

## Report on Consultation on Patient Data

### Background

The Government launched a consultation to gain views from the public on plans for how the National Health Service (NHS) will use patient data to improve services and treatments. Healthwatch Wandsworth (HWW) wanted to ensure Wandsworth residents have a voice in this consultation so we identified the aspects of the consultation that would have a significant impact on them and sought the opinions of local people through our own a survey.

Our survey included questions covering issues around accessing information and communications that would enable people to understand what happens to their personal data and we focused particularly on how the NHS should protect personal data.

We wanted to measure the views and experiences of local residents in Wandsworth and their satisfaction with the Government's proposals.

The consultation was open from 27<sup>th</sup> July 2016 until 7<sup>th</sup> September 2016.

### Findings

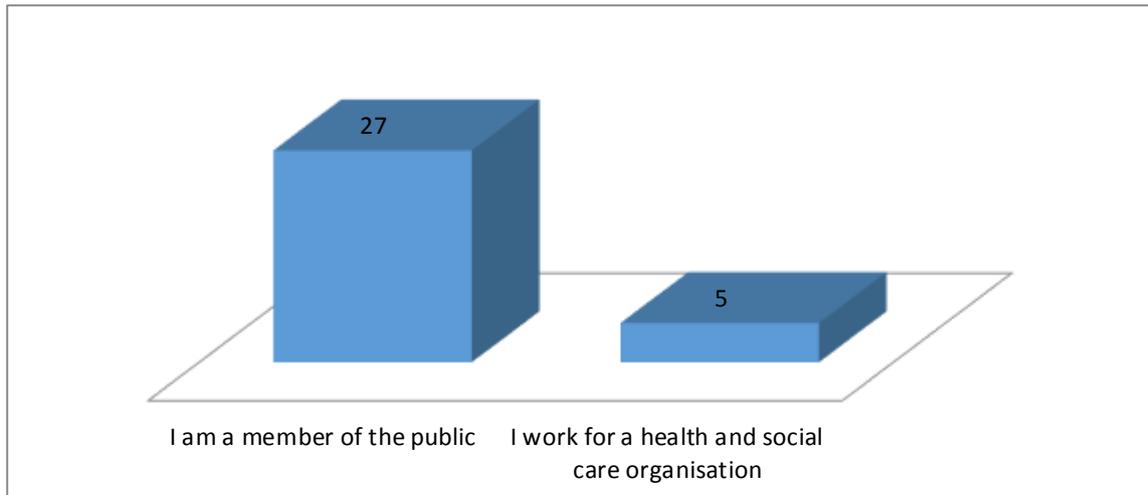
32 respondents completed the survey. A sample of the questionnaire can be found in **Appendix A**. We took the survey to outreach sessions at the following community based organizations and events; Your Way, Your Say who work alongside people with mental health issues on their journey towards independent and fulfilling lives, and Be Enriched who provide free nutritious meals and education in Wandsworth. Answers from these discussions can be found in **Appendix B**.

We also publicising via Facebook and Twitter, and on the HWW website to seek opinions from a wider audience, also focusing our poll of the week questions on the website based on the questions in this consultation to get a quick measure of opinions.

We included closed and open questions to gain a real insight in to people's thoughts and opinions and to gain a good understanding of the views of residents in Wandsworth.

Firstly, we wanted to understand a little about the point of view from which our respondent's views were coming from. This would also help us better understand the context of their answers to the survey.

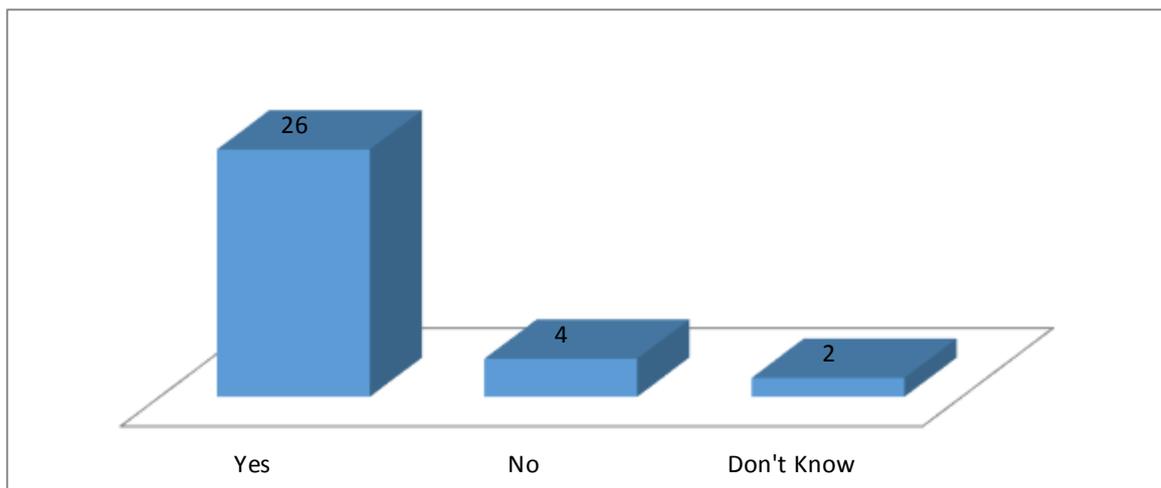
**Q1: Do you belong to a particular health or social care organisation or are you responding as a member of the public?**



Graph 1: Shows that of the 32 respondents who took part in the survey 27 of them were members of the public.

We then asked respondents how much of a priority they feel the NHS and social care providers should give to data management. This question was designed to understand perceptions on how important data management is to our respondents and their level of concern to the issues.

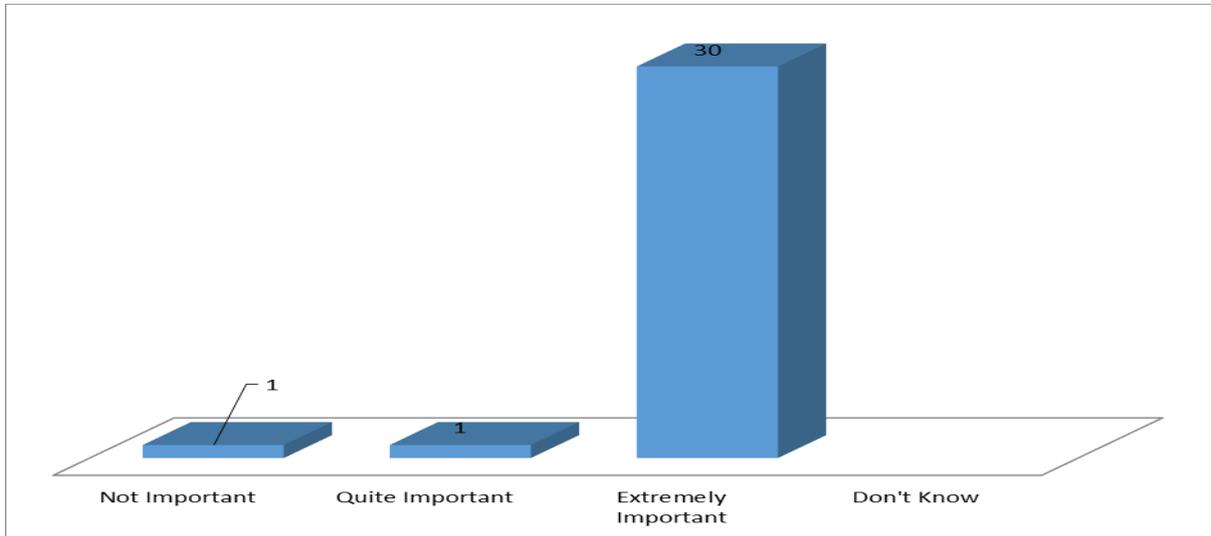
**Q2: Do you agree with the proposals that recommend that NHS and social care organisations give the same level of importance to overseeing data and information management as they do to managing their finances and making clinical decisions?**



As the graph shows a high percentage of respondents perceived that it is important that their personal data is given the same amount of protection, if not more protection, than given to financial data, and they would like to have reassurance that their data is not susceptible to data hacking.

We then wanted to understand from our respondent's how important they thought it was that those who have access to their data have been fully trained to protect the data they have access too.

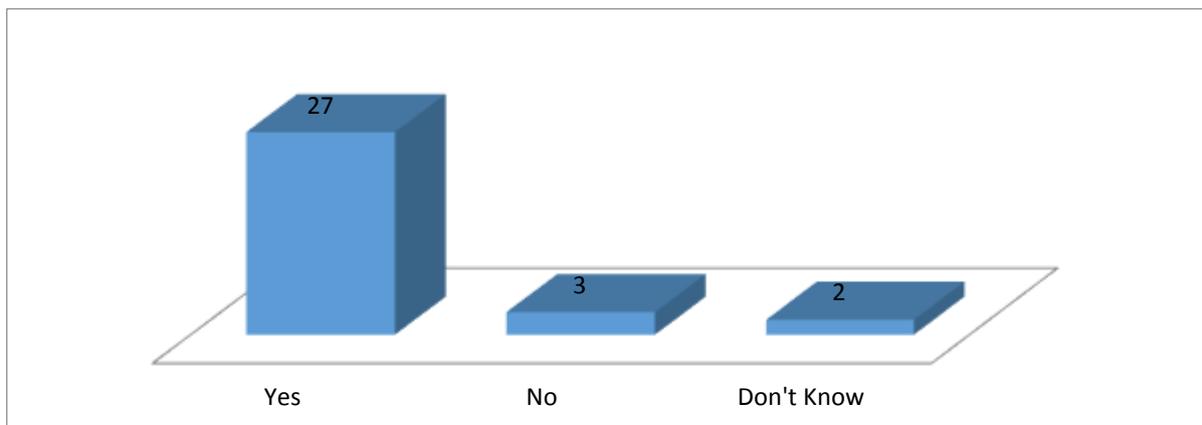
**Q3: How important do you think it is for all NHS and care staff, not just IT professionals and managers, to be fully trained in how to keep data safe and share information appropriately?**



Responses to this question suggested that the majority of respondents thought that it was extremely important that those who have access to their personal data have had the appropriate training, and are held accountable for securing the data.

We asked how residents would like to receive communications about data management. This question would also indicate how residents could be reassured about responsible management of their data.

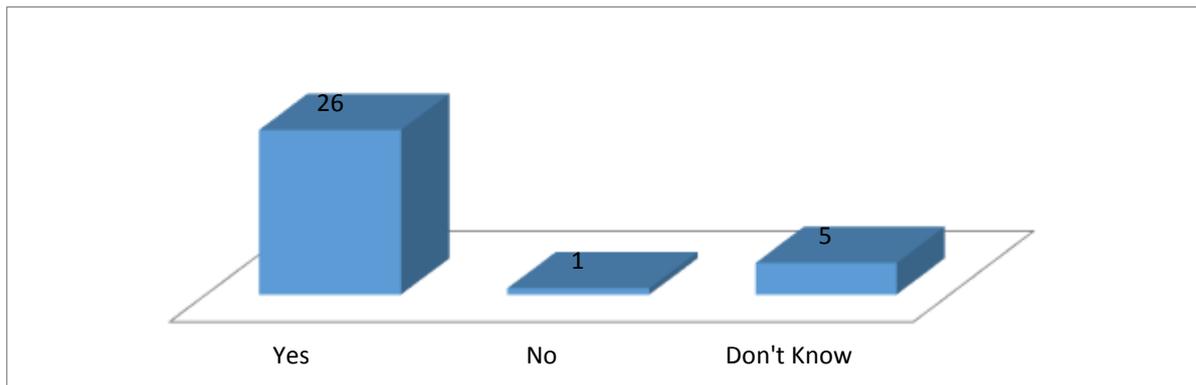
**Q4: Would you want to see more communication from the NHS, for example posters on hospital wards, to help reassure you that those responsible for your care are managing your information safely?**



As the graph shows a high percentage felt that more communication is required, there were a few respondents that expressed their concerns as this was the first time they had heard of the proposals been made.

We then wanted to understand if our respondents felt that Government sanctions to ensure good data management were necessary, and if this would reassure them.

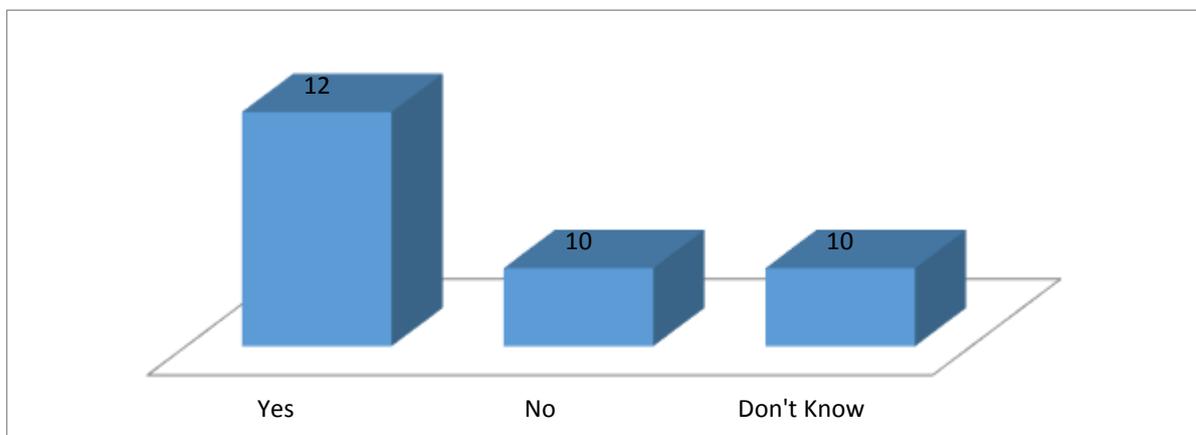
**Q5: Do you support the idea of the Government introducing stronger sanctions, including possible criminal penalties, for those who fail to adequately protect your data, or who use it inappropriately?**



As the graph shows the majority of respondent felt that there should be sanctions for those who do not adequately protect their data as this would dis-incentive improper use of data. A few respondents expressed their concerns that their data may be shared for improper usage.

To find out if residents felt they were given sufficient information to decide how their data is used, we asked them to give us as much information about their answer to gain an insight in to what was important to them.

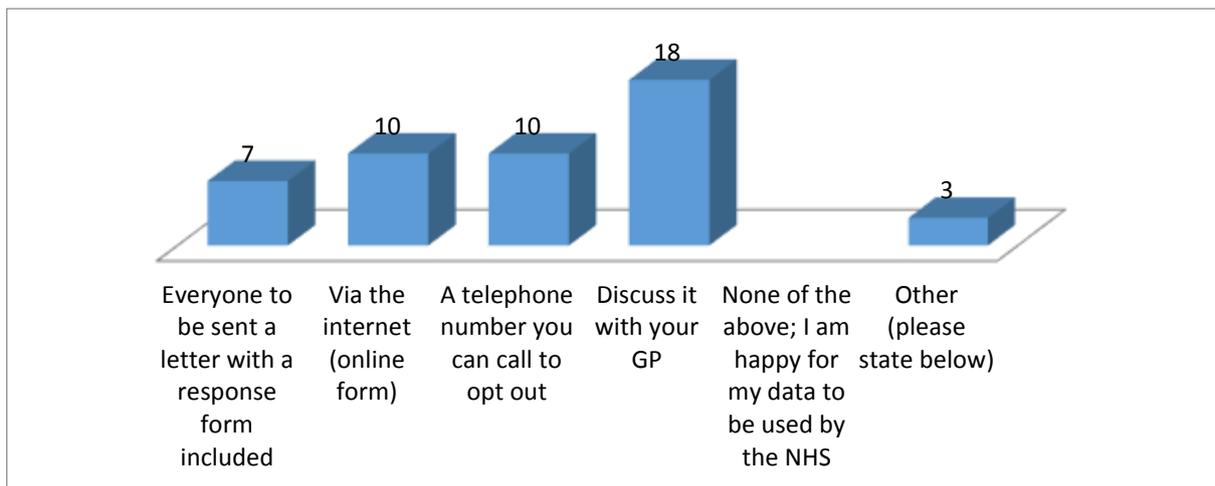
**Q6: The proposals being put forward is designed to give you control over how your personal data is used by healthcare professionals. Do you think this approach gives you sufficient choice over how your data is used?**



We found that two third of the respondents said that they did not feel that the approaches being proposed provided them with sufficient choice over how their data would be used. Concurringly, the respondents we talked too did not feel that they had any choice, this is concerning as it appears that there is a lack of knowledge in what is being proposed.

We then asked residents how they would prefer to opt-out of sharing their information. Answers would tell us how they would engage with this issue and the way they would feel able to control the management of their data. The perception was that by not giving people a suitable or accessible option to control the management of their data would mean that people would not have any control over where and how their data was shared.

**Graph 7: In order to opt-out of having your information shared, you will be required to actively make your wishes known. Which of the following would be your preferred option for doing this?**

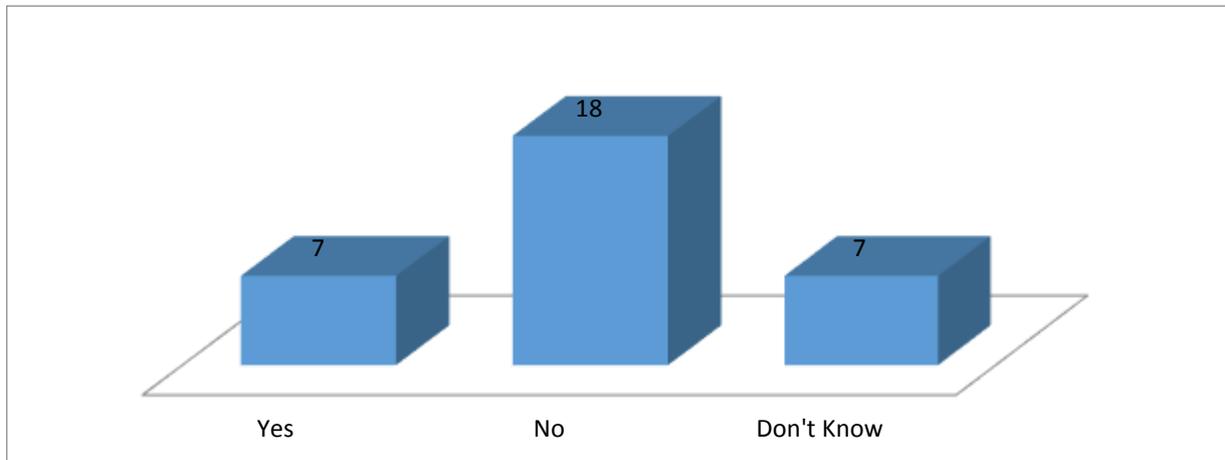


The above results illustrate a very mixed response from respondents, the majority of respondents would prefer to have the opportunity to discuss the options available and the implications directly with their General Practitioner.

A respondent also expressed that they would prefer that people were given the option to opt-in rather than opt-out, as it was felt that this was unfair.

Following on from the question above, we wanted to find out how people were likely to find out more about the issues and benefits of data sharing. Again, answers to this question would suggest which methods of communication and information provision would be accessible and appropriate for residents of Wandsworth.

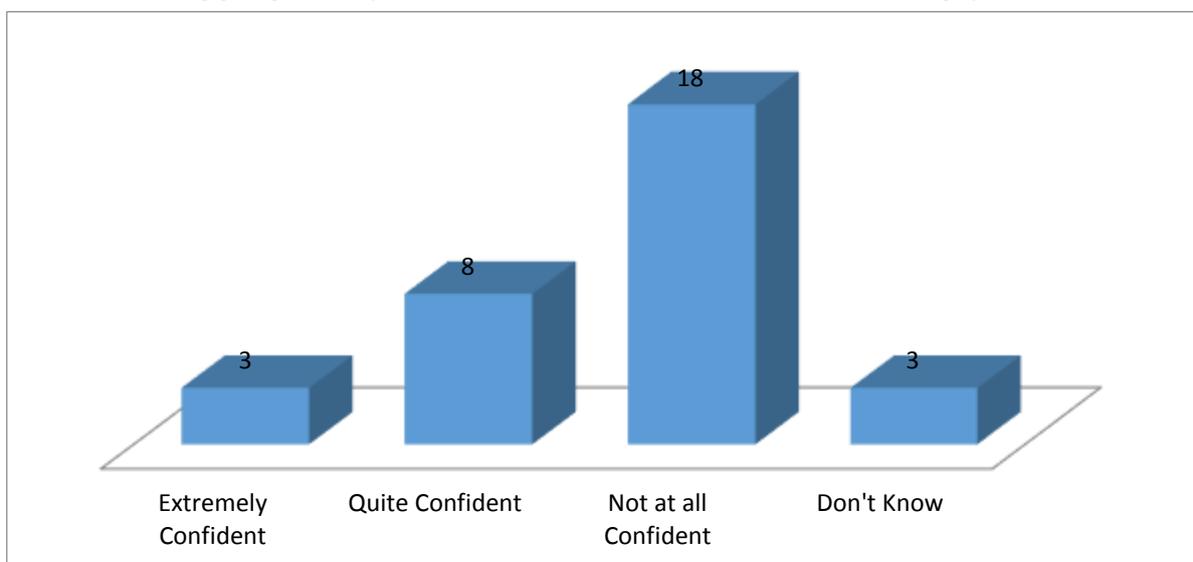
**Q8: Improved data sharing across the NHS offers significant potential for both developing new treatments and improving services. However it is up to each of us to decide how our data should be used? If you wanted to find out more about data sharing in the NHS and what the opt-out options actually mean, would you know where to go?**



The responses show that a very high proportion of the respondents did not know where to go to find more information on the implications of data sharing, or where to find further information as to feel better informed.

Finally we wanted to measure the level of confidence in the proposals and how personal data would be managed in reality. Confidence levels is likely to affect how many people will opt in once the proposals are implemented.

**Q9: Are you confident that the proposals mentioned above will ensure your data is used appropriately and that the NHS will be able to keep your data safe?**



The results to this question vary. Almost half of the respondents stated that they do not feel confident that the proposals being mentioned will ensure that their data is used appropriately or will be safe. Whilst others felt quite confident that their data would be safe. One responded stated that with the new proposals “there is scope for data being mishandled and abused for possible financial gain.”

## Conclusions

Although we found conversations around the new proposed changes to patient data difficult due to the technicality of some of the questions, which many found were not user friendly, we still have a good response, engaged in useful discussions, and had useful comments. We spoke to a range of people across a varied range of groups, and we found that people clearly feel that more can be done to inform them of the changes taking place and their rights.

One person highlighted that “your data shouldn’t be shared unless you agree to it- not that it will be unless you stop it, there is already a problem with people not needing to see their GP and NHS England now suggesting people are struck off for being healthy.”

An additional respondent commented that “any information sharing should seek consent from individual on each occasion, instead of a blanket consent which could be manipulated to allow inappropriate data sharing.” However, it was reassuring to hear from one respondent that “when I gave consent for the NHS to put my data on a computer system I understood that staff were well trained on data security, data protection, and that my data would not be sold or used by third parties.”

This consultation made it clear that there was a desire for the more information on what is being proposed and for the information to be easily accessible and delivered in different formats to help people make an informed choice. One person highlighted “I can’t read and write so some of the options are not suitable.”

We hope that the comments of Wandsworth respondents will help inform the delivery of the Governments formal Patient Data Consultation.

## Appendix A - The Questionnaire

### Patient Data Consultation

The Government is seeking views from the public on plans for how the **NHS will be able to use patient data to improve services and treatments**. In particular they are looking at how the NHS should be working to protect your data and how you can choose what your data is used for.

The following questions reflect some of the issues being tackled by the Government in the formal consultation, but we have focused on the elements of most relevance to the public.

**Do you belong to a particular health or social care organisation or are you responding as a member of the public?**

- I am a member of the public
- I work for a health and social care organisation

**The proposals recommend that NHS and social care organisations give the same level of importance to overseeing data and information management as they do to managing their finances and making clinical decisions.**

Do you agree with this approach? Yes  No  Don't Know

Please comment: \_\_\_\_\_

**How important do you think it is for all NHS and care staff, not just IT professionals and managers, to be fully trained in how to keep data safe and share information appropriately?**

Not important  Quite important  Extremely important  Don't know

Please comment: \_\_\_\_\_

**Would you want to see more communication from the NHS, for example posters on hospital wards, to help reassure you that those responsible for your care are managing your information safely?**

Yes  No  Don't Know

Please comment: \_\_\_\_\_

**Do you support the idea of the Government introducing stronger sanctions, including possible criminal penalties, for those who fail to adequately protect your data, or who use it inappropriately?**

Yes  No  Don't Know

Please comment: \_\_\_\_\_

**The proposal being put forward is designed to give you control over how your personal data is used by healthcare professionals.**

This means you will have the choice to opt out of the following:

- Your personal data being used for medical research purposes
- Your personal data being used to help the NHS improve how it runs services

The NHS will still be able to share anonymised data (information about you with all personal details removed), but strict new rules will be put in place around how this data is used and who will have access to it. For example, the proposals confirm that anonymised data will never be used for marketing or insurance purposes.

**Do you think this approach gives you sufficient choice over how your data is used?**

Yes  No  Don't Know

Please comment: \_\_\_\_\_

**In order to opt-out of having your information shared, you will be required to actively make your wishes known. Which of the following would be your preferred option for doing this?**

- Everyone to be sent a letter with a response form included
- Via the internet (online form)
- A telephone number you can call to opt out
- Discuss it with your GP
- None of the above; I am happy for my data to be used by the NHS
- Other (please state below)

Please comment: \_\_\_\_\_

**Improved data sharing across the NHS offers significant potential for both developing new treatments and improving services. However it is up to each of us to decide how our data should be used. If you wanted to find out more about data sharing in the NHS and what the opt-out options actually mean, would you know where to go?**

Yes  No  Don't Know

Please comment: \_\_\_\_\_

**Are you confident that the proposals mentioned above will ensure your data is used appropriately and that the NHS will be able to keep your data safe?**

- Extremely confident
- Quite confident
- Not at all confident
- Don't know

Please comment: \_\_\_\_\_

***Thank you for taking the time to complete this questionnaire!***

**What happens next?** We anonymise all the information and use your responses to help us formulate our formal submission to the Government's consultation.

**Sign up to our mailing list:** become a member to receive our e-bulletins, invitations to our events and to take part in local and national consultations.

Name: ----- Email Address: -----

## Appendix B

**2. The proposals recommend that NHS and social care organisations give the same level of importance to overseeing data and information management as they do to managing their finances and making clinical decisions. Do you agree with this approach?**

- Should be doing more to protect
- They are both important (financial and data management)
- Very Important
- Hopefully to avoid hacking
- Not sure about the security of personal data
- I think a charge should be made for missed appointments as it takes up valuable time.
- Even more importance to data / information.
- No harm in asking
- Attention to detail is important
- Our personal data must be protected
- They need training on confidentiality too!

**3. How important do you think it is for all NHS and care staff, not just IT professionals and managers, to be fully trained in how to keep data safe and share information appropriately?**

- All NHS staff need to know so they help you in the best way.
- This should be in training
- We all improve with good training
- I don't agree with sharing information
- This is crucial to confidence in the NHS
- Training is very important not only on the medical side but in patient communication
- It is important for our personal data for whom can access it.
- Information is widely available and easily leaked via the internet. The safer we can keep our personal data, the better.

**4. Would you want to see more communication from the NHS, for example posters on hospital wards, to help reassure you that those responsible for your care are managing your information safely?**

- Yes that would be nice so they know more and, with that hope, they help more.
- More evidence of training, especially in regards to GP usage.
- People will respond well to this and will be more receptive to attending GP and NHS appointments.
- Very important as I had never heard of it.
- Again, this would put patients at ease
- Too much print is not good! Think of the rainforest.

- I would like to see coloured lines on the flooring directing patients to the correct department as it can be very confusing to patients who are not familiar with the hospital.
- But I see the potential for data to be mishandled, have errors in it, crash, have issues due to human error, and used to make money. None of this is reassuring.
- No. When I gave consent for the NHS to put my data on a computer system I understood that staff were already well aware and trained on data security, data protection and that my data would not be sold or used by third parties.

**5. Do you support the idea of the Government introducing stronger sanctions, including possible criminal penalties, for those who fail to adequately protect your data, or who use it inappropriately?**

- Money helps and makes life less stressful.
- Perhaps being struck off.
- Depends on what the situation is
- The patient information is confidential and should not be passed on to other companies.
- Data must be kept safe.
- This would be a disincentive to improper use of data.
- But how will they know the data is being used inappropriately? Could those who misuse the data end up lobbying/paying the government to look the other way?
- It would be a good incentive for those responsible to keep personal data safe.
- Yes, but it depends on what the breach is. If information is knowingly shared or sold outside the NHS - then it should be a criminal offence. GP's (and their staff) are NHS contractors and should be treated in the same way as NHS staff.

**6. The proposal being put forward is designed to give you control over how your personal data is used by healthcare professionals. Do you think this approach gives you sufficient choice over how your data is used?**

- I wouldn't want my data used. The fewer people that know about my data, the better. I need more information on that. What are they going to do with the data?
- We should still be able to choose whether to opt out.
- Need to be stringent.
- Unsure of how this would work in practice.
- I agree that personal data is obtained but definitely not passed on for commercial benefit.
- Need further information
- I don't want my data to be given to private companies.

- It gives you no choice at all! It is what the NHS/government wants without the option of removing your data completely. This is not a choice at all! It's an **illusion** of choice.
- Any information sharing should seek consent on each occasion - not just a blanket consent which can then be manipulated to allow inappropriate data sharing. What is the definition for medical research and service improvement?

**7. In order to opt-out of having your information shared, you will be required to actively make your wishes known. Which of the following would be your preferred option for doing this?**

- I'd rather just be left alone. I don't want my data shared. I don't see why I have to contact them to not have my data shared.
- Community based / help and advice to explain the process.
- I can't read and write so some of the options are not suitable.
- As much options as possible as we all have different needs.
- Text on mobile
- There should be an opt-in, not an opt-out. This is unfair. You are not given any choice at all.
- It should be the other way around - your data isn't shared unless you agree to it - not that it will be unless you stop it! There is already a problem with people not needing to see their GP and NHS England now suggesting people are struck off for being healthy! Information sharing should seek consent first not an opt-out.

**8. Improved data sharing across the NHS offers significant potential for both developing new treatments and improving services. However it is up to each of us to decide how our data should be used. If you wanted to find out more about data sharing in the NHS and what the opt-out options actually mean, would you know where to go?**

- No one has made this clear!
- Doctors, Hospital
- Possibly GP
- I do not think it's a good idea
- There are other means of data collecting and sharing
- I think the matter should be discussed with the GP
- The NHS website. But I don't expect to be given the full information of what it all involves.
- I would Google it
- No idea - and this is part of the reason people should be asked to opt in - NOT opt out.

**9. Are you confident that the proposals mentioned above will ensure your data is used appropriately and that the NHS will be able to keep your data safe?**

- NHS is a massive organisation so it would be good to know more about how this will be implemented.
- These questions are difficult to respond to as they are not accessible or easy to respond to.
- Doesn't appear to be solid information that they are providing.
- Where is the reassurance? I'm not comfortable.
- Data has been leaked before.
- There's scope for mishandling and abuse of information for financial gain. It's all about the money.
- I think there will always be weak links and people working for the NHS who don't take patient data confidentiality seriously.
- For any public organisation to suggest an opt-out of allowing your information to be shared is wrong in principle. Very disappointed that this is the approach and gives me little confidence that information will be used in a safe and approved way by all that have access. A media storm waiting to happen.