

Better use of Data: Balancing Privacy and Public Benefit

Workshop Report – West Midlands

The **Better use of Data: Balancing Privacy and Public Benefit** workshop in the West Midlands 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 Birmingham on the 10th 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.



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Overview of the workshop

The workshop in Birmingham, held on the 10th July 2017, was hosted by the West Midland Combined Authority. It brought together a wide range of professionals from the public and voluntary sectors across the area to explore the benefits of data sharing for the purpose of delivering better public services.

20 people took part in the workshop, including representatives from the combined authority and local councils, West Midlands Police, West Midlands Fire Service, and a range of local third sector and partnership groups working across the fields of 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 however 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 '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 Birmingham 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. Using case studies to explore and identify principles of good practice and ways to mitigate risks;
10. 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. 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 four small groups (with half of the tables looking at each set of examples) and then in plenary, a range of different types of beneficiaries and benefits were identified.

- **Individual service users:**
 - Early identification of needs;
 - Personalised, more bespoke services;
 - Receive a more consistent and equitable offer from providers;
 - Only have to tell their story once and information is held on one platform or site; and
 - Reductions in the time it takes to access services.

- **The wider public (or sectors of the public):**
 - Reduced inequalities;
 - Better targeted services provided at reduced costs;
 - Greater confidence in the system to address and resolve issues;
 - Communities that work e.g. through improved community safety, social cohesion etc.; and
 - More effective use of the 'public pound'.

- **Service Providers:**
 - Efficiency savings;
 - Able to deliver better, and better targeted, services;
 - Greater public trust in services;
 - More joined up working;
 - Reduced bureaucracy;
 - Better decision making;
 - Better identification of needs, trends and the services required;
 - Supporting policy decisions with hard evidence;
 - Informed resource allocations and funding decisions;
 - Synergy and positive knock on effects for other services;

- Supporting innovation;
 - Better co-ordination of resources between organisations; and
 - Informs strategic long term planning.
- **Staff delivering services:**
 - Cutting down noise and increasing confidence in their decisions;
 - Greater awareness of other services;
 - Freeing up time to enable staff to focus on more challenging decisions /cases;
 - Greater ability to evaluate service impacts; and
 - Reduced frustration.

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.

In approaching this task each of the four groups adopted a different criteria as their principal consideration.

1. The number of people benefiting

In this group the discussion focussed on the numbers able to benefit directly from the use of data, resulting in example 3: Linking data to improve Health and Social Care Outcomes being ranked most highly by the group. Participants in the group noted that this largescale use of linked data, to improve performance and identify individuals in need of interventions, could enable significant improvements to be made in how health and care services were provided, ultimately benefiting large numbers of people.

2. Ability to provide multiple benefits

A second group, looking at the same set of examples, instead focussed on the range and different types of benefits that the model of data sharing was able to deliver. This again led to example 3: Linking data to improve Health and Social Care Outcomes being identified as most beneficial, because it offered clear benefits to patients but also provided service providers with a tool to monitor performance and inform planning. Examples that were seen to primarily benefit service providers, with little direct, positive impact on the public, were considered to be the least beneficial overall by this group (e.g. 4: Empty Homes Initiative and 5: Housing Regeneration and Health).

3. The severity of the social problem being addressed

Participants at the third table focused their considerations on perceived levels of need and the ability of an initiative to have impacts on the most vulnerable people, or the most severe social problems. This led to examples that addressed improving health and social care provision (e.g. A: Kent Integrated Dataset) tackled social inequalities cause by multiple deprivation (e.g. D: Funding GP Practices in Socially Deprived Areas) and supported homeless individuals (e.g. F: Homeless support in Bristol) being ranked as most beneficial.

4. Ability to deliver long term impacts

Long term impacts, both on service planning and, ultimately, on the provision of better services for the public was the key criteria used by the final group in this workshop. They therefore ranked examples that focussed on strategic and preventative approaches most highly (e.g. D: Funding GP Practices in Socially Deprived Areas and B: Predicting the Prevalence of Loneliness).

Financial implications

Another cross-cutting consideration that appears to have featured across a number of the discussions was cost – either in relation to the costs involved in delivering effective interventions as the result of the data analysis (e.g. 5: Housing Regeneration and Health) or the cost savings able to be delivered through this model of data use. Examples of the type of cost savings that could potentially be delivered to service providers included the ability to more effectively allocate staff and resources to ‘hot-spot’ locations (e.g. 6: Information Sharing to Tackle Violence and B: Predicting the Prevalence of Loneliness) and the effective evaluation of service to demonstrate if they were delivering value for money impacts, and therefore warranted continued investment (e.g. 3: Linking data to improve Health and Social Care Outcomes and E: Justice Data Lab).

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:**

- Identification, or re-identification, from the use of data that results in unfair targeting by services;
- Loss of personal control over how information about them is used;
- Being labelled or 'flagged' for potentially unwanted interventions;
- That vulnerable people do not access services because of fear how information they provide might be used;
- That individuals who choose not to provide information to services miss out on support; and
- The risk of bias being shown to an individual by staff (consciously or unconsciously) on the basis of information that has been shared.

"I worry the over reliance on data means that people in need can fall through the cracks or be declared not eligible for services - 'the computer says no'."

Workshop Participant

- **Risks to the wider public:**

- The ineffective distribution of resources within communities based on poor data use;
- That data is used to confirm existing biases about an area and leads to stigma;
- A lack of transparency about how data based decisions are made e.g. using 'black box algorithms';
- That there are less responsive services locally because a formulaic data based solution is used to plan services everywhere; and
- The removal of valued services that are judged to be inefficient.

- **Risks to service providers and staff:**

- That appropriate data is not shared to allow informed decisions;
- That poor quality data identifies the need for the wrong service in wrong place;
- That data is used to identify problems that services are unable to intervene effectively to solve;
- The reputational risk if data is used badly, insecurely;
- That services or staff do not comply with data protection legislation;
- That data is used to justify existing, false assumptions;
- That data use attributes value to evidence in ways that support wrong conclusions; and

- That the professional judgement of staff and experts becomes devalued.

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. Again, in this workshop each group identified a different criteria as their primary consideration for assessing risk.

1. The risks created by a poor use of data

An aspect of risk that was highlighted by one of the groups, and used to inform their overall ranking of examples, was the risk to services and the public created by the use of poor quality data and/or poor analysis of data. A key risk they focussed on was the ability of data to be selectively used, or subjectively processed, to enable dubious conclusions (e.g. B: Predicting the Prevalence of Loneliness) or confirm a pre-existing hypothesis (e.g. D: Funding GP Practices in Socially Deprived Areas).

2. The vulnerability of the data to misuse

The way that data is collected, stored, shared and controlled can also potentially create risks, both to an individual's privacy and the organisations using or sharing the data. One group therefore focused on the data control and governance used 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 data base, linking multiple data sets at an individual level, has an inherent risk of being breached, and that this risk increases in direct relation to the number of agencies and/or individuals who have access to the data (e.g. A: Kent Integrated Dataset).

3. The level of intrusion into individual privacy

Participants in this group focused on the risks associated with sharing personal, and particularly personally identifiable, data without the informed consent of individuals. This led to the example that involved blue-light services sharing the details of homes making repeated, unnecessary calls being shared with support service providers to offer alternative interventions (eg. 2: Reducing Unnecessary 999 Calls) being considered a particularly high risk intrusion into privacy.

Example 4: Empty Homes Initiative was also seen as a significant intrusion into privacy because it matched council tax data held by local authorities with data accessed by a private company about registered addresses for bank and/or credit cards. This use of data was viewed as creating a significant reputational risk to local authorities because the type of data used was considered particularly sensitive.

“the standards for demonstrating public benefit have to be seen as higher for some areas of public policy where the possible harm caused by the intrusion is higher.”

Workshop Participant

4. The risk of negative or punitive outcomes from using identifiable data

The final group again focussed on the risk of using identifiable, or potentially re-identifiable, information about individuals, but in this case they focused on negative impacts this use could have on the individuals the data was held about. They therefore also highlighted example 2: Reducing Unnecessary 999 Calls as high

risk, but because they felt this use could create harm to individuals by exposing them to unwanted or inappropriate offers of service, or causing them to feel hesitant about accessing emergency services if required. Participants also considered the risk of people being re-identified from de-personalised data had the potential to cause harm to individuals (e.g. in 6: Information Sharing to Tackle Violence by making them vulnerable to stigma or direct punitive consequences).

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 as 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 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 highlighted that the key elements participants considered necessary for a data sharing activity or programme to be described as producing 'public benefit' included:

- That it created efficiencies for the 'public purse';
- That it enabled effective targeting of resources across services;
- That it delivers clear outcomes for the public, not just individuals;
- That it can be undertaken in ways that do not infringe individual rights, including the right to privacy;
- That it has positive, long term system impacts.

Public benefit is *"something that is for the greater good, driven by objectivity, with no intent to discriminate or prejudice."*

A potential definition from the workshop

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 groups (each looking at one set of the examples) and now rank them 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.

The deliberations about acceptability focused on:

- **Spread of benefits** - The acceptability of an initiative was heightened if it was perceived to provide the greatest benefit to the greatest number of people, particularly when there were also benefits evident to service providers and the public sector more widely.
- **Identifiable benefits** – there was general consensus that, for a data sharing activity to be considered acceptable, it needed to be geared towards creating tangible benefits that would have a direct impact on people’s wellbeing and/or support improvements in public services which would have ‘knock-on’ effects for the wider public. Related to this, there were also concerns expressed that over-claiming the benefits of data use (or a particular example of data sharing) in itself created risks, particularly reputational risks to organisations if the expected benefits were not realised.
- **Identifiability** – Whether the data used in the process was identifiable, and whether it needed to be to deliver the intended outcomes, was another key consideration in determining acceptability. The use of personally identifiable information, particularly without explicit consent, generally reduced the acceptability of initiatives for participants. There was however overall acceptance that there was a case to be made for sharing personally identifiable information without consent when it was done in order to reduce a direct risk of serious harm to an individual, regardless of the intrusion into privacy.
- **Safeguards** – ‘Data Protection by Design’ was a concept that featured in a number of the discussions and related to the secure collection and storage, governance, access controls and proportionality of data sharing arrangements, particularly between different services or organisations. Further, there was a general sense among participants that well-conceived, well designed and well governed data sharing initiatives should be able to mitigate many of the potential risks involved in using personal data, or at least minimise their harmful impacts.
- **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.
- **Short or long term benefits** – While recognising that the better use of data can deliver immediate benefits to individuals, participants in this workshop tended to attribute more value to examples that were able to deliver long term, system benefits. This included benefits that were likely to apply mainly to future, rather than current, users of services.

What risks are too high to accommodate?

The previous exercise exposed four clear boundaries that participants identified as creating ‘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 no identifiable, tangible benefit established before data is shared i.e. that the sharing is not specifically purposeful;
- When the proposed use of data makes an organisation vulnerable to legal challenge or could be argued to be an infringement on human rights;
- When the data quality is poor or unreliable;

- When there are not clear limits in place regarding who is able to access the data and for what purposes.

Exploring the trade-offs in more depth

In the later part of the workshop participants were introduced to 3 case studies (Appendix C) that provided examples of systematic data sharing across a local authority area:

1. **The Camden Residents Index (CRI):** The CRI brings together data from 16 council business systems, covering 123 fields of primarily demographic information, to create a complete picture of each resident. It was created by Camden Council to streamline processes and provide a more responsive service to citizens.
2. **Troubled Families Programme:** The UK Government's Troubled Families programme sought to establish a new, co-ordinated way of supporting families who struggle with multiple issues. The programme incentivises Council's to co-ordinate services to come together and share the information they separately hold, in order to better understand the needs of the whole family and co-ordinate support accordingly.
3. **Community Safety Partnerships (CSP):** CSPs were set up as statutory bodies under Sections 5-7 of the Crime and Disorder Act 1998 to help ensure a joint approach to addressing issues of community safety. Each CSP has a statutory membership of representatives from the police, the local council, and the fire, health and probation services, although they can extend their membership to include local organisations from the voluntary and private sectors as relevant. CSPs work together to protect their communities from crime and to help people feel safer.

These case studies, and the plenary discussions that followed, were introduced to provide an opportunity for participants to explore in more detail 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 observations and comments drawn out in this exercise are included in the final section of this report.

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.

Opportunities and Challenges

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

- The better use of data and data sharing across public service providers offers an opportunity to develop a shared language and deliver a united story to the public about aims and challenges, increasing public trust that the public sector is working towards integrated goals.
- Despite continual advances in information and communications technology, that mean more data can be held and processed more securely than ever before, there remain practical challenges that service providers need to overcome in relation to infrastructure, skills and resources.
 - If we are looking at opportunities across the combined authority area then, from the outset, integration needs to be key.
- While many of the individuals, and the organisations represented in the room, may appreciate the value of using data better we don't currently have a culture of sharing widely across the region. We need to get better at identifying, and then using, opportunities to share information openly between organisations to add value to what we are all trying to achieve.
- Although data can be a powerful tool it is not always immediately apparent what the benefits might be, or who might best be able to use the information (as it might not always be the organisation that collects it).
 - A challenge therefore is how do organisations not only use the data resources they have more effectively, but also gain a better understanding of what data might be available from others.
- How the public share data on social media, and through the increased use of the internet and personal analytic devices, provides both an opportunity and a challenge for public service providers. There appears to be a paradox about how people are willing for data to be used and collected when it provides them directly with benefits that they choose, compared to how they behave in relation to accepting the use of information about them by public services.
 - The challenge therefore is how to frame the debate about benefits to encourage wider public acceptance and support for data use.
 - The increasing monetisation of data use, however, also makes this more difficult as people increasingly expect to see a direct personal benefit, rather than possibly behaving more altruistically for the good of wider society.

Insights and reflections

The workshop closed with a final plenary session which encouraged participants to share any insights or ‘take-aways’ from the discussions they had been part of. The points made in this discussion are summarised below.

- That the public and service providers (and even different branches of the public sector) are likely to evaluate the risk / benefit trade-off differently depending on their priorities, particularly when the beneficiaries may not be the ones shouldering the risks. For example, if the risk is to individual privacy but the benefit is to service provider efficiency, or alternatively, if the benefit is to vulnerable service users but the risk relates to wider public trust in how services use the information they hold about individuals then assessments of acceptability may be different.

“the benefits and risks don’t always sit in the same field.”

Workshop Participant

- That we need to get better at ensuring there is a clear link between the collection of data and how it will be used for decision making – not just to ensure we are collecting the right data, but also to ensure that we are collecting data proportionally.
- A further challenge also relates to what data is collected by organisations, and the capacity of organisations, particularly in the voluntary and community sectors, to process and share the potentially valuable information they have with the public sector.
 - In many cases it is the voluntary sector who are doing much of the public service delivery in the sectors we are focusing on, but often they are not well resourced to either collect or use data efficiently.
 - Across all providers there is also a need to get better at articulating what data needs to be collected, and why, to enable all services to improve their collection practises and how they communicate this to service users and the wider public.
- That risks and benefits are not static but change over time. This is the case not just in relation to the technology available for organisations, but also in relation to reviewing need: i.e. what we already know, and what we now need to understand.
- That data analysis and decisions on what data to use are subjective. While data can provide raw information to services providers, they then need to use intelligence and insight to turn this into something that can deliver impacts.
 - The underlying question that needs to be asked when using data is - What does this really tell us?
- That as services we maybe need to get better at reflecting on the ‘what?’ and the ‘why?’ in relation to data sharing and the balances as a conscious, deliberate process, in order to develop a clearer understanding of where our boundaries lie and what might become ‘too much’.

Moving forward with the discussion...

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

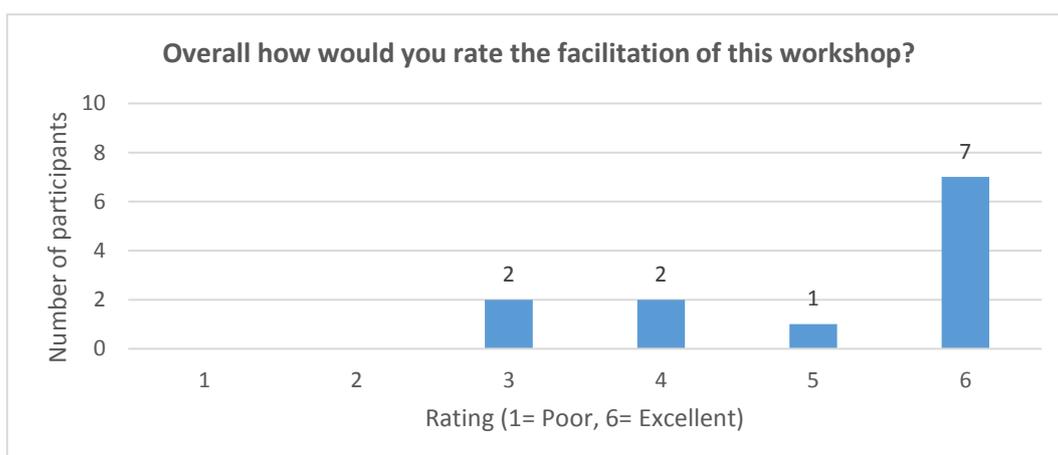
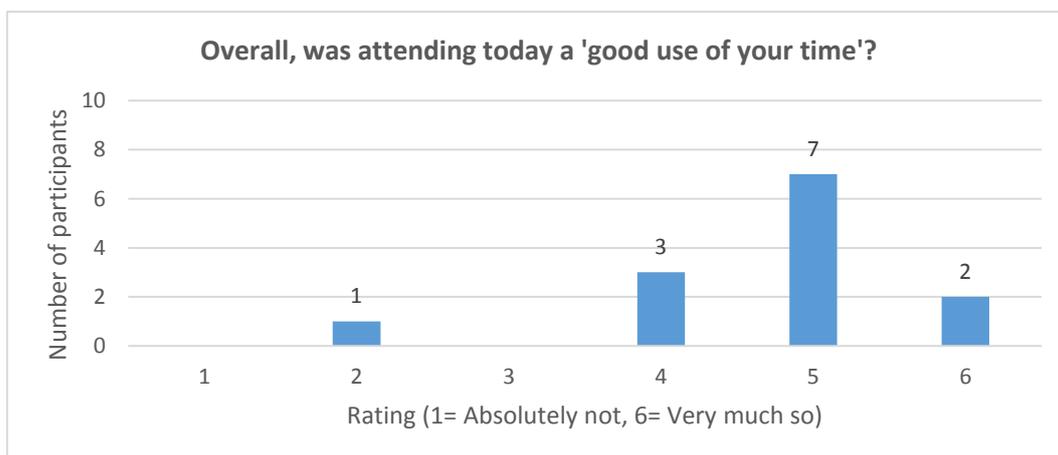
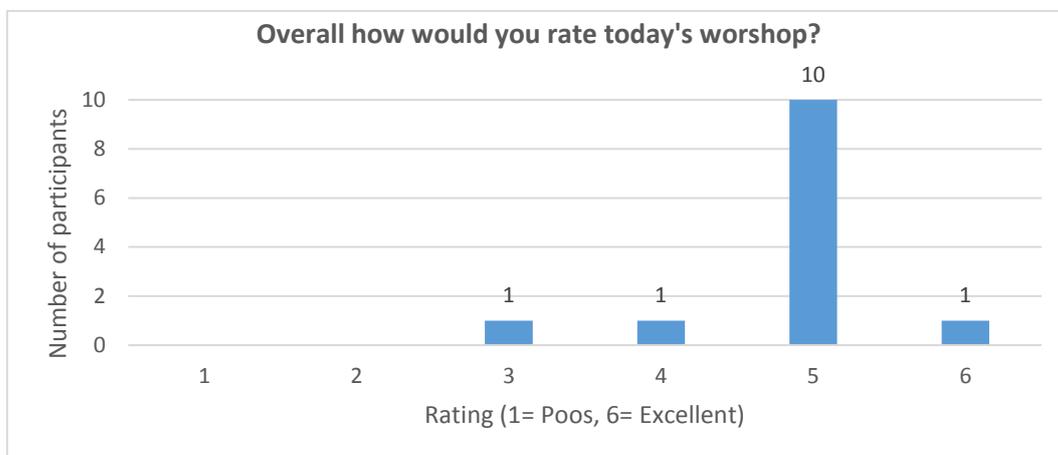
The forthcoming report being produced as an outcome of workshops like this in six local authority areas across England is designed to provide a tool to enable these conversations to take place.

Appendix A: Participants evaluation of the workshop

Number of participants: 20

Responses received: 13

Response rate: 65%



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

“Activities (risk+benefits ranking) → reflections”

“Good exploration using case studies of benefit versus risks, ethics, etc.”
“The debates on the issues on the areas where different perspectives”
“Discussions of case studies – really useful to some examples for context”
“Lots of resources to aid discussion”
“Discussion and listening to diverse views on the subject”
“Time to look in-depth at the issues; hearing the viewpoints of different sectors”
“Informative; well facilitated; conducive to good conversation; input from peers”
“The opportunity to share and discuss key aspects of data sharing”
“A different view on data sharing and its risks and potential benefits”
“Use of case studies really good”
“Slightly different conversation and a different approach to what I have done before. I liked the challenge of defining our version of 'risk' and 'benefit'. It gave a good insight into the complexities felt by those commissioning services”
“Case studies were interesting in terms of how we could work in the West Midlands”

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

“Would have been nice to come away with more knowledge or to make practical data sharing work”
“Too many examples – fewer would be to have more in-depth discussions”
“Maybe could have halved number of case studies – to talk about in greater depth”
“Liked it all”
“Too rushed... Too “structured” not enough space to explore ideas”
“At times too much to do within the time and feeling a bit pressured to get through the material”
“Having to read too many case studies as it ate into thinking and talking time”
“Was more like a training session than a workshop. It was a shame that (other than the very first introductory exercise) we didn't leave time to explore opportunities for WM”

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

“More legal background (including updates in the field) could have been provided at the start of the session”
“Less “structured” i.e. benefits, then risks, then this then that etc.”
“Spot-on”
“I think some recognition of the issues within the 'system' would have been useful. I think that very often we concentrate on services and individuals when the problems are very often a disabling system rather than an enabling one.”
“Reduce the activity to allow the afternoon to focus on actions to take forward. Be clear on expectations of the session.”

Do you have any other comments?

“Thank you. Well facilitated & enjoyable”
“A number of delegates had not received the pre-reading”
“Look forward to seeing reports!”
“Found the whole session useful and informative and look forward to seeing the report”

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

Example B

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 allocate 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) notify 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-

Example D

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 MacMillan 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) <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-identified 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/>

Case Study 1

Camden Resident Index (CRI)

In Camden the Council has created the CRI to streamline processes and provide a more responsive service to citizens.

The CRI brings together data from 16 council business systems, covering 123 fields of primarily demographic information, to create a complete picture of each resident. It is to date the largest master data management installation in local government in the UK.

Objectives

The Council created the CRI, and its integrated data dashboards, to make its public services better. The objectives were to:

- Identify and eliminate instances where staff activity was duplicated.
- Make the planning and delivery of services more efficient, higher quality and more effective.
- Identify where fraud and error were taking place.

Access to the data

To integrate data at an individual level, the CRI takes identifiers from the back end of each system, then provides cross-service reporting using these IDs. The CRI however does not extract sensitive case file information. There were however information governance challenges faced in developing the index, and fears among some staff that the CRI would enable staff to see all information about individuals.

In response, a Privacy Impact Assessment was undertaken and layers of access were agreed depending on team and role. Staff have to be approved in order to have an account on the CRI, and receive training in how to use it.

Some of the uses of the CRI have included:

- Enabling frontline professionals, such as multidisciplinary social workers, to do their jobs in ways that wouldn't previously have been possible, such as flagging safeguarding issues which otherwise wouldn't have been seen by legacy systems.
- Providing granular, multidimensional and longitudinal insight into services. In adult social care, for example, Camden mapped a ten-year journey of a very complex social care case with an anonymised citizen which shows the interactions they have had with the council and external agencies. This provided new insights around the system as a whole and flagged where interventions could have been made earlier to improve care
- Analysis looking for relationships between different factors, such as testing the hypotheses that poor school attainment was positively correlated with overcrowded housing. It also enables better service planning, for instance providing information about the number of children aged 0-5 in a ward to forecast future service levels.

A key use of the CRI however has been to enable automated fraud checking, including:

- Validation of residency for accessing council services such as school places. In the last round this flagged five school places which had been obtained through fraudulent claims about addresses.
- Identifying discrepancies in the system, such as households claiming single person council tax discount where there is more than one registered resident.
- Flagging cases of illegal subletting. Camden estimate that they saved £800k so far from identification of illegal subletting of council housing.

Case Study 2

Troubled Families Programme

The UK Government's Troubled Families programme seeks to establish a new, co-ordinated way of supporting families who struggle with factors such as debt, homelessness, mental health issues, domestic violence, poor parenting, illness or substance misuse. Families who may therefore be dealing with multiple service providers across the health, housing, criminal justice, anti-social behaviour, welfare and education sectors individually.

The programme incentivises Councils to co-ordinate services to come together and share the information they separately hold, in order to better understand the needs of the whole family and coordinate support accordingly.

Why this approach?

The rationale is that there are both individual and service level benefits to this approach as:

- those reliant on public services are not required to repeat their information multiple times and spend significant energy and time meeting bureaucratic requirements;
- clients will no longer receive reactive, disjointed and potentially overlapping services from the range of agencies they deal with;
- efficiency savings can be made by co-ordinating interventions designed to achieve long term change by addressing the root cause of the problem. (Cabinet Office 2016)

Data Sharing

Information sharing has been at the heart of the Troubled Families programme from the start, providing the intelligence local programmes need to identify families, understand their needs and demonstrate their progress. Local authorities depend on other public services providing access to their data and intelligence on family members. Without this, there is a risk that families with the highest need will not be identified and do not receive the coordinated support they need. (Centre of Excellence for Information Sharing)

Identifying families

The 1st need for data sharing is to identify families who meet the criteria established by the programme. To do this personally identifiable data is linked from datasets held by public agencies such as the Council, the NHS and health organisations, Department of Work and Pensions, the Police, the Ministry of Justice, the probation services, schools and Youth offending Team.

This may include information about an individual or family's involvement with the police, courts and probation, employment and or benefits status, anti-social behaviour, violence in the home, substance misuse, vulnerable children, health issues and/or involvement with social service departments. From this new linked data set families are identified who will be offered support.

Targeting Support

Once a family has been identified as eligible for support under this programme the profile that has been used to identify them is then generally shared with frontline workers in order to plan co-ordinated interventions and/or identify an appropriate lead case worker. While a policy decision may be made to ask for consent for this, it is not a legal requirement.

This will either be done through face-to-face meetings or via a bespoke data integration platform that provides access to information about, for example, family genealogy, involvement with different agencies such as the police or schools, and possibly their relationships to other families also known to local services. Frontline workers will then use this data to make decisions about which types of service are needed, for whom, and at which points.

Case Study 3

Community Safety Partnerships

Crime reduction and community safety are not only matters for the police, but depend on the policies, interventions and intelligence of other public services providers.

Community Safety Partnerships (CSPs) were set up as statutory bodies under Sections 5-7 of the Crime and Disorder Act 1998 to help ensure this joint approach. Each CSP is made up of representatives from the police and police authority, the local council, and the fire, health and probation services (the 'responsible authorities'). There are 301 CSPs across England.

CSPs work together to protect their local communities from crime and to help people feel safer. They work out how to deal with local issues like antisocial behaviour, drug or alcohol misuse and reoffending.

Responsibilities of a Community Safety Partnership

The Act gave local authorities the responsibility to formulate and implement a strategy to reduce crime and disorder in their area. Whilst CSPs can be responsible for a huge range of activity, the actual statutory obligations upon them are:

- set up a strategic group to direct the work of the partnership
- regularly engage and consult with the community about their priorities and progress achieving them
- **set up protocols and systems for sharing information**
- **analyse a wide range of data**, including recorded crime levels and patterns, in order to identify priorities in an annual strategic assessment
- set out a partnership plan and monitor progress
- produce a strategy to reduce reoffending
- commission domestic violence homicide reviews.

The Use of Data

Community Safety Partnerships pool and exchange data on a wide range of criminal and anti-social behaviours, and on people who engage, or who might engage, in it.

Some data are required for analytic and crime auditing purposes and can be exchanged in de-personalised, aggregated form. This allows for intelligence-led analysis, using large datasets for crime mapping, and pinpointing specific areas and offender groups to be targeted for crime reducing initiatives.

Personally identifiable Data

Other data however may be sourced from individual case records kept by the police, the probation service, the courts, social services or health authorities. This may be used to directly identify an individual or, even if de-personalised, may be easily traceable to identified individuals or households.

Further, to carry out their functions, these Partnerships increasingly rely on risk assessment tools drawing on data supplied by a range of agencies, especially those dealing with mental health, social care and social housing.