# Public Perspectives on GP Record Data:
*Appendix*

## For Understanding Patient Data

January 2025

MRS Evidence Matters™ Company Partner

QaResearch

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# 1. Appendix

## Appendix 1: Stage 1 Survey

**Primary Care Patient Data Survey**

**This study is being conducted by Qa Research, an independent research company, on behalf of Understanding Patient Data, which is part of the NHS Confederation.**

**The purpose of this study is to understand people's understanding of and views towards the different ways patient data in general practice is collected, used and shared in the NHS.**

**It should take around 10-15 minutes to complete.**

**Please click on the NEXT button to start the study.**

**This study will be carried out according to the Market Research Society's Code of Conduct and all your answers and information you provide will be treated as anonymous and confidential in accordance with the Data Protection Act.**

**Any personal data collected in this study will be held securely and will not be shared with any third party unless you give permission. You can read more about how your Personal Data is protected here ()**

## Section 1 – About you

**To ensure we gain views from a wide range of people we would first like to ask some questions about you.**

**S1. What gender do you identify with?**
***SINGLECODE***
Female
Male
In another way (Write in)
Prefer not to say

**S2. Which of the following age groups do you belong to?**
***SINGLECODE***
Under 18 **–** ***Thank and close***
18-34
35-44
45-54
55-64
65-74
75+
Prefer not to say

**S3. Which region of England do you live in?**
***SINGLECODE***
North East
North West
Yorkshire and Humber
East Midlands
West Midlands
East of England
London
South East
South West

**S4. What is the first part of your postcode (e.g. YO16 6)?**
***OPEN***

**S5. Which of the following best describes your ethnic group or background?**
***SINGLECODE***
**Asian / Asian British**
Bangladeshi
Chinese
Indian
Pakistani
Any other Asian background, please describe
**Black / African / Caribbean / Black British**
African
Caribbean

Any other Black / African / Caribbean background, please describe
**Mixed / Multiple ethnic groups**
White and Asian
White and Black African
White and Black Caribbean
Any other Mixed / Multiple ethnic background, please describe
**Other ethnic group**
Arab
Any other ethnic group, please describe
**White**
English / Welsh / Scottish / Northern Irish / British
Gypsy or Irish Traveller
Irish
Any other White background, please describe
Prefer not to say

**S6. What is the occupation of the main income earner within your household?**

**If you share a house with others but have separate finances, do not include them at this question. Only consider those who have shared incomes / outgoings.**

**If the main income earner is retired and receiving a company pension, please indicate the last job they held before retirement**
***SINGLECODE***
1. Housewife / house husband / looking after family ***(CODE AS E)***
2. Retired and only receiving state pension, not company pension ***(CODE AS E)***
3. Student ***(CODE AS C1)***
4. Casual worker without regular income, or unemployed for six months or longer ***(CODE AS E)***
5. Manual worker (e.g. Lorry driver, Holiday camp worker, Hotel Porter) ***(CODE AS D)***
6. Skilled manual worker (e.g. Silversmith, Plumber, Electrician) ***(CODE AS C2)***
7. Junior management or professional, or administrative (e.g. Most office workers, Accounts clerk, Secretary, Police Sergeant) ***(CODE AS C1)***
8. Intermediate management in large organisation, owner of small business, principal officer in civil service / local government ***(CODE AS B)***
9. Very senior management, top-level civil servant or professional (e.g. Surgeon, Partner in a law firm, Regional bank manager, Board Director of medium/large firm' ***(CODE AS A)***
10. Unemployed for 6 months or longer ***(CODE AS E)***
11. Prefer not to say

**S7. The Equality Act 2010 defines a person as disabled if they have a physical or mental impairment, which has a substantial and long-term (i.e. has lasted or is expected to last at least 12 months) adverse effect on the person's ability to carry out normal day-to-day activities.**

**Do you have a disability?**

***SINGLECODE***
Yes
No
Prefer not to say
Don't know

**SHOWCARD: In this survey, we want to understand what you currently know about patient data collected in general practice (GP), and what you think about how this data is collected, used and shared.**

**When we refer to patient data, we mean the data that is routinely collected when someone interacts with the NHS, such as visiting the GP or hospital. This includes information about the individual, their health and lifestyle and may include information such as height and weight, medical conditions, medication history and test results such as blood tests or MRI scans.**

**In particular, this survey is about data collected by your GP surgery. As part of your normal contact with your GP surgery, data is collected about you and your health and entered into your GP record. The data from your GP record can be used for your care, as well as for other purposes in the NHS and for research.**

**In this survey, we want to understand what you currently know about the data collected by your GP surgery and what you think about how this data is collected, shared and used.**

## Section 2 – About your GP record and how it is stored

**Now we would like to ask some questions about your GP record, which contains data collected about you and your health by your GP.**

**As part of your normal contact with your GP surgery, data is collected about you and your health and entered into your GP record. The data from your GP record can be used for your care, as well as for research and other purposes in the NHS such as helping to plan and evaluate health services.**

**Q1. What information do you think is available in your GP record? Please select any that you think apply.**
***MULTICODE except 'none of the above' and 'all of the above'***
Illnesses and diagnoses
Operations
Examinations and investigations
Medicines
Allergies
Vaccinations and immunisations
Test results, x-rays and scans
Notes from appointments at the surgery

Notes about appointments in other NHS settings (e.g., hospital appointments)
Notes from a non-NHS clinical setting (e.g., private GP, non-NHS mental health counselling)
Letters from other medical staff
Lifestyle information (e.g., smoking, drinking, exercising)
Height and weight
Demographic information (e.g., your name, date of birth, ethnicity)
Contact details
Communication preferences (e.g., not English as first language, visually impaired, needs large font communications)
Accessibility requirements (e.g., wheelchair user)
All of the above
None of the above
Other (please specify) - ***OPENCODE***

**Q2. Where and how do you think your GP record is held? Please select all that you think apply.**
***MULTICODE***
Digitally, managed by the GP surgery, e.g., the GP surgery stores the data in a secure online system that can be accessed on computers in the surgery
Digitally, managed elsewhere in the NHS, e.g., a national NHS body stores the data in a country-wide NHS online system which can be accessed by GPs
Physically, in the surgery, e.g., the GP stores information in paper records at the surgery
Physically, stored elsewhere, e.g., a national NHS body stores the information in paper records elsewhere and makes it available to GPs

***IF SELECTED ANY DIGITAL OPTIONS***
**Q2a. GP records are held in secure online systems. Who do you think provides the computer systems that GPs use to manage and store patient records? Please select any that you think apply.**
***MULTICODE***
My GP surgery
The NHS, but not my GP surgery specifically
A private-sector company
Other (please specify) - ***OPENCODE***

***ASK ALL***
**Q3. Alongside the GP record, which contains data collected by your GP, do you think there is a single national healthcare record which contains all the data collected about you by the NHS?**
***SINGLECODE***
Yes, I think there is a single national healthcare record
No, I do not think there is a single national healthcare record
Don't know

**Q4. For the data collected about you by your GP, would you prefer it to be stored in:**

***SINGLECODE***
A single national healthcare record covering all of the NHS, controlled by a national body e.g., NHS England or the Government
A GP record controlled by your local GP surgery
Don't know

**Q5. Please explain your answer to the previous question.**
***OPENCODE***

## Section 3 – Seeing your own GP record

**Q6. Where do you think you can find and see your own GP record?**
***OPENCODE***
Don't know

**Q7. Have you ever seen your GP record?**
***MULTICODE except "No" and "DK"***
Yes, on the NHS App
Yes, on the NHS website
Yes, on my GP's website
Yes, by specifically requesting some or all of my records from my GP surgery
Yes, on a third party health app e.g., Patient Access, MyGP, Evergreen Life
Yes, I asked my GP surgery for the information
No
Don't know

**Q8. How important is it to you to be able to see your own GP record?**
***SINGLECODE***
Very important
Somewhat important
Not very important
Not important at all
Don't know

**Q9. Please explain your answer to the previous question.**
***OPENCODE***

## Section 4 – Uses of the data in your GP record

**Your GP record contains data about you, your health and your lifestyle. This data is collected when you interact with your GP practice, or information is shared with your GP by other NHS services like hospitals. It includes your medical information (such as allergies, medicines, and test results), information about your lifestyle (such as whether you smoke or how much you drink), and your contact details.**

***ASK ALL***

**Q10. What do you think the data held in someone's GP record could be used for? Please select any that you think apply.**

***MULTICODE except 'none of the above'***

Individual care - used for their own medical care to prevent, investigate or treat a health problem a person may have
Planning and improving health services – e.g., used to assess demand for health services in your local area to manage resources and staffing
Population health – e.g., used to understand the needs of groups of people based on things they have in common like age or ethnicity and target health services to serve these groups
Research studies you have explicitly agreed to take part in – e.g., BioBank, Our Future Health or other studies to understand health conditions better and develop new treatments
Research studies you have not explicitly agreed to take part in – e.g., used to understand health conditions better and develop new treatments
None of the above
Other (please specify) - ***OPENCODE***

## Section 5 – Using GP data for your individual care

**SHOWCARD: The information recorded in your GP record is used for your individual care to help prevent, diagnose and treat any health conditions you may have. For instance, your GP record includes information about any medications you may be taking or diagnoses you may have, which can help NHS staff provide the best care for your needs.**

**Q11. Who within your GP practice do you think currently has access to your GP record for the purpose of providing you with medical care, diagnosis or treatment?**

***SINGLECODE – table format radio buttons***

Yes, I think they currently have access to my GP record
No, I don't think they currently have access to my GP record

***LOOP – RANDOMISE ORDER***

**My named GP**
**All GPs in my surgery**
**Any GP treating me**
**Practice manager**
**Nurses in my surgery**
**Receptionist or other administrative staff in my surgery**
**Other healthcare staff in my surgery e.g., a physiotherapist, podiatrist, healthcare assistant**

**Q12. Who within your GP practice would you be comfortable with having access to your GP record for the purpose of providing you with medical care, diagnosis or treatment?**

***SINGLECODE – table format radio buttons***

Yes, I would be comfortable with them having access to my GP record
No, I would not be comfortable with them having access to my GP record

***LOOP – RANDOMISE ORDER***

**My named GP**

**Any GP in my surgery**
**Any GP treating me**
**Practice manager**
**Nurses in my surgery**
**Receptionist or other administrative staff in my surgery**
**Other healthcare staff in my surgery e.g., a physiotherapist, podiatrist, healthcare assistant**

**Q13. Who outside of the GP practice do you think currently has access to information from a person's GP record for the purpose of providing medical care, diagnosis or treatment?**
***SINGLECODE – table format radio buttons***
Yes, I think they currently have access to my GP record
No, I don't think they currently have access to my GP record
***LOOP – RANDOMISE ORDER***
**Their dentist**
**Their optician**
**Hospitals**
**Paramedics and ambulance crews**
**Their pharmacy**
**District nurses/ community nurses**
**Social care services**
**Their local authority**
**Mental health services**
**Their physiotherapist**
**Private healthcare teams e.g., private GP**
**Private companies contracted by the NHS to provide a service e.g., virtual GP appointments, surgery, diagnostic test processing**

## Section 6 – Using GP data for secondary purposes

**SHOWCARD: Data from patients' GP records can be used for more than just their personal care. It can help plan and analyse health services, tailor NHS services to different groups of people, and support health research. This can only happen in specific circumstances, and where the law allows it. For example, any use of patient data must help health and care or benefit patients. Only the minimum amount of data needed is shared. In most cases, people accessing this data won't know who you are from this data because personal details like your name and address are removed or hidden.**

***ASK ALL***
**Q14. Who do you think currently has access to your GP record for these other purposes?**
***SINGLECODE – table format radio buttons***
Yes, I think they currently have access to my GP record
No, I don't think they currently have access to my GP record
***LOOP – RANDOMISE ORDER***
**People who work in the NHS to plan and analyse health services**

**People who work on health policies and laws in the government**
**Researchers at medical research charities**
**Researchers at universities**
**Researchers in pharmaceutical companies**
**Researchers in healthtech companies e.g., companies that develop medical devices or health apps**
**Private companies contracted by the NHS to provide a service e.g., software services, virtual GP appointments, surgery, diagnostic test processing**

**Q15. Who would you be comfortable with having access to your GP record for these other purposes?**
***SINGLECODE – table format radio buttons***
Yes, I would be comfortable with them having access to my GP record
No, I would not be comfortable with them having access to my GP record
***LOOP – RANDOMISE ORDER***
**People who work in the NHS to plan and analyse health services**
**People in the government who work on health policies and laws**
**Researchers at medical research charities**
**Researchers at universities**
**Researchers in pharmaceutical companies**
**Researchers in healthtech companies e.g., companies that develop medical devices or health apps**
**Private companies contracted by the NHS to provide a service e.g., software services, virtual GP appointments, surgery, diagnostic test processing**

**Q16. Who do you think is responsible for making decisions about how data from your GP record is used or shared for purposes other than your individual care? Please select any that you think apply.**
***MULTICODE except "None of the above" and "DK"***
My named GP
Any GP in my practice
Practice manager
Receptionist or other administrative staff in my surgery
Someone else working at my GP practice
National health bodies e.g., NHS England
The Government (e.g. the Department of Health and Social Care)
None of the above
Don't know

**Q17. Who do you trust to make decisions about data from your GP record being used or shared for these other purposes? Please select any that you think apply.**
***MULTICODE except "None of the above" and "DK"***
My named GP
Any GP in my practice
Any GP treating me
Practice manager
A receptionist or other administrative staff in my surgery
A nurse
A pharmacist

Anyone working at my GP practice
A national group of GPs
National health bodies e.g., NHS England
The Government (e.g. the Department of Health and Social Care)
None of the above
Don't know

**Q18. Please explain your answer to the previous question.**
***OPENCODE***

**Q19. For what purposes are you happy for data from your GP record to be shared?**
***MULTICODE except 'None of the above' and 'All of the above'***
Individual care – e.g., using data to prevent, investigate or treat a health problem you may have
Population health – e.g., used to understand the needs of groups of people based on things they have in common like age or ethnicity and target health services to serve these groups
Planning and improving health services – e.g., used to assess demand for health services in your local area to manage resources and staffing
Research – e.g., sharing data with medical researchers and academics to understand health conditions better and develop new treatments
All of the above
None of the above
Other (please specify) - ***OPENCODE***

## Section 7 – Level of involvement in decision making

***ASK ALL***
**Q20. When it comes to information about how data from your GP record is used, shared, stored and managed, which of the following statements most applies to you.**
***SINGLECODE***
I do not want/need any more information about how my GP record data is used, shared, stored and managed
I want the option to ask for and receive more information about how my GP data has been used
I want to receive more information, without having to ask, about how my GP record data is used, shared, stored and managed

**Q21. When it comes to making decisions about how data from your GP record is used, shared, stored and managed, which of the following statements most applies to you.**
***SINGLECODE***
I trust my GP surgery to make decisions on my behalf
I trust the NHS in general to make decisions on my behalf
I trust my GP surgery and any other NHS organisation to make decisions on my behalf

I want other organisations, like charities and community groups who speak on behalf of patients, to represent me
I want to have a direct say in how my GP record data is used, shared, stored and managed

## Section 8 – Information about how your GP data is stored, used and shared

***ASK ALL***

**Q22. How far do you agree with the following statement: I would like to be able to see more information about how my GP data is stored, used and shared.**

***SINGLECODE***

Strongly disagree
Disagree
Neither agree nor disagree
Agree
Strongly agree

**Q23. Where would you go to find information about how your GP data is stored, used and shared?**

***MULTICODE***

My GP surgery
My GP website
NHS website
NHS app
Non-NHS website
Other (please specify) - ***OPENCODE***

**Q24. How much information, if any, has your GP surgery given you about:**

***LOOP – RANDOMISE ORDER***

**How my data is stored e.g., what protections are in place to make sure my data is held securely**
**How my data is used e.g., what purposes your data can and cannot be used for**
**How my data is shared e.g., which organisations can access your data and in what circumstances**
**My choices about my GP data e.g., how to opt out of sharing my GP data for purposes other than my own care, diagnosis and treatment**

***SINGLECODE***

No information
A little information
A lot of information

***ASK IF 'A LITTLE' OR 'A LOT' FOR ANY OF THE QUESTIONS AT Q24, OTHERS GO TO Q25***

**Q24a. You said that your GP surgery provided you with a little or a lot of information about *[TEXT SUB ACCORDING TO RESPONSE AT Q24]*. What information did you receive?**

***OPENCODE***

**Q24b. How did you receive that information?**
***MULTICODE***
Available in practice – posters or information
Available in practice – GP staff
Online – GP website
Email
Text message
Letter
NHS App
Other (please specify)

**Q24c. How clear was the information you received?**
***SINGLECODE***
Very clear
Quite clear
Not very clear
Not at all clear

***ASK IF 'NOT VERY' OR 'NOT AT ALL'***
**Q24d. How could the information you received be made clearer?**
***OPENCODE***
Don't know

***ASK ALL***
**Q25. What elements of how your GP record data is stored, used and shared would you like to receive more information about? Please select all that apply.**
***MULTICODE except "None of the above"***
Who can access my data
What protections are in place to help keep my data secure
Why my data is being used
Where my medical record has been accessed
How my data is used
How data use is benefiting patients and the NHS
None of the above
Something else (please specify) - ***OPENCODE***

**Q26. How would you like to receive information about your GP record data? Please select any that apply.**
***MULTICODE***
Available in practice – posters or information
Available in practice – GP staff
Online – GP website
Email
Text message
Letter
NHS App
Other (please specify) - ***OPENCODE***

**Q27. Who should this information come from? Please select any that apply.**
***MULTICODE***
My GP surgery
My local hospital or other local health service
National health body e.g., NHS England
The Government
A charity or community group that speaks on behalf of patients
Someone else (please specify)

## Section 9 – Comparing the GP record to other health records

**As a reminder, your GP record contains data about you, your health and your lifestyle. This data is collected when you interact with your GP practice, or information shared with your GP by other NHS services like hospitals. It includes your medical information (such as allergies, medicines, and medical tests), information about your lifestyle (such as whether you smoke or how much you drink), and your contact details.**

**Other health records also contain data about you, which is collected when you interact with other health services. For example, hospitals hold data about your appointments, treatments and tests.**

***ASK ALL***
**Q28. Do you feel differently about your GP record compared to other health records (e.g. hospital records, dentist records, records held by specialist clinics)?**
***SINGLECODE***
Yes
No
Don't know

**Q29. Please explain your answer to the previous question.**
***OPENCODE***

## Section 10 – Final questions and quality control

**Q30. Do you have any other comments or questions about the use or sharing of GP data?**
***OPENCODE***

**Q31. Thank you for your time answering this survey. Just to double check for quality control purposes, please write your age in the box below**
***OPENCODE***
Prefer not to say

***THANK AND CLOSE***

## Appendix 2: Stage 2 Discussion guide

# HEALT04-9520 GP Record Data Public Attitudes Research
# Understanding Patient Data
# Online Workshop Discussion Guide

**Respondent Profile:**

- Demographic mix from across England
- Group 1 – Pre-family – excl. strong negative views on data sharing
- Group 2 – Pre-family – excl. strong positive views on data sharing
- Group 3 – Family – excl. strong negative views on data sharing
- Group 4 – Family – excl. strong positive views on data sharing
- Group 5 – Post-family – excl. strong negative views on data sharing
- Group 6 – Post-family – excl. strong positive views on data sharing

## Section 1: Introduction – 5 mins

**Welcome**

- Qa - Welcome, thank you for coming
- Qa is undertaking this research on behalf of Understanding Patient Data, an independent initiative hosted by the NHS Confederation. The purpose of UPD is to make the way patient data is used visible, understandable and trustworthy, for patients, the public and health professionals.

***[SHARE SCREEN]*** **Ground rules:**

- Should last no longer than 90 minutes
- Video and audio recording - consent
- Please have your cameras on but please mute when not speaking if possible
- £40 thank you payment transferred via bank transfer this week
- Confidential – everything you say will be reported anonymously
- No right or wrong answers – just want your honest feedback
- No such thing as a silly question. The final aim of this research is to make a poster which explains this topic to the general public. Therefore, it's really useful for us to hear any "silly questions", as its very likely that if you don't understand it, others won't either, and we want to find out what people want to know.

- Please be respectful of each other's views even if you do not agree with them
- To ensure we all hear what each of you has to say, please try not to talk over each other – but feel free to make comments in response to each other's points.
- Qa follows the MRS Code of Conduct which means you have the right to withdraw from the research at any time, and don't have to answer any question if you don't want to.

**What is this online workshop about?**

This workshop is about the data held in your GP record. As part of your normal contact with your GP surgery and other NHS services, data is collected about you and your health and entered into your patient record. We want to understand what you know about this data, including how it is collected, used and shared, and what information you'd like to know more about. This isn't a test, so don't worry about saying if you don't know or aren't sure – that's the whole point! As we discuss different topics, we'll show you slides and explain any important information you need to know, which will help our discussion.

## Section 1: Introductions and warm-up discussion – 5 mins

Let's go round the room and everyone can introduce themselves.

Firstly, before we discuss the information collected by your GP surgery, I'd like to start off by asking a broad question. Remember, there are no wrong answers here, we're just interested in hearing what you think, and we will discuss this more in detail later.

**When thinking about your patient records in the NHS, what do you think about? [UNPROMPTED AT FIRST]**

- *Prompt if needed (but ideally we want people's unprompted thoughts): Do you think this is one patient record or several? Who do you think has these records? What format?*
- *Prompt if people say they don't know what they mean when we say patient record: As part of your normal contact with different health services, such as your hospital, your GP surgery, or your physiotherapist, information is collected about you and your health. We will discuss this later.*

**Off the top of your head, what, if anything, would you want to learn more about this topic?**

- *If they don't know, let them know we'll discuss this more later.*

## Section 2: Levels of knowledge about how data in GP record is stored, used, shared and managed – 15 mins

Now I'd like to understand what you already know and understand about how the data in your GP record is stored, used, shared, and managed. Again, this isn't a test, so don't worry about saying if you don't know or aren't sure.

*If any major concerns about the data in their GP record arise, reassure that this will be discussed in later section on information needs*

**SHOWCARD 1:** As part of your normal contact with your GP surgery, data is collected about you, your health and your lifestyle and entered into your GP record. A person's GP record includes personal information such as their name, date of birth, NHS number and gender; information about their lifestyle such as whether they smoke or how much they drink; notes from their GP appointments; and test results. It also includes information about their medical conditions, illnesses or allergies; any vaccinations they've had or medicines they've been prescribed; and some information shared with the GP surgery by other NHS services, such as hospitals or community services (e.g. occupational therapists or district nurses).

This data collected in a person's GP record is used to provide them with individual medical care.

**SHOWCARD 1a:** Here are some examples of what your GP record could look like on your GP surgery's system. You'll see that these example GP records contain information about the person's health, their age, date of birth, their height and weight, and their alcohol intake, amongst other details. *If needed: These GP records are mock-ups and don't show real people's details*

**Does this make sense?**

- Any questions or clarifications?

**Were you aware that GP surgeries collect and hold this data in a person's GP record?**

- Does this match up with your expectations about the data collected and held in your GP record?
- Is there any data that's collected about you or your health that you did not expect?
- *Probe on awareness & understanding of different types of data collected and held in GP record*

**Do you know how to find and see your GP record?**

- Have you ever seen your GP record?
- If so, how did you access it? (*NHS website, NHS App, requested information from GP surgery etc.)*

**SHOWCARD 2:** As mentioned, when someone interacts with their GP surgery, information is entered into a patient record. However, it is not just GPs that hold patient records.

Other health and care services also collect data about you and your health during your interactions with them. Different organisations in the NHS - such as hospitals, community services, physiotherapists or mental health services – hold their own records containing information about a person and their health and care.

These records are held separately by different NHS organisations. This means that there is no single national healthcare record containing all the information collected about you by NHS organisations in one place. Each organisation in the NHS is responsible for managing their own records.

Non-NHS health and care providers, such as private hospitals or dentists, also hold their own records containing information about a person and their health, collected when a person interacts with them. They are also responsible for managing their own records.

**Does this make sense?**

- Any questions or clarifications?

**Were you aware that different parts of the NHS hold separate patient records?**

If you have questions at this stage, that's okay. We will discuss this in a bit more detail after this next section.

Now we are going to talk a little bit about what information, if any, you have received to date about your GP records.

## Section 3: Information received to date about GP record data – 5 mins

**Have you previously received any information about the data collected and held in your GP record?**

- *Probe if required: information about what is in your GP record; how it's stored; how it's shared; how it's used, your choices over the data in your GP record e.g. information about opting out of sharing information for healthcare research and planning (National Data Opt-Out)*
- If yes, what information did you receive?
- Where did the information come from? (*probe on whether this was from within the NHS (e.g. via GP or NHS website or App) or from outside the NHS (e.g. online via a news website, social media etc.) If in their GP surgery, who did the information come from? (e.g. their GP, a nurse in their GP surgery etc.*)
- How was this information communicated to you? (*probe on method)*

- Did you ask for or seek out this information or did you receive it without asking for it?
- *If actively looked for information* - What did you want to know more about?
- Did you find it easy to understand?
- What, if anything, would have made the information more accessible or easier to understand?

## Section 4: Information needs – 10 mins

Now I'd like to discuss what, if anything, you would like to know about what information is held in your GP record and how this information is stored, used, shared or managed.

**Would you like to personally receive more information about how the data held in your GP record is stored/used/shared/managed?**

- Why/why not?

**SHOWCARD 3**: This slide shows some topics that you may feel that you want to know more about. To get an initial sense of what, if anything, you'd like to receive more information about, I'd like you to raise your hand if you want to know more about a certain topic. (*run through each topic and ask for show of hands*)

***Explore each topic…***

- Why do you [want/not want] to know more about this topic?
- Within this topic, what would you like to know more about? (*probe for details – we need to understand what they want/need to know specifically e.g. if they say 'everything' pick on specific details)*
- Is there anything else you'd want to know about the data held in your GP record that is not on this slide?
    - *Probe on:*
    - How to view your GP record
    - Safeguards in place to keep your data private and safe
    - Your choices in how your data is shared, including whether you can opt out
    - How using this data can benefit you, NHS services and other patients
    - The potential risks of sharing and using the data
    -

## Section 5: Discussion of topics of interest and answering questions – 25 mins

You said you were interested in receiving more information about (*summarise which topics or questions people wanted more information about)*. Let's discuss some of those topics (*skip to relevant showcards 4-8 depending on what topics people expressed an interest in, showing the ones people wanted to hear about).*

**SHOWCARD 4: HOW RECORDS ARE STORED** When entering information into a patient's GP record, GP staff use an online system. Historically, however, paper records were used. This means that patient records held by a person's GP surgery may be stored in a combination of physical (paper records) and digital (computer records) formats.

Your individual GP surgery manages these records. With paper records, this means that they are stored and held in your GP surgery. With digital records, your GP surgery stores your data in a secure online system that can be accessed on computers in the surgery. These digital systems are supplied by private IT companies that have been approved by NHS England, the national body overseeing the health service. GP surgeries choose which approved IT company they wish to use.

**Does this make sense?**

- Any questions or clarifications?
- *Probe on awareness & understanding of specific details*
- *Probe on the level of detail they'd want to know about if they were looking for this information – would they want to know all the details presented? More? Less? Which are the key details they would want to know about?*

**Are you aware that:**

- The digital systems GPs use to hold the information stored in the GP record are provided by private companies contracted by GP surgeries?

**SHOWCARD 5: HOW ORGANISATIONS ACCESS RECORDS FOR INDIVIDUAL CARE** Information held in your GP records can sometimes be accessed by different NHS organisations outside of your GP surgery to help provide you with medical care.

*For example, a summary of the information held in your GP records is available across the NHS (for instance, paramedics) to help treat you. This will - at a minimum - include the most important information about you such as any allergies or current medication. For most, it also includes information like long term health conditions, communication needs and relevant medical history.*

*A system called GP Connect provides access to patient records to authorised users in the NHS for individual care. For instance, a pharmacy views prescribing and medical information from a patient's GP record to support additional prescribing and other pharmacy services.*

*NHS organisations in your local area can also access some information from your GP record through a shared care record – a patient record with information that is shared across GPs, hospitals, community services and other care settings in a given area - in order to provide you with medical care. For instance, a hospital can view your medication history from a shared care record to help provide you with treatment.*

**Does this make sense?**

- Any questions or clarifications?
- *Probe on awareness & understanding of specific details*
- *Probe on the level of detail they'd want to know about if they were looking for this information – would they want to know all the details presented? More? Less? Which are the key details they would want to know about?*

**SHOWCARD 6: HOW RECORDS ARE USED FOR OTHER PURPOSES**

Data from patients' GP records can be used for more than just their individual medical care. This can only happen in specific circumstances, and where the law allows it. Any use of patient data must be for the benefit of patients. In most cases, de-identified data is used - meaning most identifying details about patients have been removed or disguised. Identifiable data can only be used for specific purposes, and only when it is not possible to get the same result using de-identified data. For example, your local health service may look at patterns in data to identify groups of people with similar risk factors for disease, in order to provide additional services to help them. For instance, local health analysts may use data from GP records to understand how many people are at risk of heart disease and decide how to improve or create services like social prescribing schemes to fit their needs. To do this, they need to be able to re-identify people in order to contact them and offer them the services (for instance, healthy eating advice).

Data from the GP record can be used to help:

- Plan and analyse health services, for example using data to assess demand for health services in your local area, improving how resources and staffing are managed

- Understand population health, for example using data to understand the needs of groups of people based on things they have in common like age or ethnicity and target health services to serve these groups
- Conduct health research, for example using data to better understand health conditions and develop new treatments

For example:

- *Information from the GP record is used to help deliver vaccination programmes as the data can help identify groups of people (e.g. numbers of people over age 50 in Bedfordshire) who would be eligible for the Covid-19 vaccine in a given area at a given time.*

**Does this make sense?**

- Any questions or clarifications?
- *Probe on awareness & understanding of specific details*
- *Probe on the level of detail they'd want to know about if they were looking for this information – would they want to know all the details presented? More? Less? Which are the key details they would want to know about?*

**SHOWCARD 7: HOW ORGANISATIONS ACCESS RECORDS FOR RESEARCH OR PLANNING**

Organisations outside your GP surgery can sometimes access data from your GP record for planning, population health or research. Remember, in most cases, this data has been de-identified. (*if not already explained – This means that most identifying details about patients have been removed or disguised – and identifiable data can only be used for specific purposes, and only when it is not possible to get the same result using de-identified data)*.

For example:

- *Cancer Research UK, a medical research charity, applies for de-identified data from GP records of patients in England diagnosed with cancer to do research to understand the disease better*
- *CVDPREVENT audit: Analysts at NHS England and the Office for Health Improvement and Disparities, a national health body, access de-identified data from GP records of people with cardiovascular disease or risk factors for cardiovascular disease to understand how cardiovascular services in primary care are performing at a national, local and practice level and identify ways to improve treatment. The programme is funded by the NHS and data is automatically extracted from GP records.*

Some organisations, such as UK BioBank and CPRD, also collect and hold de-identified information from GP records in databases that researchers can apply to access for health research.

People can also volunteer to share information from their GP record for clinical research studies, such as Our Future Health.

**Does this make sense?**

- Any questions or clarifications?
- *Probe on the level of detail they'd want to know about if they were looking for this information – would they want to know all the details presented? More? Less? Which are the key details they would want to know about?*

**Were you aware that these organisations have access to the data from your GP record for certain purposes beyond your personal medical care?**

- Does this match up with your expectations about who has access to the data from your GP record?
- Anything unexpected about who has access or why they have access? Why/why not?
- Do you think these organisations have access to your full GP record or parts of your GP record?
- Do you think that any of the data that they may access is personally identifiable (i.e. you could be identified from the data they use)? If so, for what purposes?

**SHOWCARD 8: WHO MAKES DECISIONS ABOUT GP RECORDS** There are over 6000 GP surgeries across England. All GP surgeries are private businesses which provide services to the NHS, rather than individual GPs being directly employed by the NHS. Each GP surgery is its own legal entity, which means that, under the law, each GP surgery is responsible for records about the care they provide. The GP surgery is responsible for managing records, storing them in a secure way, and making decisions about how the information is used and shared.

**Does this make sense?**

- Any questions or clarifications?
- *Probe on the level of detail they'd want to know about if they were looking for this information – would they want to know all the details presented? More? Less? Which are the key details they would want to know about?*

**Were you aware that individual GP surgeries are responsible for the data they collect and hold in the GP record?**

- Did you expect this to be the case? Why/why not?
- Would you like to be made aware of this?
- Does it matter to you that individual GP surgeries control the information they collect?

**Do you 'feel' differently about your GP records compared to other patient records in the NHS?:**

- Do they feel more sensitive, or personal?
- How health records are used and shared?
- Who has access to these health records?
- Who should be responsible for how the data in these health records is used and shared?
- Why/why not?

## Section 6: Communication preferences – 25 mins

Now we're going to talk about how you'd like to be communicated with about your GP record.

**How, if at all, do you typically find out information about how the NHS works?**

- *Prompt if needed: For example, who runs health and care services (e.g. hospitals) in your local area, which NHS services provide specialist treatment, or how NHS services use new technologies to help provide treatment*
- Does this come from within the NHS (e.g. via GP or NHS website), or from outside the NHS (e.g. online via a news website or a charity)?
- *Probe on source of information e.g. NHS App, NHS website, GP surgery website, non-NHS website, social media etc.*
- Do you tend to actively seek out this information, or do you tend to receive this information without asking or searching for it?
- *If actively looked for information* - What did you want to know more about?

**Where would you go to find out more information about how the data held in your GP record is used, stored, shared, and managed? [UNPROMPTED]**

- Why?
- *After asking unprompted, prompt:* Would this be within the NHS (e.g. via GP or NHS website), or from outside the NHS (e.g. online via a news website or a charity)?

- *Probe on source of information e.g. NHS App, NHS website, GP surgery website, non-NHS website, social media etc.*
- Why?

**Would you prefer to:**

- **Automatically receive information (by text, email or letter for example) about the data held in your GP record,**
- **Have the option to request this information only if you're interested (from your GP surgery for example),**
- **Or search for this information online only if you're interested?**
- Why do you prefer this option?
- *If first option* – If you received information about your GP record without asking, would you read it or not? Why?
- *If second or third option* – Can you think of any situations that might prompt you to want more information about how your GP data is used, shared, stored or managed?
- *If second or third option* - Would you like to be told how you can find out more information? If so, what's the best way to tell you?
- *If they don't want to know information about their GP record* – Would you want to know any other information about how your data is used/shared/stored/managed in the NHS, aside from your GP record? If so, what? How would you like this information to be made available to you?

**SHOWCARD 9: What information about how the data held in your GP record is used, stored, shared or managed should be directly communicated to you without you having to ask (by text, email or letter for example)? And what information should be available to you if you want to find out more (by searching for it online or requesting it from your GP surgery for example)?**

- **ACTIVITY**: *ask participants to sort the key topics into the two categories on showcard and explore why*
- *If first option* - How often should this information be sent out? *Probe on practicalities of this*

**SHOWCARD 10: Who would you like to receive information from about how the data held in your GP record is used, stored, shared, or managed?**

- Who do you trust to provide you with reliable and accurate information? Why?

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- Is there anyone who you wouldn't like to receive information from? Why? *Probe extensively on the 'why' for these questions*
- Who should provide you with information if you want to find out more? Does this differ?

**SHOWCARD 11: In which format would you prefer to receive information?**

- Why is this your preferred method of communication? *Prompt on both how it's **disseminated** and the **format** of the information itself e.g. plain text, video, images*
- If you received information this way, how would you interact with it? *Probe extensively for each preferred method as we want to know what they'd <u>really do</u> if they received information this way – e.g. would they:*
    - *Take the time to engage with all the information provided in detail?*
    - *Engage with the information provided and look for more information?*
    - *Scan through some of the information provided?*
    - *Not engage with the information provided?*
- Why would you take this action?
- In which format should information be if you wanted to find out more? *Prompt if needed e.g. further information available on NHS or GP website, information available from GP on request etc.*

**From what we've discussed today, is there anything about how GP records are used, shared, stored, or managed that you or others may struggle to understand?**

- Any difficult or unfamiliar words, terms or jargon?
- Any difficult topics or concepts?
- What could be changed to make it easier to understand?

## Section 6: Final comments and thanks

**Do you have any final questions or comments about the data held in your GP record or about what you'd like to know about it?**

Thank you for your contributions to our discussion today. Your incentive will be paid shortly.

As you should already be aware, we are running a second round of workshops in w/c 25th November. The workshop will build on this session as we're planning to work with you to develop a resource poster that will explain key aspects of the GP record to members of the general public. As with today's session, these workshops

will start at 18:15pm, will last 90 minutes and you'll receive an incentive as a thank you for taking part. We're running fewer workshops so not everyone will be able to participate. We'll get in touch with those who we'd like to take part in the next round of workshops shortly so please keep an eye out for a phone call from one of my colleagues at Qa.

**CLOSE GROUP**

*Moderator: Please make a note of anyone who is likely to contribute well in the co-development workshops*

## Appendix 3: Stage 2 Stimulus

GP Record Data Stimulus Slides
Understanding Patient Data

November 2024

QaResearch

### Ground rules

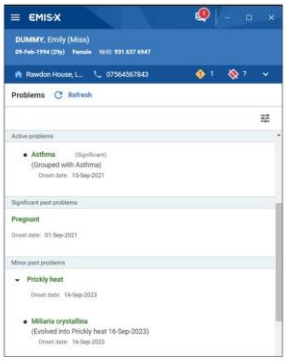
- No longer than 90 minutes
- Video and audio recording
- Cameras on but please mute when not speaking
- £40 thank you payment
- Confidential
- No right or wrong answers
- No such thing as a silly question
- Respect each other's views
- Try not to talk over each other
- MRS Code of Conduct

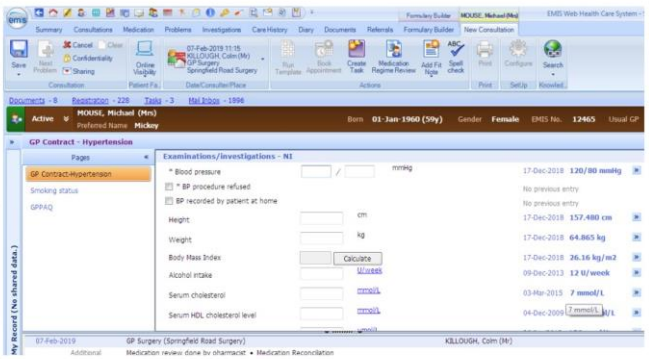
### 1. What information is stored on your GP record?

- **Personal:** name, DOB, NHS number, gender
- **Lifestyle**: smoking, drinking, exercise
- **History:** notes from your GP appointments, results from tests arranged by your GP surgery
- **Conditions:** conditions and illnesses that you've been diagnosed with, allergies
- **Medications & vaccinations:** vaccinations you've had, medicines that your GP has prescribed
- **Correspondence:** letters that hospitals or specialists in other care settings have sent to your GP
- **Your other records:** information about you held by other healthcare services that hasn't been shared with your GP

## 1a. What information is stored on your GP record?

Here are some examples of what your GP record could look like:



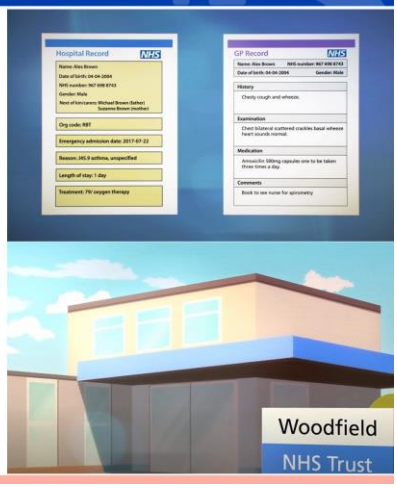




## 2. What other records are there?

It is not just GPs that hold patient records. Other health and care services also collect data about you and your health during your interactions with them.

Different organisations in the NHS - such as hospitals, community services, physiotherapists or mental health services – hold their own records containing information about a person and their health and care.

Non-NHS health and care providers, such as private hospitals or dentists, also hold their own records containing information about a person and their health, collected when a person interacts with them.

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## 3. Would you like to receive more information on…?

How GP records are **stored**

Who can **access** GP records for individual medical care

How GP record data can be used for **research and service improvement**

Who can **access** GP record data for research and service improvement

Who is **responsible** for GP records

Something else?

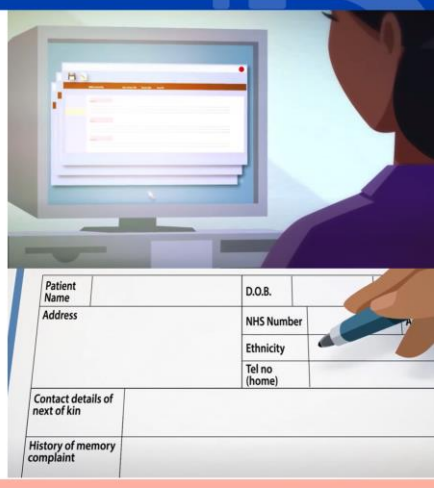
## 4. How are GP records stored?

**Digital records**

- GP records are mainly stored in secure online systems, accessible at the GP surgery
- These digital systems are supplied by private IT companies that have been approved by NHS England, the national body overseeing the health service. GP surgeries choose which approved company they wish to use

**Paper records**

- Historically, paper records were used, and some information may still be held in paper records stored in your GP surgery




## 5. Who has access to your GP record for individual medical care?

Information held in your GP records can sometimes be accessed by different NHS organisations outside of your GP surgery to help provide you with medical care.

*For example, a summary of information from your GP records is available across the NHS (for instance, paramedics) to help treat you. At a minimum, this contains the most important information about you such as any allergies or current medication.*

*A system called GP Connect provides access to patient records to authorised users in the NHS for individual care. For instance, a pharmacy views prescribing and medical information from a patient's GP record to support additional prescribing and other pharmacy services.*

## 6. How can information from GP records be used for other purposes?

Data from the GP record can be used for purposes beyond personal medical care:

- Planning and analysing health services
- Understanding population health needs
- Research

In most cases, de-identified data is used - meaning most identifying details about patients have been removed or disguised – and identifiable data can only be used for specific purposes, and only when it is not possible to get the same result using de-identified data.

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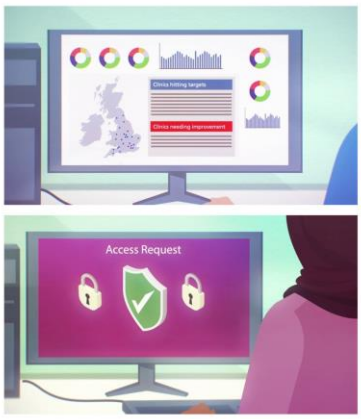
## 7. Who has access to information from your GP record from outside your GP surgery?

Organisations outside your GP surgery can sometimes access data from your GP record for planning, population health or research. Remember, in most cases, this data has been de-identified.

For example:

- *Cancer Research UK, a medical research charity applies for de-identified data from GP records of patients in England diagnosed with cancer to do research to understand the disease better*
- *Analysts at NHS England, a national health body, access de-identified data from GP records of people with cardiovascular disease to understand how cardiovascular services in primary care are performing and improve treatment.*



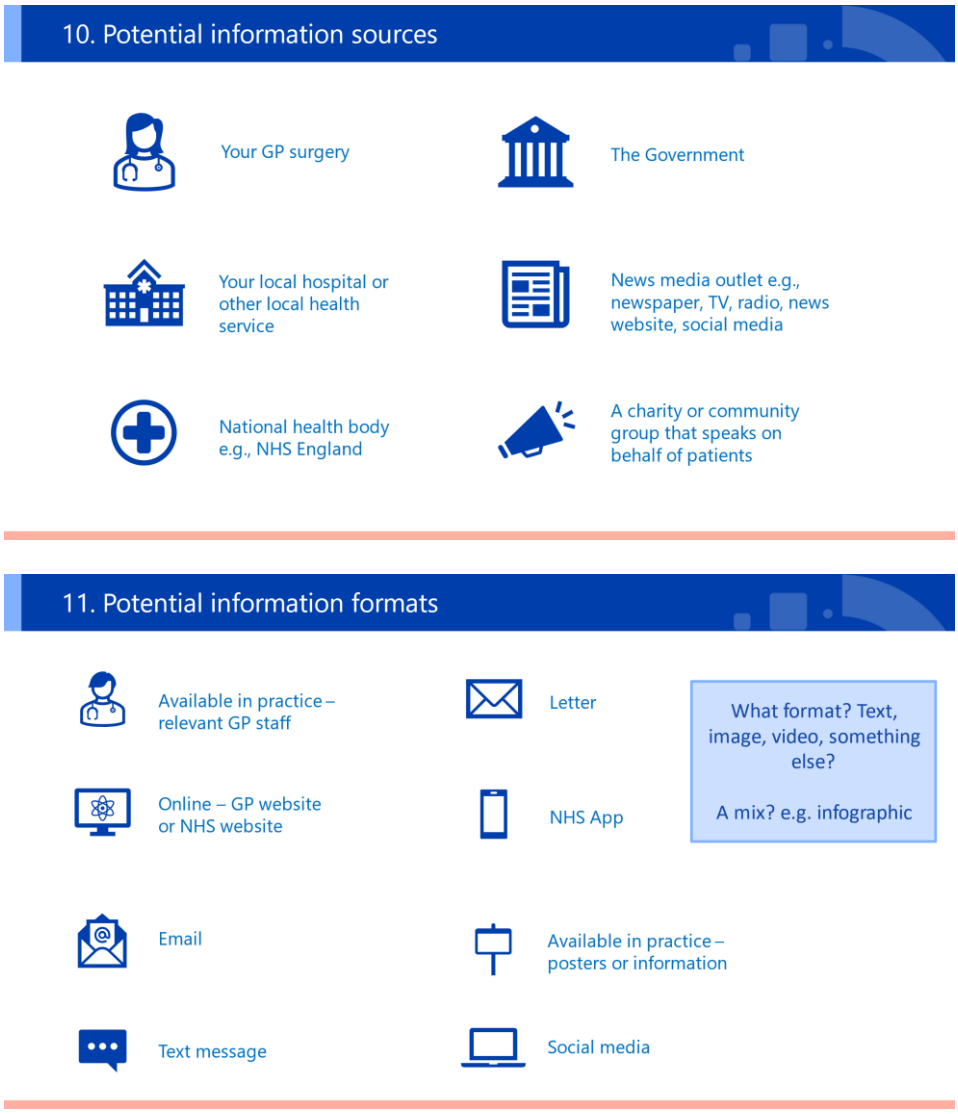



## 8. Who makes decisions about GP records?

- There are over 6000 GP surgeries across England, and each one is **its own legal entity.**
- Under the law, **each GP surgery** is responsible for records about the care they provide
- The GP surgery is responsible for managing records, storing them in a secure way, and making decisions about how the information is used and shared

## 9. Would you like to receive information about...?

| Provided to you without needing to ask | Available to you if you want to find out more |
|---|---|
| The **content** of your GP record | Who can **access** your GP record |
| **Risks** of using your data | **Safeguards** in place to keep your data private and safe |
| The **storage** of your GP record | **How to view** your GP record |
| Who is **responsible** for your data | **Benefits** of using your data |
| **Your choices** in how your data is shared | |

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## Appendix 4: Stage 3 Discussion guide

# HEALT04-9520 GP Record Data Public Attitudes Research
# Understanding Patient Data
# Online Workshop Discussion Guide

**Respondent Profile:**

- Demographic mix from across England
- Group 1 – Pre-family
- Group 2 – Family
- Group 3 – Post-family

## Section 1: Introduction – 5 mins

**Welcome**

- Qa - Welcome, thank you for coming
- Qa is undertaking this research on behalf of Understanding Patient Data, an independent initiative hosted by the NHS Confederation. The purpose of UPD is to make the way patient data is used visible, understandable and trustworthy, for patients, the public and health professionals.

**Ground rules:**

- Should last no longer than 90 minutes
- Video and audio recording - consent
- Please have your cameras on but please mute when not speaking if possible
- £50 thank you payment transferred via bank transfer this week
- Confidential – everything you say will be reported anonymously
- No right or wrong answers – just want your honest feedback
- As with the first workshop, there's no such thing as a silly question. It's really useful for us to hear any "silly questions", as its very likely that if you don't understand it, others won't either, and we want to find out what people want to know.
- Please be respectful of each other's views even if you do not agree with them
- To ensure we all hear what each of you has to say, please try not to talk over each other – but feel free to make comments in response to each other's points.

- Qa follows the MRS Code of Conduct which means you have the right to withdraw from the research at any time, and don't have to answer any question if you don't want to.

**What is this online workshop about?**

The purpose of this workshop is to co-develop a poster which aims to explain key facts about the GP record to the general public. As a reminder, your GP record contains data about you, your health and your lifestyle collected as part of your normal contact with your GP surgery.

This workshop builds on the findings from the last set of workshops which you participated in, where we asked you questions about what you know about your GP records and what you would like to know about the information held in GP records. Today we want to work with you to develop a poster that is clear, easy-to-understand, engaging, and covers the key facts you'd like to know about the information held in the GP record and how it's shared and used. We want to hear your suggestions, whether that's identifying what would make the poster effective, or letting us know what the poster should not include.

## Section 1: Introductions and reflections on previous workshop – 10 mins

You may recognise some people from the last workshop, but there will also be some unfamiliar faces so let's go round the room and everyone can introduce themselves.

Firstly, before we get your thoughts on the draft poster, I'd like to start off reflecting on the last workshop, in which we discussed what you knew about the data held in your GP record, including how it is collected, used and shared, and what information you'd like to know more about.

Following our discussions in the previous workshops, we found that people mainly wanted to know more information about:

- The types of information collected and held in the GP record
- How to find and see their GP record,
- What the data collected and held in the GP record is used for,
- Who has access to data from the GP record and what data they have access to,
- The protections in place to keep data held in the GP record safe and secure,
- Their choices around opting-out of this data being used for purposes beyond your individual medical care.

*If needed: this is a broad summary of sentiments across multiple workshops, therefore there may be things that you wanted to know about that I haven't mentioned which we can discuss later*

**Does this broadly cover what you'd like to know more information about?**

- Is there anything else you want to know about the data held in your GP record? Why?
    - *Prompt:*
    - How GP records are stored

- How using data from the GP record can benefit you, NHS services and other patients
- The potential risks of sharing and using data from the GP record
- Who is responsible for GP records

**After the last workshop, did any questions arise that you wanted to know the answer to? If so, what?**

- *Moderator: use facilitator information sheet to answer any questions*

**Since the last workshop, have you looked for any information about your GP record?**

- If yes, what did you want to know more about?
- Were you able to find the information you needed?
- Where did you look for information? *Probe on whether this was from within NHS (e.g. NHS website, NHS App, GP surgery) or outside NHS (e.g. online via news website)*
- How was the information communicated to you? *Probe on format (e.g. simple text, video etc.)*
- Did you find it easy to understand?
- What, if anything, would have made the information more accessible or easier to understand?

**Section 2: Thoughts on example posters – 20 mins**

Before we discuss your thoughts about designing a poster explaining the GP record, I'd like to hear your thoughts on some different posters that have been created to explain similar topics to the general public. We want to understand what works well and what doesn't work well about these posters, so we can develop our poster to make sure it is clear, easy-to-understand, and impactful.

The posters I'm about to show you are not about the information that is held in the GP record. Therefore, **you do not need to focus on the content of these posters**. Instead, I would like your thoughts on how the information is presented and whether this is effective. I'll ask you for your feedback on different aspects, such as the language, layout and visual style used.

***Show each poster and ask the questions below for each*** *(tailor the questions to each poster and probe on what makes them effective/ineffective as we want to understand what makes an impactful poster):*

1. [SHARE SCREEN – Resource 1 - Why Patient Data Matters Infographic.pdf] Firstly, I'd like to show this poster which has been designed to support conversations about patient data with Black and South Asian communities. I'll give you a minute to read this and then we'll discuss your thoughts. Remember, we'll be discussing how the information is presented, rather than your thoughts on the information itself.
2. [SHARE SCREEN – Resource 2- HDR-UK-How-Health-Data-is-Used-for-Mental-Health.pdf] Now, I'd like to show this poster which aims to explain how health data is used for mental health research. I'll give you a minute to read this and then we'll discuss your thoughts.
3. [SHARE SCREEN – Resource 3 - Kings_fund_nhs_funding_flow_april_2020.pdf] Finally, I'd like to show this infographic which aims to explain how funding flows in the NHS. I'll give you a minute to read this and then we'll discuss your thoughts.

**What are your initial thoughts?**

- Does anything stand out?
- What parts work well? Why?
- What parts don't work well? Why?
- What do you think it's trying to tell you? Does it communicate this information effectively? Why/why not?

**What do you think about the layout and format?**

- Is it clear? Does it make sense? Why/why not?
- Is it easy or difficult to follow?

**What do you think about the visual style?**

- Do you think the images are effective or not? Do they complement the text? Why/why not?
- What do you think about the colours?

**Is the text easy to read?**

- What do you think about the text size and colour?
- What do you think of the length of the text? Is there too much, not enough or just the right amount?

**What do you think about the use of examples?**

- *Probe on specific examples*
- What makes them effective or not?

**Are there any words, phrases or sentences that are difficult to understand?**

- Any jargon or terminology that is difficult to understand?
- What makes it difficult to understand?

[SHOWCARD 1 - Stimulus V1.pptx] **Now we've discussed all the different posters, I'd like to compare them.**
**I'd like you to imagine that these posters were on display in your GP surgery. Which poster would you be drawn to? Why?**

**Which poster is the most effective and why?**

- *Prompt on:*
    - Structure and layout
    - Visual style
    - Ease of understanding

## Section 3: Structure preferences – 15 mins

Now we've looked at some different examples, I'd like to begin to discuss how we should develop a poster to explain the key facts about the data held in the GP record to the general public.
In our session today, we want to develop the poster with you. We want to make sure the poster is clear, easy-to-understand and engaging. Therefore, we want to hear your ideas on how to design an effective poster that shows people what they want to know about the data held in the GP record.
Firstly, I'd like to explore your ideas for how the poster should be structured before we get into more detailed discussion.

**Thinking back to the last workshop, and to the example posters we have just discussed, do you have any ideas on how to present information about data held the GP record in a poster format?**

- Why would this make an effective poster?

I'd now like to show you two ideas for structuring the poster. As you'll see, each idea gives you a broad overview of what the structure of each poster would look like. I'll explain the idea for each structure, let you read them, and then we'll discuss your thoughts. We are going to discuss the layout, therefore **you do not need to focus on the wording used here**. It's important to remember that these are just ideas

intended to help our discussion. If you think a different structure, or a combination of both these structures, would be more effective, then we'd like to hear your ideas. [SHARE SCREEN – UPD Infographic Print Structure 1.pdf] As you can see, this poster would use a question-and-answer structure. The poster would provide answers to key questions which people want to know about the information held in their GP record and how it is used and share.
[SHARE SCREEN – UPD Infographic Print Structure 2.pdf] This poster would be structured around an example person and would follow their information on a journey from being collected in their GP record to being used and shared.

**Which structure would make the most effective poster?**

- Why?
- *Prompt:*
    - Which structure is clearer and easier to understand?
    - Which structure is easiest to follow?
    - Which structure is most engaging/feels more relevant to you?
    - If you saw these two posters, which one would be more likely to spark your interest and want to look at it more carefully?
- Would a different structure (beyond these two ideas) be more effective? *If yes: explore in detail what this would look like*

**Thinking back to what you wanted to know about the data held in the GP record, which structure do you think would explain this information best?**

- Why?

**For your preferred structure, is there anything you'd change to improve it?**

- *If it could be improved:* How would you change it?
    - *Probe on: order of sections, page layout, flow between sections*

## Section 4: Content preferences – 20 mins

Now I'd like to focus on the content of the poster. To help our discussion, I'll show you a draft poster which aims to explain key facts about the information held in the GP record. This poster is a mock-up based on the question-and-answer structure we've just discussed.
[*if preferred Structure 2* – I know you said you preferred the data journey structure *[or if group preferred something else altogether, repeat what they said they wanted it to look like]* and we'll take your feedback onboard, but we're now focussing on the content of the poster, rather than the overall structure] This mocked-up poster is not the final version. It's intended to give you an idea of what the poster *could* look

like, so you have a point of reference when we talk about what the final poster should and should not include.
[SHARE SCREEN – UPD Infographic Digital Scheme A.jpg] I'll give you a few minutes to read the poster and then we'll discuss your thoughts.
**Firstly, do you have any questions or concerns about the information held in GP records after reading this poster?**

- Could the poster be changed to address these questions/concerns? If so, how?

**Thinking back to our discussions in the last workshop, does the poster tell you what you need to know about the information held in your GP record?**

- Why/why not?
- Is there anything that is missing that you would expect to see?
- What do you think about the level of detail? Is there too much detail, not enough detail, or the right amount? *If too much or not enough: we'll discuss how it could be changed shortly*

**Thinking back to our discussions in the last workshop, what's the MOST important topic for the poster to cover when explaining about the information held in your GP record? [UNPROMPTED AT FIRST]**

- Why?
- *Prompt if needed:* In the last set of workshops, people told us that these were the topics they wanted to know about:
    - The types of information collected and held in the GP record
    - How to find and see the GP record
    - What the data collected and held in the GP record is used for
    - Who has access to data from the GP record and what data they have access to
    - The protections in place to keep data held in the GP record safe and secure
    - Their choices around opting-out of this data being used for purposes beyond your individual medical care

**Is there anything else that you'd like to know about that should be included in this poster? [UNPROMPTED AT FIRST]**

- Why?

- *Prompt:* Some of the topics that you might want to know more about include:
    - The potential risks of sharing and using data from the GP record
    - How using data from the GP record can benefit you, NHS services and other patients
    - How GP records are stored
    - Who is responsible for GP records
    - Anything else that you learnt in the workshop that you think is important to include?
- What details do you think would need to be added to the poster to explain this?
    - *Probe for specifics about what they'd like to know*

**Are there any topics that are currently included in the poster that do not need to be covered?**

- *Probe on each section of the poster*
- If you had to remove a section from the poster, which section would you remove and why?
- Why is this information less important to cover?

**For the topics that aren't important for the poster to cover, would you still want information to be made available if you wanted to find out more?**

- If so, which topics should this include? *Probe based on answers to previous questions*
- If so, how should this information be made available? *Probe on method (e.g. website, social media post etc.), source (GP surgery, NHS England etc.) and format (e.g. simple text, video etc.)*

Now I'd like to discuss each section of the poster in more detail to explore how it could be developed to make sure it is clear, easy-to-understand, and tells you what you want to know about data held in the GP record.

***Go through each section and discuss in detail:***

- After reading this section, do you understand [*what a GP record is / how you can view your GP record / what the data in the GP record can be used for etc.*]?
    - Is there a better way to explain it? If so, what would you change?

- Is this the right level of detail? Does this need more or less detail or is it about right?

- Would you want any examples? If so, what would the example/s need to include?
    - For Section 5 "How can data from a person's GP record be used for purposes beyond their medical care?" Do these examples make sense? Why/why not?
    - Is the Cancer Research UK example helpful or not? Would a different example work better? (*For example: Researchers from a pharmaceutical company apply to access de-identified data to research and develop more effective medication)(For example: Analysts at NHS England and the Office for Health Improvement and Disparities access de-identified data from GP records of people with cardiovascular disease or risk factors for cardiovascular disease to understand how cardiovascular services are performing)*

- What information, if any, should be cut out and why?
    - *Pick words and sentences and explore whether they could be cut out*
    - If we cut these details out, does the explanation still make sense?

**Now we've discussed each section of the poster: Which sections, if any, should have more detail? And which sections, if any, should have less detail?**

- Why do you say this?

## Section 5: Language – 10 mins

I'd now like to discuss your thoughts on the language that should be used to explain key facts about the data held in the GP record. We want to make sure the poster is clear and easy to understand. Therefore, the poster needs to use language that makes sense.

**Firstly, on the mocked-up poster, are there any words, phrases or sentences that are difficult to understand? [UNPROMPTED]**

- How would you change it to make it easier to understand?
    - Would you want to replace it with a different word or sentence, or would you want the word or sentence to be explained or given an example?
    - *Probe for details on what people would need in order to understand it*

Now I'd like to hear your feedback on some specific language choices to ensure that the poster makes sense.

**In the header for each section, the poster refers to "a person's GP record" (e.g. Who has access to data from a person's GP record?). This could be changed to "your GP record" (e.g. Who has access to data from your GP record?).**

- Which option do you prefer? Why?
- Should the poster use impersonal (e.g. the GP record) or personal (e.g. my or your GP record) language throughout? Why?

**The poster refers to "the data from a person's GP record" throughout (e.g. Who has access to the data from a person's GP record?).**
**This could be changed to "the information from a person's GP record" (e.g. Who has access to the information from a person's GP record?) or it could be changed to "GP record data" (e.g. Who has access to GP record data?)**

- Which option do you prefer? Why?
- Does the use of the word 'data' or 'information' matter to you? Do they mean different things or conjure up different ideas?

**The poster refers to "individual medical care" (e.g. It can also be used for more than just individual medical care).**

**This could be changed to "individual care" (e.g. It can also be used for more than just individual care) or it could be changed to "medical care and treatment" (e.g. It can also be used for more than just medical care and treatment)**

- Which option do you prefer? Why?
- Anything else?

**What do you understand the term "patient records" to mean?**

- Would this term need to be explained on the poster?

**What do you understand the term "de-identified data" to mean?**

- Do you think de-identified data could be used to identify someone or not?
- Would this term need to be explained on the poster?
    - Does the explanation used on the poster make sense? ("…meaning personal details that could identify you – such as your name or date of birth – have been removed or disguised.")
    - Is there anything else you'd want to know about de-identified data?

## Section 5: Presentation and visual style – 10 mins

Now we've discussed the content and language, I'd like to know what you think about how the poster should be presented. We want to make sure the poster is clear, easy-to-understand and engaging. Therefore, if you think something doesn't work well or could be changed to make it more effective, we'd like to know what you would do to improve it.

[SHARE SCREEN – UDP_Infographic_Digital_Scheme_B.jpg] **Here is another version of the poster with the imagery changed and some of the information removed in sections 5, 7 and 8. Which version of the poster do you prefer?**

- Which imagery do you prefer and why?
- From the poster you prefer less, would you use any of the images? If so, which images and why?
- Do you prefer the version with more or less detail? Why?
    - *Probe on sections 5, 7 & 8:*
    - Does the explanation still make sense with some of the information removed?
    - Would you need more information? If so, what would you need?

[SHARE SCREEN – UPD_Infographic_Digital_Scheme_C.jpg] **Here is another version of the poster with the colour scheme changed. Which colour scheme do you prefer?**

- Would you prefer a different colour scheme to the versions I've shown you? If so, what colour scheme would you prefer and why?

**For the poster you prefer, what, if anything, would you change about the visual style?**

- *If it could be improved:* How would you change it? Why would this change make it more effective?
- *Probe for details on images, icons, colour scheme, amount of text*
- [SHOWCARD 1 – Stimulus_V1.pptx] Thinking back to the different examples we looked at, would you use any of the imagery, or the style of images, from these posters? Why?

**What do you think about the title?**

- Does it make sense? Does it summarise the contents of the poster? Why/why not?
- Does it draw your attention to the poster? Why/why not?
- *If it could be improved:* How would you change it? Why would this change make it more effective?
    - *Probe for details on wording, text size, text colour, tone*

**Is the text easy to read?**

- What do you think about the text size and colour?
- What do you think of the length of the text overall? Is there too much, not enough or just the right amount?
- *If it could be improved:* How would you change it? Why would this change make it more effective?
    - *Probe for details on text size, text colour, spacing, text length*

## Section 6: Summary – 5 mins

Now we've discussed your feedback on the poster in detail, I'd like to end our session by understanding what you, as a group, think the final version of the poster should look like.

**Thinking about everything we've discussed, such as structure, content, language and visual style, if you were designing the final version of the poster:**

- What does the poster definitely need to include? Why?
    - *Check for consensus across the group, we want to understand strength and breadth of sentiment to inform the design process*

- Is there anything the poster definitely does not need to include? Why?
    - *Check for consensus across the group, we want to understand strength and breadth of sentiment to inform the design process*

- What's your one key suggestion for how the poster should be presented (i.e. visual style and layout)?

## Section 7: Final comments and thanks

**Do you have any final questions or comments about the data held in your GP record or about what you'd like to know about it?**

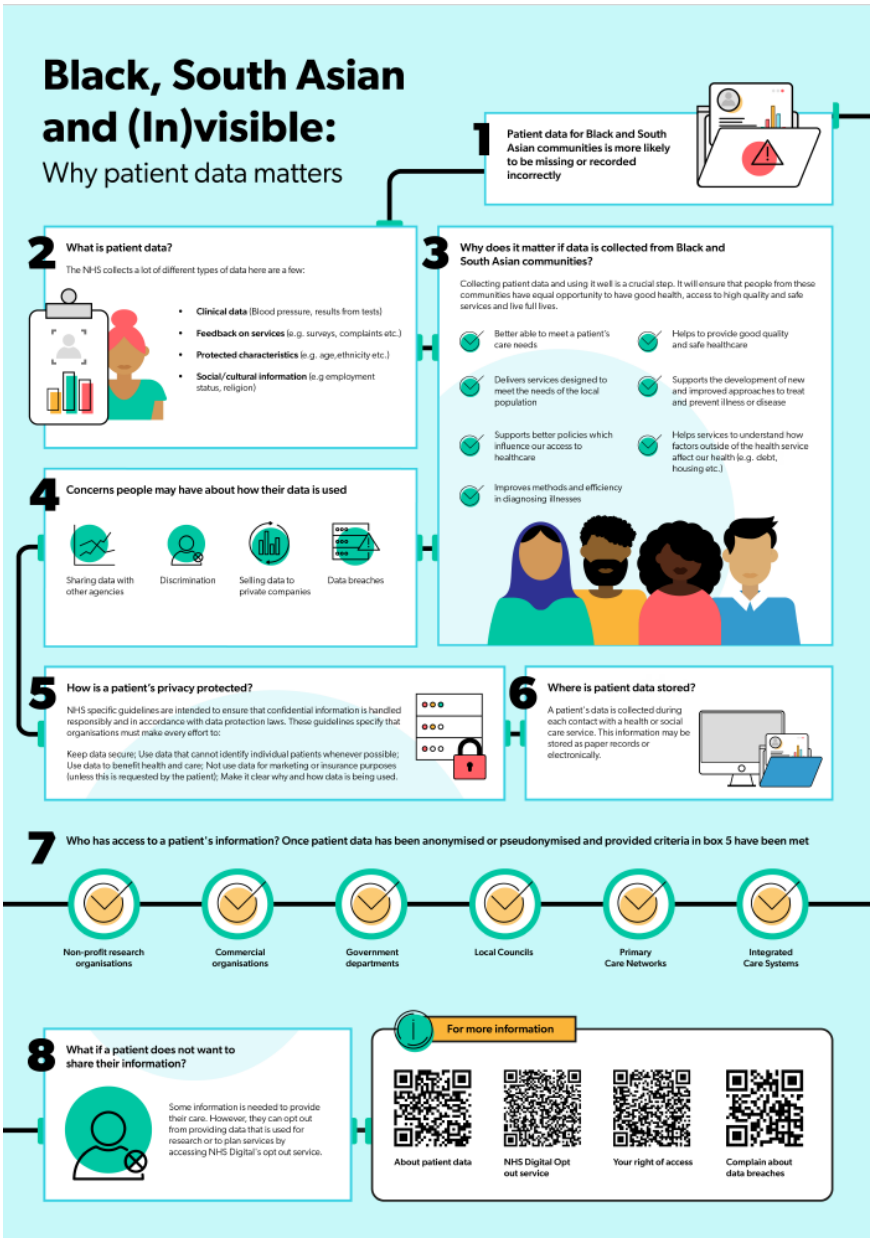
Thank you for your contributions to our discussion today. Your incentive will be paid shortly.

We will use your feedback from these sessions to produce the final version of the poster, which will be made publicly available on Understanding Patient Data's website.

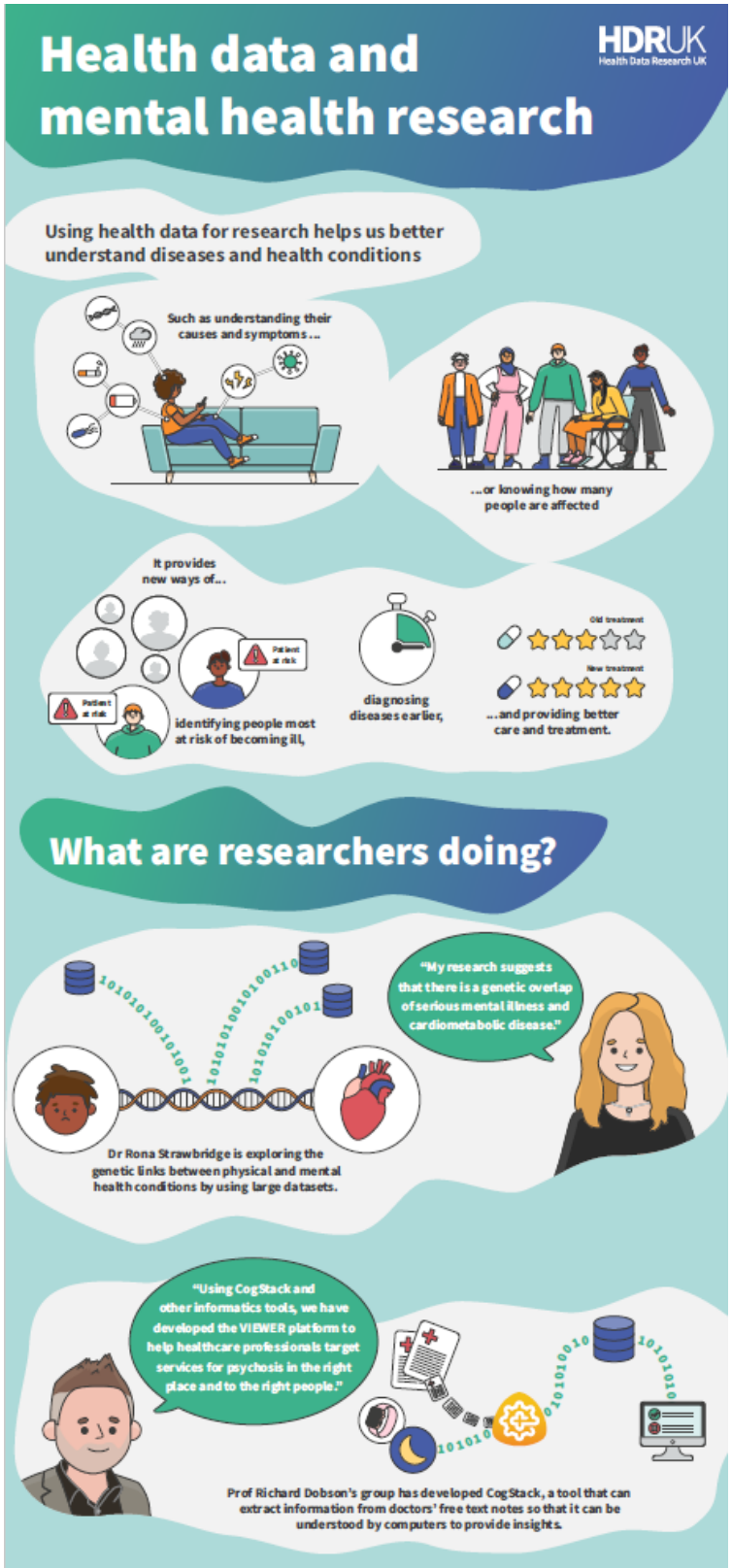
**CLOSE GROUP**

## Appendix 5: Stage 3 Stimulus

Resource Example 1:

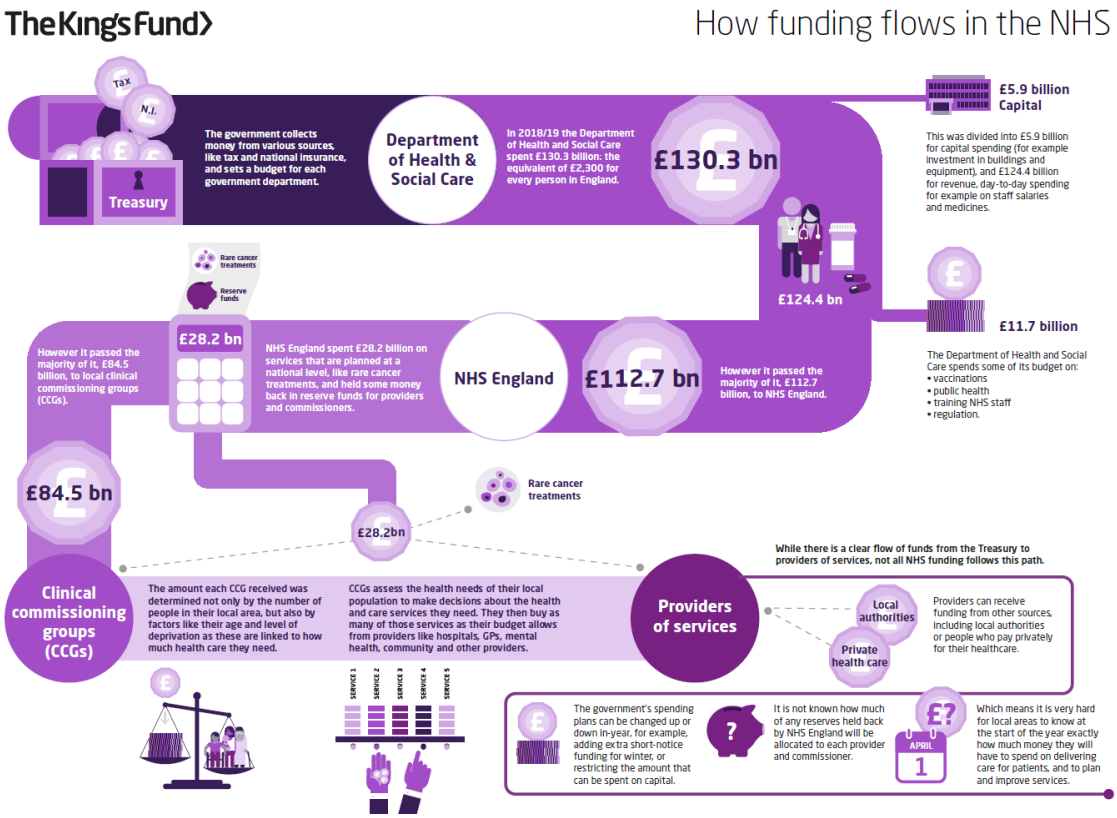


Resource Example 2:



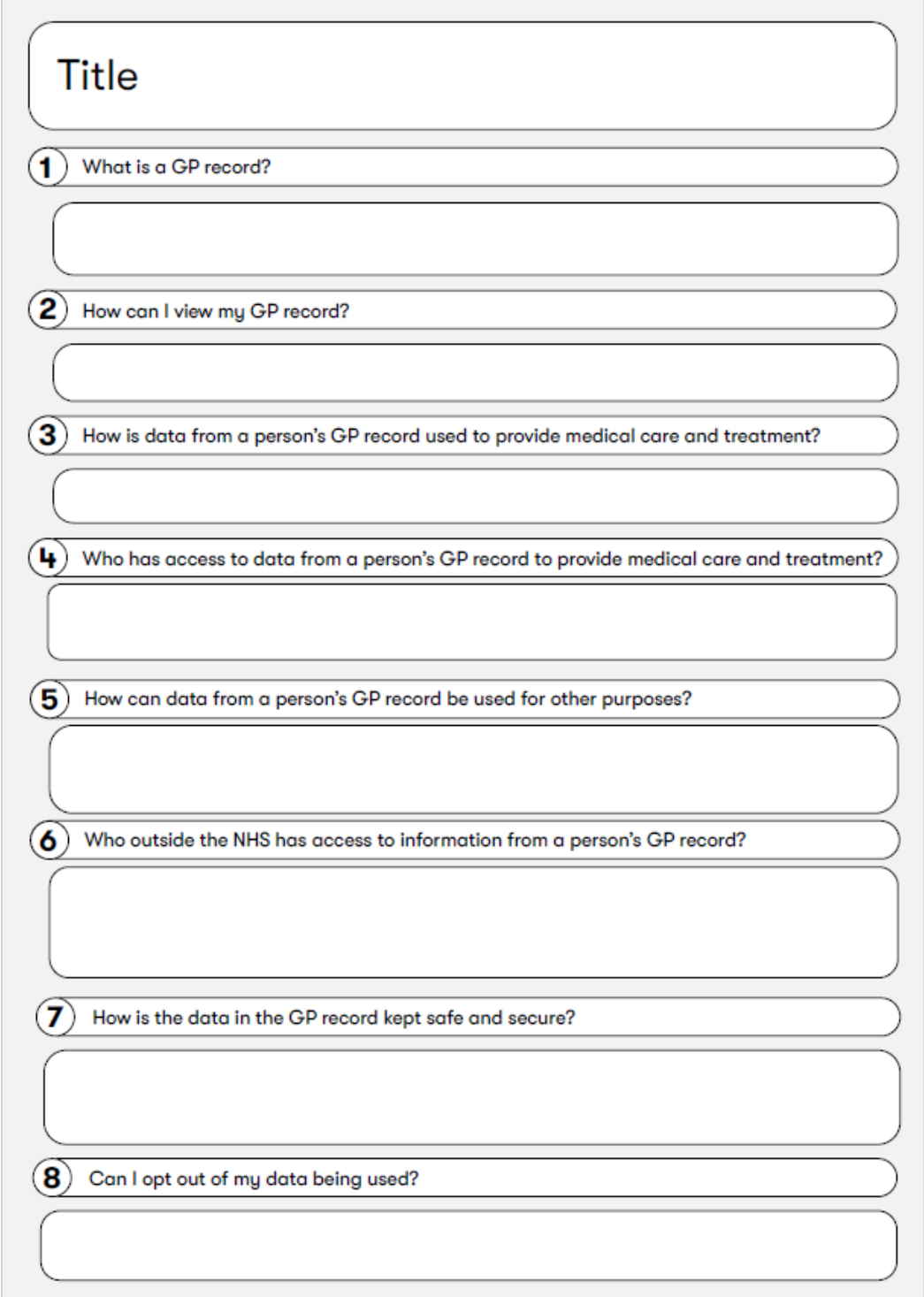

https://qaresearch.sharepoint.com/sites/QaData_S-ProjectFiles/Shared Documents/ProjectFiles/U/Understanding_Patient_Data/HEALT04-9520_GP_Data_Public_Attitudes_Research/Reports/GP_Data_Report_Appendix_V1_clean.docx

Resource Example 3:

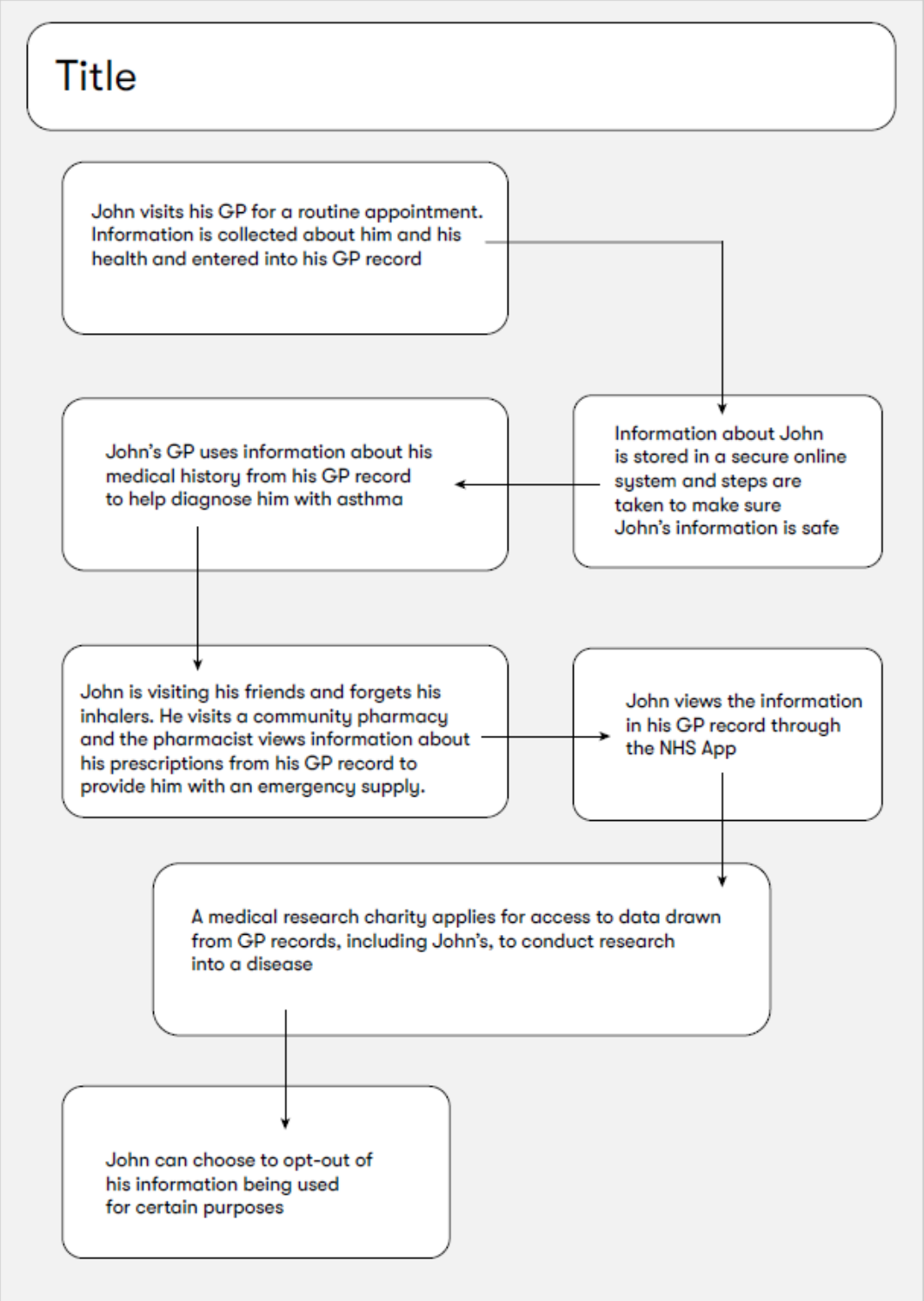



https://qaresearch.sharepoint.com/sites/QaData_S-ProjectFiles/Shared Documents/ProjectFiles/U/Understanding_Patient_Data/HEALT04-9520_GP_Data_Public_Attitudes_Research/Reports/GP_Data_Report_Appendix_V1_clean.docx

Structure Idea 1:

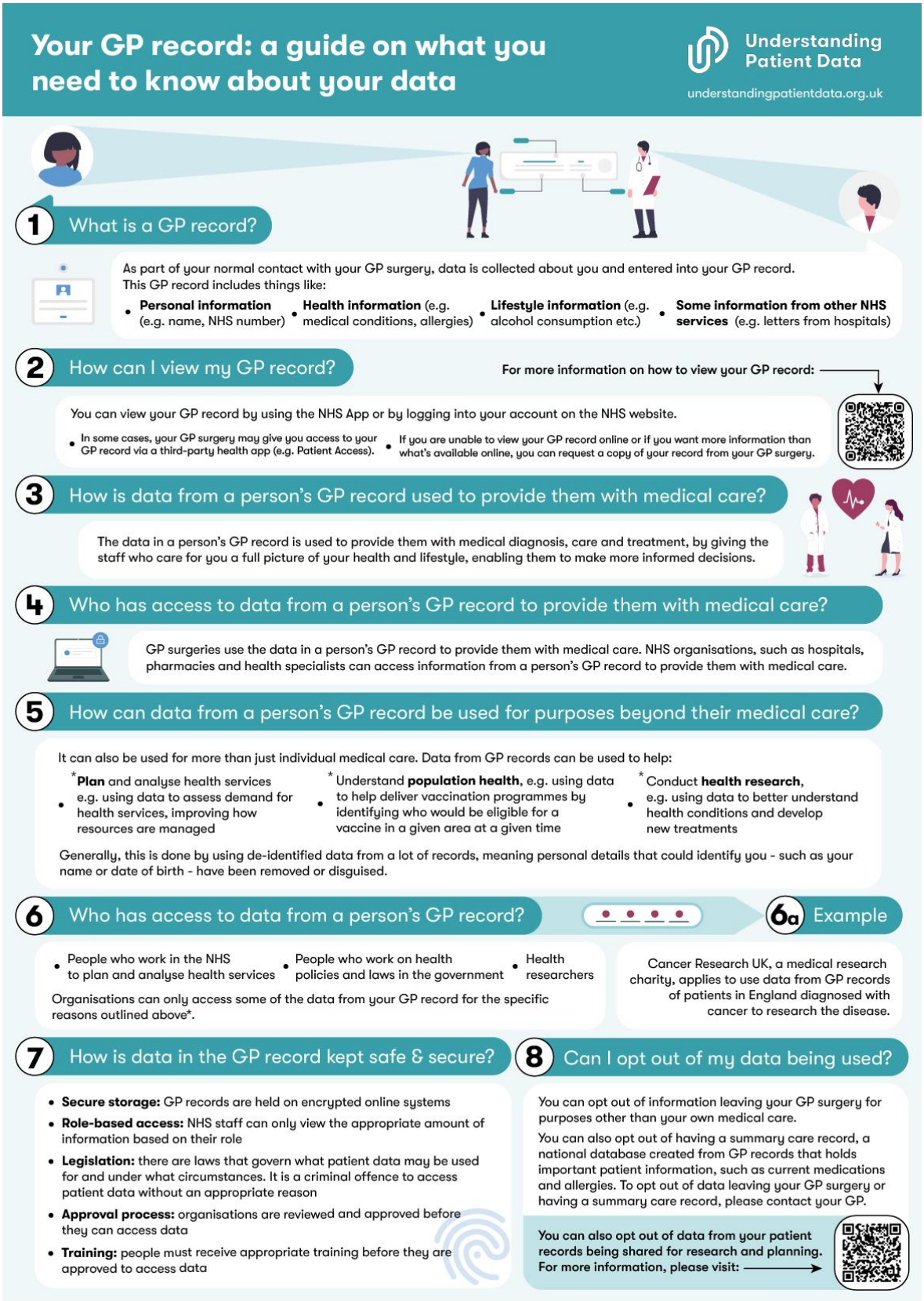


Structure Idea 2:



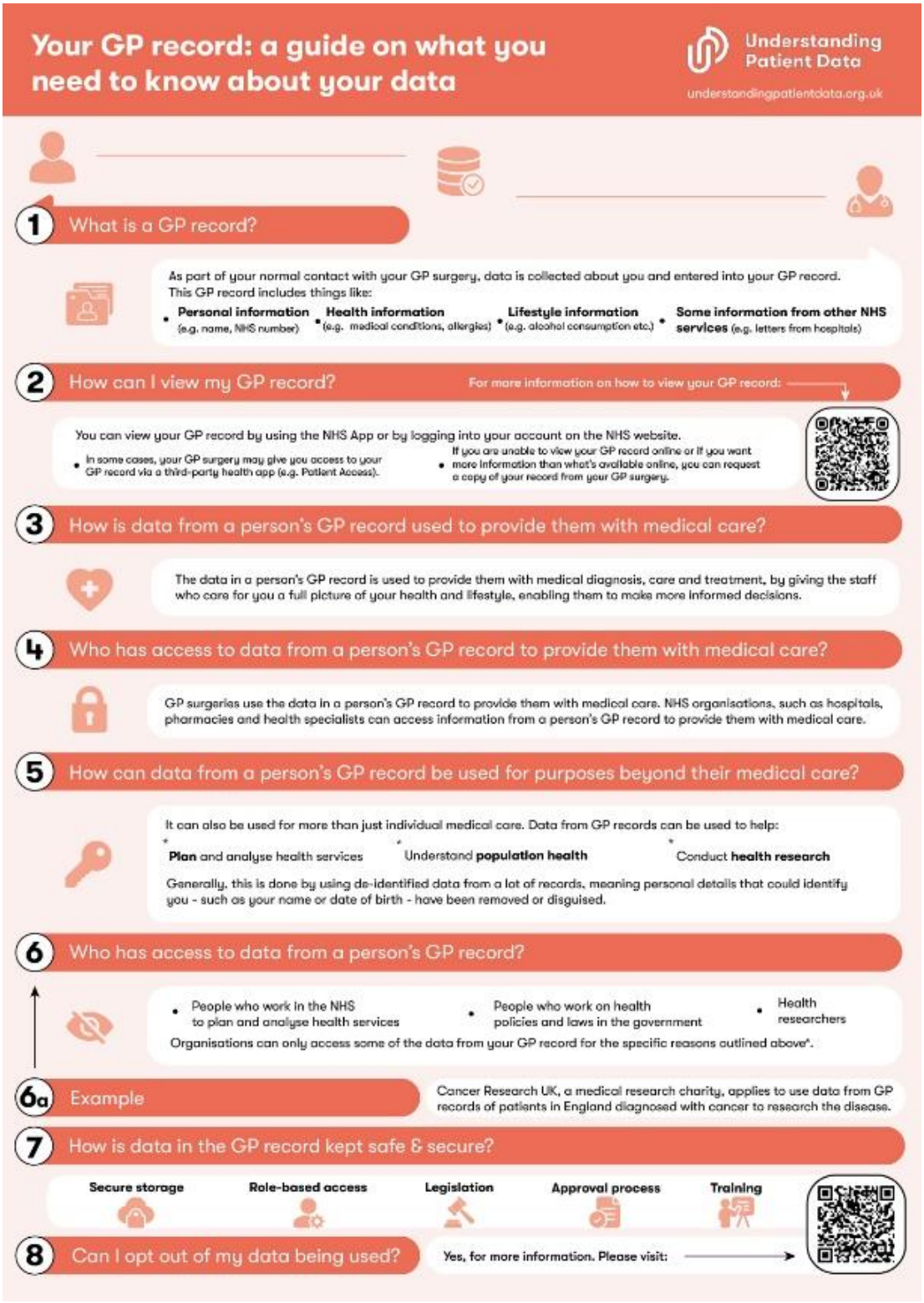

https://qaresearch.sharepoint.com/sites/QaData_S-ProjectFiles/Shared Documents/ProjectFiles/U/Understanding_Patient_Data/HEALT04-9520_GP_Data_Public_Attitudes_Research/Reports/GP_Data_Report_Appendix_V1_clean.docx

Draft Resource – Version A:



## Draft Resource – Version B:

Draft Resource – Version C:




https://qaresearch.sharepoint.com/sites/QaData_S-ProjectFiles/Shared Documents/ProjectFiles/U/Understanding_Patient_Data/HEALT04-9520_GP_Data_Public_Attitudes_Research/Reports/GP_Data_Report_Appendix_V1_clean.docx

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This research has been carried out in compliance with the International standard ISO 20252, (the International Standard for Market and Social research), The Market Research Society's Code of Conduct and UK Data Protection law.

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