Better use of Data: Balancing Privacy and Public Benefit

Workshop Report - Essex

The **Better use of Data: Balancing Privacy and Public Benefit** workshop in Essex 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 Essex workshop on the 4th 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

This workshop, hosted by Essex County Council, was held in the Essex Records Office in Chelmsford on the 4th July 2017. The workshop ran from 10am until 4pm and 10 people from across the Council and their partners took part. In this workshop most of the participants either had a professional background in data governance or were actively involved in data sharing initiatives across the county.

Framing the discussions

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. Further, in all of these fields, decisions about what data to share, when to share it, and who to share it with can not only create ethical dilemmas for professionals but also have potentially significant impacts for individuals.

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 of data sharing may lie. Despite considerable effort being made in the weeks leading up to the workshop to encourage participation from the voluntary sector, very few participants on the day came from outside of the public sector.

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; and

- 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;

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

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

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

In Essex 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. Using sets of 6 examples of data sharing practice to identify dimensions of public benefit;

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

4. Using a different set of 6 examples of data sharing practice to identify areas of risk and concern, and then ranking them in order of risk (negotiating criteria at each table);

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

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

7. Using a case study to explore the acceptability of a systematised use of data linking within a local authority area;

8. Using case studies to explore and identify principles of good practice and ways to mitigate risks;

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

A summary of participants' feedback after the workshop is included as an 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. There has to date however 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.

> *"If we can't explain and demonstrate the benefits of sharing data should we be doing it?"*
> Workshop Participant

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). Each set of examples was constructed to stimulate debate and discussion (rather than to illustrate good practice); cut across a range of sectors (housing, health, welfare, social care and community safety); involve the use of different types of personal data; and feature a variety of intended outcomes. The sets of examples used during the workshop are included as Appendix B.

Working firstly in two small groups (each using a different set of examples), and then in plenary, a range of different types of beneficiaries and benefits were identified:

- **For individual service users:**
    - Better and more effective services overall;
    - Better targeted services so that people with greatest need get the help they need;
    - Better quality of care through early intervention;
    - Quicker and easier access to care and support when needed;
    - Improving perception from users that the service is meeting their needs efficiently; and
    - More personally tailored services enabling greater self-management.

- **For the wider public (or sectors of the public):**
    - Better and more appropriate services offered to communities; and
    - More efficient public services through the better targeting of resources.

- **For Service Providers:**
    - Cost effective delivery of services;
    - There are efficiency and cost savings associated with using data efficiently i.e. 'doing better with less';
    - Less duplication;
    - Reduced failure demand;
    - Plan more effective future services;
    - The ability to provide better targeted and safer care to the most vulnerable;
    - Enabling 'root cause' analysis of problems;
    - Evidence that interventions are making a difference;

- Enhanced impact through being able to develop better interventions;
- Greater insight into the demand for different services across agencies; and
- Increased collaboration between agencies, allowing for integrated service delivery based on shared outcomes and indicators.

- **For staff delivering services:**
  - Increased job satisfaction through being able to do their job better;
  - Being more empowered to act on the basis of the information they are able to access;
  - Improved productivity through being able to use their time more effectively;
  - Improved motivation by getting more things right, more often;
  - Increased levels of safety;
  - Evidence that they are 'making a difference';
  - Helping to break down silos between different agencies to enable more joined up, user centred working; and
  - Greater insight into the root causes of the social problems they are trying to address.

Participants in the workshop also identified how the more effective use of data in the provision of public services was able to deliver a range of **cross-cutting political benefits:** including transparency, accountability and commitment to evidence-based decision making. These additional benefits were seen to not only demonstrate wider aspects of good governance, but also as being key to enhancing public trust in government and public service providers overall.

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 set of examples they were working with in order of their ability (or potential ability) to deliver public benefit.

In approaching this task each group adopted a different criteria as their principal consideration for determining public benefit.

1) ## The ability to deliver demonstrable impacts

   The first group focused on the ability of the data sharing practice to directly deliver clear and demonstrable benefits, with the numbers that stood to benefit being used as a related consideration. This led to them ranking as most beneficial example C: Tacking Fuel Poverty, a national programme wherein the data sharing enables the identification of eligible individuals to receive an automatic rebate on their energy bill. Applying this same criteria also resulted in example E: Justice Data Lab being assessed as able to deliver high public benefits. In this case they argued that this nationwide system of sharing of data with the Ministry of Justice about participants in interventions designed to reduce re-offending allowed the success of those interventions to be effectively evaluated in order to inform the design of future programmes and ultimately improve outcomes for offenders.

   Using this same logic, those examples that were strategically or financially enabling but demonstrated no evidence of delivering impacts were ranked lower (resulting in examples B: Predicting the Prevalence of Loneliness and D: Funding GP Practices in Socially Deprived Areas, which were both designed to provide evidence that could inform strategic planning, being ranked towards the bottom of their list).

   For this group therefore it seems that certainty of impact, and being able to demonstrate a clear return on the investment made in the data sharing process, were the primary determinates of benefit.

2) ## The effectiveness of the data sharing model

   The second group focused on whether the process was an effective use of data as their primary criteria of an example's ability to deliver public benefits. The flexibility, scalability and replicability of the model were also key considerations for this group. This resulted in example 1: Routes from Diagnosis being ranked most highly by this group because of it being a clear and purposeful use of data to deliver long-term benefits to services and patients. They also noted that the potential transferability of model to other subjects or types of services other than cancer care.

   In this group there also appeared to be a focus on how data could be used to create wider community and sector benefits (rather than simply benefit a specific service or set of individuals). Thus examples that used data sharing to address multiple needs, or where there was seen to be potential for indirect benefits were also favoured - e.g. 5: Housing Regeneration and Health; 3: Linking data to improve Health and Social Care Outcomes; and 6: Information Sharing to Tackle Violence.

Other factors:

Analysis of the rankings and the comments collected throughout this exercise also identifies a number of other factors that were considered during these discussions, including:

- **Confidence in the concept** – a number of comments captured during this stage of the workshop made reference to the 'reality link' between the data sharing process and the intended or reported outcomes. There was some hesitancy in the room to accept the likely delivery of some of the suggested impacts in a few of the examples of data sharing (e.g. 4: Empty Homes Initiative and B: Predicting the Prevalence of Loneliness).

- **Numbers vs degree of impact** – the challenge of measuring the value delivered by an initiative able to directly benefit a large number of people, against the value of one that might have a potentially life-changing impact on a small number, was also highlighted throughout the discussions (e.g. in determining the ranking of C: Tacking Fuel Poverty compared to the F: Homeless support in Bristol example). In this case both groups tended to prioritise benefits that were available to higher numbers.

- **Immediate vs long term impacts** – the relative benefit of creating immediate change, compared to addressing the root causes of a problem was also debated within the groups (e.g. in determining the ranking of examples 5: Housing Regeneration and Health and 6: Information Sharing to Tackle Violence).

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 therefore asked to look at a fresh set of examples, this time focusing on identifying any risks and concerns relating to how data was being used. Participants in this workshop focussed on two main areas of risk – risks to the public and risks to service providers. By examining the examples provided they identified a range of different types of risks to these groups which are summarised below.

The main risks identified for **the public** related to:

- Individual privacy:
    - From a lack of choice over what information an individual may want known about them in a given circumstance, particularly if data is shared without direct consent; and
    - from de-personalised data being used to re-identify an individual, either through misuse or through a combination of data sets making re-identification possible.

- Negative impacts on people and communities:
    - From de-personalised or anonymised data being used to profile an area, or community, and lead in stigmatisation e.g. "There is a risk of marginalising or stigmatising communities with high health needs for example, and that could have knock-on impacts on insurance, employment, social perceptions etc."; and
    - that data sharing between services could have the unintended consequence that people stop using a service because they are worried about how information about them might be used or concerned that they may be targeted for unsought after interventions.

- Effects on the services they receive:
    - That personally identifiable data could be used to profile individuals and have a negative impact on the services they receive through stereotyping or inaccurate assumptions about an individual's needs; and
    - that 'over-targeting', stemming from an over-reliance on the use of some types of data, leads to services focussing exclusively on people pre-identified as 'at risk' or 'a risk' at the expense of others.

The main risks identified for **service providers** related to:

- The impacts of the use of poor quality data, or analysis, on service provision:
    - That out of date data is used to inform service design or planning;
    - that the use of selective data sets, and/or the subjective analysis of data, provides misleading evidence for resource allocation or policy making decisions;
    - that, because organisations using shared data cannot always be sure of the quality of the original data, 'believing blindly' in the data might lead to the wrong decisions being made about resource allocation; and

- that, because of the availability of data about a subject (and/or the lack of data available about another), there is a risk that service planning over-focuses on one area i.e. that services 'can't see the woods for the trees'.

- Reputational risks:
  - If individuals are re-identified through data sharing and this information is used to their detriment then reputational, and possibly legal, consequences are likely for the data collector;
  - from ineffective or inconsistent data security, storage and access controls leading to data loss or misuse;
  - that, if the use of data identifies 'new' needs it will put pressure to act on already over-stretched public services, and service providers could become "victims of their own data success!";
  - from sharing with organisations outside the public sector, including the private and/or the voluntary sectors, as these organisation may have different motivations for using data e.g. to generate profit, to target their own services at individuals or justify the use of a particular approach;
  - if the creation of linked data sets about individuals, even if de-personalised, creates a target for hacking;
  - that the creation of new data sets prompts Freedom of Information requests, particularly if information is being used for purposes the public may not expect; and
  - if using data in ways that the public is not aware of leads to a loss of public trust in service providers.

Assessing Risk

When participants were again asked to rank the examples they were considering, this time in order of the risk this type of data sharing posed, three key criteria appear to have underpinned their deliberations.

1) ### The risk of data being used to re-identify individuals
   Discussions here focused on the likelihood that an individual could be identified on the basis of data shared and linked about them (when this was not the purpose of the data sharing) and the potential impacts of being identified. These concerns resulted in the A: Kent Integrated Dataset, being considered highly risky due to the number of datasets linked at an individual level, and the risk this poses for re-identification of individuals if the data is misused. The importance of data security and controlling access also featured in these discussions.

   Similar concerns also led to example 6: Information Sharing to Tackle Violence, being ranked as most risky by one of the groups. This was primarily because of the (acknowledged) risk that the information shared with Community Safety Partnerships from A&E about the time and date of an incident, the location of an incident and the means of assault could lead to individuals being identified, even if the data itself was not personally identifiable. It was agreed that being identified in the context of having been involved in a violent incident could have serious negative impacts on the individuals concerned.

2) ### Consent and public expectations about how data about them may be used
   There was considerable concern raised about examples that appeared to be using personal data, and at times personally identifiable data, without the explicit consent of the individual data subject (e.g. A: Kent Integrated Dataset and 2: Reducing Unnecessary 999 Calls).

There were also concerns that some of the uses of personally identifiable data presented in the examples went beyond what the public would reasonably expect information about them to be used for. One particular example that raised concerns in this area was example C: Tacking Fuel Poverty, not only because identifiable information was being shared with a private company but because it was considered particularly sensitive personal information as it related to an individual's financial position. The risk of this data being used inappropriately was seen as particularly acute here because a private company was involved in the sharing. It was felt that public and private companies have fundamentally different motivations for data sharing, and participants were suspicious that they would attempt to monetize this data in ways that could cause detriment to members of the public.

3) Data quality and analysis

Confidence in the quality of the data sets being used to draw conclusions or inform action was also central to the discussions in both groups – including the age, accuracy and size of the data set. Concerns were raised about the quality of the data used in a number of examples, but 1: Routes from Diagnosis was particularly highlighted by participants as relying on inconsistent, out of date and self-reported data.

The importance of transparency and objectivity in the processing and analysis of data was also highlighted by participants. The confirmation bias perceived in example D: Funding GP Practices in Socially Deprived Areas, which used anonymised data sets to demonstrate the need for redesigning how funding for GPs is allocated, drew significant criticism on the basis that data seemed to be being used to provide evidence for a pre-existing argument.

What risks are too high to accommodate?

In the workshop there were a number of types of risk, or areas of potential risk, that people identified as creating 'red lines' for data sharing which should not be crossed regardless of the benefits that may be provided:

- Lack of public awareness, if not direct consent, that data about them may be used for different purposes;

- Data being shared without a clear purpose, i.e. when data is linked or shared on a 'fishing expedition' to see if anything useful emerges;

- Lack of transparency about how data is being used and processed;

- The use of identifiable personal data (and particularly sensitive personal data) when the purpose can be achieved through different means;

- 'Purpose creep' i.e. when data initially shared for a specific purpose is used for other ends; and

- When the quality of the data is questionable.

Acceptable uses of data sharing

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.

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 take one set of the examples that they had looked at previously and 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.

Across the two groups a range of criteria for assessing acceptability were identified and are presented below (in no particular order):

- The strategic benefit of the data sharing – recognising that valuable long term benefits may be achieved by projects that do not always demonstrate the highest immediate impacts.

- The ability to deliver clear impacts for people.

- The ability to describe and *'sell'* a data sharing process as delivering benefits i.e. the availability of easy to identify and measurable impacts.

- The likelihood and impact of an individual being re-identified through data sharing (intentionally or otherwise).

- The additional investment required to actually achieve in relation to measurable impacts.

- The quality of the data used / available for use.

- The likely ability to deliver services to address needs once they are identified, i.e. the value of the information to service providers in the *'real world.'*

- The ability to deliver systemic shifts i.e. long term changes that get to the root causes of issues.

- The impacts and knock-on effects for other services, both short and long-term in relation to savings and demand.

- the distribution of risks.

- the acceptability of the overall purpose (even if the realities of practice may need improvement).

To achieve the task they had been set, each of the two groups chose a distinctly different type of focus as their primary criteria for ranking their case studies:

- Group 1 focused on **using high quality data securely to provide direct benefits to people**. This resulted in examples being ranked most acceptable when was a clear and bounded reason for the data sharing; strong security controls in place; and a specific route for using the data to deliver measurable benefits to the public (E: Justice Data Lab and C: Tacking Fuel Poverty).

- Group 2 focussed on **the strategic use of data to address the root causes of issues**. Taking this focus led to examples using anonymised data to demonstrate how early intervention can improve a service user's journey and which aimed to reduce the demand on crisis services in the long term being ranked most acceptable (1: Routes from Diagnosis and 5: Housing Regeneration and Health).

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. These were used to further explore the trade-offs that may be required to allow governments and public service providers the flexibility to use the information they hold to provide better and more responsive services, whilst also ensuring that data sharing is constrained to purposes that offer clear benefits to the public and respect individual privacy. The case studies were:

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 seeks establish a new, co-ordinated way of supporting families who struggle with multiple issues. The programme incentivises Councils to co-ordinate the sharing of information, which would otherwise be held separately by different organisations, in order to better understand the needs of the whole family and integrate interventions.

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.

The outputs from the discussions provoked by these case studies are presented below.

Purpose and Proportionality

In looking at the case study outlining the Camden Residents Index workshop participants were immediately drawn to the risks associated with the model of data use, rather than the benefits.

While recognising the obvious efficiency savings that this type of systematic data sharing could bring to a Council, participants generally remained quite uncomfortable with this model in practice. Their concerns focused on purpose and proportionality and included, that:

- The model of data use was very wide in scope i.e. to create a picture of 'all residents.'

- The all-encompassing nature of the Index would make it very hard to secure informed consent from residents (although it was equally acknowledged that relying on consent would limit the potential uses of the Index).

- There was a perceived lack of transparency about how the data would / could be used.

- The Index appeared to rely on historical data, which may be inaccurate.

- The intrinsic risk of linking lots of data together creates a data set that can be misused.

- This model goes far beyond just using data linking to confirm identity / eligibility and has the potential to identify people accessing specific services and target them with unsolicited offers.

Features that underpin acceptability

In the last exercise of the day, participants were asked to look at again at two case studies - the Community Safety Partnerships and the Troubled Families Programme. Both of these models have been instigated by central government as a way of solving complex, multi-dimensional problems within communities. In each case, success relies on the use of personal data, and at times personally identifiable information.

Both of these models were quite familiar to participants in this workshop, and broadly supported by most, so the discussions focused on identifying what the features of these contexts for data sharing are that make them acceptable.

- **A socially acceptable purpose** – in both cases it was felt that organisations, and the wider public, would recognise a clear, positive purpose behind these uses of information. Protecting vulnerable families and improving community safety were both purposes that participants felt contributed to public benefit in the widest sense.

- **Clear parameters** – ensuring that the use of data is purposeful and bounded by a clear objective was seen to increase its acceptability. As noted in relation to how data is used in Community Safety Partnerships, it is not about 'creating a pot to fish for criminals in' but analysing available information to provide insight into a specific, identified issue. In the Troubled Families Programme clear criteria for identifying 'troubled families' are established before any data sharing begins, and those that match this profile are then targeted for intervention (although some participants noted their discomfort with the very act of using data to profile people).

- **A rationale for needing data** – in each of these cases service providers were able to provide clear arguments about why data sharing, and the need for personally identifiable data, was required to achieve the desired outcomes.

- **Measurable impacts** – the ability to demonstrate clear causal links between the use of data and direct impacts for individuals and communities was considered to increase the acceptability of using data (even sensitive personally identifiable data) for politicians, decision makers and the wider public.

- **Trusted partners** – the perceived 'public standing' of the organisations involved in data sharing arrangements, including whether they were from the public or voluntary sectors, was seen as an important factor in establishing public trust in processes. Likewise good relationships between partners, based on trust and mutual respect, were identified as essential for making data sharing arrangements work in practice.

- **Efficient use of resources** – being able to show that using data enabled the more effective allocation of scarce public sector resources (e.g. by reducing duplication, supporting an integrated approach or enabling more accurate targeting) was also viewed as a key factor in increasing acceptability.

- **Effective data management and security** –being able to respond to questions related to how data was being used with a clear statement of the storage and processing procedures, access restrictions and the controls in place to protect individual privacy was seen as vital to ensuring the acceptability of data sharing between organisations.

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 Essex. The workshop also closed with a final plenary session which encouraged participants to share any insights or 'take-aways' from the discussions they had been part of.

Opportunities and Challenges

Throughout the workshop participants were generally quite optimistic about the potential for greater data sharing to support the delivery of more efficient, effective and responsive public services. They were not however, blind to the difficulties and risks involved in delivering these benefits in practice. Key points that emerged during the workshop are summarised below.

- There are opportunities at the moment in Essex to encourage and support organisations to work together to use a single information sharing framework, but the complexity of the organisational landscape makes this also a challenge.
    - To participate the voluntary and community sectors may need access to specialist support (which can be provided) but it seems many in the sector are not aware of the resources, assistance, networks, templates etc. that are available to them.

- Using data better in a public service context should enable the delivery of better services to the public. There is much that we can learn from the private sector in this regard to develop offers that are "frictionless," more responsive and "fit for the 21st century".
    - At the same time, however, it was suggested that there are additional challenges, and a greater feeling of responsibility within the public sector, to getting data use 'right'. This may be because members of the public cannot choose whether or not to interact with public service providers in the same way they could move away from using a private sector company if they are uncomfortable with how their data was being used.

- Effective data sharing between organisations is still constrained by technical difficulties and system incompatibilities. While the intent may be there it is often hampered by legacy IT systems that do not allow efficient sharing (let alone the challenge of how the vast amount of valuable information that is not even stored electronically but in filing cabinets, boxes etc. can be shared).
    - Overcoming this in a systematic way will involve persuading decision makers to invest in IT systems (which is difficult enough in large organisations, never mind smaller ones) and virtually impossible if service providers don't get better at being able to demonstrate returns on investment from data sharing.
    - The variety of potential beneficiaries and the intangible nature of some of the potential benefits, however, makes it difficult to set out convincing investment case, and this means that too often data sharing is still seen as an overhead rather than a cost benefit.

- The information maturity of organisations varies greatly, in relation to understanding what can be shared, when, how and under what circumstances. There is also the reality that some organisations have limited time and resources available to put towards better understanding this landscape.
    - The GDPR (General Data Protection Regulation) due to come into force in May 2018 could provide an opportunity to better co-ordinate how data is used and shared across services, given that processes and procedures may need to change at that point anyway. But there is

also a risk that the introduction of GDPR could actually inadvertently entrench existing organisational siloes, as organisations become more nervous about data sharing in order to ensure compliance during the transition period.

- It is difficult to know what information is out there that could be shared, what is available, what would be useful to access, and how it could be harnessed to deliver benefits.
  - o Creating a co-ordinated data asset registry, made available across departments and partners, could help with this.

"There is an opportunity at the moment to turn challenges into opportunities by building trust between organisation AND the public."
Workshop Participant

Insights and reflections:

- That developing an effective culture of data sharing is going to involve a significant cultural shift towards a culture of 'openness' more generally.

- That the purpose of the data sharing should to be allowed to define the type of data that is needed. It was felt that there is a 'cultural nervousness' among organisations regarding the use of some types of data e.g. data on health, mental health, sexual health, sexual exploitation, vulnerable children. This can lead to behaviours in relation to data sharing that, while they may reduce the risk of harm, may not be effective and sometimes even damaging if leads to a poorer service being received.
  - o There was a recognition that, as a group of professionals, they were decidedly 'risk adverse' and concerns were raised about whether this may be actually detrimental to the goal of providing benefit, or whether this was part of the 'duty of care' of professionals to the public.
  - o Participants in the workshop questioned whether it may in fact be a case of 'professional' rather than 'cultural' nervousness about sharing different types of information, and speculated that the public might actually be less risk adverse than they were?

- That while purpose and proportionality are key, the processes used for data sharing are also vitally important. Those involved in information governance need to ensure therefore that there is also a focus on the "how, not just the why". For data sharing to deliver benefits it needs to be well managed and the data securely protected.
  - o It was also acknowledged that, when there are high profile incidents of data breaches, this sets back the maturity of the public acceptance of data sharing "back by a decade" and can have a significant impact on public trust in how data is managed.

- Establishing trust between organisation involved, or potentially able to be involved, in data sharing agreements was itself problematic – with concerns raised about trust that other organisations will hold data securely, are able to provide robust data, or may operate different security or access standards than expected by partners.
  - o Without trust being achieved between organisations, it is impossible to expect the public to trust organisations to share their data safely and effectively.

- There were strong feelings expressed in the room about the importance of meaningfully engaging the public in proposals for data sharing. It was acknowledged that while services are getting better at informing people about what they are doing with the information they hold about them, they were still not very good at involving them in the design of programmes and decisions about how data could, or should, be used.
    - It was noted that councils already carry out complex, and sometimes difficult, consultations with the public around planning permission, for example. So there is existing expertise and mechanisms for engagement which could be repurposed for discussions about data sharing.
    - Discussions identified a number of existing 'access points' which could be repurposed to take conversations about data sharing to where the public are, for example taking discussions to residents' panels or parish councils.
    - Another possibility raised was involving members of the public in Privacy Impact Assessments.
    - However, it was also acknowledged that service providers "need to know how to walk before we can run" – i.e. that it is worth taking the time to get public engagement, consultation, planning for data sharing and implementation and evaluation of data sharing right the first time, rather than blundering into detrimental consequences or ill-informed conversations.

- Services need to get better at telling the stories of impact if there is any hope of the public developing a better understanding of how data can be used to deliver benefits, and becoming more supportive of different uses of data.

- Participants also felt there was a general need to educate people about data and data protection. This could not only help reduce people's worries about how data about them might be used, but also increase transparency and enhance trust.

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 framework or approach that stakeholders seek to drawn 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.

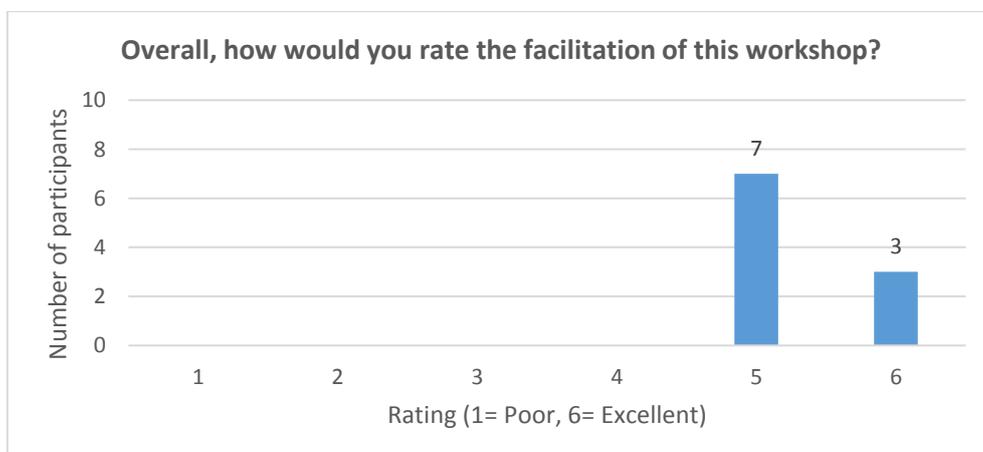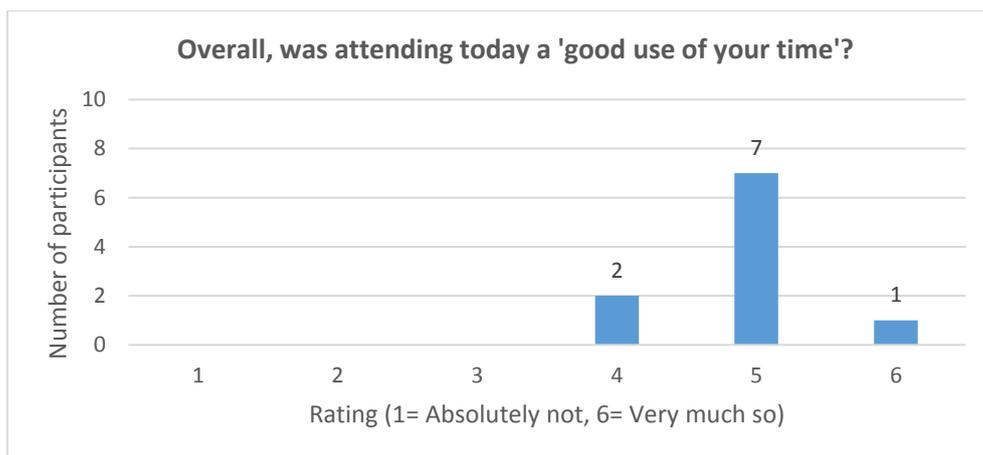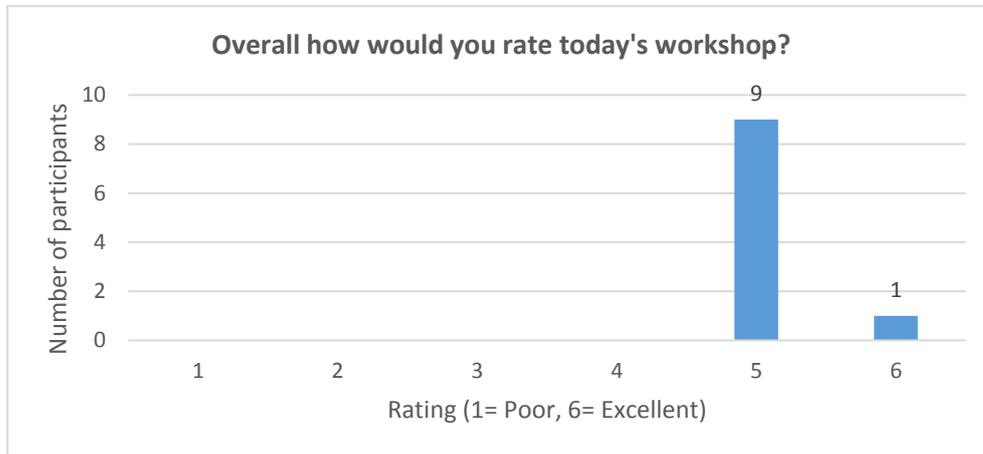*"It's a difficult conversation…. But we need to have it."*
Workshop Participant

Appendix A: Participants evaluation of the workshop

Number of participants: 10
Responses received: 10
Response rate: 100%

Overall how would you rate today's workshop?

Number of participants vs Rating (1= Poor, 6= Excellent)

Rating 5: 9
Rating 6: 1

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

Number of participants vs Rating (1= Absolutely not, 6= Very much so)

Rating 4: 2
Rating 5: 7
Rating 6: 1

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

Number of participants vs Rating (1= Poor, 6= Excellent)

Rating 5: 7
Rating 6: 3

Appendix A: Participants evaluation of the workshop

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

"Pace and small groups and networking"

"The case studies in the morning session"

"Case studies – consideration of risk/benefits"

"Contacts other people in group"

"Challenges to perspectives"

"The opportunity to explore an area of work that's very important but not my main focus"

"Nice group. Size. Interesting topics"

"Case studies and workshop reviews"

"Group mix"

"Exploring the meaning of public benefits"

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

"Heat in room (not your fault)"

"The case study exercise in the afternoon"

"Lack of breadth of attendance by local organisations (Both public and VCS)"

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

"More time on real case studies and considerations for implementing. More inspirational pieces to show potential. Real life examples and challenges"

"More people in attendance"

"More Essex solution exploration"

"More info about what the drivers are for the workshop/context"

Do you have any other comments?

"Worthwhile, looking forward to seeing report"

"Really enjoyed today. Thank you"

"Can we share the attend list for contacts?"

"Very interesting. Please provide slides"

"Very good session. Many thanks"

"I feel in hind sight we could have done more to promote a very valuable discussion"

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 allocated their resources to tackle this problem: enabling both the development of tailor-made interventions to address loneliness in prioritised areas and an assessment of whether existing services were reaching areas of need.

Predicting the prevalence of loneliness

WHO: Age UK

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

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

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

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

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

Example C

Tackling Fuel Poverty

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

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

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

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

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

Tackling Fuel Poverty

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

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

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

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

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

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

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

Funding GP Practices in Socially Deprived Areas

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

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

Funding GP Practices in Socially Deprived Areas

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

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

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

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

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

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

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

Example E

Justice Data Lab

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

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

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

Justice Data Lab

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

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

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

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

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

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

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

Homeless Support in Bristol

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

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

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

Homeless Support in Bristol

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

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

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

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

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

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

Example 1

Routes from Diagnosis

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

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

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

Routes from diagnosis

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

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

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

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

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

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

Example 2

Reducing unnecessary 999 calls

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

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

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

Braunstone Blues partnership information sharing agreement – reducing unnecessary 999 calls

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

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

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

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

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

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

Example 3

Linking data to improve health and social care outcomes

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

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

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

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

Linking data to improve health and social care outcomes

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

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

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

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

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

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

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

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

Example 4

Empty Homes Initiative

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

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

Empty Homes Initiative

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

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

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

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

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

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

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

Example 5

Housing regeneration and health

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

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

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

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

Housing regeneration and health

WHO: Academic researchers at Swansea University

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

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

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

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

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

Example 6

Information Sharing to Tackle Violence (ISTV)

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

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

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

- increasing patrols at key times and locations;

- the creation of dispersal zones;

- providing evidence to licensing reviews.

Information Sharing to Tackle Violence (ISTV)

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

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

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

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

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

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

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

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 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 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 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.