

# Written evidence on Public Attitudes on Consent and Data Security for the National Data Guardian Review Team

Submitted by Healthwatch England

30<sup>th</sup> November 2015



## Summary of our response

We are grateful for the opportunity to provide the National Data Guardian with evidence to be used for the development of the consent and opt-out policy.

We believe the establishment of the National Data Guardian is an important step towards the achievement of public trust in information sharing initiatives as well as an opportunity to achieve a single, or at least a more harmonised, regulatory regime in data sharing in health and care in England.

We believe people should be the owners of their personal records. Records should be licensed to organisations, acting as stewards of information, but the ownership of the records should stand with people. Adopting this approach might provide additional clarity when communicating with the public as well as ensuring that the right security systems are in place.

We believe it might be beneficial to divide the use of personal health data between three categories:

- Direct care (in both health and social care);
- Research; and
- Performance management.

Recognising a distinction in the different uses of data by purpose might provide additional clarity in the policy of information sharing.

Adopting this approach in conjunction with recognising that people are the owners of their data is the best way to achieve clarity in the policy of consent, minimise security risks and gain public trust.

We believe our ten principles for good information sharing should be taken into consideration when collecting and sharing people's data:

1. People should be able to access their own health and social care data and records to see what the system has collected and who they are sharing it with.
2. Data should be collected and shared in a manner that does not unjustifiably compromise people's anonymity, safety or treatment.
3. Collecting and sharing data should not be used to justify treating people on an unequal basis with others.

4. Data collection and sharing should not have impact on a person's wellbeing by, for example, causing them additional anxiety or distress.
5. People should be provided with all the information they require about Care.data or any other data sharing initiative, to make an informed choice about whether they want to opt in or out.
6. Frontline professionals should be upfront and honest about the benefits of opting in or out of Care.data or any other similar programme.
7. If an opt out is offered, it should be a genuine option (i.e. not overly burdensome) and people must be informed about the restrictions and limitations of this option.
8. If someone raises a concern or makes a complaint about the collection or sharing of their records, this should be taken seriously and staff should take immediate action to address the concern and, if it relates to a breach of confidentiality, put safeguards in place to restore the person's anonymity.
9. People should be able to opt out of Care.data later if they change their mind about the programme in future.
10. People should be offered an opportunity to get involved in local decisions at their GP surgeries about whether or not records are shared with the Care.data programme.

## Introduction

We appreciate the opportunity given to Healthwatch to provide our feedback and evidence on public attitudes towards consent and data security. We hope they will be used by the National Data Guardian's review team to develop the future consent and opt-out policy.

Healthwatch England is the consumer champion in health and social care which was formed as part of the 2012 reforms that set out the ambition to put people at the heart of health and social care. There is a local Healthwatch in every local authority area in England and Healthwatch England is the national body. Healthwatch is unique in that its sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

Healthwatch England has a particular interest in how the public is involved and consulted on the topic of personal data because the public is concerned with the information held about them, how it is collected, who has permission to use it, the purposes for which it is used, and how and when it is disposed.

People should have access to their individual records and be able to change or verify the information held about them. They should have the chance to express their consent for the use of personal data and the right to opt-out from their data being shared. Equally, the public expects timely, clear and effective communication about how personal data is safeguarded.

We believe that ownership of personal information, including health and social care records, should lie with the individual. We appreciate that this might represent a considerable change in data governance across health and care, however we believe that now is the time for a radical re-think about information ownership. If the public owned this information but gave it to health and social care organisations under license, or with a duty of stewardship, they could be far more confident in the system.

It is by establishing clear rules for consent and opt-out - ensuring that the right safeguards and public engagement are in place - that public trust in information sharing initiatives can be achieved.

We also believe that a differentiation across the uses of data by the health and social care system would be useful. We suggest that three categories are necessary:

1. Data for medical and treatment purposes;
2. Data for research; and
3. Data for performance management.

By clearly differentiating data, the system would be able to ensure that the right consent policies are in place and that the right safeguards are established.

In addition we want to use this occasion to state that we see the recent establishment of the National Data Guardian as a step towards achieving public trust in data sharing, as well as an opportunity to achieve a more harmonised, regulatory regime in information sharing across health and care.

## **Healthwatch and information sharing initiatives**

At Healthwatch England we have a strong interest in information sharing initiatives, consent and data security. The local Healthwatch network has always informed us about public concerns on the developments of national data sharing initiatives. With over a quarter of the network reporting worries about the development of recent national data sharing initiatives, we can say with confidence that data sharing, consent and security is a key interest for the public.

In all our advisory and engagement activities on the development of information sharing initiatives, we have always played a critical friend role. We recognise the potential benefits of data sharing, yet we see as critical that the public's views are listened to and championed by an independent organisation. It is precisely by listening to those views that public trust in information sharing initiatives can be achieved. Our ten principles on data sharing specified above could be useful in achieving such a goal.

The aim of this document is to present the evidence that together with local Healthwatch we have gathered regarding consent and data security. Specifically, this material has been developed to provide evidence in response to the following questions asked by the National Data Guardian to patient groups and representative of the civil society:

1. *Consent*: What is the current perception and understanding of consent models in the health and social care system? How can we best design a new consent model that is easily understood by patients and service users? How do we make it absolutely clear to patients/service users what information is used for what purposes?
2. *Security*: What easily understandable standards for security of personal data, whether held on paper or electronically, should be applied to the whole health and care system? How can data security standards be assured? What information do patients and service users need to know that health and care information about them is safely and appropriately used?

We aim to respond to these questions by providing the evidence we have gathered on this issue at a national level, as well as that gathered by the Healthwatch network.

We conclude by providing insights on how a model of consent might work for the public and with some notes on data security.

## Evidence gathered by Healthwatch England

At the beginning of 2015 we ran a national poll to explore public attitudes on information sharing initiatives<sup>1</sup>. We also ran a series of focus groups jointly with Healthwatch Surrey, Healthwatch Luton, Healthwatch Waltham Forest and Healthwatch Southend on Sea to explore public attitudes to Primary Care. Details of the focus groups are reported in Appendix I.

Our research has identified the following issues:

### Public trust

Our national poll identified that:

- The public trust their GPs in handling their data but personal data is still sensitive, with 65% of respondents indicating trust in their GPs knowing how to use their personal data and 57% of respondents indicating that there are aspects of their personal health data they would rather their GP did not share.

### Attitudes to data sharing

Our national poll identified that:

- Respondents appeared broadly in favour of sharing data if it was anonymous, (66% of positive responses) and the majority of them reported trust in the NHS, with 58% indicating that they believe their rights as a patient are respected in the NHS.
- Only a minority of respondents reported not being willing to share their data, even if anonymous (22% reported not being willing to share their personal health data with researchers, even if it was anonymous).

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<sup>1</sup> The poll was run by YouGov on behalf of Healthwatch England. The poll was run online with a base of 2071 adults in England. The sample is representative of the English population, although caution should be given in interpreting the results, especially when it concerns minorities and hard to reach groups. Care should also be given in interpreting the results as the audience might be skewed towards more technologically literate members of the public.

- The vast majority of respondents reported that if their health information could help others (e.g. via research) they would be happy to share it, as long as it does not have the potential to harm the donors (72%).
- The majority of respondents reported it being important that health providers can access their data quickly (67%).
- 57% of respondents reported believing that increased data sharing can lead to better integration across health and care.
- A number of respondents see increasing data sharing as the only way for the NHS to achieve higher efficiency in the future (43%)
- There are important sensitive areas to consider regarding public attitudes to information sharing. When it comes to the use of social care services, mental health status and sexual health status, a low number of respondents reported being happy to share this information with health professionals and NHS services (39%, 38% and 34% respectively). A different picture is achieved when asked about sharing information on prescribed drugs, test results and information about own body and lifestyle (58%, 55%, 55% and 51% of positive responses respectively).

### Public communication

Our national poll identified that:

- The majority of respondents would like to be informed about the developments of large national data sharing initiatives (72%).
- More should be done to explain to patients how the NHS protects their personal health data and who can access them (39% of respondents reported feeling informed on these topics).
- There is a need to share better information with the public about the developments of big information sharing initiatives (only 20% of respondents reported feeling informed about government's plans to use personal health data).

### Consent and opt-out

Our national poll identified that:

- 64% of respondents reported they would like the NHS to allow them to opt-out of sharing their personal data at all times.
- Respondents reported preferring different ways of opting-out from sharing their personal health data. 53% of respondents reported wanting to opt-out online, 25% would prefer to tell their GP, 7% reported preferring to do that via letter<sup>2</sup>.

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<sup>2</sup> Note that, being this poll run online, the results might be skewed towards more technically literate respondents and it might not represent the preferences of specific population groups.

- The majority of respondents (58%) expressed an interest in being able to choose which government sharing programmes with whom to opt out of sharing data. 29% of respondents reported being willing to opt-out of all government sharing programmes in one go.
- When asked about attitudes to opt-out, assuming opting-out would not negatively affect their personal care, 50% of respondents reported deciding whether to opt-out based on who the data is being shared with, 43% reported deciding whether to opt-out based on why the data is being shared, 31% reported preferring being able to opt-out of all instances of data sharing in one go, 12% reported not knowing and 5% reported not preferring anyone of the choices above<sup>3</sup>.

### Areas of concern

Our national poll identified that:

- 55% of respondents were worried that if they share their data now they might regret it later.
- A considerable number of respondents indicated being worried that their personal health data might be sold with third parties (46%).

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<sup>3</sup> This question allowed for multiple choices.

# Qualitative research

## Identified worries and fears

*“When he [the child] was born I used to go to this breast feeding group on a Monday. When we had a doctor’s appointment and the doctor went out of the room, I saw on his computer screen that a record had been made of every time I’d gone to this breast feeding group , and I didn’t know that information was shared with my GP. [Mother 2] the problem is I probably was asked my consent, because you go to this children’s centre, fill in a load of forms, you’ve got a screaming baby on your arm, so you just sign away [...] I don’t know, who can have access and what can they access? Can schools access it? I wouldn’t know”*

*Female, 20-65, Focus group in Southend-on-Sea 2015*

Our qualitative research run in focus groups has also identified the following key areas of concerns for members of the public relating to the sharing of personal health records.

- Fears of others looking into personal data;
- Fear of personally identifiable data being used, as opposed to anonymised;
- Fear data sharing won’t work;
- Fear that personal data will be shared with private companies (especially insurance companies);
- Low public confidence;
- Fear of errors and inaccuracies; and
- Preference to keep data sharing in the medical context only.

## Perceived benefits identified

*“My daughter died of something called Reye syndrome and, if they hadn’t collected data on that, [...] they wouldn’t have found the connection between that and Aspirin, [...] now you [known that you] shouldn’t give Aspirin to a child under 12.*

*Female, Over 65, Focus Group in Surrey 2015*

Our qualitative work has also found evidence of perceived benefits from data sharing. More specifically, data sharing might:

- Help achieving more joined-up services;
- Help people avoid having to explain their condition/situation to different health professionals and consultants;
- Improve medicines for rare diseases;
- Allow care professionals to be informed if somebody is unconscious;
- Allow a more efficient acquisition of medicines once prescribed by a GP.

We found that the views of mothers of small children were particularly complex in relation to this issue. This group identified the potential benefits of sharing personal data for both mothers and children. The same group, though, expressed clear concerns about not knowing the purposes for which data was collected, as well as expressing concerns for the way their consent was asked.

Additional quotes from Healthwatch England’s focus groups are reported in Appendix II.

## Evidence available from the Healthwatch network

The Healthwatch network has consistently expressed an interest in the public’s desire to be informed and engaged on information sharing initiatives.

The results the Healthwatch network identified on the public’s attitude to information sharing is consistent with the results identified on a national level.

The evidence provided comes from a variety of sources: focus groups, surveys and direct communication from the public. Details on the methods of evidence collection for a single local Healthwatch are reported in Appendix I.

Local Healthwatch identified the following key points:

- Respondents appear to be largely in favour of sharing personal data for medical purposes;
- If data is shared for other purposes, respondents would like to express their consent for data sharing;
- In all occasions respondents would like to be informed about who extracted their data, who has access to their data and for what purposes;
- Respondents did not feel informed enough about data sharing;
- Respondents believe that data sharing might lead to better integration of health and social care, however some sensitivities were identified with respondents not

wanting to share all of their medical data with social carers or authorities in social care;

- Respondents expressed a need to understand the context and conditions under which personal data was collected and shared;
- Respondents expressed a clear desire to be involved in decisions regarding the sharing of their personal data.

Specific points identified by Healthwatch Surrey are below

### Public trust

- There is greater trust in and understanding of the role medical/health professionals than of social care professionals.
- The majority of people (77%) felt that it should be a combination of patient and professional who decides how records are shared. (Patient and doctor together, 42%, or patient, doctor and social care practitioner, 35%).

### Attitudes to data sharing

- Over a third of respondents were unaware prior to taking part in the survey that health and care records are not readily shared between health and care professionals.
- 58% had personal or family experience of having had to repeat their stories to different health or care professionals, or of their care being affected by lack of record sharing.
- 91% of respondents would share **all or part of their records**. Only 7% would opt out of sharing completely
- 94% of respondents would share with **all or some of the health and care professionals involved in their care**, nearly two thirds of these would be happy to share with all the relevant professionals.
- Nearly all respondents were willing to have their records shared between GPs (96% in favour) and hospital doctors (93%). Nearly three quarters were happy to share with other medical staff giving care whether in a GP surgery or a hospital environment (75%, 69%). Less than half of respondents were happy about having records shared with social care professionals (45%), especially home care workers (30%).
- Most people were willing to share information such as current/most recent medications, list of allergies, vaccination record but less content to share information on social care and support packages.
- If name, address and NHS number were removed from the records, 61% (an additional 18% said 'possibly') of respondents would agree to records being shared with medical researchers, and 57% (an additional 21% said 'possibly') with health and social care planners to help plan local services.
- It was necessary to constantly restate the boundaries of the proposed record sharing and reaffirm that records would be shared only between health and care professionals involved in the person's care. When the discussion moved beyond these confines, particularly on social media, it escalated fairly quickly into concerns over third party access.

- Older people were generally more willing to have their records shared between the professionals involved in their care. In focus groups with over 65s there were comments from older people about the difficulty of remembering all the relevant details of their health history and keeping lists in order to ensure they had all the details to hand.
- There appears to be some diversity among older people in terms of technical literacy.
  - One group asked for more data sharing.
  - The second one (less tech literate) asked for more data sharing with health professionals as they struggle to remember their medication needs. This group supported more health data being shared with social care professionals to achieve integration across health and care.

### Areas of concern

- The most common area of concern with respect to record sharing was **access by third parties**. Other common concerns centred on **accuracy** of the records being shared, **confidentiality**, and **privacy**. People were less concerned about the issue of sensitive information being shared.
- A General Medical Council review of public and professional attitudes to privacy of healthcare data suggested that people are generally *“sympathetic to data exchange between health professionals within the NHS as long as it leads to improved care and information is secure”*<sup>4</sup>. However, it also found that the greater the distance from those directly involved in patient care, the greater the concerns around access.

Healthwatch Lambeth organised a deliberative event with members of the public to discuss the developments of the Lambeth DataNet initiative, a local data sharing initiative which looks at the sharing of anonymised GP patient records to help plan and improve local healthcare services. In that event, participants expressed the following points:

- During the pilot of the engagement session of a local data sharing initiative in Lambeth, the Lambeth DataNet (LDN)<sup>5</sup>, with the Lambeth Patient Participation Group Network, participants were keen to seek assurances on data security, specifically to confirm that not ‘everyone in the NHS’ or any researcher had access to this database. Questions such as, “Who can see the data?” and “Who can extract the information?” were asked. With regards to pseudonymisation, a few participants were concerned that the process could be reversed to reveal a patient’s identity. Despite reassurances on the protection in place of the data and the pseudonymisation process, one participant reiterated his apprehension, saying

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<sup>4</sup> Cambridge Health Informatics . [http://www.gmc-uk.org/GMC\\_Privacy\\_Attitudes\\_Final\\_Report\\_with\\_Addendum.pdf\\_34090707.pdf](http://www.gmc-uk.org/GMC_Privacy_Attitudes_Final_Report_with_Addendum.pdf_34090707.pdf).

[www.gmc-uk.org](http://www.gmc-uk.org). [Online] November 2007.

<sup>5</sup> Lambeth Data Net is a local data sharing initiative which looks at joining data for commissioning, clinical and research purposes  
<http://www.lambethccg.nhs.uk/your-health/Information-for-patients/Pages/DataNet.aspx>

“I have concerns over hacking; even the tightest security databases can be hacked.”

- Noting that people’s health status and conditions can vary over time; participants raised queries as to how and when LDN is updated with patients’ current health information and what happens if someone has not been to the GP for many years. They also queried the impact of missing data from those not registered with a GP on the accuracy of LDN analysis and representation of Lambeth’s health as a borough.
- A few participants shared experiences of their own records containing mistakes, and questioned how widespread this may be across health records.
- Young people in particular discussed the need for updating their registration forms following adolescence to ensure that the information held with the practice reflected their current identities. Demographic information such as ethnicity, gender and sexuality, recorded during the GP registration process, were identified as data fields that do not always remain static for patients and therefore may need to be revised and checked at later dates.
- Participants commonly expressed their disapproval for any anonymised data to be provided to third parties, typically commenting “I don’t mind who has access to my records so long as it is not a commercial company i.e. insurance companies”. In relation to this, one participant shared his concern about ensuring the data did not get into the ‘wrong hands’ and questioned “what would stop a researcher from selling it on?”

### Public communication

In their meeting with the care.data team Healthwatch Bedford Borough noted that members of Healthwatch Reference Group (HRG) indicated that:

- There is a risk of communication on information sharing initiatives going unnoticed if the right channels of communication are not used.

Healthwatch Lambeth identified the following points from the participants to the deliberative event to capture the views of the public on the local data sharing initiative Lambeth DataNet:

- Participants were frequently surprised that they had not heard about LDN [the local data sharing initiative] and asked why this was. However, no participant was visibly upset with respect to this. Although participants found the content on LDN interesting, in general, they saw it as a ‘nice to know’, rather than a ‘need to know’. Only a few participants asked about the option to opt-out. This was not a common theme across the meetings suggesting it was not something that was considered by many.
- There was a call for greater transparency of LDN and accessibility to findings from research using LDN data, analysis of LDN data and the implications of such analyses for patients and the public.

## Consent and opt-out

In their meeting with the care.data team Healthwatch Bedford Borough noted that members of HRG indicated that:

- People with learning disabilities might have difficulties in understanding what was required in terms of having to 'opt-out' from the programme
- Carers are often 'forgotten' because they are caring for someone and have also neglected the need to 'opt-out' if necessary

## A possible model of consent

In our work we have recognised that there is no coherence or consistency in the current consent arrangements.

Health and care data is used for three main broad purposes: medical/treatment data, research data, and performance information.

- i. **Medical/treatment data.** As evidenced by the analysis done by the Healthwatch network, many members of the public are surprised that medical data is *not* shared across the system. For this reason the following option might be considered:
  - i. **Medical/treatment data** consent should be automatic. People should be enrolled as a matter of course (but should be able to opt-out if they wish). Further, when treatment is being offered or planned there should be an opt-out available (for people opted in) and an opt-in (for people previously opted out). This process should be adopted for all sharing of medical records for treatment purposes: that includes everyone apart from the patient and their GP. Explicit consent could be required only for the sharing of sensitive codes that do not necessarily affect direct care, similarly to the consent model adopted by the Summary Care Record.
  - ii. **Research data** has been problematic ever since it was revealed that the HSCIC was selling data to the private sector. So the basic principle has to be that an opt-in applies to all data to be used for research purposes. However, we can also recognise that, whilst some people would want to opt out completely, there are others who have a more sophisticated approach to sharing their personal medical information. So whilst the default position should be to opt in, there should be three levels of 'opt':
    1. **Level One.** Opt-in to research conducted by a University, the NHS, a research council or other body on a list of organisations certified to keep the data secure, to

- anonymise it, and to use it for the benefit of health and wellbeing of the community.
2. **Level Two.** Opt-in to research conducted by a non-for-profit organisation (not in level one) that is certified to keep the data secure, to anonymise it, and to use it for the benefit of health and wellbeing of the community.
  3. **Level Three.** Opt-in to research conducted by a profit-making organisation that is certified to keep the data secure, to anonymise it, and to use it for the benefit of health and wellbeing of the community.
- iii. **Performance Data.** The basic principle of data used for monitoring provider performance should be that personal data should not be collected or stored. Information for billing, or management purposes, should only include data that is *necessary* (not desirable) for those purposes.
  - iv. By separating medical/treatment data, research data, and performance data, it would be possible to overcome many of the current problems with personal medical data. For instance, by separating out the two uses of data there would be no danger that opting out of research data would have any impact on receiving medical treatment. We recognise this would be a radical step for the health and social care services, but feel it is needed to rebuild people's trust.

## Security

The principles of security with personal medical data should be:

- a) Follow the Data Protection principles.
- b) Follow the revised Caldicott principles.
- c) There should be a register of licensed data processors, based on principles (a) and (b) and which strict pass security and anonymisation tests.
- d) The National Data Guardian should be the registrar.
- e) Access to medical/treatment data should be on a 'need to know' basis, and restricted to licensed medical practitioners.
- f) Access to research data should be based on a clear research case, sound statistical techniques, and planned publication of results (to the standards applied by the NIHR).
- g) Collection of performance data should be on a clear business case, and start from the default position that personal data is *not* collected.
- h) As we have said in previous consultations, there should be a system of tough sanctions for breaches of data security.

## Next steps

We recognise the complexity of addressing the issue of consent, opt-out and data security. We are available with the National Data Guardian to provide additional information if required.

## Appendix I – Technical details of methods of evidence collection

Healthwatch Name	Evidence collection method	Technical details
Healthwatch England	National Poll	The poll was run by YouGov on behalf of Healthwatch England. The poll was run online with a base of 2071 adults in England. The sample is representative of the English population, although caution should be given in interpreting the results, especially when it concerns minorities and hard to reach groups. Care should also be given in interpreting the results as the audience might be skewed towards more technologically literate members of the public.
Healthwatch England and Healthwatch Surrey	Focus group	Focus group with older people (over 65). The focus group was composed 10 participants, 8 females and 2 males.
Healthwatch England and Healthwatch Luton	Focus group	Focus group with teenagers. The focus group was composed 9 participants, 7 females and 2 males.
Healthwatch Surrey	Survey	Healthwatch Surrey looked at public attitudes to sharing personal data records between health and care professionals by conducting a survey commissioned by Surrey County Council and carried over the summer of 2015 (557 surveys completed).
Healthwatch Surrey	Focus group	The issue was also explored with four focus groups with

		people over 65 years of age in locations across the country.
Healthwatch Bedford Borough	Notes from HRG meeting 5 <sup>th</sup> June 2015	This meeting occurred between HW Bedford Borough and the care.data team. In that occasion HW Bedford Borough expressed concerns about members of the public with learning disabilities to understand the need to opt-out from the programme.
Healthwatch Lambeth and King's College London	Lambeth DataNet Community Engagement Project. This project involved: a) Stakeholder Consultation and b) Deliberative Engagement	The purpose of this project was to establish and evaluate a method of promoting transparency in how patient data is being used in Lambeth to improve services. Stakeholder Consultation involved 42 people from two Patient and Public Involvement Groups. 129 people from 7 community groups took part in deliberative engagement meetings of 45-60 minutes between May and August 2015.

## Appendix II – Quotes from Healthwatch England's Focus Groups

Sub theme	Key Quote	2015 Focus Group
Consent	the problem is I probably was asked my consent, because you go to this children's centre, fill in a load of forms, you've got a screaming baby on your arm, so you just sign away	Female, Mother of small child, Southend on sea
Fear of errors	When I was in hospital after my triple A, they were doing the nurse handover as they do and one was saying, oh she's this she's this she's this, she's an ex-alcoholic. I said I beg your pardon. {laughter} How on earth that got in there I do not know. And I've also been accused of being incredibly overweight [very thin lady]. So I think the idea of sharing information is great, but it would be nice if we could check it.	Female, over 65, Surrey

Fear of others looking	You know there's confidentiality, we can check our records and whose been accessing it and stuff, but most of us don't do that, so when the receptionist asks what's wrong with me I'm like "I don't have to tell you". And then I'm just afraid because she'll probably be checking because of the way she's speaking to me. And then I don't want to go to the GP I know that my GP won't be... like I can trust him, but will I trust her?	Female, 19, Luton
Helping research	My daughter died of something called Reye syndrome and they, if they hadn't collected data on that, because its so rare they wouldn't have found the connection between that and Asprin, because now you shouldn't give Asprin to a child under 12, its virtually disappeared. If they hadn't collected that data, and that's the sort of thing that they really do need.	Female, over 65, Surrey
It won't work	I heard about this NHS England, care dot data and I thought "Absolute rubbish". "A" it won't work because they won't get a computer system through the country, "B" it will be inaccurate. and I ticked the box and made sure my GP surgery knew I was not participating in that	Female, over 65, Surrey
Joining up services	It holds up a lot of things, so like my nephew, wanted to go to nursery and they needed a letter for like special food or whatever and my sister kept going back to the dietician to send the letters over, whereas if information sharing was available than the nursery nurse could have spoken to the dietician. Herself instead of my sister having to run after these people.	Female, 22 Luton
Joining up services	Symptoms everything, but also if you're seeing someone new, you have to go right back to the beginning and explain how it interacts with other things that you might have. What you were talking about [at the beginning] about joining up hospitals so they can access peoples records throughout I think that is absolutely essential.	Female, over 65, Surrey
Joining up services	But imagine you're semi-conscious, how wonderful that they can get your GP record, which will hopefully be accurate, it would be such a weight off my mind, I mean it terrifies me if you [C] have to go in in the middle of the night and me having to remember everything you're on, I'd be feeling really upset.	Female, over 65, Surrey
Joining up services	Shared records are good, because I had a situation, I went to Center Parks for one night, in Luton, my brother had booked it, I thought I'd packed everything, accept for my[ medication] and then when I got there, once I realised I'd forgotten some vital medication and then I was thinking, oh my god, I've got to go all the way back to Ilford, a 2 hour drive and I'm only here for a night, and how dumb is that, why didn't I pack my medicine? And then I thought hang on a minute, they'll have out of hours emergency or something here, so I had a fantastic experience, it took me 2 hours to get there, back, see a GP, and have my medicine in my hand, within two hours and I had no ID with me, absolutely no ID, I didn't have my NHS number, I just had my name and my date of birth. When I got to the Luton hospital I said to them I've got no Id, but this is my name, but my details came up, the medicine, which I couldn't spell, came up and then they gave me an emergency supply. And because, that was amazing, I thought thank god they shared the system.	Female, Pakistani Community, Waltham Forest
Keep them medical	My experience of social care has been so appalling, that I wouldn't want to share it with social care	Female, over 65, Surrey

Keep them medical	My medical records are medical and, it should stay within the medical profession	Female, over 65, Surrey
Making the NHS easier to use	I don't think I mind in that the children go to a child minder twice a week and if she needed to take them to hospital and for some reason they couldn't get in contact with me, because she's not their parent, I'd want who ever saw them to have to be able to be able to access anything they needed to access, for that purpose.	Female, Mother of small child, Southend on sea
Making the NHS easier to use	Maybe I'm a bit more blasé, but I just don't care, maybe because like I say my Mum's in Scotland, I like the idea that anywhere across the country if something was to happen you can get my information, rather than to ask my other half, who would be like "I don't know she deals with all of that".	Female, Mother of small child, Southend on sea
Public confidence	A:but the impact of the backlash from it, there's a two year hold up, of things that could have benefited us, and the public need to have confidence B: That it's not going to be sold to drug companies, seen by secretaries...	Females, over 65, Surrey
Transparency	I don't think there's enough clarity about what data is shared, how it's shared, where it goes	Female, Mother of small child, Southend on sea
Transparency	Yeah I think I'd be okay with it, but I'd like to be notified before that happened and know the reason why, but yeah I'd be okay for it to be used, and my children's as well.	Female, Mother of small child, Southend on sea

## Appendix III -Local Healthwatch Reports-

- 1) Healthwatch Surrey, "*If I've told you once - People's views on record sharing between health and social care professionals involved in their care in Surrey*". November 2015.

<http://www.healthwatchesurrey.co.uk/if-ive-told-you-once>

- 2) Healthwatch Lambeth and King's College London, "Lambeth DataNet Community Engagement Project" Project Report October 2015