services are facing.
    - It can also be a valuable tool for measuring the impact they are having, individually and collectively, in addressing these issues.

- Using the data that services collect and hold more effectively provides an opportunity to move from a 'siloed', piecemeal approach towards a more strategic, coherent and integrated approach to public service delivery.
    - There are clear opportunities created by working in partnership as a city region to develop gateways that will enable information to flow better between agencies.
    - But services don't necessarily know what data is out there, or who holds information that could inform better service delivery.

> *"We need to stop and take a stocktake of what data is out there – and just what we can do with it."*
> Workshop Participant

- Data capture is inconsistent across organisations and therefore it's sometimes impossible to get the big picture from the data that is being collected e.g. How many volunteers there are in Sheffield? What impact does this have on Sheffield?
    - Part of this comes down to the capability of organisations to collect and process data (including the skills and time available within an organisation to do it, particularly in small voluntary sector organisations), but it also comes down to be clear on what information is useful city wide and what should be prioritised for collection.

- There are also opportunities to learn from the success private companies have had in encouraging citizens to make use of their own personal data to better understand their behaviour patterns and contribute to meeting their own support and care needs i.e. through what is termed 'personal analytics'.

- There appears to be a growing mind-set of openness from the public in terms of sharing information on social media, but still a real hesitancy to allow services to use the personal data they hold about them.
    - Obtaining consent from people for data about them to be used for purposes beyond direct service provision remains a challenge, as people are generally suspicious about how data may be used.
    - A key challenge therefore, to enable the better use of data by public services providers, is winning over 'the hearts and minds' of the public to the view that agencies using and sharing the information they hold about them is in their, and the wider public's, interest.

Insights and reflections:

- That, as a council, we collect a lot of data about individuals but rarely have a conversation with the public about how we can, or should, use this data.
    - We need to get better at communicating with the public (in readily understandable, layman's terms) about what the data collected is, or could be, used for - and also what are the benefits and risks of using data in different ways.

- That there are too many demands and toolkits and from central government regarding data sharing – "and they are all different!" To support local authorities to really develop effective data sharing procedures and protocols there needs to be a consistency in standards and expectations.

- That we need to be careful that an increased reliance on data does not blind us to its limitations – data about service users needs to be seen as one source of intelligence only.
    - We also need to recognise the analysis of data is not objective, but rather interpretive.
    - Also that data shouldn't be used solely on its own, but rather used as part of determining the solution. Information on its own is unlikely to generate real impact.

- That making the trade-offs in reality is not just a matter of balancing benefits and risks.
    - Instead the benefits have to outweigh not just the risks but the effort, time, costs, resources, risk mitigation controls etc. involved in pursuing a particular type of data sharing.

> *"The benefits achieved by the use of data have to outweigh not just the risks, but also the effort, time, financial outlay, resources and opportunity costs involved."*
> Workshop Participant

- That just because there is a perceived risk in a particular type of data sharing activity, this should not discount this data being used to deliver clear pubic benefits. Instead the focus needs to be on how the risks can be minimised / mitigated.
    - It also needs to be recognised that 'risk' is different to potentially 'negative effects/impacts' caused by data sharing.

- That actually, it could be considered "unacceptable" that the data held by public services isn't being shared better to deliver benefits to the public. Maybe the discussion we should be having is about when it is acceptable or necessary not to share?
  - There is a need to enhance the quality of the data that is held across organisations, with the expectation that it will be shared.

"Maybe the discussion needs to be focussed on 'When should we not share?"
Workshop Participant

- That the discussions during the workshop have made the group focus on what are 'appropriate' uses of data by public service providers and highlighted that we need to think about criteria/principles regarding purpose and priority.
  - We need consistent terms and frameworks to evaluate benefit;
  - We need a toolkit of things to consider – with criteria and guidance;
  - We need a tool to enable prioritisation.

- That, while some opportunities for using data better within public services may not open up technical or legal risks, they are still considered very risky because they are harder to 'sell' to the public.
  - The risk, therefore, is primarily in relation to whether service providers are willing to have the argument / conversation with the public – to make 'the invisible visible'.
  - Can we justify, convincingly, why the greater use of data is needed?

"No matter how you frame it – prioritising needs and service responses is political."
Workshop Participant

- That determining public benefit is ultimately dependent on perspective and perceptions – what is good for the many may not always be good for the few - and not everyone is going to understand 'benefit' in the same way.
  - Considering values, both individually and the values of the wider public, is therefore a key factor.
  - Understanding how the wider public value different type of benefits will require involving them in the conversations.

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.
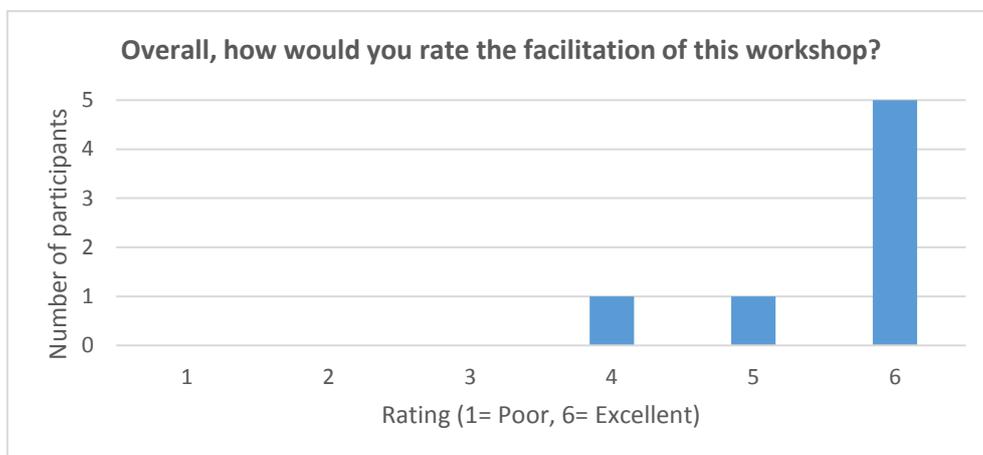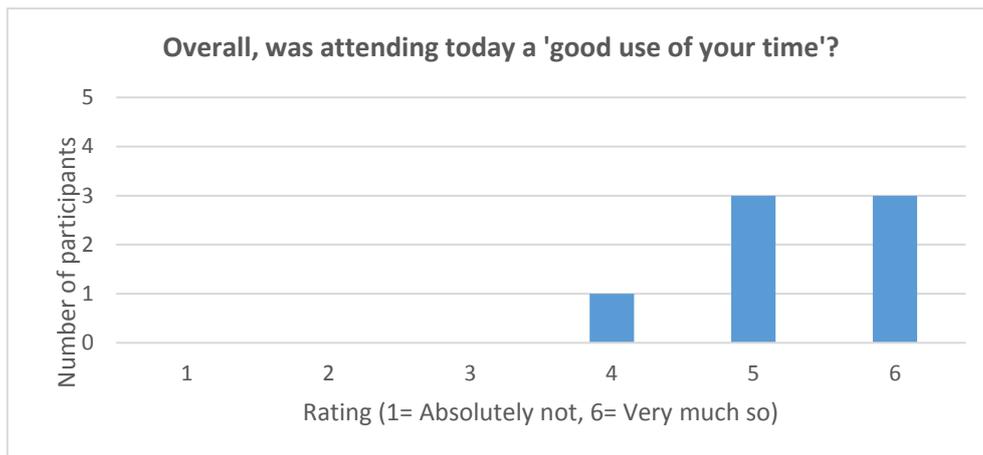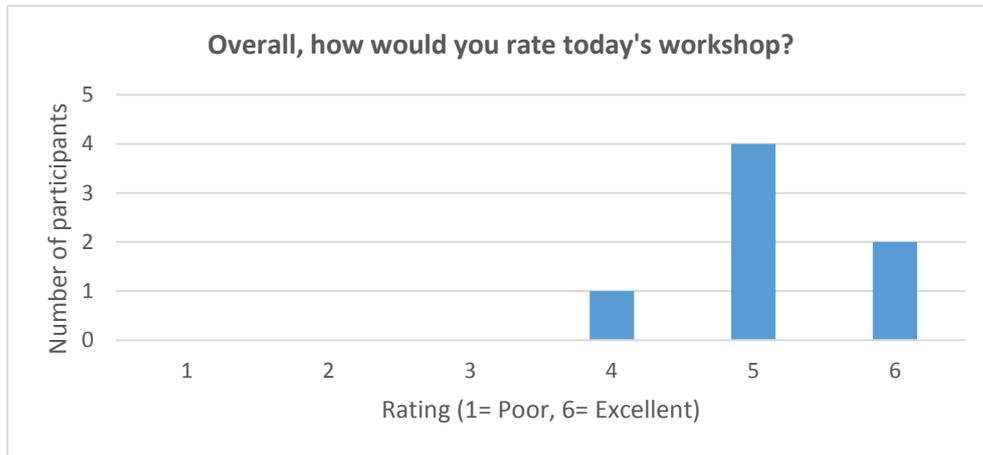
The forthcoming report being produced as an outcome of workshops like this in six local authority areas across England is designed to provide a tool to enable these conversations to take place.

Appendix A: Participants evaluation of the workshop

Number of participants: 15
Responses received: 7
Response rate: 47%

Overall, how would you rate today's workshop?

Y-axis: Number of participants (0–5)
X-axis: Rating (1= Poor, 6= Excellent)

Rating	Number of participants
4	1
5	4
6	2

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

Y-axis: Number of participants (0–5)
X-axis: Rating (1= Absolutely not, 6= Very much so)

Rating	Number of participants
4	1
5	3
6	3

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

Y-axis: Number of participants (0–5)
X-axis: Rating (1= Poor, 6= Excellent)

Rating	Number of participants
4	1
5	1
6	5

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

"Range of case studies, and digging into them"

"Case studies + critical evaluation"

"Shared insight"

"Got us into some really challenging, meaty questions, without being too daunting!"

"Space to think about when + why we share data + to interrogate our own responsibility"

"Discussions"

"The discussions. There were some challenging ideas"

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

"Background to DEA (Digital Economy Act) – wasn't so clear how it fit in"

"Wordy case studies"

"Hard to evaluate scenarios without a criteria which made some groups difficult to engage with"

"Felt slightly rushed – conversations stopped to move on"

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

"It worked very well – no need to change anything – maybe intros to the people in the room/other participants"

"Deeper look into particular case studies to get to bottom of risks"

"Perhaps some other case studies to work with? As in additional, not a substitution! Also good to hear about other's examples"

Do you have any other comments?

"Looking forward to the report"

"Good to stay silent on IT/tech aspects of this"

"Thank you"

"It has made me think more about the sharing of data and the consequences of doing so"

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

Example F

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.

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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/