Understanding residents' attitudes to Camden Council's use of data

Executive Summary

In order to inform the further development of a Data Charter and support other engagement work happening with residents, Camden Council has conducted interviews with 42 residents from a wide demographic spread. During the interviews residents were each presented with a case study (see Appendix 2) about real or proposed uses of data at Camden Council. This was supported by a lean literature review conducted by Reply, a design and research agency.

We found the following key topics that were important to residents:

- Security, privacy and ethics was a significant theme for residents and although The Data Charter will not be responsible for handling security and privacy, there is a clear need to educate residents around legislation and council departments that already cover this (GDPR and the information rights team) and communicate clearly what this means, and how this will be handled, if not via the data charter. There are concerns around hacking, misuse of data, lack of privacy, disproportionate use of data and sharing data with third parties.
- Transparency was a key theme that was evident from the interviews, and was raised as a way to build trust between Camden Council and residents. In addition, it is a way to show commitment to The Data Charter. Residents want easily accessible access to the personal data Camden Council stores on them and they need information that helps them to understand how Camden Council's uses, stores, and shares their data.
- Accessibility was a common worry in respect to both inclusion and digital access needs and community understanding about the concept of data and data use and what that means for residents. Camden Council needs to use clear language in the data charter and provide supporting information, making sure everyone understands in a way that makes sense to them. Camden Council should identify how people in the community with additional needs will be supported.
- Scrutiny was raised by residents, with concerns focusing on the need for oversight and accountability of Camden Council's handling of residents' data. The Data Charter should provide clear information on how Camden Council will ensure the correct use of data including commitments to oversight and accountability and explanations around the use of automation and technology.
- Participants highlighted several potential benefits to the community that Camden Council's use of their data could achieve. These benefits included both efficiency for the Council and the residents, and increased help for the community. Communicating the benefits to individuals within a community and the benefits to communities as a whole will increase understanding of data and data uses

Finally residents were asked about communication preferences. There was no real standout platform preferred by residents, suggesting that there's a need to provide varied opportunities for communication using both online and offline methods.

Background

Camden Council is currently developing a [Data Charter](#) to provide council officers with a policy framework and set of principles to guide their approach to how they use the data they hold, both now and in the future. Going beyond existing legislation, the Charter is intended to define and govern the

They have taken a deliberative approach and consulted with residents about the challenges and opportunities surrounding the use of data. In a set of interviews and other engagement activities, local residents have been presented with different case studies (see Appendix 2) in which the council could use their data. The aim is to determine how residents feel about the use of data, identify under what circumstances and conditions they are supportive of its use, and where they have misconceptions or concerns.

This research report provides an overview of the key thematic insights gathered from a qualitative research study conducted by Camden Council's community researchers, supported by insights gathered from a literature review.

Methodology

Camden Council's community researchers conducted 42 interviews by phone, over a number of weeks in July and August 2021.

Camden Council used a combination of channels, such as their website, social media platforms, digital and paper newsletters and community groups representing a range of Camden's communities to advertise an initial survey. The survey allowed residents to express their opinions and understanding of how Camden uses their data and put themselves forward for an interview over the phone with a community researcher for a more in depth discussion about data use at Camden.

The interview participants were each given a case study about real or proposed uses of data at Camden Council, detailing the reasons why data had been used in that manner and how the risks and benefits of that approach had been weighed up. These were the same case studies produced for an earlier piece of public engagement work around the Data Charter, called the Distributed Dialogue. That piece of work similarly sought the views of Camden residents to real world uses of data in order to understand what their ethical boundaries were and what would be important to them to include in a Data Charter.

The data collected by Camden Council community researchers was analysed by pulling out significant quotes and grouping them into recurring sentiments. From here a thematic analysis was conducted by grouping these sentiments into common themes, which were broken down and reworked during synthesis.

In addition to analysis of participant quotes, responses to closed questions were graphed in various ways to gain a better understanding of participants' views.

Alongside the thematic analysis, we undertook additional desk research to explore a range of academic and industry texts on the topic of public attitudes to data sharing, with a particular focus on the UK.

Demographics

Of the 42 interview participants:
- 57.1% were female and 42.9% were male.
- 52.4% identified as White British, 16.7% as White Other, 11.9% as Black, African, Black British or Caribbean, 11.9% as Other, and 7.1% as Asian or Asian British.
- 2.4% were 18-24 years old, 11.9% were 25-34, 14.3% were 35-44, 19% were 45-54, 14.3% were 55-64, 21.4% 65-74, and 16.7% were over 75.
- 31.7% were council tenants, 26.8% owned property, 19.5% were private tenants, 19.5% were housing association tenants, and 2.4% selected other.

Case Studies

The case studies presented to participants ahead of their interviews were:

1. Verifying identity for Blue Badge applications - 'How Camden Council is using automation and its existing data to reduce wait times for applicants and streamline staff workloads.'
2. Using data to understand residents' needs - 'Analysing historical data to help us understand why someone falls into crisis helps us design and offer services to help, rather than add to the problem by simply chasing council housing rental arrears.'
3. NHS Test and Trace - 'How sharing data between the NHS and Camden Council aides contact tracing, and is helping to control coronavirus outbreaks and keep communities safe.'
4. Linking health and social care data - 'Linking sensitive health and social care data to ensure medical and care needs are understood by everyone caring for an individual in order to provide consistent and quality care for our most vulnerable residents, without them constantly having to re-tell their story.'
5. Deciding where to put electric vehicle charging points - 'Using data science and an algorithm to maximise the use and fair distribution of electric vehicle (EV) charge points in Camden to promote and encourage more EVs.'

Links to access each of these case studies can be found in Appendix 2.

Perspectives on data use

1. Security, Privacy and Ethics

Across case studies one to four, participants raised several concerns around security, privacy and ethics. At this stage it is worth noting that The Data Charter will not be responsible for handling security and privacy, as that is already handled by GDPR legislation which Camden Council must abide by. The council also has in place a dedicated *Information Rights* team that ensures every project must go through rigorous scrutiny of their data protection measures before approval.

That said, the research still highlighted that there were concerns around security and privacy, mainly focused on:

- Hacking
- Misuse of data by the council
- Lack of privacy
- Disproportionate use of data
- Sharing of data with third parties.

Many participants (20%) identified the possibility of hacking as a key risk arising from the case studies:

> *'I am worried that the data may get into the [wrong] hands and that the system can be broken into.'*
> *- Using data to understand residents' needs*

> *'...if the system was hacked [this] could result in staff being locked out of the system for [a long period of time].'*
> *- Linking health and social care data*

> *'Afraid of sensitive information being hacked. Security is very important.'*
> *- Linking health and social care data*

Highlighted by a few participants (10%), these concerns potentially stem from residents' uncertainty around Camden's current security measures and history of data security:

> *'Explain how you are going to keep my information secure in layman terms and to be open and honest about if Camden have been hacked before and what they did to stop it happening again.'*
> *- Linking health and social care data*

> *'It would be nice to find out what they're doing around data security and how they're upgrading their IT infrastructure.'*
> *- Linking health and social care data*

As Ghafur et al. suggest in their study of public perceptions of data sharing in the UK and USA, these kinds of security and privacy concerns have become more prevalent in recent years. Mainly due to

several well publicised data breaches that have raised public awareness around the risks of data sharing[1].

In addition, another resident described security concerns relating to their lack of confidence with technology:

'…I'm an older person, so technology can be very confusing, and sometimes you wonder how much your data is being protected. If I make an inquiry online, I'm inundated with messages on Facebook, etc, afterwards. That's what worries me in some respects.'
- NHS Test and Trace

This highlights the way in which a lack of understanding around data privacy may be central to these security concerns, as well as the importance of effective transparency in communicating how Camden Council keeps residents' data secure.

Another potential security risk many participants (21%) were concerned about was deliberate misuse of data by council employees:

> *'It should be ensured that nothing could be copied, e.g. by disabling USB drives or any other recording device attached.'*
> *- NHS Test and Trace*

> *'There needs to be more traceability of who logs in and sees the data.'*
> *- NHS Test and Trace*

> *'Risk might [be that] data is shared inappropriately possibly by [a] member of staff…'*
> *- Linking health and social care data*

Similar to their worries about hacking, a few residents (7%) raised concerns about Camden Council's history of data protection:

> *'I also have [reservations] because of Camden's recent history of data misuse.'*
> *- Verifying identity for Blue Badge applications*

> *'I'm concerned around training: a few years ago in the Camden New Journal there was a story that residents' information was accessed by an intern and passed on to a third party. As a result, the Council had to contact elderly residents about a data leak and work with the residents to keep them safe.'*
> *- Linking health and social care data*

Again this suggests that publicised breaches are currently a cause of mistrust and uncertainty for participants.

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[1] Ghafur, S. (et al.) (2020) 'Public perceptions on data sharing: key insights from the UK and the USA', *The Lancet*, vol.2, no.9, p.3

Among some of the participants there were also concerns raised about a lack of privacy from Camden Council handling resident data. Several (14%) felt that the scenarios described in the case studies were too intrusive or had the potential to be, mirroring previous patterns in research studies by Lounsbury et al. and Ghafur et al. which found that privacy is a particularly common concern for the public when it comes to sharing data[2]:

> *'I feel it is an intrusion of privacy.'*
> *- Using data to understand residents' needs*

> *'There is potential to be misused. It is a [infringement of] privacy.'*
> *- Linking health and social care data*

> *'...then there's privacy: I might not want a Council officer to know my Covid status.'*
> *- NHS Test and Trace*

> *'I am worried that this can be very intrusive.'*
> *- Using data to understand residents' needs*

For several residents (17%), their worries about privacy and security were centred on what they saw as a lack of control in data sharing:

> *'...once that data is shared, it becomes much harder to control. The more organisations that have access to the data, the more chance there is of security being compromised.'*
> *- NHS Test and Trace*

> *'...there may be lots of changes of staff who are seeing the data and sharing information; this can become an endless amount of people who are accessing the data.'*
> *- NHS Test and Trace*

For others (21%), privacy concerns were centred on the possibility of Camden Council sharing residents' data with third parties:

> *'...I would be more comfortable if Camden showed how the data will be shared with third party or not.'*
> *- Linking health and social care data*

> *'Just being careful with third party providers.'*
> *- NHS Test and Trace*

> *'What other persons/agencies outside LBC will have access to the data?'*
> *- NHS Test and Trace*

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[2] Wellcome Trust (2016) *The One-Way Mirror: Public attitudes to commercial access to health data* (*Key Findings*); Ghafur, S. (et al.) (2020) 'Public perceptions on data sharing: key insights from the UK and the USA', *The Lancet*, vol.2, no.9

Similar worries also came up in the Wellcome Trust's research into public attitudes to sharing health data, which found 'uncertain future users' as a key concern for participants[3].

Participants' third party privacy concerns also suggested a greater level of trust towards Camden Council in looking after their data than other organisations, as well as a general hesitance towards sharing data for commercial purposes, as was also found by Ghafur et al.[4]:

> *'My worry is that data sharing of this intimacy is so sensitive that it must stay within organisations and institutions that we trust, i.e. the NHS and Camden Council. I don't have a problem with this degree of data sharing, unless the sharing involves a private provider that I don't know. In that case, I have a big problem with it.'*
> *- NHS Test and Trace*

> *'I'm not worried about Camden sharing this data, because it helps identify the problem. I would be worried if Camden used the data for informing people outside the NHS and the Camden local authority.'*
> *- NHS Test and Trace*

Another privacy concern in the case studies for many participants (31%), was whether residents' data would be used and shared proportionally by Camden Council. The significance of this is evident as *1. A proportionate use of data (minimum data necessary)* was the third most selected as the most important commitment on Camden Council's Data Charter (Appendix 1. Figure 1), and 95.3% of participants believed it was 'very important' or 'important' that Camden Council used the minimum data necessary to achieve desired outcomes (Appendix 1. Figure 2).

Several (10%) saw proportionate use as a method of minimising the risk of security breaches and deliberate misuse:

> *'Need to make sure that info is shared on a need to know basis only. Ensuring the Notes/data shared is confidential and protected. For example that emails are securely shared to avoid misuse of data.'*
> *- Linking health and social care data*

> *'...I know from experience that in emergencies people will often look at as many databases as they have access to, and they might share data inadvertently. The focus should be on making sure it was only available to a limited number of people.'*
> *- NHS Test and Trace*

Whilst others (14%) felt proportionate use was less intrusive on their privacy:

[3] Wellcome Trust (2016) The One-Way Mirror: Public attitudes to commercial access to health data (Key Findings) p.12

[4] Ghafur, S. (et al.) (2020) 'Public perceptions on data sharing: key insights from the UK and the USA', *The Lancet*, vol.2, no.9, p.1

> *'...my data should only be accessible to relevant departments/parties. Maybe an option to give permission to pass this information.'*
> *- Linking health and social care data*

> *'Need to make sure that info is shared on a need to know basis only.'*
> *- Linking health and social care data*
> *'...there's always a tendency to use [data] for other means, and people need to trust that it is being used only for the reason it was given for.'*
> *- NHS Test and Trace*

For many participants (20%), these risks could be somewhat mitigated through assurances from Camden Council about the security measures they have in place, as well as a commitment to transparency if a security breach were to happen:

> *'...should there be a breach of the persons' data or confidentiality, that they would investigate and that it would be corrected.'*
> *- NHS Test and Trace*

> *'If they...make sure that the data is protected, I could be more comfortable with them collecting it.'*
> *- NHS Test and Trace*

> *'That they keep their word as to what's in their data protection programme.'*
> *- NHS Test and Trace*

> *'...you are trusting Camden with your data and trusting that it will be looked after.'*
> *- Deciding where to put electric vehicle charging points*

Finally regarding security and privacy, two case studies – linking health and social care data and NHS Test and Trace - raised the most concerns from participants. Though this could be due to more participants studying these two case studies than the others, with 12 (29%) participants looking at NHS Test and Trace, and 11 (26%) looking at Linking health and social care data, in comparison to only 3 (7%) participants looking at Verifying identity for Blue Badge applications, it may still suggest that the scenarios presented in these case studies provoke greater concern among participants.

Similarly, it is worth noting the comparative lack of security and privacy concerns from the six participants who looked at the fifth case study on electric vehicle charging points.

Overall, the residents who discussed this case study were the least concerned about potential risks (only one participant was 'slightly worried'), and all were in favour of the potential benefits. Although this is too small a sample to form any firm conclusions, it follows a similar pattern observed by the

Wellcome Trust in which the less personal and identifiable the data being used, the more acceptable sharing is to participants[5].

Key recommendation: Increased education and communication around data privacy for residents, including how their information is already covered by GDPR.

2. Transparency

Across all five case studies, participants voiced a range of perspectives around transparency. Concerns raised included: understanding Camden Council's use, storage, and sharing of their data; and having access to the personal data Camden Council stores on them. Other significant points raised included transparency as means of building trust between Camden Council and residents, and as a means of measuring Camden Council's commitment to the Data Charter.

The most common concern for many participants (43%) in regards to transparency, was understanding what data Camden Council keeps on them, how it's stored, and how it's used:

> *'Transparency means showing the types of data and the use of data'*
> *- Linking health and social care data*

> *'Transparency - Camden being honest about what data is shared.'*
> *- Linking health and social care data*

> *'Communicating openly about the way the work is going on...'*
> *- Using data to understand residents' needs*

> *'Transparency - honest and open about how we use the data, that there are measures to secure it. Also retention period for holding data.'*
> *- Linking health and social care data*

Within this, three participants also had more specific concerns. For example, one participant questioned whether residents would have the right to be forgotten:

> *'People will need to know that the data can disappear i.e. the right to be forgotten. example transgender people, the gender that they we born may be different from the one they presently hold; particularly if the person doesn't want to disclose this information. Or if a person move out of the borough how will they information be held.'*
> *- Linking health and social care data*

A few others (10%) raised concerns about being able to see and understand Camden Council's decision-making processes when using residents' data:

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5 Wellcome Trust (2016) The One-Way Mirror: Public attitudes to commercial access to health data (Key Findings) p.9

> *'Transparency – being able to understand why a particular decision has been made and…what data people had access to when making a particular decision or providing a particular service.'*
> *- NHS Test and Trace*

> *'Transparency – underline decision process is visible and [understandable] outside the organisation.'*
> *- Deciding where to put electric vehicle charging points*

Another frequently raised concern (by 30% of participants) was whether, and how easily, residents would be able to access specific information on how Camden Council uses their data:

> *'Transparency – having information available in a public form without having to go through a Freedom of Information request.'*
> *- NHS Test and Trace*

> *'Transparency – it means that nothing is done behind anyone's back and you can look and find out what is being sent from A to B to C.'*
> *- NHS Test and Trace*

> *'Transparency – We know exactly how the data is collected, and why it is being used, and this information is made public and easy to find.'*
> *- NHS Test and Trace*

These concerns were also present in their answers to the closed questions, as all participants believed it was 'very important' or 'important' that Camden Council access, use and sharing of data is transparent (Appendix 1. Figure 3), and *3. Camden's use of data must be transparent and publicly available* was the most selected choice as the most important commitment in Camden Council's Data Charter (Appendix 1. Figure 1). Furthermore, 97.7% of participants believed it was 'very important' or 'important' that Camden Council was committed to an Open Data Charter which gave residents the right to access data (Appendix 1. Figure 4).

Perspectives like this were also present in desk research, as Oswald and Lounsbury et al. both found that transparency was an important influence on people's willingness to share data[6].

For many participants (38%) transparency was a reflection of the relationship between Camden Council and residents, which built trust and demonstrated respect towards the community:

> *'…it's about dignity and respect.'*
> *- Linking health and social care data*

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[6] Oswald, M. (2014) 'Share and Share Alike? An Examination of Trust, Anonymisation and Data Sharing: with particular reference to an exploratory research project investigating attitudes to sharing personal data with the public sector', *SCRIPTed*, vol.11, no.3, p.270; Lounsbury, O. (et al.) (2021) 'Opening a 'Can of Worms' to explore the public's hopes and fears about health care data sharing', *Journal of Medical Internet Research*, vol.23, no.2, p.1

'I assume Camden Council will apply proper handling of my data. Having a clear ongoing discussion about use of data policy is best practice.'
- Deciding where to put electric vehicle charging points

'...you are trusting Camden with your data and trusting that it will be looked after.'
- Deciding where to put electric vehicle charging points

'Not being transparent creates mistrust.'
- Using data to understand residents' needs

This was further highlighted by participants' definitions of trust and ethics, which several (26%) directly related Camden Council's handling of their information:

'Trust - that [Camden] will not abuse the data that we share. Data used as and when appropriate.'
- Linking health and social care data

'Trust - trusting Camden not to misuse the data.'
- Linking health and social care data

'Trust - being able to trust that Camden will use my data appropriately and make sure that my data is not misused.'

- Using data to understand residents' needs
'[Ethics] - reasonable use of the data.'
- Linking health and social care data

'Ethics - that Camden keeps its promise as to how it would use my data.'
- NHS Test and Trace

Finally, one participant raised the point that transparency would act as a means for the public to see if Camden Council is upholding the other commitments in the Data Charter:

'Camden's use of data must be transparent and publicly available - because without transparency you can't verify any of the other commitments.'
- NHS Test and Trace

Key recommendation: Providing more information around what data is kept on residents, and how their data is used, stored and shared.

3. Accessibility

Across all five case studies a common worry for many participants was accessibility. Primarily regarding access to technology, digital literacy, and comprehension of Camden Council's handling of resident data, concerns raised focused on two main issues:

- Inclusion
- Community understanding

Many participants (21%) highlighted concerns over inclusion for members of the community who may need additional support accessing digital services:

> *'Accessibility should be considered and Camden should provide support to those who can't/ struggle to gain access.'*
> *- Verifying identity for Blue Badge applications*

The groups identified by the participants were the elderly, disabled, and other vulnerable people, with the main concern being their ability to access the internet and use technology, as well as the knock-on effect of this on their ability to understand Camden's handling of their data:

> *'...I work with vulnerable clients who aren't tech savvy and don't have easy access to the internet, such as single people living alone, with no immediate family support, so no informal help.'*
> *- Verifying identity for Blue Badge applications*

> *'...I think that a lot of people my age don't have the facility to go on the computer and check things, so it should be made as easily understandable as possible. I know neighbours who don't understand what an email address or a mouse is.'*
> *- NHS Test and Trace*

Though one participant also discussed worries about people in these groups being more at risk from wider concerns about security and privacy:

> *'With information about older people and people with a disability, their data should be handled carefully as they may not be aware of people or organisations misusing their data.'*
> *- Verifying identity for Blue Badge applications*

Many participants (21%) also discussed concerns about community understanding. In comparison to their statements around inclusion, these concerns centred more broadly on the importance of everyone in the community understanding Camden Council's handling of their data through the use of uncomplicated language and clearly defined terms:

> *'...publishing things publicly isn't the same as making it transparent, because not many people have enough background knowledge to understand the documents that would be published.'*
> *- NHS Test and Trace*

'Camden's use of language can be confusing, it [needs] to be clear and accessible to all. Often information provided by Camden seems like double Dutch to me.'
- NHS Test and Trace

'It is important that we are careful [of the] wording we use. Words that can be vaguely interpreted must be [clearly] explained'
- Linking health and social care data

The importance of accessibility was also demonstrated by the participants' answers to the closed questions, with 90.5% of participants believing it is 'very important' or 'important' that anything Camden Council publishes to explain their data handling must be easily available and understandable (Appendix 1. Figure 5), 9.5% selecting *6. Published documentation must be easily understandable to the public* as the most important commitment in Camden Council's Data Charter (Appendix 1. Figure 1), and 95.2% believing it was 'very important' or 'important' they understand how Camden Council handles their data (Appendix 1. Figure 6).

As two participants highlighted, placing an emphasis on accessibility in this way demonstrated respect for residents' personal information and helped build trust with the community:

'[It's] about making sure that residents [understand]/know what is being done with their data, [it's] an important part of who people are.'
- Linking health and social care data

'I think it is critical that when Camden take [decisions] [for them] to be explained fully in a clear and understandable manner and listen to our views.'
- Deciding where to put electric vehicle charging points

Key recommendation: Using plain language in the Data Charter and supporting information provided to residents, and identifying how people in the community with additional needs will be supported.

4. Scrutiny

In discussions of all five case studies participants brought up the importance of scrutiny, with concerns raised focusing on the need for oversight and accountability of Camden Council's handling of residents' data.

Firstly, a main concern among several participants (24%) was the shift in some of the case studies towards a greater use of technology within Camden Council's processes:

'Risk of automating the system rather [than] having a human input.'
- Using data to understand residents' needs

> *'…it should have a human touch and not mechanical.'*
> *- Using data to understand residents' needs*

A concern that is evident in that 85.7% of participants believed it was 'very important' or 'important' that the risks of any new technologies are considered and there is sufficient human oversight of data used for decision making (Appendix 1. Figure 7). In addition to this, *2. Any new technology allowing greater automation must be carefully considered before use and have sufficient human oversight* was the second most commonly selected as the most important commitment in Camden Council's data charter (Appendix 1. Figure 1).

Three raised specific concerns that a lack of human involvement would mean less individual consideration within decision making, potentially removing the nuance offered by human experience:

> *'Algorithms are [good] to a [certain] point but do not rely entirely on them because there is no room for exception.'*
> *- Deciding where to put electric vehicle charging points*

Four participants were also worried that without human oversight, there could be an increase in errors and mistakes:

> *'I think this is important because data needs to be monitored by a trusted human as it will limit mistakes or incorrect information. I don't think that Artificial Intelligence can ever work effectively without human oversight. It can leave people vulnerable and can be dangerous if incorrect data is used.'*
> *- Linking health and social care data*

Beyond technology, other participants (17%) had similar concerns about inaccurate or misinterpreted data being shared. Either as a result of human error:

> *'A risk would be the inputting of incorrect data - need to be careful here and not just use AI without human oversight as well as checks for incorrect human inputting.'*
> *- Using data to understand residents' needs*

Or as a result of data bias:

> *'It might be used to build a picture in a particular way and doesn't tell the full story.'*
> *- Linking health and social care data*

These concerns were also found in OneLondon's report on public expectations of the use of health data, which found that participants had concerns about the standard of information kept on them and the consequences for poor quality data being used and shared[7].

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7 OneLondon (2019) Understanding public expectations of the use of health and care data. p.9

In relation to these concerns, many residents (24%) voiced that Camden Council should be accountable through internal and external oversight.

Internal oversight was particularly important, as all participants believed it was 'very important' or 'important' that Camden Council's access, use and sharing of data is accountable through internal standards and assessments. Specific points participants discussed around internal oversight were the importance of Camden Council taking ownership of the data, and having clear lines of responsibility for any failings:

> *'There should be one person that becomes the guarantor of the information at local level (and also at national level). So this person would have to sort out any issues that arise.'*
> *- NHS Test and Trace*

One participant also highlighted the importance of external oversight and public scrutiny as method of deterring misuse of residents' data:
> *'...considering the risks and limits of new technologies is different from having human oversight. There needs to be human oversight for things other than just new technologies. Something not mentioned is a commitment to allow external oversight to ensure that services meet this charter.'*
> *- NHS Test and Trace*

Furthermore, two participants raised the point that there should be consequences for any security breaches:

> *'There should be criminal sanctions if [the] council use my data for purpose not agreed.'*
> *- Deciding where to put electric vehicle charging points*

> *'...to ensure that there are no breach of privacy and if there are, that people or organisations are held accountable...Because if this is not in place the system is open to abuse.'*
> *- Using data to understand residents' needs*

The Wellcome Trust found this as a way to reassure participants to share data, along with other transparency related factors[8].

Finally, these perspectives on accountability were also mirrored by several participants' (12%) definitions of justice and corporate social responsibility.

> *'CSR - as [an] organisation taking ownership of the measures that they put in place, to monitor when, how and where we use the data. Ensuring that staff comply with those requirements.'*
> *- Linking health and social care data*

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[8] Wellcome Trust (2016) The One-Way Mirror: Public attitudes to commercial access to health data (Key Findings) p.10

'Justice - is a feeling of security - knowing if there is a breach - that people/service will be held accountable.'
- NHS Test and Trace

'Justice - people being accountable if data [is] misused.'
- NHS Test and Trace

Key recommendation: Providing greater detail on Camden Council's use of technology in handling residents' data, as well as commitments in the Data Charter to oversight and accountability.

5. Benefits to Community

Across case studies one to four, participants highlighted several potential benefits to the community that Camden Council's use of their data could achieve. These can be separated into efficiency, and increased help for the community.

In regards to efficiency, several participants (12%) noted time saving advantages for both residents and council staff:

'Faster applications. I'm not registered for a lot of services, but I've got multiple health problems; I have periods when I'm not well. If everything's registered properly that should speed up the process.'
- Verifying identity for Blue Badge applications

'Automating the system may free up the system given Camden staff to concentrate on other operations'
- Using data to understand residents' needs

A few participants (10%) also pointed out ways Camden Council using their data could spare residents some effort, particularly for those who use multiple council services:

'The fact that you give your information (data) once is so much easier. No constant giving of information for the person and saves time.'
- Linking health and social care data

'Not having to repeat your story multiple times.'
- Linking health and social care data

Several participants (14%) noted ways Camden Council's use of resident data could improve the quality of some community services:

'Combining health and social care data would be good, so that they can communicate and work together better.'
- Linking health and social care data

Particularly for vulnerable groups:

> *'I think it's a brilliant idea. It will allow us to work more easily and efficiently. It will improve her health in the long term and enable her health to be monitored and minimize the risk of safeguarding issues. Professionals would be able to give her the best care at the right time.'*
> *- Linking health and social care data*

> *'It's a protective factor because from my personal experience I know that there can be many different workers and different shifts, this means the person will not be left without necessary care as the same information will be shared. If new information is added all parties would be on the same page, and less likely that the patient would be left without the care that they need.'*
> *- Linking health and social care data*

Furthermore, 97.7% of participants believed it was 'very important' or 'important' that Camden Council's use of data to deliver a service must have clear benefits for residents and serves the public good (Appendix 1. Figure 8), suggests the importance of making residents aware of the potential benefits of Camden Council using their data and, as Lounsbury et al. found, the impact raising awareness of these benefits can have on public support for data sharing[9].

Key Recommendation: communicating the benefits to both the individuals within a community and the benefits to communities as a whole will increase the understanding and trust in data and the utilisation of it.

6. Communications

From the four options presented to them in their interviews, participants favoured statements via Camden's website as their preferred method of communication (28.7%). Second to this was educational videos available on YouTube and the Camden website (27.7%), followed by communications on the back of their council tax bills (25.7%), and finally via a Data Privacy Impact Assessment (17.8%).

Residents also highlighted several alternatives by which Camden Council could keep them informed, which can be broken down into public and private channels.

Public methods of communication participants suggested included:
- social media channels such as Twitter and Facebook
- local press, such as the Camden New Journal, The Camden Magazine, and the Hampstead and Highgate Express
- handouts, leaflets and newsletters through residents' doors
- community spaces such as libraries and local cafes
- in public spaces through street advertising

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[9] Lounsbury, O. (et al.) (2021) 'Opening a 'Can of Worms' to explore the public's hopes and fears about health care data sharing', *Journal of Medical Internet Research,* vol.23, no.2, p.1

Which of the following ways Camden
could inform the public about its data
handling would you find most useful?
(tick all that apply)
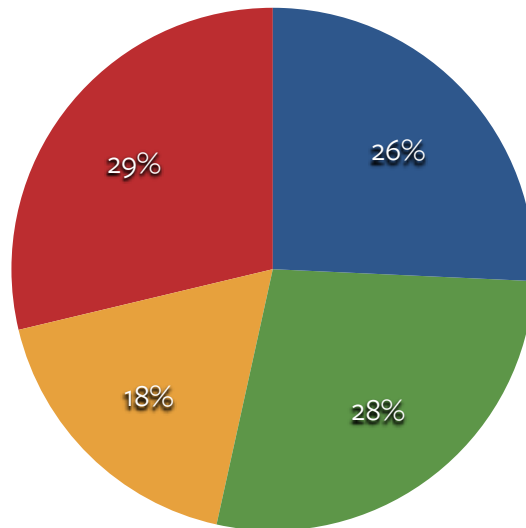
🔵 On the back of your Council tax bill
🟢 Educational videos available on YouTube and the Camden website
🟠 Statement on website
🔴 Data Privacy Impact Assessment

Private methods of communication participants suggested included:

- text messages
- email
- personal mail
- a dedicated helpline at the council

Of these alternatives, the majority (67%) are offline or have both online and offline versions, suggesting a preference among participants towards non-digital forms of communication.

Accessibility and inclusion was also raised as a concern in regards to communication, again specifically for elderly and disabled residents, as well members of the community who lacked computers or internet access. Additional methods of communication suggested include public forums, one to one meetings (in person, via Zoom, and over the phone), as well as forums specifically for carers or other representatives.

Like transparency, participants saw good communication between Camden Council and residents as building trust and demonstrating respect:

> 'There should be more of these, because having these communications can build confidence with the Council...That's one way of building a good relationship with the public.'
> - NHS Test and Trace

'I think this is great that Camden is reaching out to residents to co-create the Data Charter, it's a way of humanising who we are.'
- Linking health and social care data

'I think it's a very good idea that you are taking views properly into account; taking the time to hear properly what I have to say.'
- NHS Test and Trace

The overall significance of communications was evident in that 92.7% of participants believed it was 'very important' or 'important' that Camden Council committed to consistent periodic deliberation with residents around their handling of data (Appendix 1. Figure 9).

Conversely, previous personal experiences of poor communication among participants encouraged mistrust and uncertainty as to whether Camden Council would take on board participants' concerns:

'I worry that too often decisions have been made against public opinion.'
- Verifying identity for Blue Badge applications

'Periodic deliberation with residents' should include consultation and genuine response to public opinion, e.g. as needed in the cycling lanes consultation.'
- Verifying identity for Blue Badge applications

'We can't trust Camden council with handling of our data no matter what we the residents say. This is like a tick box exercise.'
- Using data to understand residents' needs

Finally, a few participants (10%) highlighted the importance of ensuring everyone in the community had the opportunity to express their views on Camden Council's use of their data:

'Camden needs to find as many ways as possible to offer access or [creative] ways to involve residents in these discussions (data charter) so there are not the same residents always being consulted.'
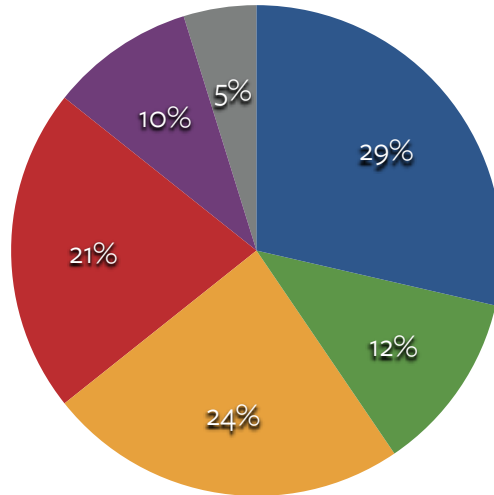*- Linking health and social care data*

Key recommendation: Providing varied opportunities for communication between Camden Council and residents, using a mixture of online and offline methods.

Appendices

Appendix 1.

Which commitment do you think is most important to have included in Camden's Data Charter?

- 🔵 Camden's use of data must be transparent and publicly available
- 🟢 Commitment to consistent public engagement on our use of data
- 🟠 Any new technology allowing greater automation must be carefully considered before use and have sufficient human oversight
- 🔴 A proportionate use of data (minimum data necessary)
- 🟣 Published documentation must be easily understandable to the public
- ⚪ Camden must justify all data use in documentation and publish it publicly

Figure 1

The use of data is proportionate to the resident need. Camden will use the minimum data necessary to achieve the desired result
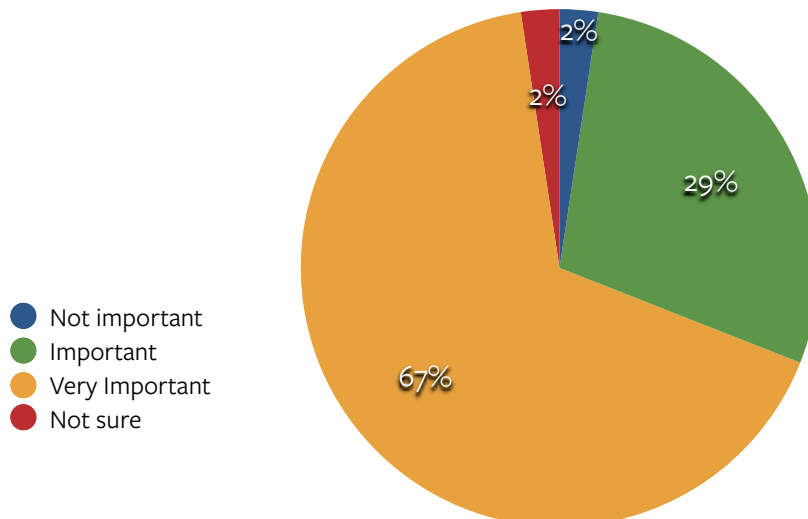
- 🔵 Not important
- 🟢 Important
- 🟠 Very Important
- 🔴 Not sure

Figure 2

Camden's access, use and sharing of data is transparent and accountable through internal data standards assessment procedures, which will be communicated clearly and accessibly to the public.
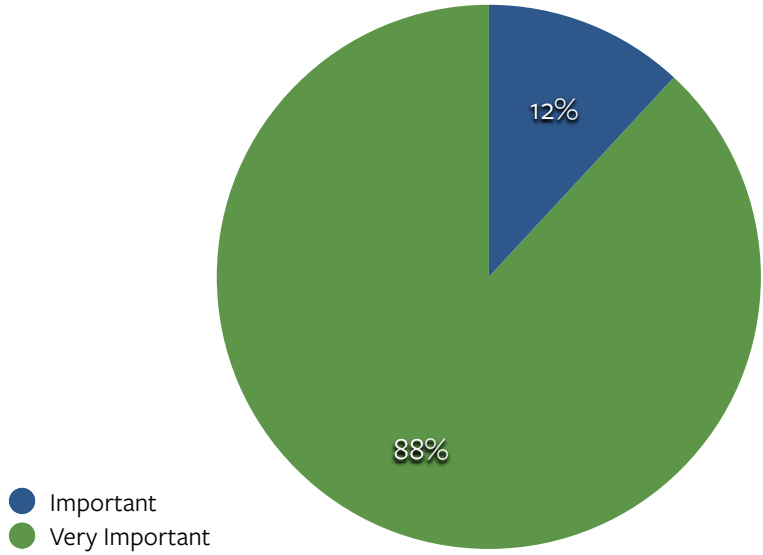

- Important
- Very Important

12%

88%

Figure 3

Camden is committed to an Open Data Charter. We believe that residents have a right to access data, which does not compromise people's privacy
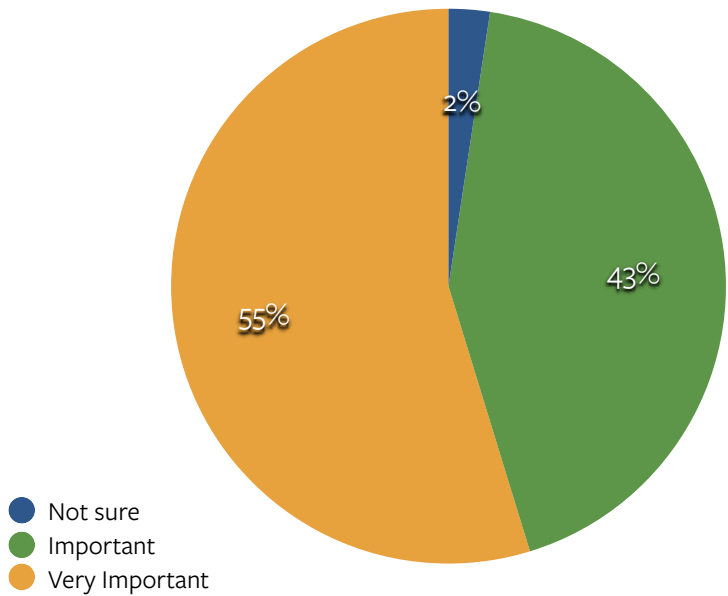

- Not sure
- Important
- Very Important

2%

43%

55%

Figure 4

Camden must ensure that anything published to explain our data handling must be easily available and understandable

- Not sure
- Important
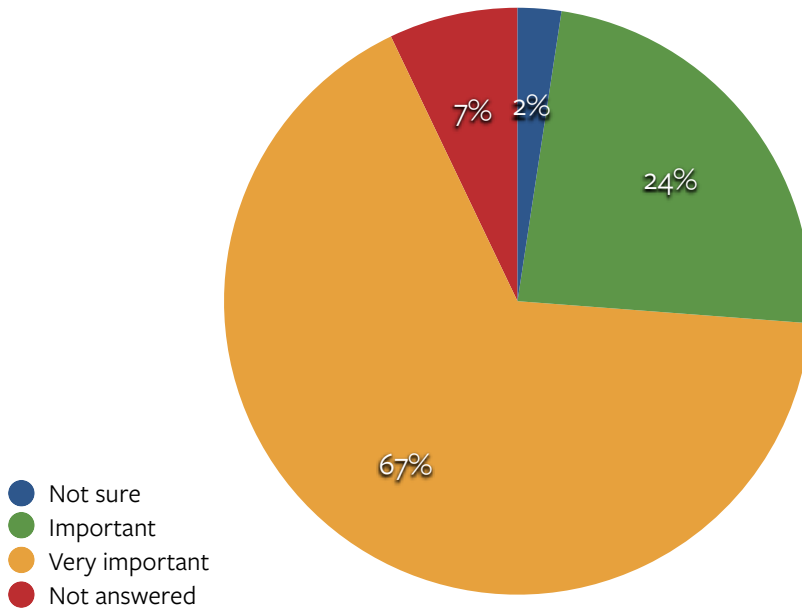- Very important
- Not answered

2%
24%
7%
67%

Figure 5

How important is it for you to understand how Camden handles your data?
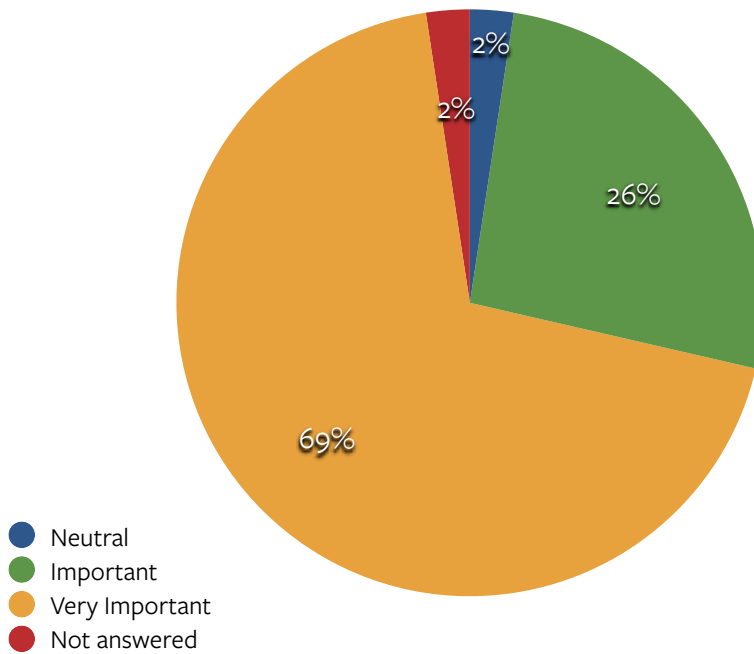

- Neutral
- Important
- Very Important
- Not answered

2%
2%
26%
69%

Figure 6

The risks and limits of new technologies (like facial recognition) are considered and there is sufficient human oversight of data used for decision making.
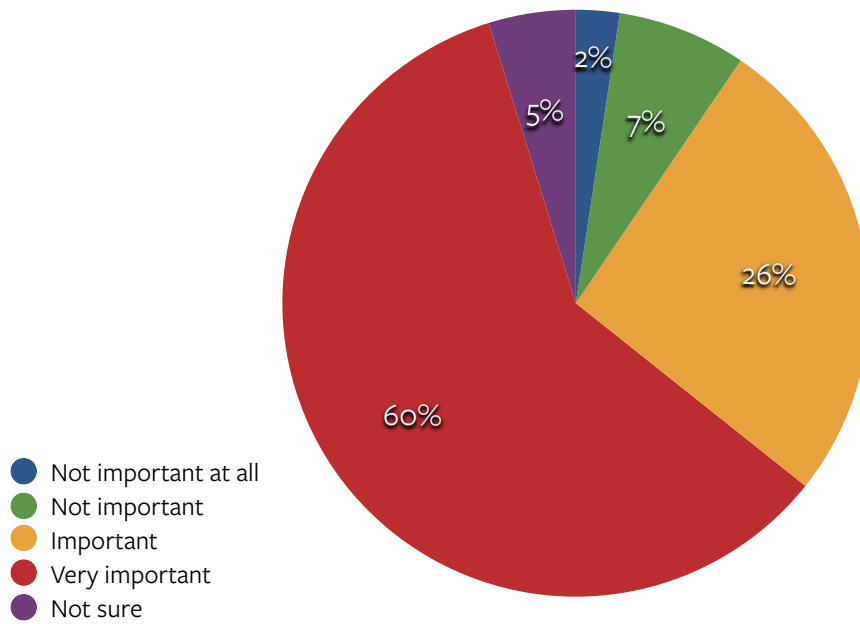

- Not important at all
- Not important
- Important
- Very important
- Not sure

2%
7%
5%
26%
60%

Figure 7

The use of data to deliver a service must have clear benefits for residents and serves the public good, justified in documentation that is published publicly.
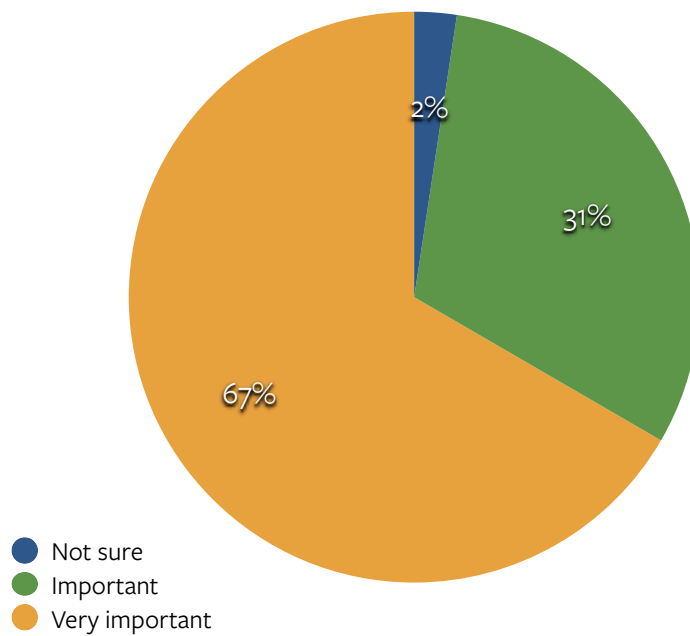

- Not sure
- Important
- Very important

2%
31%
67%

Figure 8

Camden commits to consistent periodic deliberation with residents around the subject of our handling of resident data.
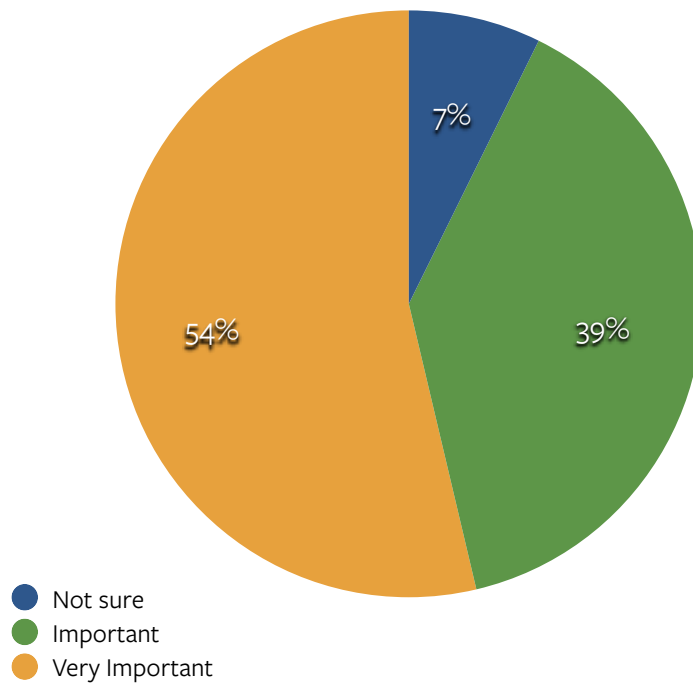

Not sure
Important
Very Important

Figure 9

Appendix 2: Case Studies

1. Verifying identity for Blue Badge applications
'How Camden Council is using automation and its existing data to reduce wait times for applicants and streamline staff workloads.'

Read this case study here

2. Using data to understand residents' needs
'Analysing historical data to help us understand why someone falls into crisis helps us design and offer services to help, rather than add to the problem by simply chasing council housing rental arrears.'

Read this case study here

3. NHS Test and Trace
'How sharing data between the NHS and Camden Council aides contact tracing, and is helping to control coronavirus outbreaks and keep communities safe.'

Read this case study here

4. Linking health and social care data
'Linking sensitive health and social care data to ensure medical and care needs are understood by everyone caring for an individual in order to provide consistent and quality care for our most vulnerable residents, without them constantly having to re-tell their story.'

Read this case study here

5. Deciding where to put electric vehicle charging points
'Using data science and an algorithm to maximise the use and fair distribution of electric vehicle (EV) charge points in Camden to promote and encourage more EVs.'

Read this case study here

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