UK Research and Innovation

NHS AI Lab Public Dialogue on Data Stewardship

Final report appendices
November 2022

Ipsos, in partnership with the Open Data Institute and Imperial College Health Partners

Contents

Appendix A: Method

Oversight Group composition

Name	Role and organisation
Natalie Banner (Chair)	Director of Ethics, Genomics England
Kira Allmann	Former Public Engagement Researcher, Ada Lovelace Institute
Phil Booth	Coordinator, medConfidential
Sophie Brannan	Senior Policy Advisor (Medical Ethics), British Medical Association
Margaret Charleroy	Head of Strategy for Centre for Improving Data Collaborations, NHS Transformation Directorate
Vicky Chico	Senior Privacy Officer, Office of the National Data Guardian
Mark Halling-Brown	Head of Scientific Computing, Royal Surrey County Hospital
Ruth Keeling	Former Head of Data Strategy, NHS Transformation Directorate
Jasmine Leonard	Technology Consultant & Advisor
Sinduja Manohar	Senior Manager, Public and Patient Involvement and Engagement, Health Data Research UK
Joseph Savirimuthu	Senior Lecturer in Law, University of Liverpool
Susheel Varma	Head of AI & Data Science, Information Commissioner’s Office (ICO)
Joseph Watts	Head of Cross Government Data Strategy, NHS Transformation Directorate

Stakeholder Group composition

Name	Role and organisation
Tim Davies	Research Director, Connected by Data
Ryan Dunn	Head of Data Science, DWP Digital Newcastle
Nikita Japra	Senior Manager, Data & Society Accelerator Program, The Patrick J. McGovern Foundation
Carly Kind	Director, Ada Lovelace Institute
Miranda Marcus	Global Mental Health Databank Product Lead, Wellcome Trust
Jessica Morley	Director of Policy, Bennett Institute for Applied Data Science, University of Oxford
Kasia Odrozek	Director, Mozilla Insights
Soujanya Sridharan	Research Analyst, Aapti Institute

David Stone	Managing Director, Kaleidoscope Consultants
Wen Wha Lee	Chief Executive Officer at Action Against AMD & Chair, Data Trust Advisory Board at HDRUK INSIGHT Hub

Sample composition

Quotas		No. of participants
Gender	Female	26
	Male	21
Age	18-24	7
	25-44	12
	45-64	15
	65+	13
SEG	AB	14
	C1C2	21
	DE	12
Ethnicity	White ethnic background	20
	Black ethnic background	10
	Asian ethnic background	11
	Mixed/other ethnic background	6
Location	North-East England	12
	North-West England	
	Scotland	
	Northern Ireland	
	East Midlands	15
	East England	
	Yorkshire & Humber	
	Greater London	10
	South-East England	
	Wales	10
	West Midlands	
	South-West England	
Data attitudes*	Data absolutists	17
	Data pragmatists	16
	Data unconcerned	14
Health	Those who have a long-term health condition such as Asthma, Bronchitis &/or COPD	18
Final number of participants		**47**

*Data attitudes were assessed by asking "**I am worried about… Information and data about people's health and healthcare being used by the NHS to make decisions about what health services are needed and where to put them".** Agreement was recorded using a 7- point scale (where 1 is strongly agree and 7 is strongly disagree). Participants were then categorised accordingly:

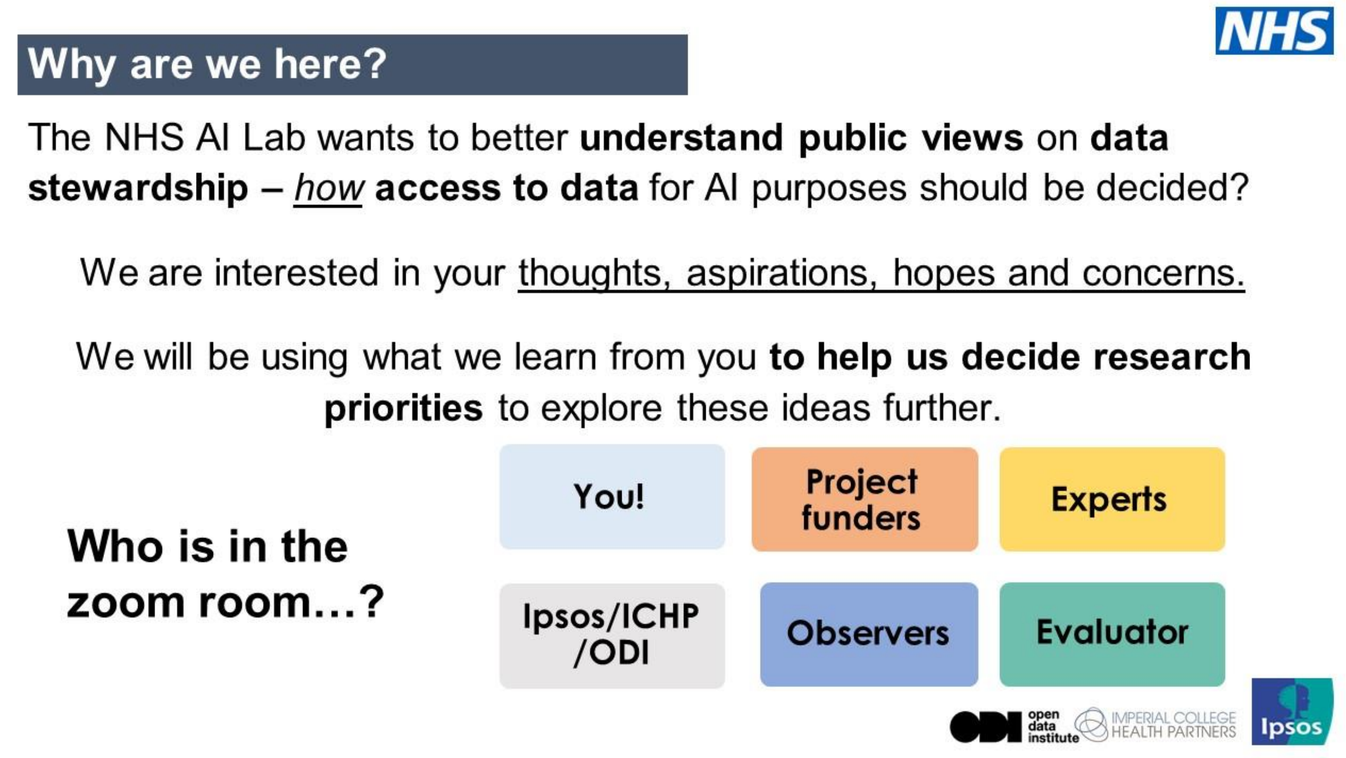
- Data absolutist – 1-2
- Data pragmatist – 3-5
- Data unconcerned – 6-7

Appendix B: Dialogue materials

Workshop 1 – PowerPoint slides

NHS AI Lab Public Dialogue - Workshop 1

Thursday 7th July 2022 18.00-21.00pm



Why are we here?

The NHS AI Lab wants to better **understand public views** on **data stewardship** – *how* **access to data** for AI purposes should be decided?

We are interested in your thoughts, aspirations, hopes and concerns.

We will be using what we learn from you **to help us decide research priorities** to explore these ideas further.

Who is in the zoom room…?

You!

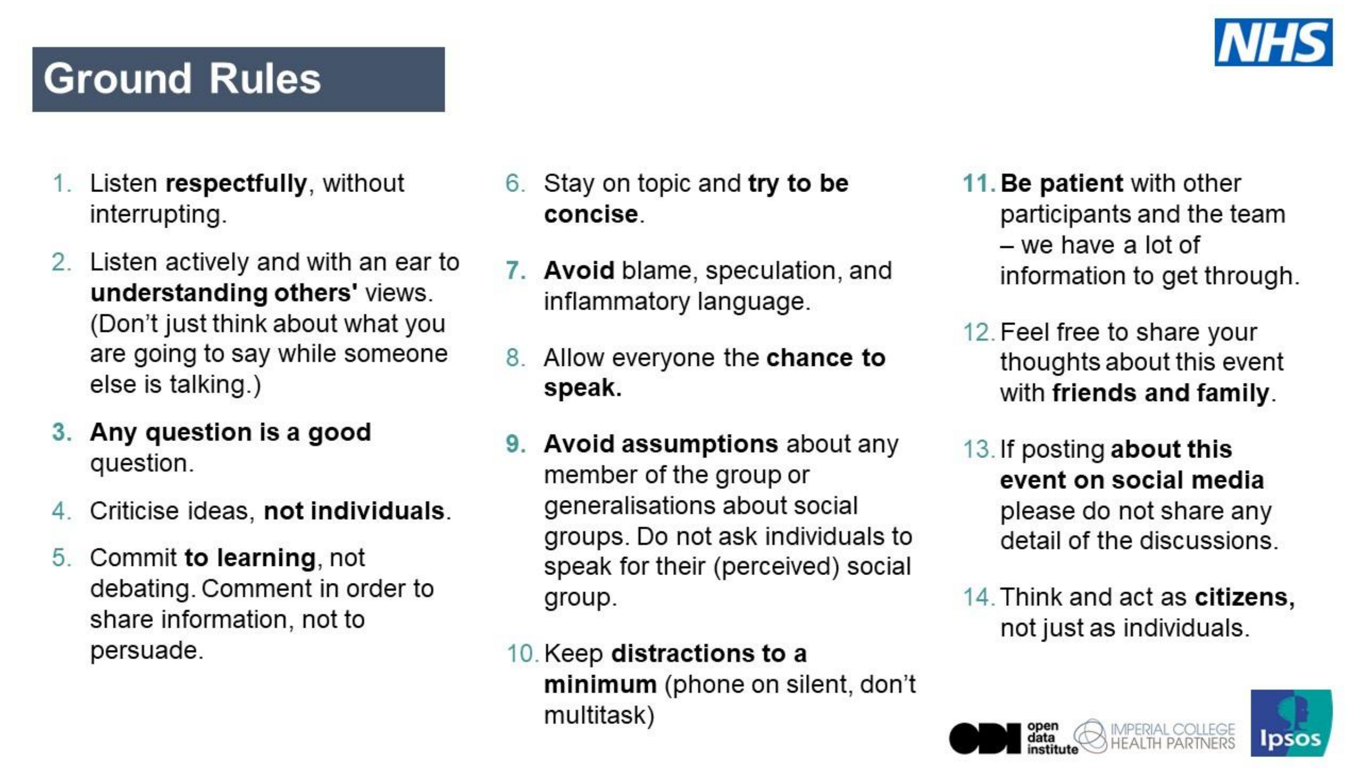
Project funders

Experts

Ipsos/ICHP /ODI

Observers

Evaluator

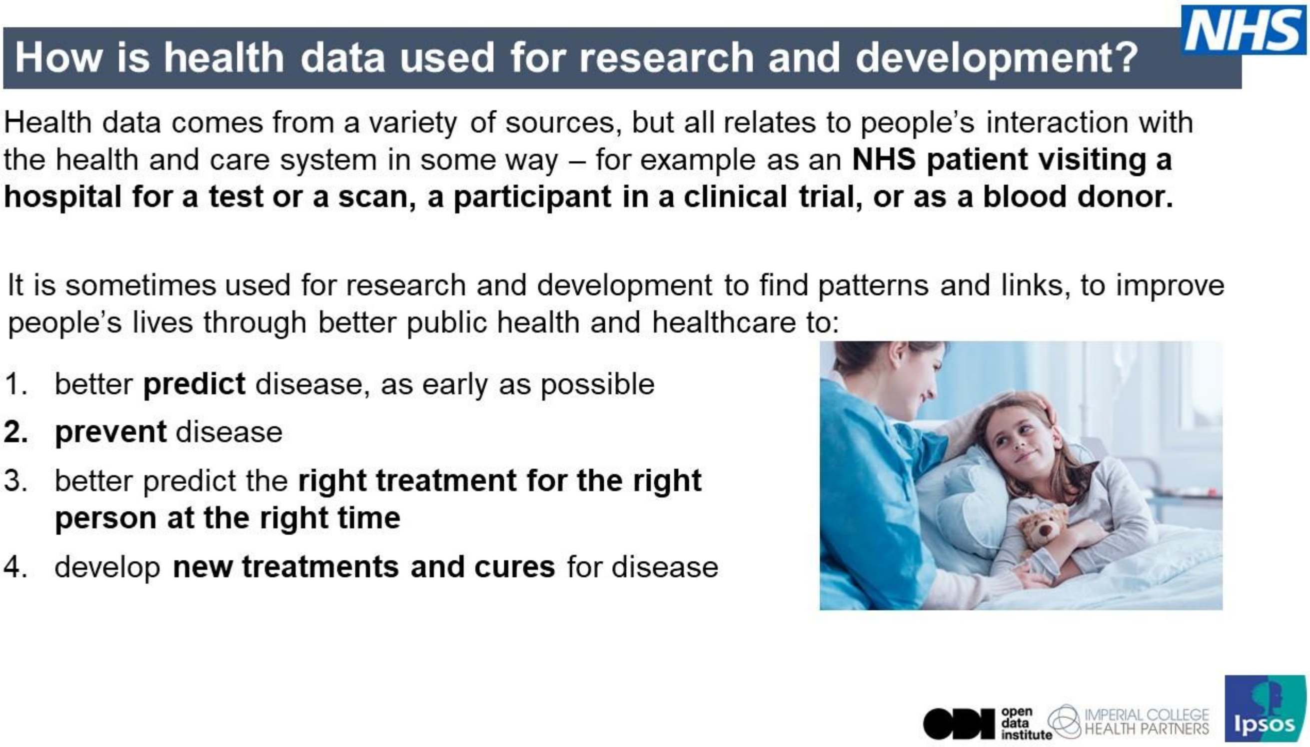


Ground Rules

1. Listen **respectfully**, without interrupting.
2. Listen actively and with an ear to **understanding others'** views. (Don't just think about what you are going to say while someone else is talking.)
3. **Any question is a good** question.
4. Criticise ideas, **not individuals**.
5. Commit **to learning**, not debating. Comment in order to share information, not to persuade.
6. Stay on topic and **try to be concise**.
7. **Avoid** blame, speculation, and inflammatory language.
8. Allow everyone the **chance to speak.**
9. **Avoid assumptions** about any member of the group or generalisations about social groups. Do not ask individuals to speak for their (perceived) social group.
10. Keep **distractions to a minimum** (phone on silent, don't multitask)
11. **Be patient** with other participants and the team – we have a lot of information to get through.
12. Feel free to share your thoughts about this event with **friends and family**.
13. If posting **about this event on social media** please do not share any detail of the discussions.
14. Think and act as **citizens,** not just as individuals.

Introduction to health data for AI research

Natalie Banner, Director of Ethics, Genomics England

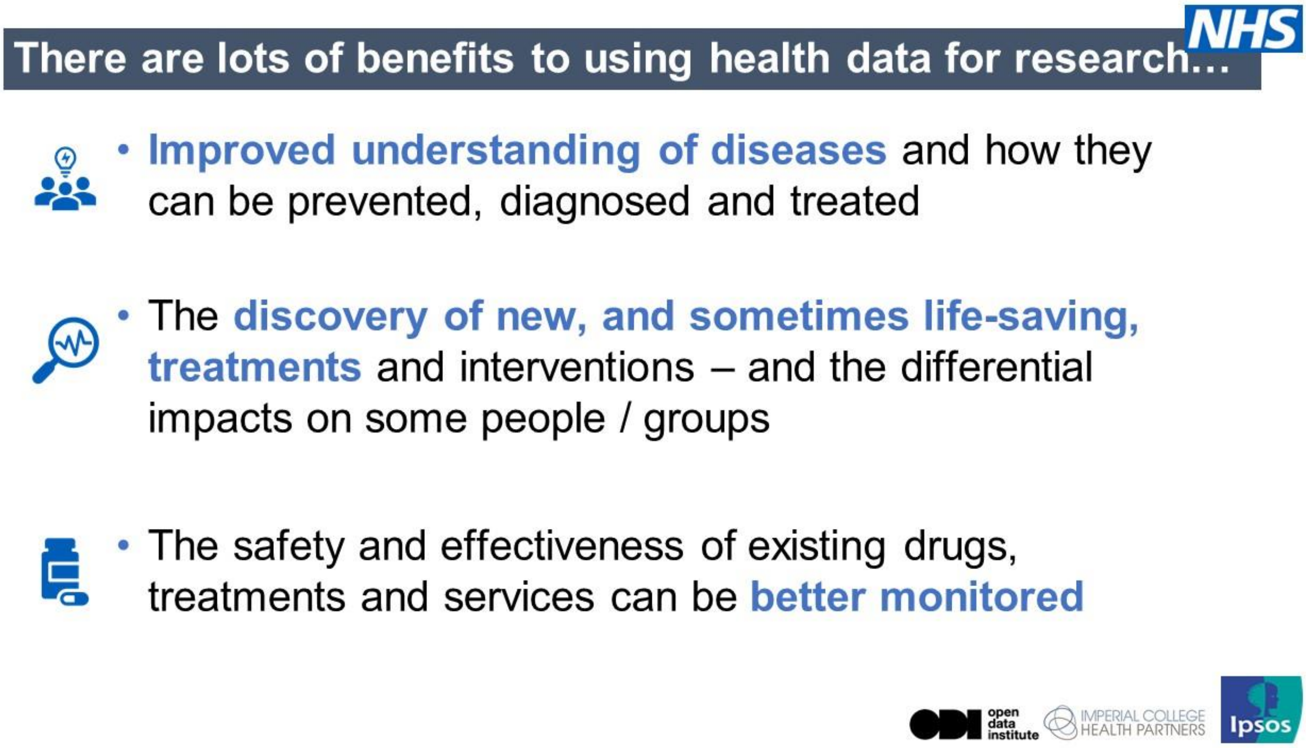


How is health data used for research and development?

Health data comes from a variety of sources, but all relates to people's interaction with the health and care system in some way – for example as an **NHS patient visiting a hospital for a test or a scan, a participant in a clinical trial, or as a blood donor.**

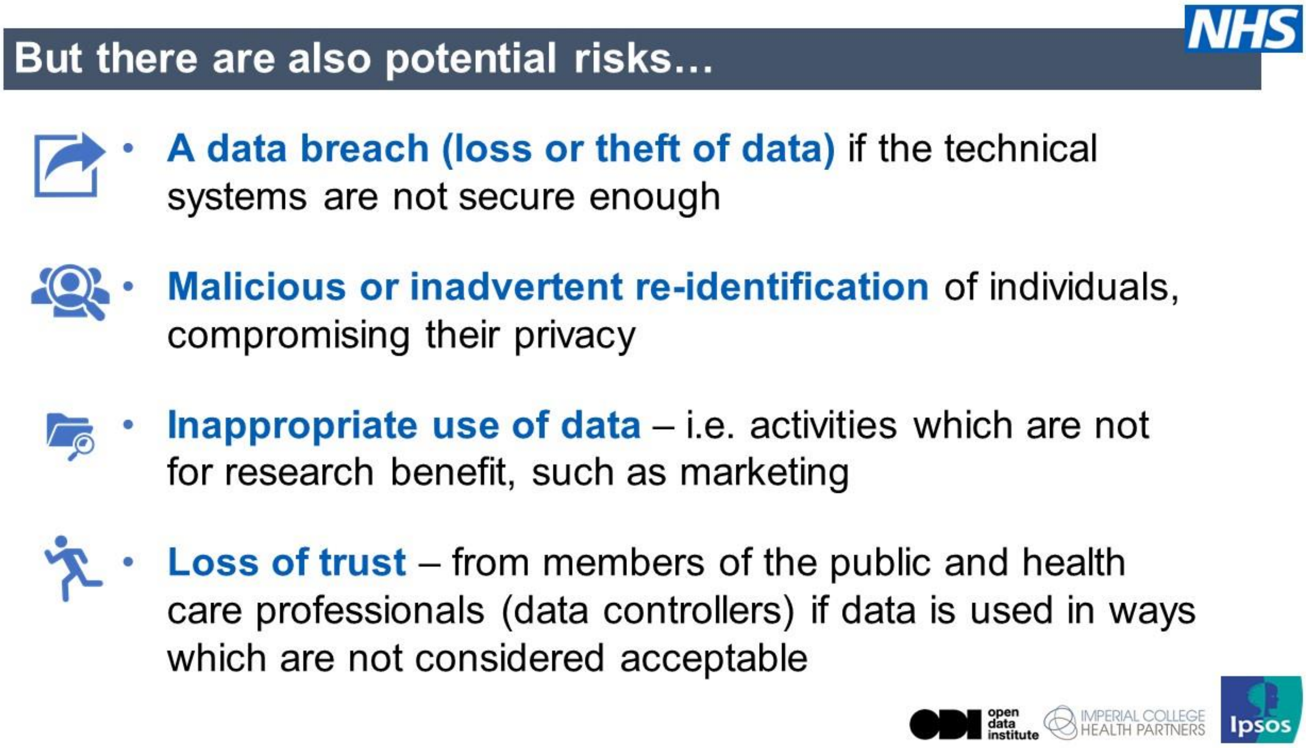
It is sometimes used for research and development to find patterns and links, to improve people's lives through better public health and healthcare to:

1. better **predict** disease, as early as possible
2. **prevent** disease
3. better predict the **right treatment for the right person at the right time**
4. develop **new treatments and cures** for disease



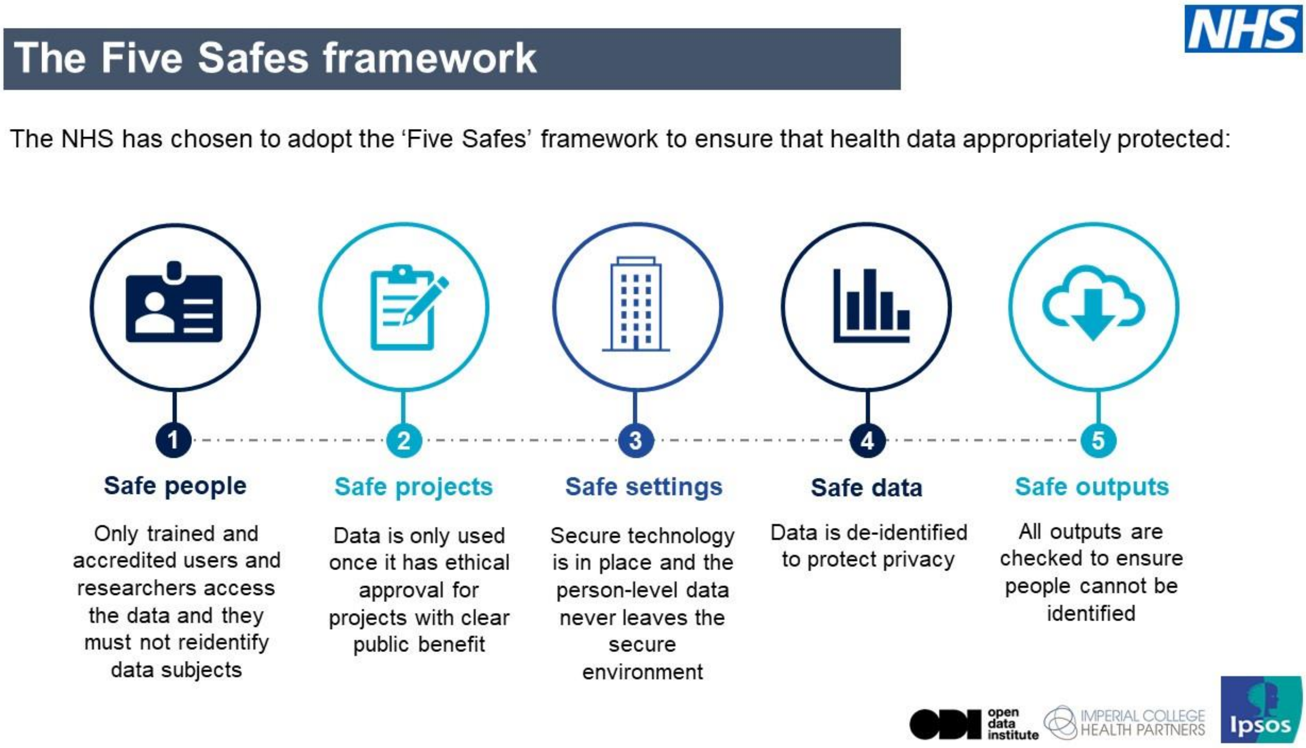
There are lots of benefits to using health data for research…

- **Improved understanding of diseases** and how they can be prevented, diagnosed and treated
- The **discovery of new, and sometimes life-saving, treatments** and interventions – and the differential impacts on some people / groups
- The safety and effectiveness of existing drugs, treatments and services can be **better monitored**



But there are also potential risks…

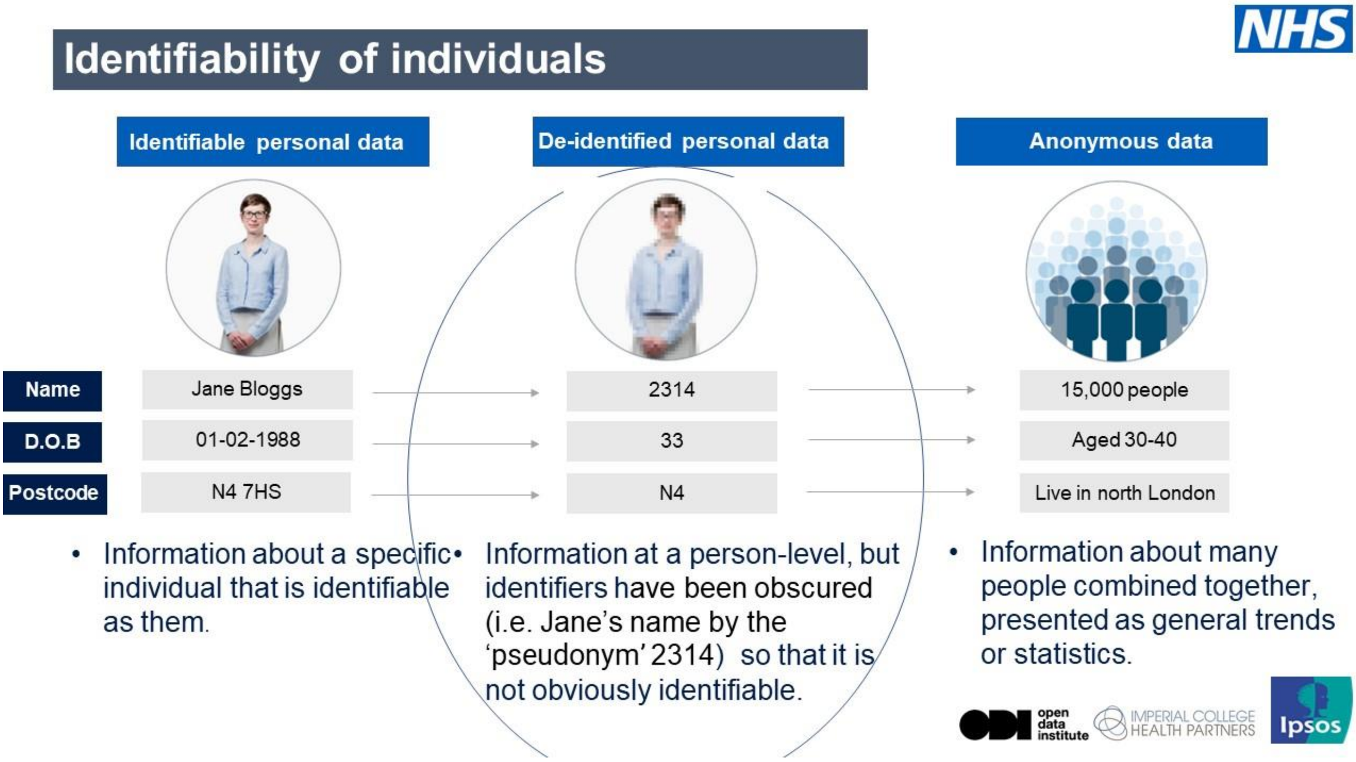
- **A data breach (loss or theft of data)** if the technical systems are not secure enough
- **Malicious or inadvertent re-identification** of individuals, compromising their privacy
- **Inappropriate use of data** – i.e. activities which are not for research benefit, such as marketing
- **Loss of trust** – from members of the public and health care professionals (data controllers) if data is used in ways which are not considered acceptable



The Five Safes framework

The NHS has chosen to adopt the 'Five Safes' framework to ensure that health data appropriately protected:

1. **Safe people** – Only trained and accredited users and researchers access the data and they must not reidentify data subjects
2. **Safe projects** – Data is only used once it has ethical approval for projects with clear public benefit
3. **Safe settings** – Secure technology is in place and the person-level data never leaves the secure environment
4. **Safe data** – Data is de-identified to protect privacy
5. **Safe outputs** – All outputs are checked to ensure people cannot be identified



Identifiability of individuals

	Identifiable personal data	De-identified personal data	Anonymous data
Name	Jane Bloggs	2314	15,000 people
D.O.B	01-02-1988	33	Aged 30-40
Postcode	N4 7HS	N4	Live in north London

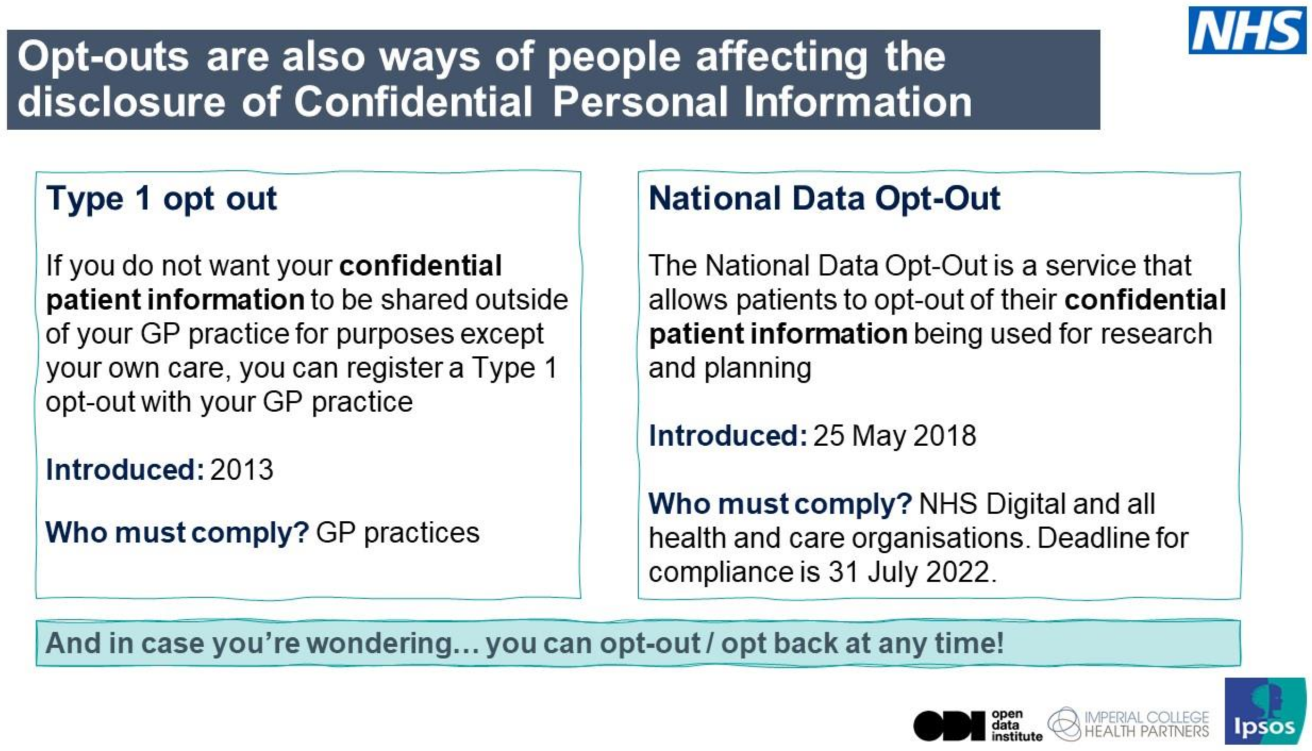
- Information about a specific individual that is identifiable as them.
- Information at a person-level, but identifiers have been obscured (i.e. Jane's name by the 'pseudonym' 2314) so that it is not obviously identifiable.
- Information about many people combined together, presented as general trends or statistics.

Processing of health data is covered by several legal frameworks

The use of personal information relating to an individual's health and/or care is subject to:

1. data protection legislation, which defines health information as 'special category' information and makes it subject to additional protections beyond those that apply to the use of 'personal data';
2. the common law duty of confidentiality (CLDC); and
3. The legal frameworks of each health and care organisation

A **legal basis** to process data is required under each framework.



Opt-outs are also ways of people affecting the disclosure of Confidential Personal Information

Type 1 opt out

If you do not want your **confidential patient information** to be shared outside of your GP practice for purposes except your own care, you can register a Type 1 opt-out with your GP practice

Introduced: 2013

Who must comply? GP practices

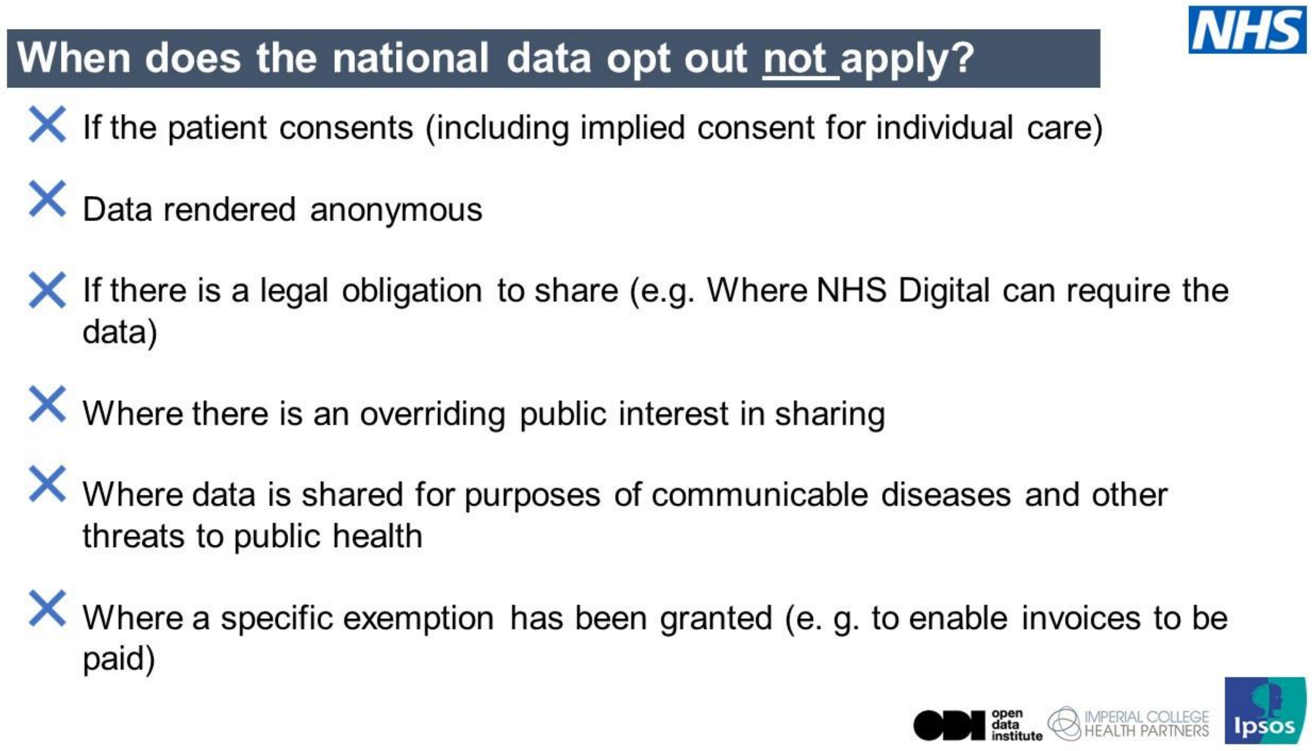
National Data Opt-Out

The National Data Opt-Out is a service that allows patients to opt-out of their **confidential patient information** being used for research and planning

Introduced: 25 May 2018

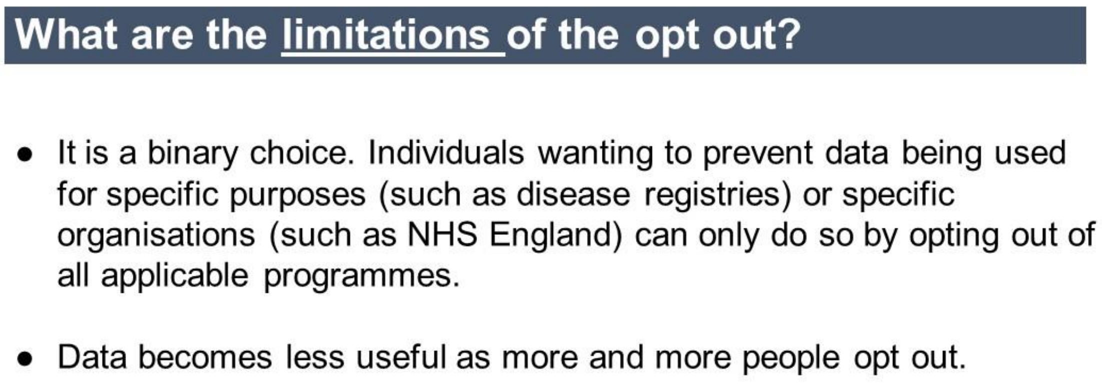
Who must comply? NHS Digital and all health and care organisations. Deadline for compliance is 31 July 2022.

And in case you're wondering… you can opt-out / opt back at any time!



When does the national data opt out not apply?

- ✕ If the patient consents (including implied consent for individual care)
- ✕ Data rendered anonymous
- ✕ If there is a legal obligation to share (e.g. Where NHS Digital can require the data)
- ✕ Where there is an overriding public interest in sharing
- ✕ Where data is shared for purposes of communicable diseases and other threats to public health
- ✕ Where a specific exemption has been granted (e. g. to enable invoices to be paid)

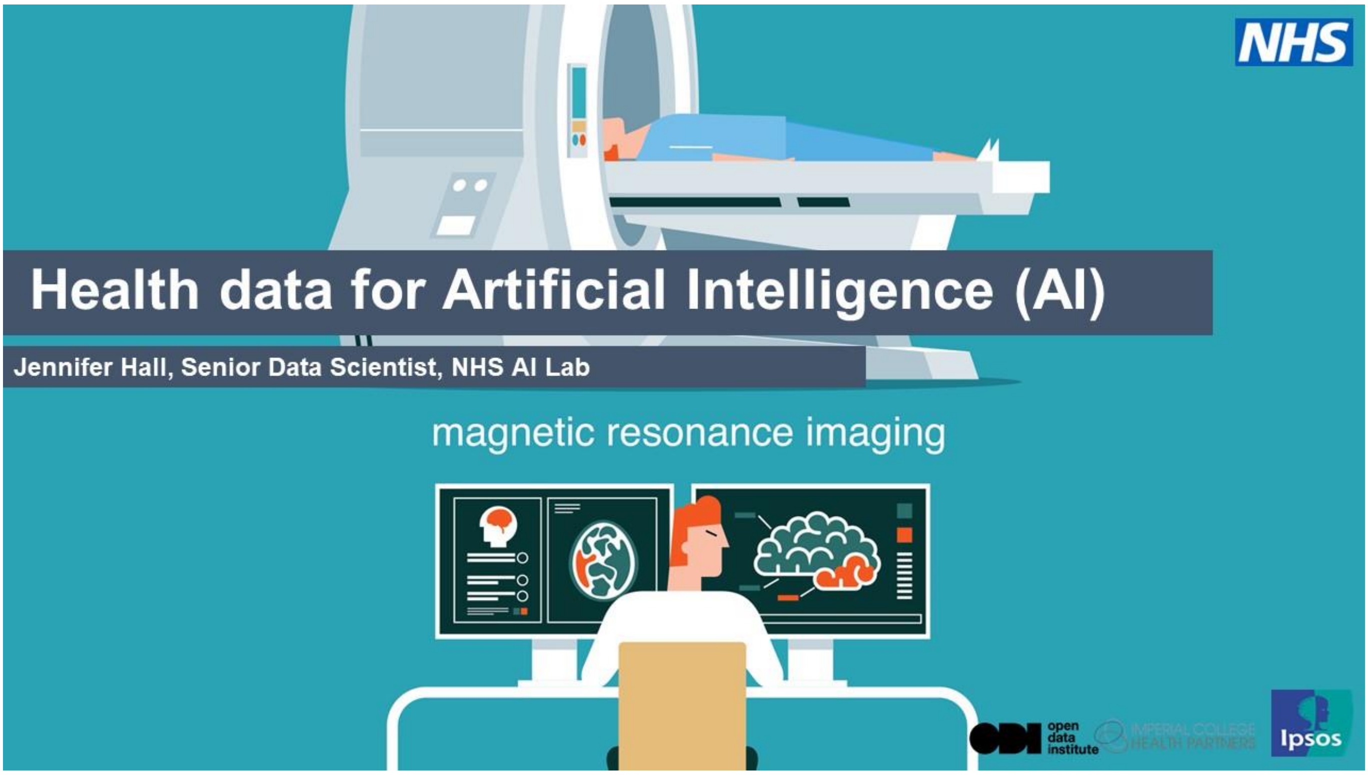


What are the limitations of the opt out?

- It is a binary choice. Individuals wanting to prevent data being used for specific purposes (such as disease registries) or specific organisations (such as NHS England) can only do so by opting out of all applicable programmes.
- Data becomes less useful as more and more people opt out.

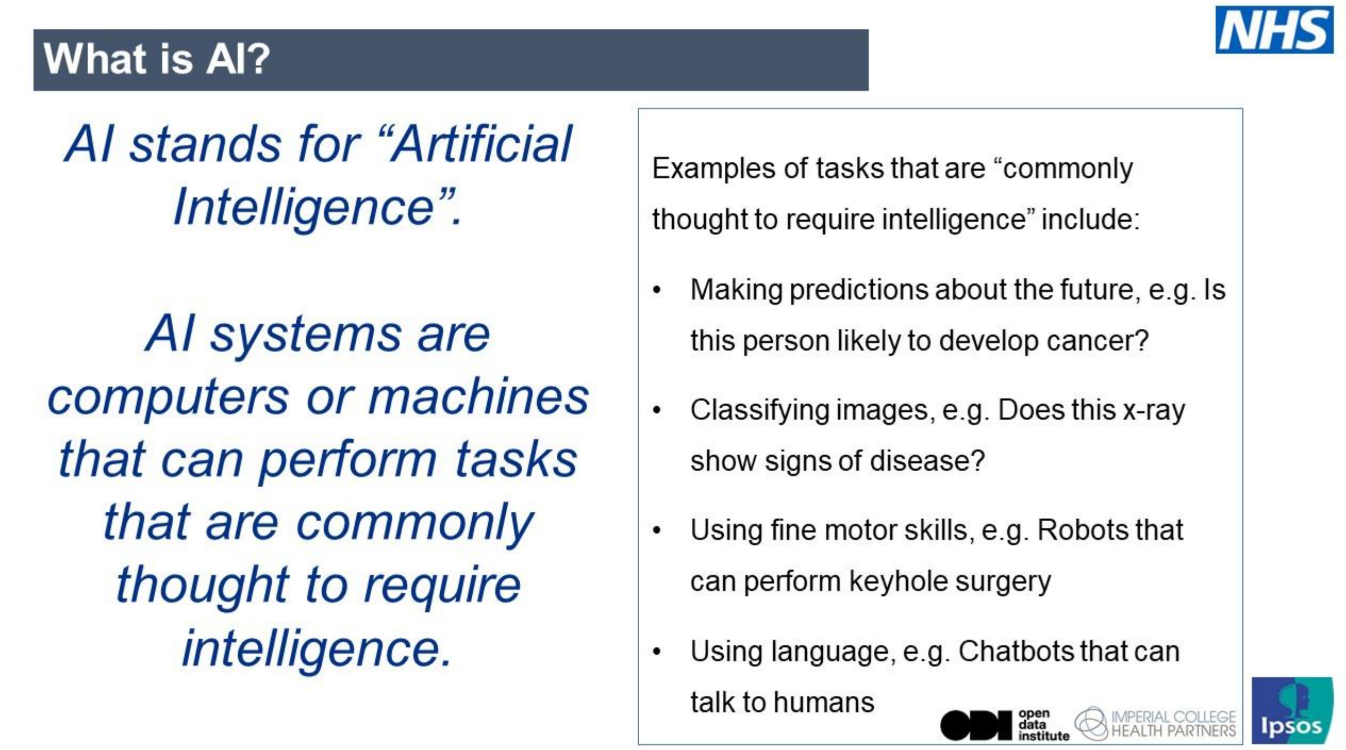
How is research using health data approved?

- All research using health data must be approved by the Health Research Authority (HRA). HRA also provides approval for the formation of a database, the research planned by the core research team, the sharing of data to third parties and the processes by which this sharing should take place.
- The Confidentiality Advisory Group (CAG) is an independent review body which provides expert recommendations to HRA on any proposed use of confidential (identifiable) patient information.
- HRA does not specifically approve which third parties can access the database and for what purposes. This is typically decided by a Data Access Committee, made up of experts. We will be exploring how these decisions about third-party access should be made as part of this dialogue.



Health data for Artificial Intelligence (AI)

Jennifer Hall, Senior Data Scientist, NHS AI Lab



What is AI?

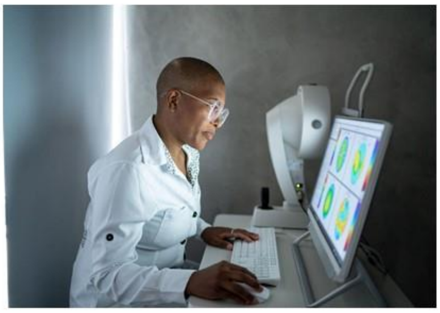
AI stands for "Artificial Intelligence".

AI systems are computers or machines that can perform tasks that are commonly thought to require intelligence.

Examples of tasks that are "commonly thought to require intelligence" include:

- Making predictions about the future, e.g. Is this person likely to develop cancer?
- Classifying images, e.g. Does this x-ray show signs of disease?
- Using fine motor skills, e.g. Robots that can perform keyhole surgery
- Using language, e.g. Chatbots that can talk to humans

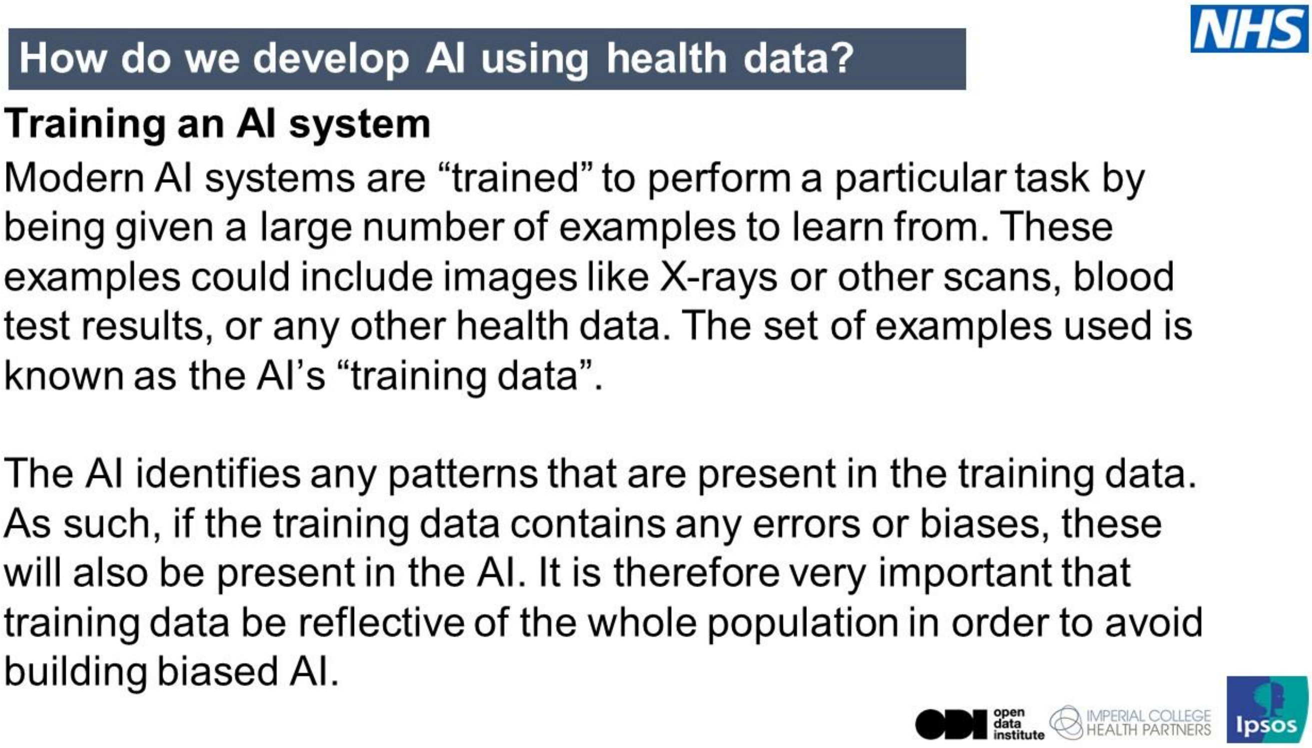
Case study A – Reviewing eye scans



- An NHS hospital partnered with a globally recognised technology company to see if machines could help review eye scans at the same level of accuracy as a doctor.
- The problem (facing the NHS) was that the number of eye scans being carried out is growing at a pace much faster than human experts who are able to interpret them.
- Health researchers from the technology company worked alongside the NHS and reviewed de-identified patient scans.
- The researchers found that machines could detect the presence of disease for over 50 eye diseases with 94% accuracy and doctors could then refer patients for follow-up. This matched the accuracy of world-leading eye experts.
- Experienced doctors are still needed to review scans - the technology is only assistive - but it can help doctors spot conditions earlier and refer the most serious eye diseases for immediate treatment.

Case study B – Screening for causes of dementia and stroke

- Academic researchers in a university partnered with an NHS hospital to develop and test an artificial intelligence (AI) algorithm which can help screen for signs of stroke and dementia on a brain scan (CT).
- At the moment, doctors diagnose the disease that causes stroke and dementia by looking for changes to white matter in the brain during MRI or CT scans. However, this relies on a doctor gauging from the scan how far the disease has spread and it can be difficult for doctors to diagnose the severity of the disease by the human eye.
- The university researchers tested the AI algorithm on de-identified brain scans, linked to health records from primary care and social care. They found that the algorithm was very accurate in being able to detect and therefore help doctors estimate the spread of the disease which causes stroke and dementia from CT and MRI scans.
- There is hope that such systems will be applied to making balanced decisions for acute stroke and enabling precise dementia diagnosis and monitoring.

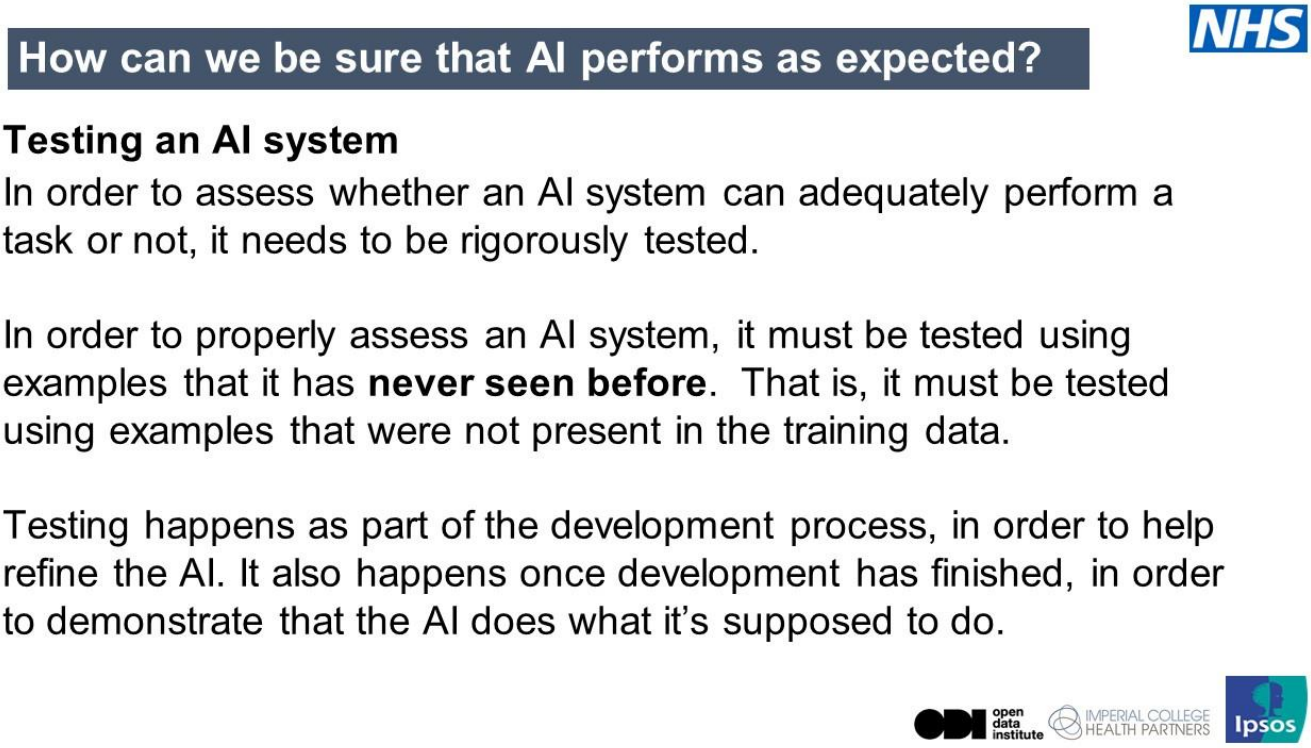


How do we develop AI using health data?

Training an AI system

Modern AI systems are “trained” to perform a particular task by being given a large number of examples to learn from. These examples could include images like X-rays or other scans, blood test results, or any other health data. The set of examples used is known as the AI’s “training data”.

The AI identifies any patterns that are present in the training data. As such, if the training data contains any errors or biases, these will also be present in the AI. It is therefore very important that training data be reflective of the whole population in order to avoid building biased AI.



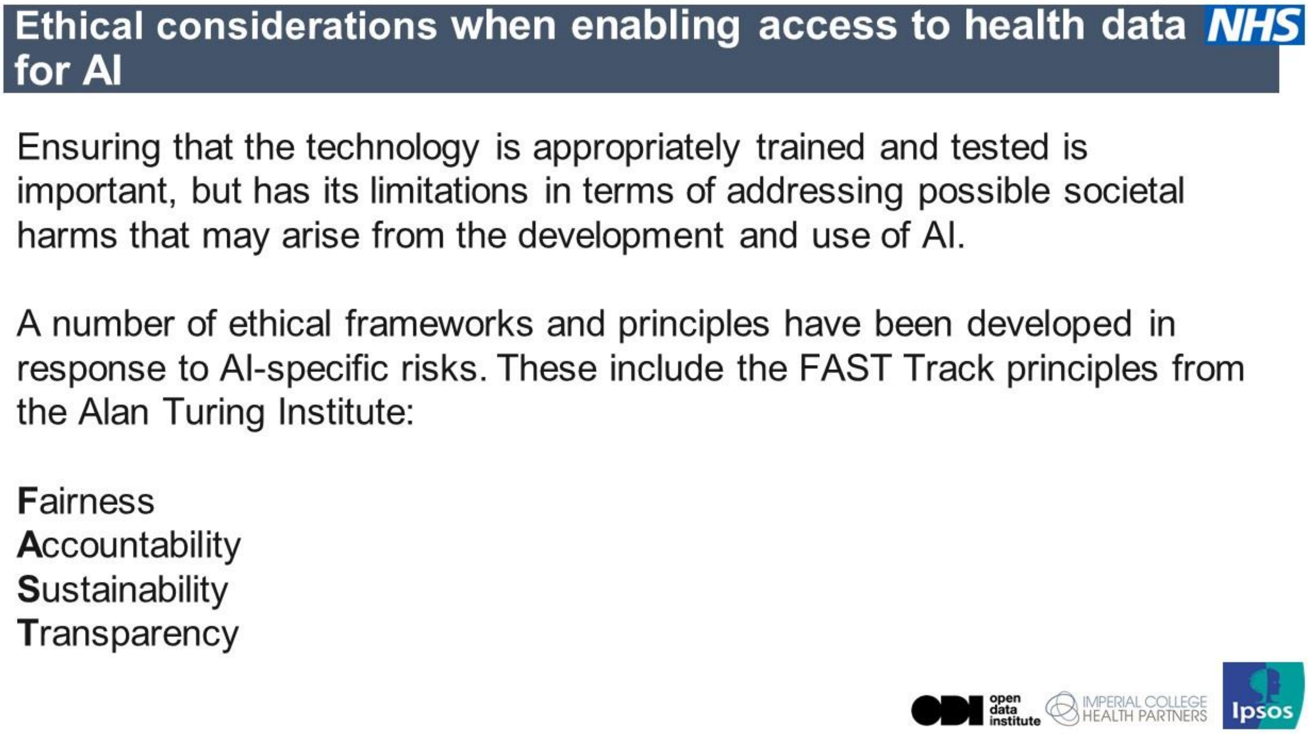
How can we be sure that AI performs as expected?

Testing an AI system

In order to assess whether an AI system can adequately perform a task or not, it needs to be rigorously tested.

In order to properly assess an AI system, it must be tested using examples that it has **never seen before**. That is, it must be tested using examples that were not present in the training data.

Testing happens as part of the development process, in order to help refine the AI. It also happens once development has finished, in order to demonstrate that the AI does what it’s supposed to do.

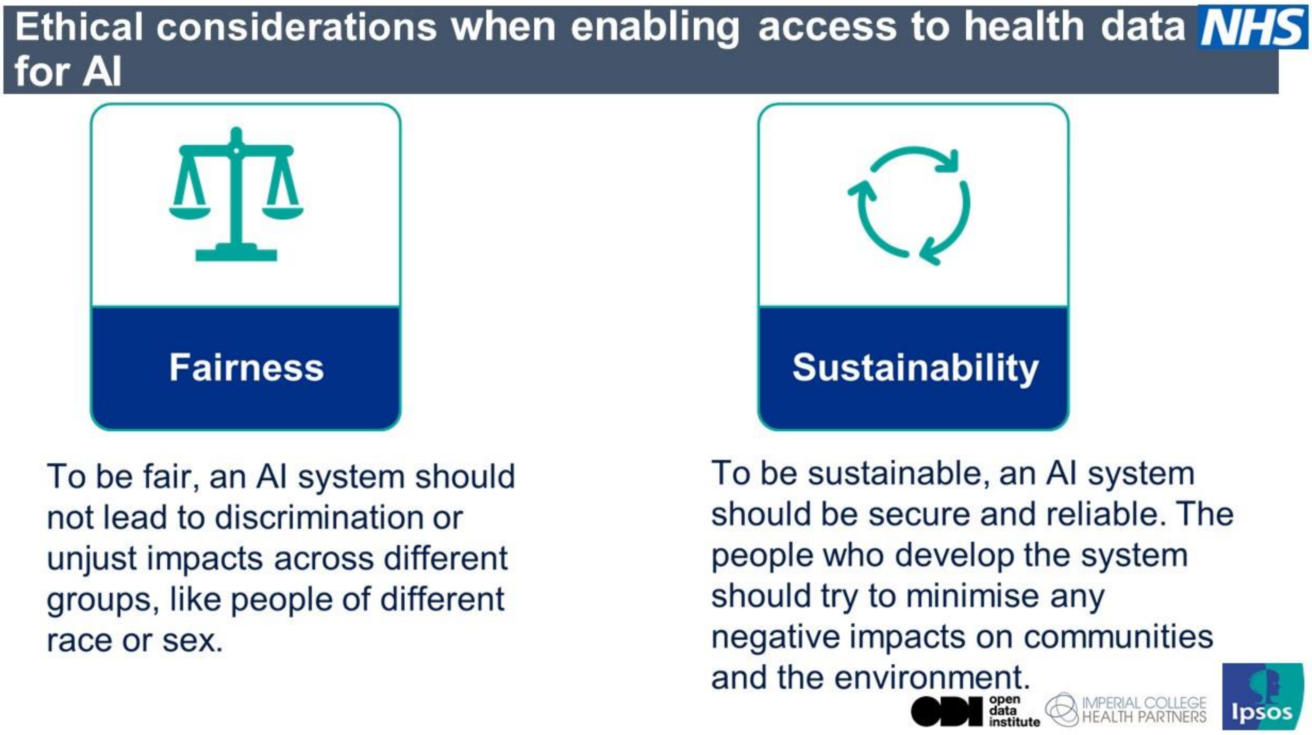


Ethical considerations when enabling access to health data for AI

Ensuring that the technology is appropriately trained and tested is important, but has its limitations in terms of addressing possible societal harms that may arise from the development and use of AI.

A number of ethical frameworks and principles have been developed in response to AI-specific risks. These include the FAST Track principles from the Alan Turing Institute:

Fairness
Accountability
Sustainability
Transparency



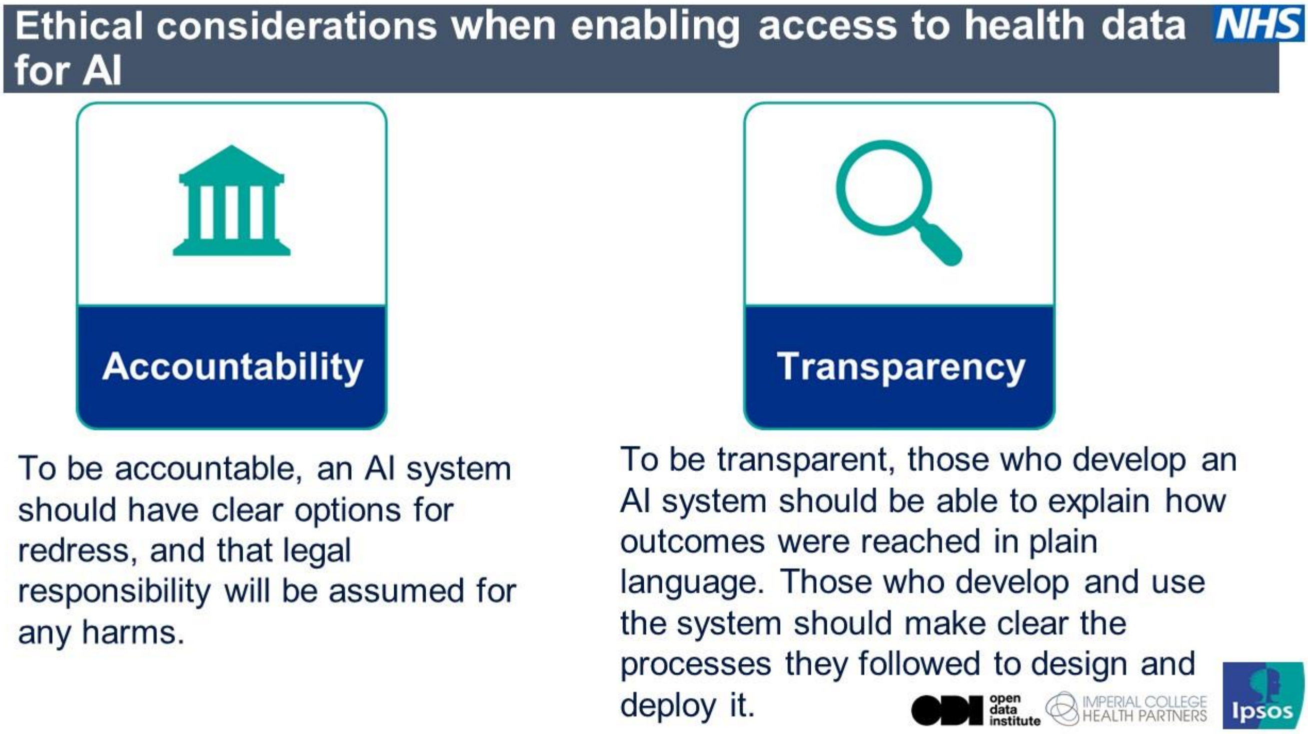
Ethical considerations when enabling access to health data for AI

Fairness

To be fair, an AI system should not lead to discrimination or unjust impacts across different groups, like people of different race or sex.

Sustainability

To be sustainable, an AI system should be secure and reliable. The people who develop the system should try to minimise any negative impacts on communities and the environment.



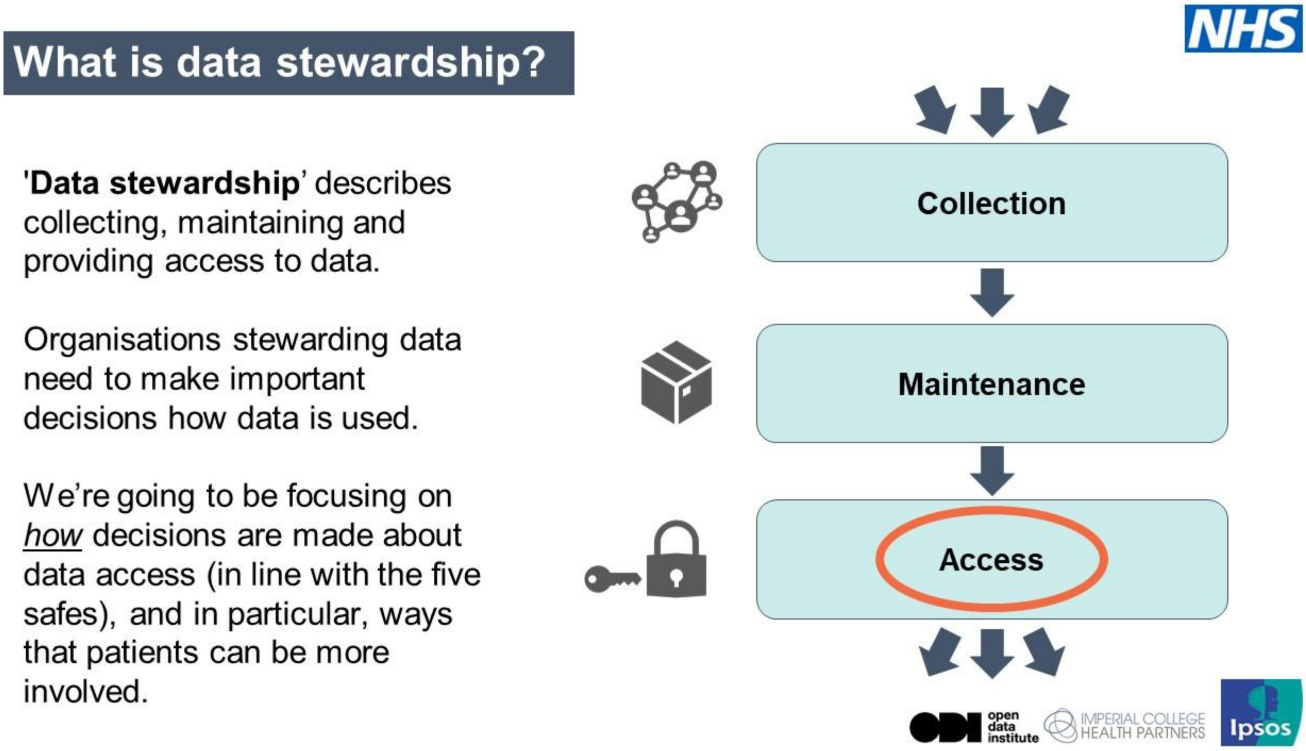
Ethical considerations when enabling access to health data for AI

Accountability

To be accountable, an AI system should have clear options for redress, and that legal responsibility will be assumed for any harms.

Transparency

To be transparent, those who develop an AI system should be able to explain how outcomes were reached in plain language. Those who develop and use the system should make clear the processes they followed to design and deploy it.



What is data stewardship?

'**Data stewardship**' describes collecting, maintaining and providing access to data.

Organisations stewarding data need to make important decisions how data is used.

We're going to be focusing on *how* decisions are made about data access (in line with the five safes), and in particular, ways that patients can be more involved.

Workshop 1 – Discussion guide

Thursday 7th July 6-9pm

DISCUSSION GUIDE

Time	Discussion structure	Process, Questions and materials
17.30-17.55	**Set-up: Facilitators check in** **25 mins**	● Test link, mic and camera. ● Test who has the host/co-host function and ensure it is allocated to the right team member(s) for recording break out rooms. Make all moderators Co-hosts. ● Change screen name to NAME – Org – Chair/Moderator. ● Check everyone is on the WhatsApp group for facilitation team to be able to ask questions etc ● Meanwhile tech support is assigning participants who are in the waiting room, notes takers, moderators, experts and observers to break-out rooms.
17.55-18.05	**Participant Check-in** **10 mins**	**Participants log into the online session** ● Participants encouraged to join the zoom session early to check-in and check their video/mic. ● Participants encouraged to get a pen and paper and have their participant pack with them. ● Register as people join and change screen names as necessary to First name and first initial of surname (i.e. John H).
18.05-18.10	**Introduction and scene setting** **Plenary 1** **5 mins**	**Ipsos Chair to give a warm welcome to the first of four online workshop (<u>5 mins</u>):** ● Introduce Consortium (Ipsos, ODI, ICHP), NHS AI Lab and Sciencewise (SLIDE 1) ● Chair to explain why we are here: expert commentators, any observers, and facilitators and note takers (SLIDE 2) ● Chair to explain that a lot of information will be provided to participants over the course of four workshops, and to always ask or note down any questions/ queries and ask for clarification when needed. ● There will be a lot of quite technical information. If you have questions, raise these with your facilitator and we will either respond there and then or come back to you with a response ● We may cover topics (for example diseases) which people might have personal experience of. If anything that we do cover is triggering, feel free to take a break or come and talk to me (Chair) ● We have a quiet room for anyone who needs a break at any point ● Chair also to cover ground rules (SLIDE 3) and additionally… ○ We will be going in to break out rooms -we've set these up so you don't need to do anything – just let it happen ○ If we lose connection to you at any point in the session [INSERT NAME] will call you to see if we can help bring you back in again ○ We'll be capturing discussions live for our own notes. ○ Confidentiality: we are interested in what you say not who said what. Your comments will not be attributed back to you in our report. ○ We have shared materials with you, but please respect that these have been designed for the purpose of this exercise, and please don't post photos or content from these on social media or share otherwise.

18.10-18.40	**Meet and greet and initial discussion about health data for research** **Breakout 1** **30 mins**	**Facilitators to welcome their group and do introductions (5 mins)** **Facilitators to ask participants to write down words that come to mind when they hear 'health data for research' and share them with the group. (10 mins)** *Okay, now let's take a few minutes to map ideas – you can make notes on a piece of paper, or on your phone – whatever suits you best. We're going to think about what comes to mind when you hear the words 'health data for research'. Have a think, and jot down some ideas, then in a couple of minutes I'll ask you each to share your thoughts.* - Give two minutes for this, then invite each participant to share if comfortable - *Thanks everyone. Let's go around and hear what people have written down.* - Reflect back where thoughts are similar and different - Gently probe for more detail if needed **Facilitator to explore the following with participants (15 mins):** ● What kind of information about you (health data) do you think might be used in health research? ● Has anyone heard of artificial intelligence or AI or AI health research? ○ IF ANYONE SAYS THEY HAVE: Would you mind having a go at describing this to the rest of the group? ○ IF EVERYONE SAYS THEY HAVE NOT: That's ok, we will hear more about what this is in the next presentation! ● Who do you think makes decisions about the use of information about you (health data) for health research?
18.40-18.55	**Introduction to health data for research** **Plenary 2** **15 mins**	**Presentation (Natalie Banner) to introduce Health Data for Research (<u>15 mins</u>) –** SLIDES 4-14 Before Ipsos chair introduces the speaker, to explain to participants that they might want to jot things down throughout the presentation but also that they have these slides in their packs. - How is health data used for research and development? (slide 5) - Benefits of using data for research (slide 6) and risks (slide 7) - Five safes framework (slide 8) - Identifiability of individuals (slide 9) - Legal landscape and the national data opt out (slides 10 to 13) - How research using health data is approved (slide 14)
18.55-19.05	**BREAK**	*Facilitators to explain to participants that they must be back promptly for a <u>19.05</u> start. That they can turn off their cameras and their mic's during the break. Explain that just before 19.05, we will be automatically moved back into breakout rooms.*
19.05-19.20	**Reflections on health data for AI research** **Break-out 2**	**Facilitator to welcome participants back to their group and explain that we are going to have a discussion about what we have just heard. Remind people that they have the information in their packs to refer to.** **Reflections (15 mins)** ● How aware were you about the use of health data beyond individual care, for research? ● What are your first thoughts on the use of health data for purposes beyond your individual care?

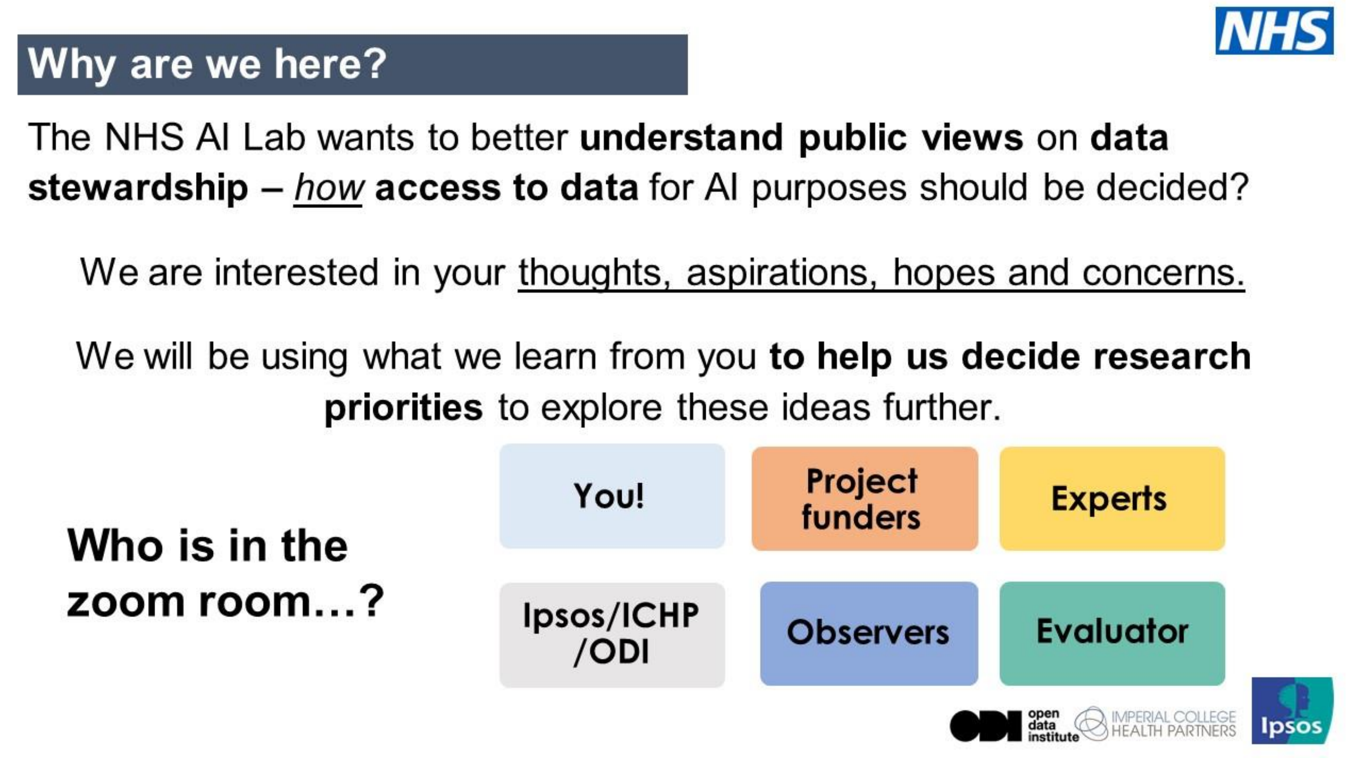
	15 mins	● What did you think about the benefits and risks highlighted? ● And the five safes framework? ● Are you left with questions or concerns? *Facilitators to note down questions that people have.*
19.20-19.30	**Introduction to health data for AI** **Plenary 3** **10 mins**	**Presentation (Jennifer Hall) to introduce Health Data for AI (<u>10 mins</u>) –** SLIDES 16-23 Before Ipsos chair introduces the speaker, to explain to participants that they might want to jot things down throughout the presentation but also that they have these slides in their packs. - What is AI? (slide 16) - Case studies (slides 17 and 18) - How do we develop AI using health data and how can we be sure AI performs as expected (slides 19 AND 20) - Ethical issues when enabling access to data for AI (slides 21 to 23)
19.30-19.50	**Initial discussion and reflection about health data for AI** **Break-out 3** **20 mins**	**Facilitators to welcome people back and explain that we are going to digest and discuss the new information about health data for AI.** **Reflections (20 mins)** ● How familiar, or unfamiliar, was the information presented to you? ● What did you think about the ethical considerations in relation to access to health data for AI? ● What questions, if any, does this information raise for you?
19.50-20.00	**BREAK**	*Facilitators to explain to participants that they must be back promptly for a <u>20.00</u> start. That they can turn off their cameras and their mic's during the break.*
20.00-20.40	**Case study exercise to introduce and socialise examples of health data being used for AI research** **Break-out 4** **40 mins**	***Facilitators to introduce talk through two case studies about possible research projects involving the use of health data for AI research [shuffle order across groups] – spending roughly 20 mins per case study*** 1. *Reviewing eye scans* 2. *Screening for causes of dementia and stroke* **Case study 1: Reviewing eye scans (20 mins)** ● **What are your initial thoughts on the case study?** ○ What do you think are the benefits/risks in the use of health data in this example? ● **How acceptable / unacceptable do you find this example? Why do you say that?** ○ In relation to the type of organisation (a global technology company working directly in partnership with NHS clinicians?) ○ In relation to the type of data (using de-identified data about patients) ● **What would make you feel more comfortable about how this data is being used/ accessed?**

		● **Who would you expect would make decisions around whether this data should be accessed for this kind of research?** **Case study 2: Screening for causes of dementia and stroke (20 mins)** ● **What are your thoughts on the case study?** ○ What do you think are the benefits/risks in the use of health data in this example? ● **How acceptable / unacceptable do you find this example? Why do you say that?** ○ In relation to the type of organisation (university academics working directly in partnership with a NHS hospital?) ○ In relation to the type of data (using de-identified / linked data about patients) ● **What would make you feel more comfortable about how this data is being used/ accessed?** ● **Who would you expect would make decisions around whether this data should be accessed for this kind of research?**
20.40-20.55	**An introduction to data stewardship** **Break-out 5** **15 mins**	**Facilitator to share 'What is data stewardship?' slide (SLIDE 24) and read through the slide** ● First off, does anyone have any questions about this? ● When AI research takes place using patients' health data in the UK, who do you think makes decisions about access to the data? ○ IF PEOPLE SAY <u>PATIENTS</u>: ASK WHY? WHO? HOW? ○ IF PEOPLE SAY <u>THE NHS</u>: ASK WHO IN THE NHS? DOES IT MATTER WHO? ○ IF PEOPLE SAY THAT <u>THEY DON'T KNOW</u>: EXPLORE WHO THEY WOULD EXPECT TO MAKE DECISIONS ABOUT ACCESS TO DATA FOR AI RESEARCH.
20.55-21.00	Thank and close in plenary	

Workshop 2 – PowerPoint slides

NHS AI Lab Public Dialogue - Workshop 2

Saturday 9th July 2022 10.00-13.00pm



Why are we here?

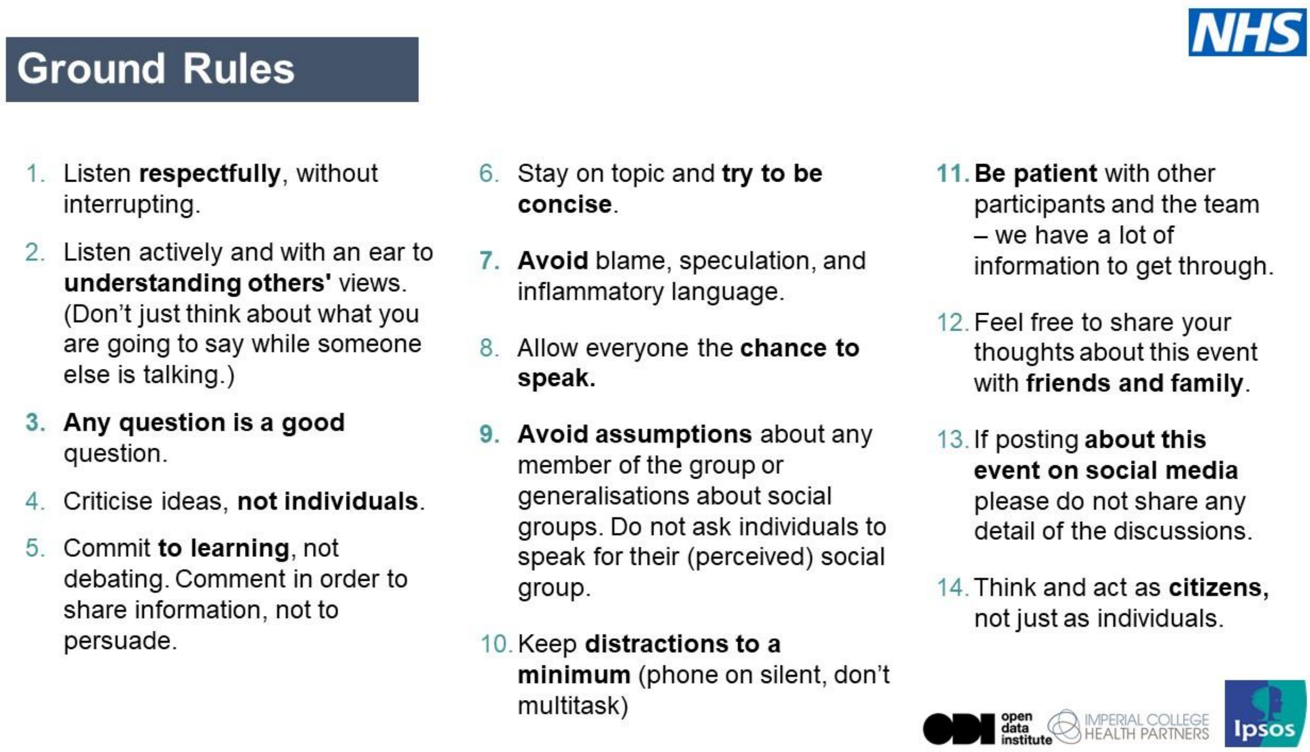
The NHS AI Lab wants to better **understand public views** on **data stewardship** – *how* **access to data** for AI purposes should be decided?

We are interested in your thoughts, aspirations, hopes and concerns.

We will be using what we learn from you **to help us decide research priorities** to explore these ideas further.

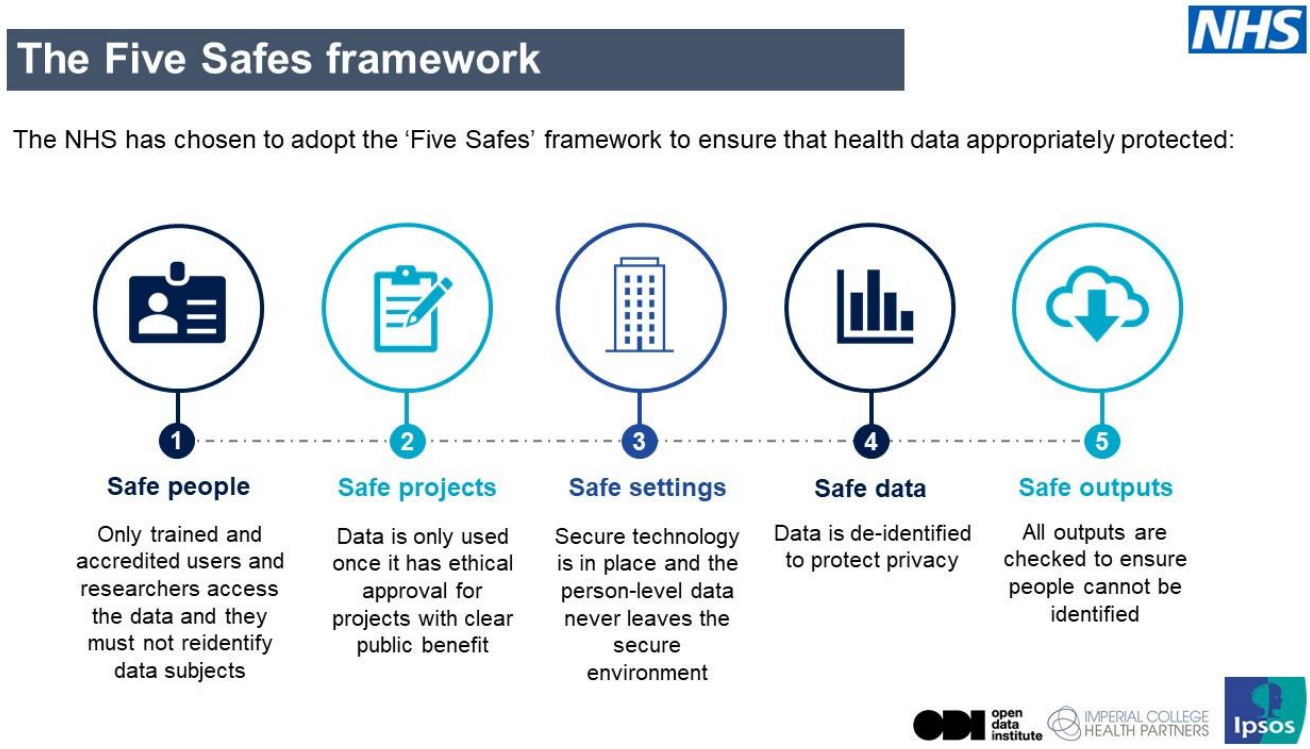
Who is in the zoom room…?

- You!
- Project funders
- Experts
- Ipsos/ICHP/ODI
- Observers
- Evaluator



Ground Rules

1. Listen **respectfully**, without interrupting.
2. Listen actively and with an ear to **understanding others'** views. (Don't just think about what you are going to say while someone else is talking.)
3. **Any question is a good** question.
4. Criticise ideas, **not individuals**.
5. Commit **to learning**, not debating. Comment in order to share information, not to persuade.
6. Stay on topic and **try to be concise**.
7. **Avoid** blame, speculation, and inflammatory language.
8. Allow everyone the **chance to speak.**
9. **Avoid assumptions** about any member of the group or generalisations about social groups. Do not ask individuals to speak for their (perceived) social group.
10. Keep **distractions to a minimum** (phone on silent, don't multitask)
11. **Be patient** with other participants and the team – we have a lot of information to get through.
12. Feel free to share your thoughts about this event with **friends and family**.
13. If posting **about this event on social media** please do not share any detail of the discussions.
14. Think and act as **citizens,** not just as individuals.



The Five Safes framework

The NHS has chosen to adopt the 'Five Safes' framework to ensure that health data appropriately protected:

1 **Safe people**

Only trained and accredited users and researchers access the data and they must not reidentify data subjects

2 **Safe projects**

Data is only used once it has ethical approval for projects with clear public benefit

3 **Safe settings**

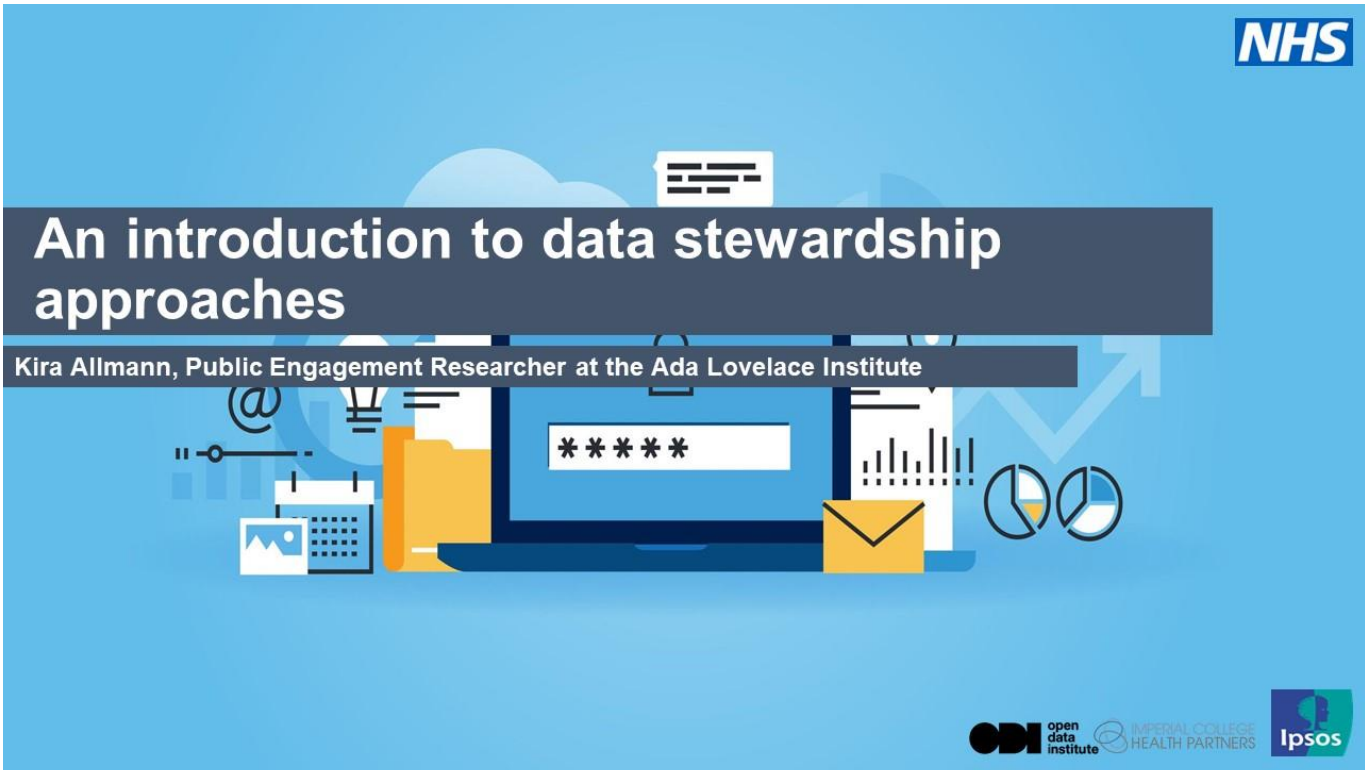
Secure technology is in place and the person-level data never leaves the secure environment

4 **Safe data**

Data is de-identified to protect privacy

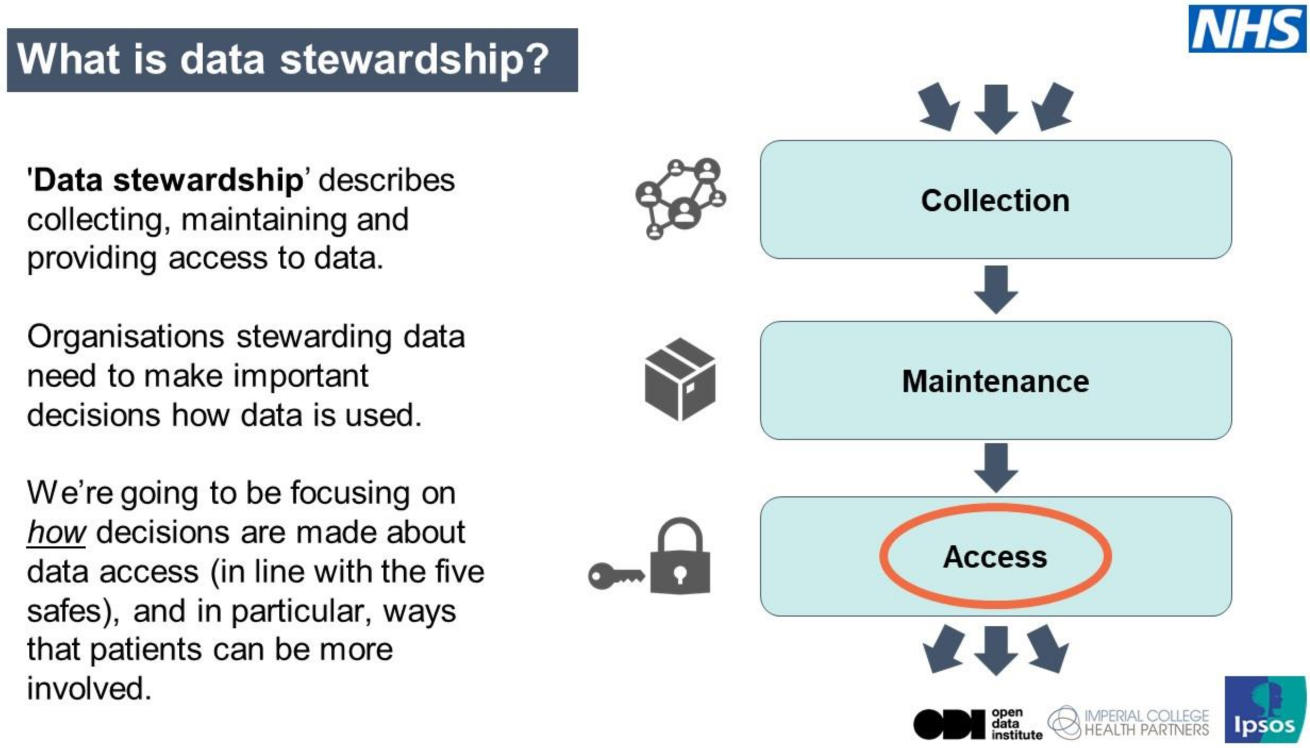
5 **Safe outputs**

All outputs are checked to ensure people cannot be identified



An introduction to data stewardship approaches

Kira Allmann, Public Engagement Researcher at the Ada Lovelace Institute



What is data stewardship?

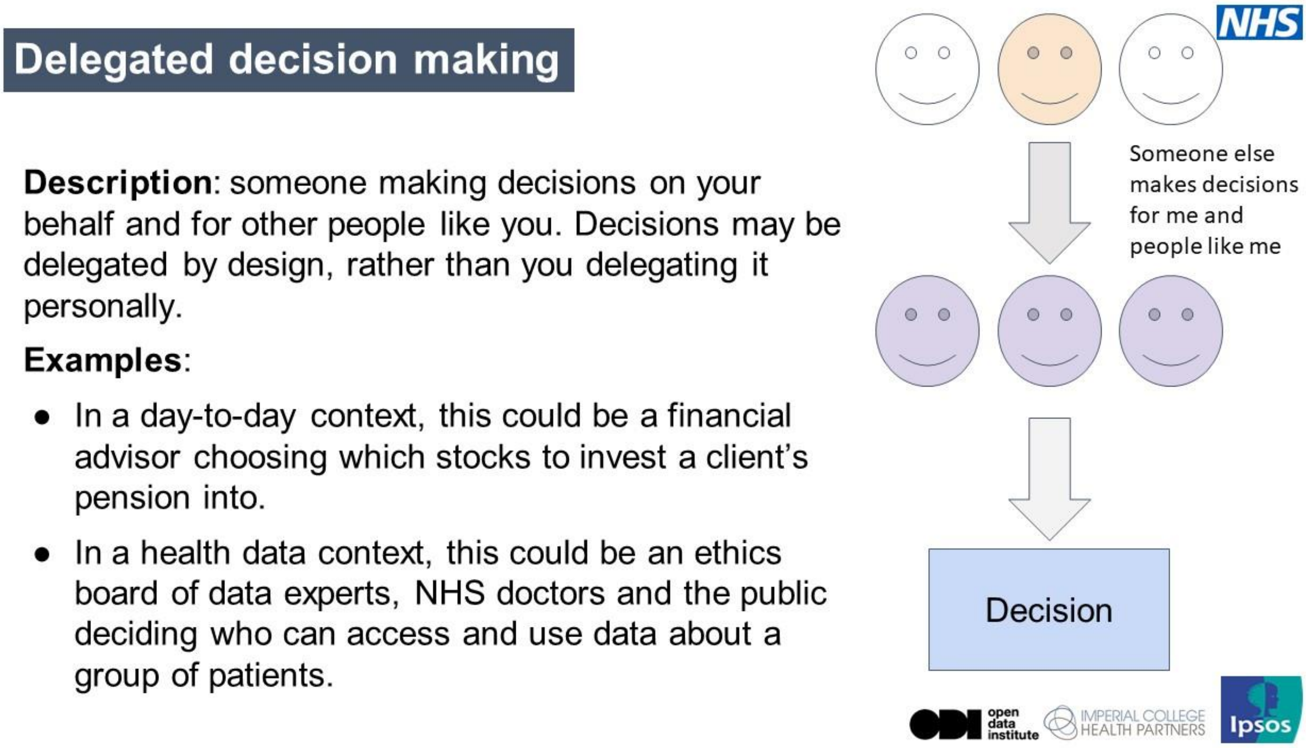
'**Data stewardship**' describes collecting, maintaining and providing access to data.

Organisations stewarding data need to make important decisions how data is used.

We're going to be focusing on *how* decisions are made about data access (in line with the five safes), and in particular, ways that patients can be more involved.

How can decisions about data access be made?

Delegated	Someone making decisions on your behalf and for other people like you.
Collective	People making decisions as part of a larger group.
Individual	People making decisions for themselves or on behalf of someone they care for.

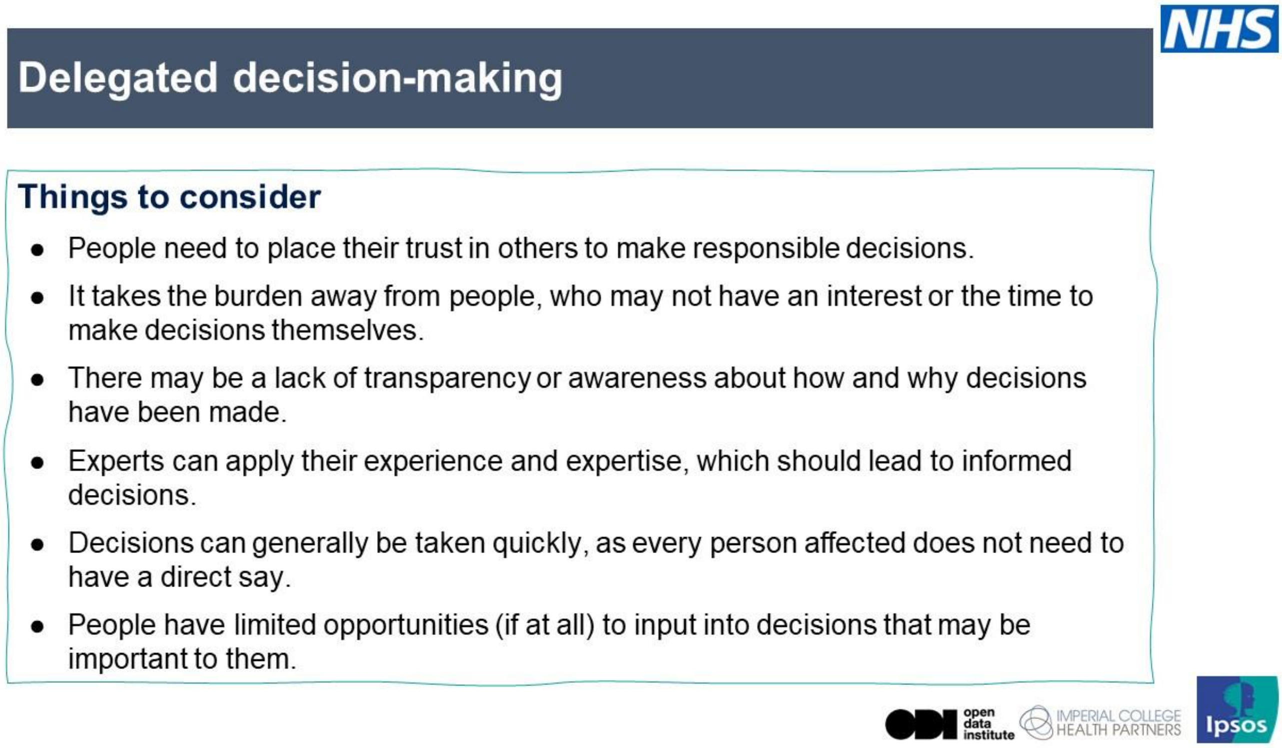


Delegated decision making

Description: someone making decisions on your behalf and for other people like you. Decisions may be delegated by design, rather than you delegating it personally.

Examples:

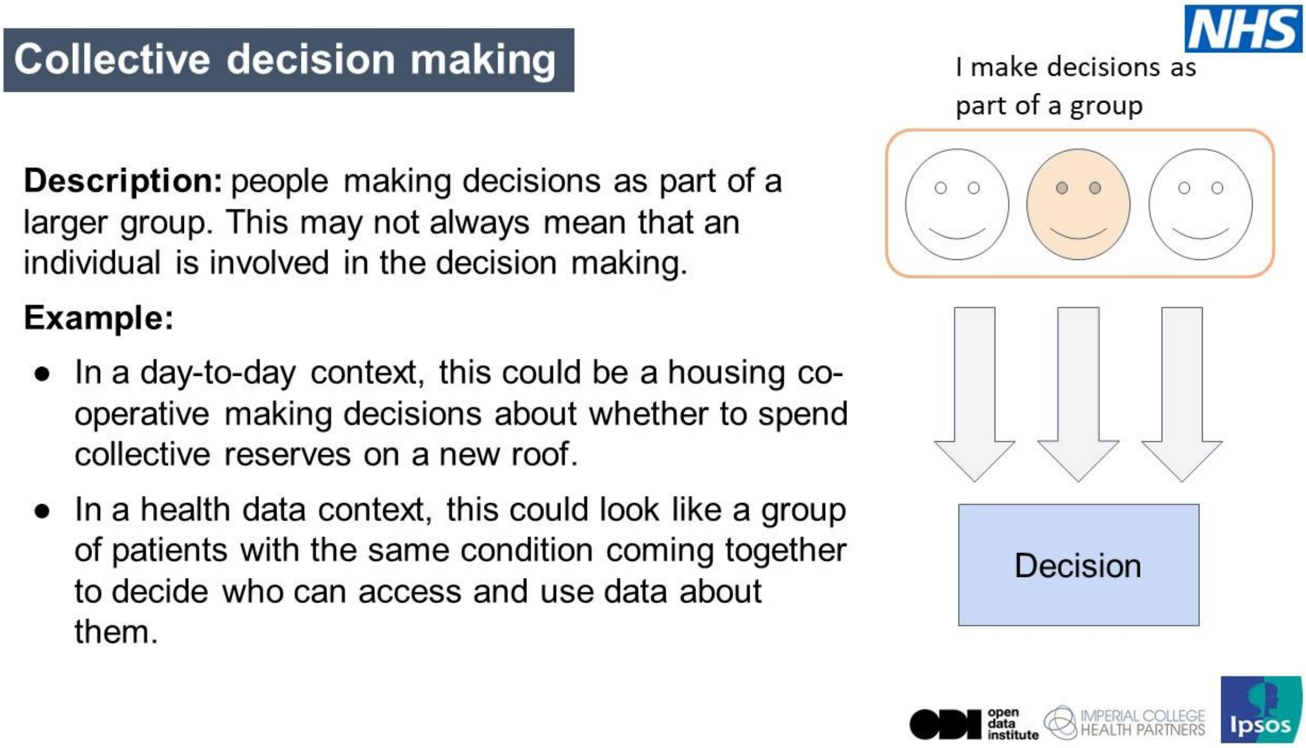
- In a day-to-day context, this could be a financial advisor choosing which stocks to invest a client's pension into.
- In a health data context, this could be an ethics board of data experts, NHS doctors and the public deciding who can access and use data about a group of patients.



Delegated decision-making

Things to consider

- People need to place their trust in others to make responsible decisions.
- It takes the burden away from people, who may not have an interest or the time to make decisions themselves.
- There may be a lack of transparency or awareness about how and why decisions have been made.
- Experts can apply their experience and expertise, which should lead to informed decisions.
- Decisions can generally be taken quickly, as every person affected does not need to have a direct say.
- People have limited opportunities (if at all) to input into decisions that may be important to them.



Collective decision making

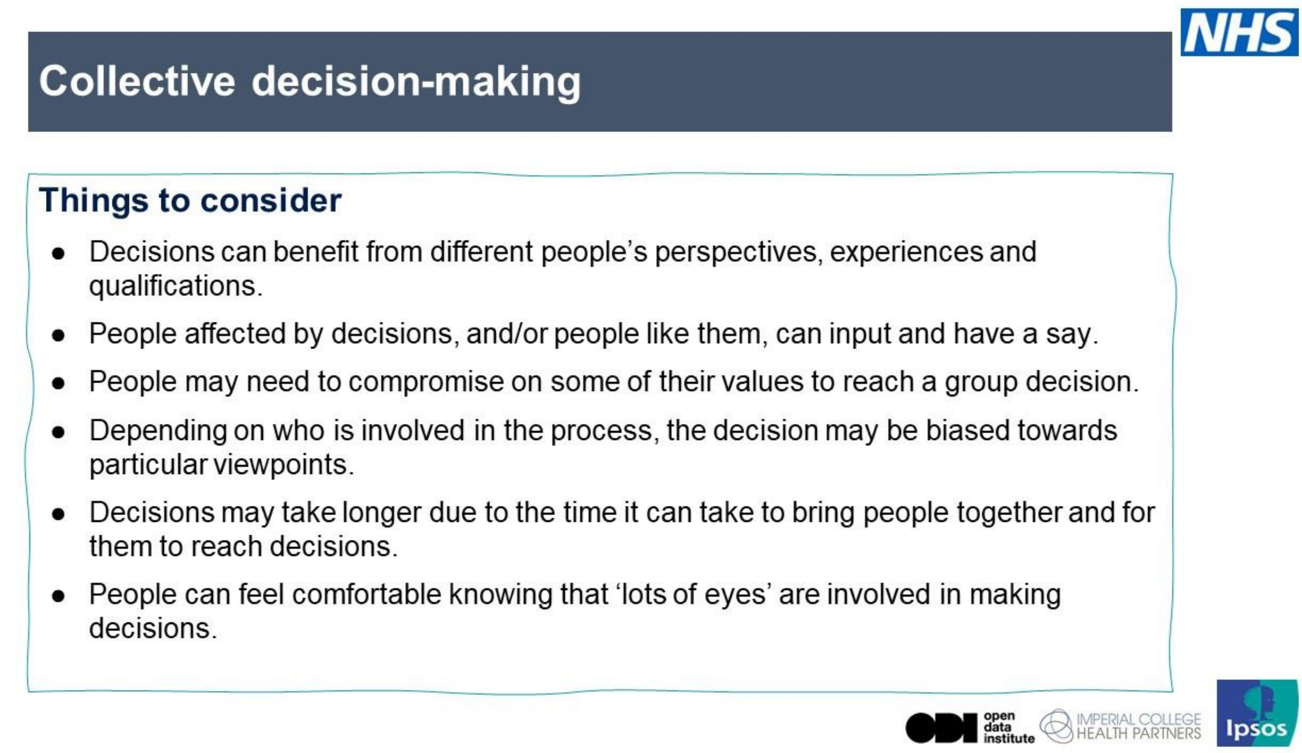
Description: people making decisions as part of a larger group. This may not always mean that an individual is involved in the decision making.

Example:

- In a day-to-day context, this could be a housing co-operative making decisions about whether to spend collective reserves on a new roof.
- In a health data context, this could look like a group of patients with the same condition coming together to decide who can access and use data about them.

I make decisions as part of a group

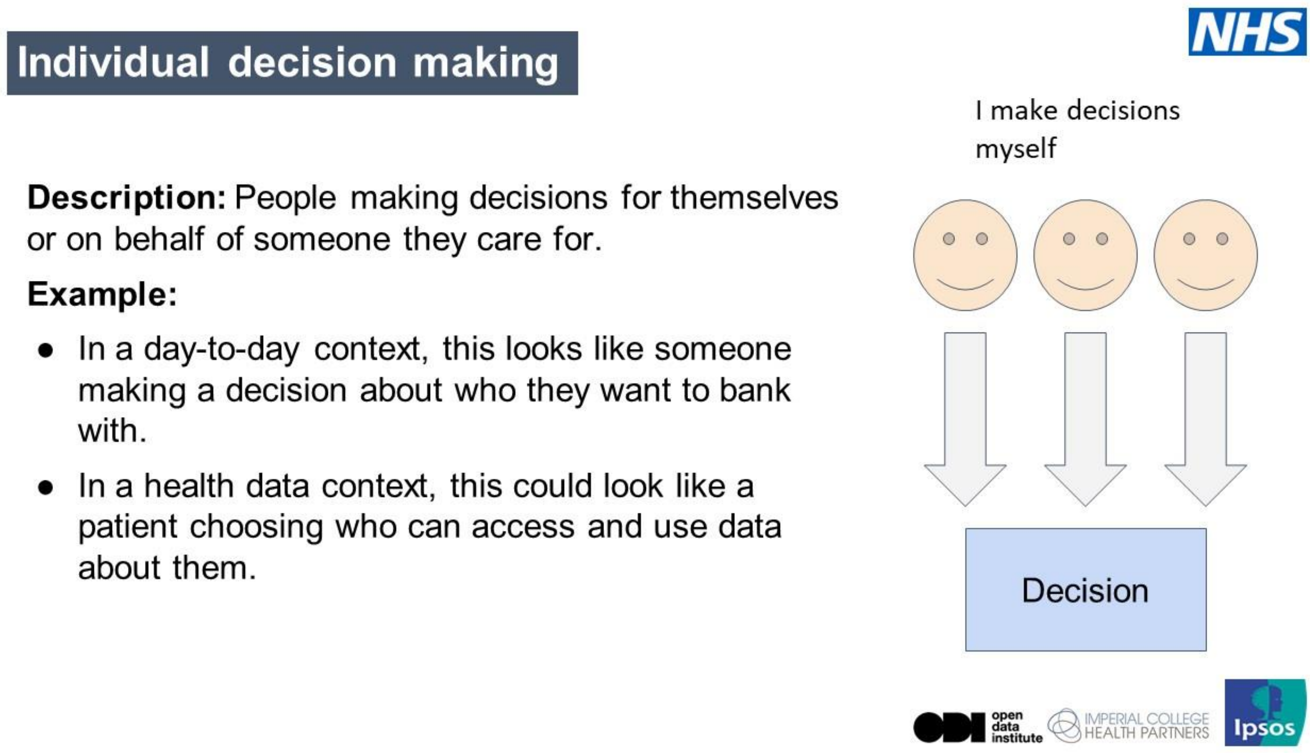
Decision



Collective decision-making

Things to consider

- Decisions can benefit from different people's perspectives, experiences and qualifications.
- People affected by decisions, and/or people like them, can input and have a say.
- People may need to compromise on some of their values to reach a group decision.
- Depending on who is involved in the process, the decision may be biased towards particular viewpoints.
- Decisions may take longer due to the time it can take to bring people together and for them to reach decisions.
- People can feel comfortable knowing that 'lots of eyes' are involved in making decisions.



Individual decision making

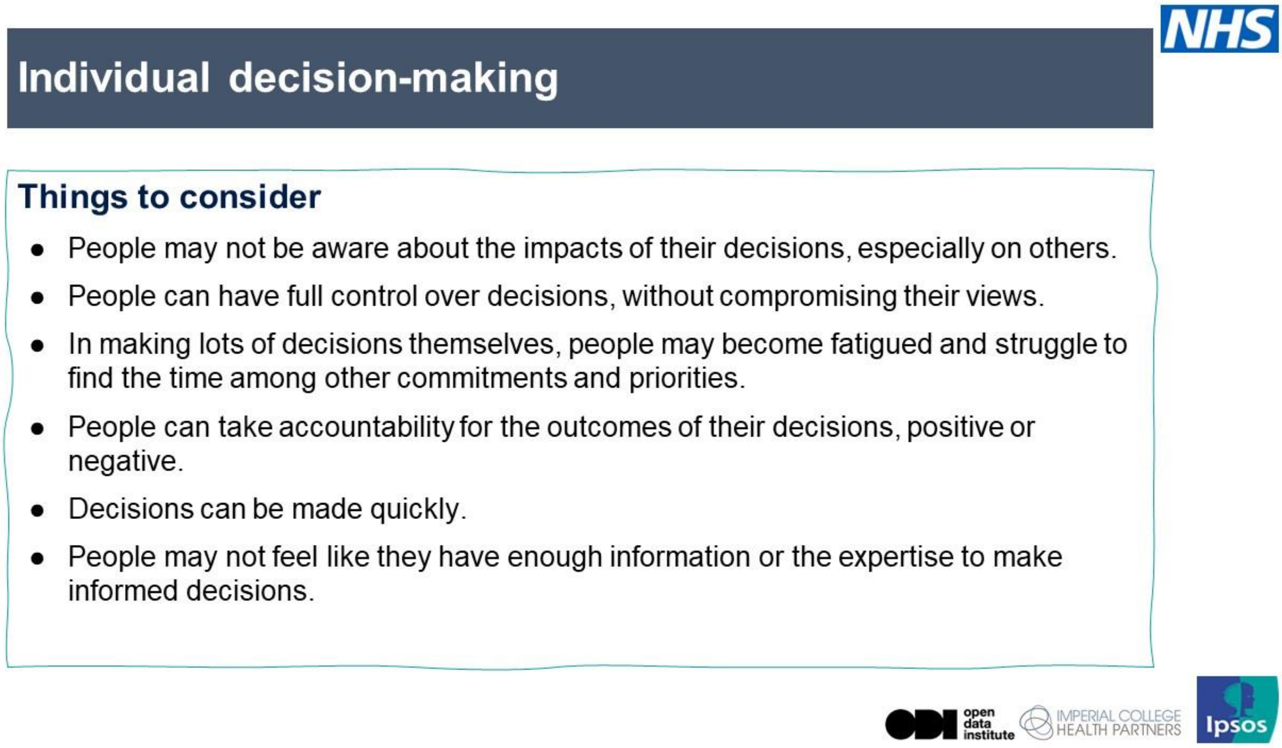
Description: People making decisions for themselves or on behalf of someone they care for.

Example:

- In a day-to-day context, this looks like someone making a decision about who they want to bank with.
- In a health data context, this could look like a patient choosing who can access and use data about them.

I make decisions myself

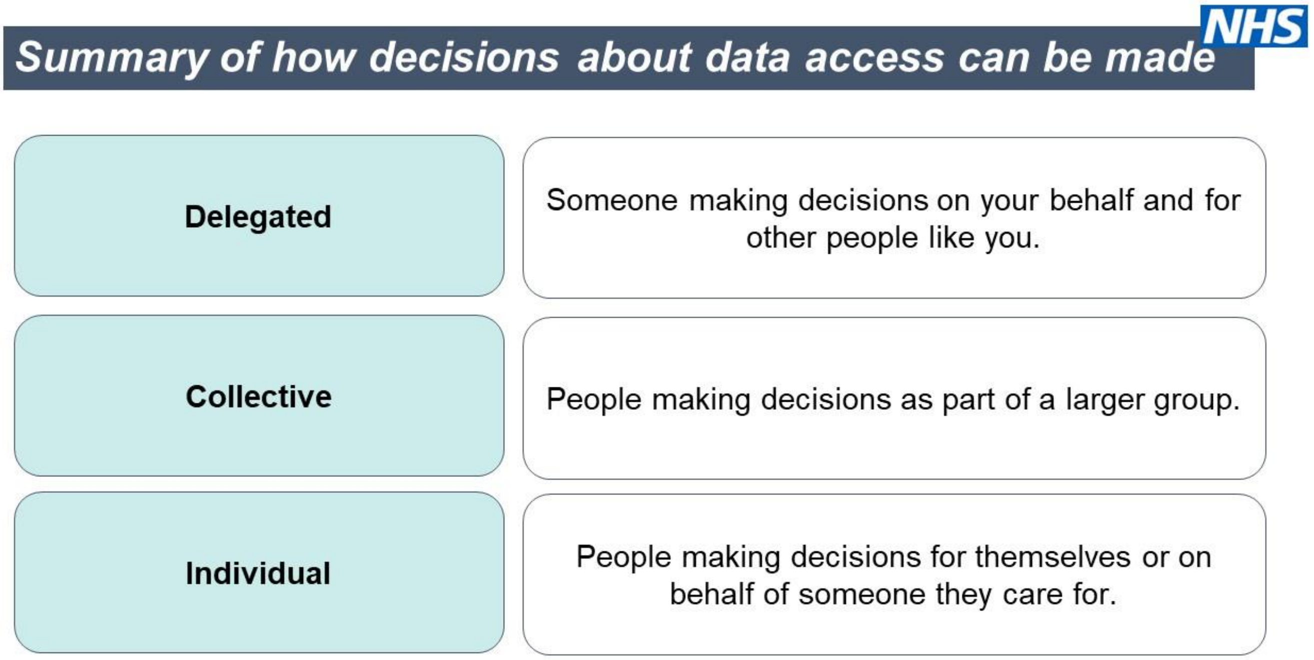
Decision



Individual decision-making

Things to consider

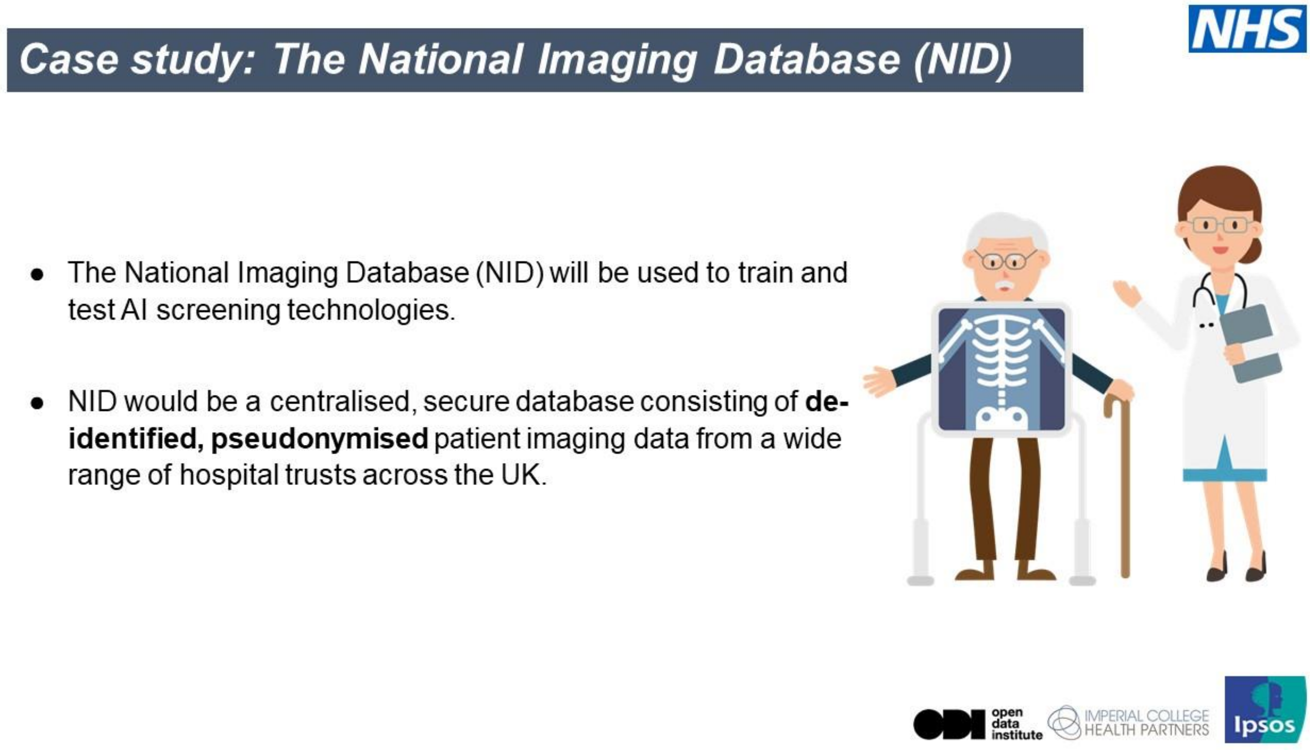
- People may not be aware about the impacts of their decisions, especially on others.
- People can have full control over decisions, without compromising their views.
- In making lots of decisions themselves, people may become fatigued and struggle to find the time among other commitments and priorities.
- People can take accountability for the outcomes of their decisions, positive or negative.
- Decisions can be made quickly.
- People may not feel like they have enough information or the expertise to make informed decisions.



Summary of how decisions about data access can be made

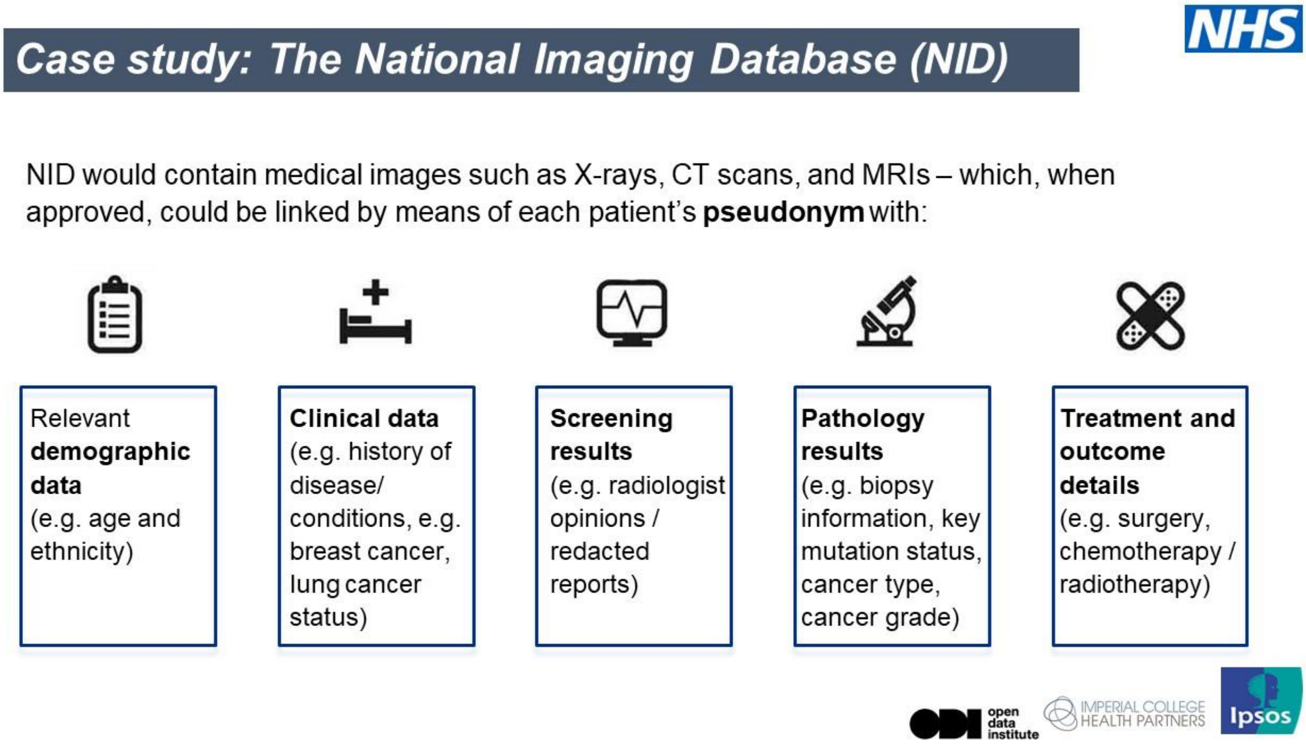
Delegated	Someone making decisions on your behalf and for other people like you.
Collective	People making decisions as part of a larger group.
Individual	People making decisions for themselves or on behalf of someone they care for.

The National Imaging Database (NID)



Case study: The National Imaging Database (NID)

- The National Imaging Database (NID) will be used to train and test AI screening technologies.
- NID would be a centralised, secure database consisting of **de-identified, pseudonymised** patient imaging data from a wide range of hospital trusts across the UK.



Case study: The National Imaging Database (NID)

NID would contain medical images such as X-rays, CT scans, and MRIs – which, when approved, could be linked by means of each patient's **pseudonym** with:

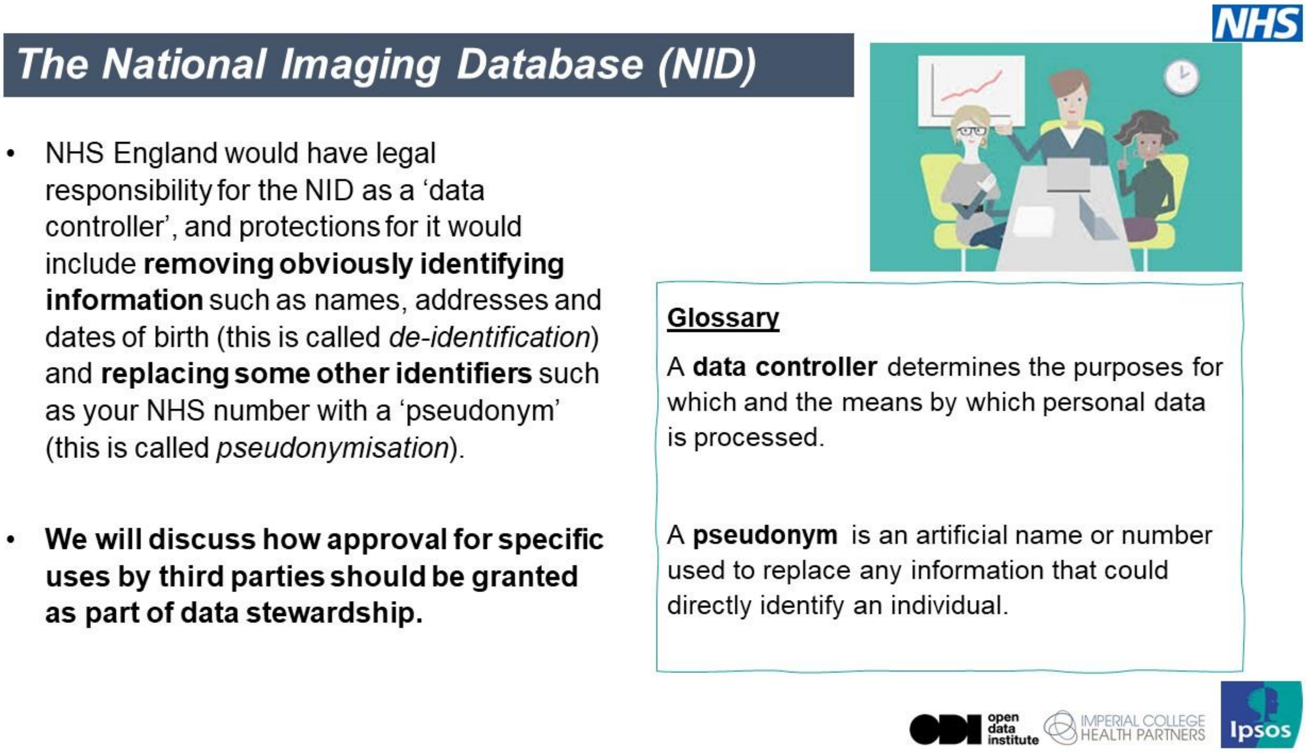
Relevant **demographic data** (e.g. age and ethnicity)

Clinical data (e.g. history of disease/ conditions, e.g. breast cancer, lung cancer status)

Screening results (e.g. radiologist opinions / redacted reports)

Pathology results (e.g. biopsy information, key mutation status, cancer type, cancer grade)

Treatment and outcome details (e.g. surgery, chemotherapy / radiotherapy)



The National Imaging Database (NID)

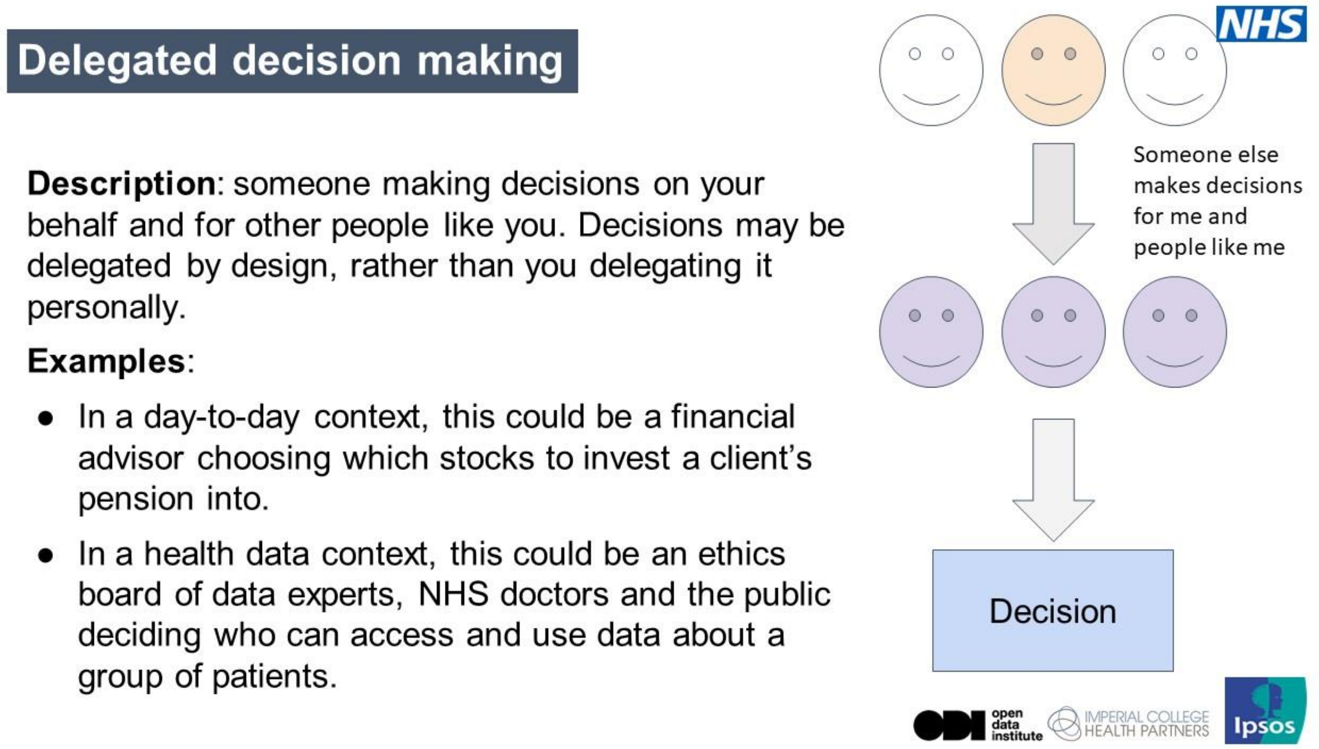
- NHS England would have legal responsibility for the NID as a 'data controller', and protections for it would include **removing obviously identifying information** such as names, addresses and dates of birth (this is called *de-identification*) and **replacing some other identifiers** such as your NHS number with a 'pseudonym' (this is called *pseudonymisation*).
- **We will discuss how approval for specific uses by third parties should be granted as part of data stewardship.**

Glossary

A **data controller** determines the purposes for which and the means by which personal data is processed.

A **pseudonym** is an artificial name or number used to replace any information that could directly identify an individual.

Delegated Scenarios



Delegated decision making

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Examples:

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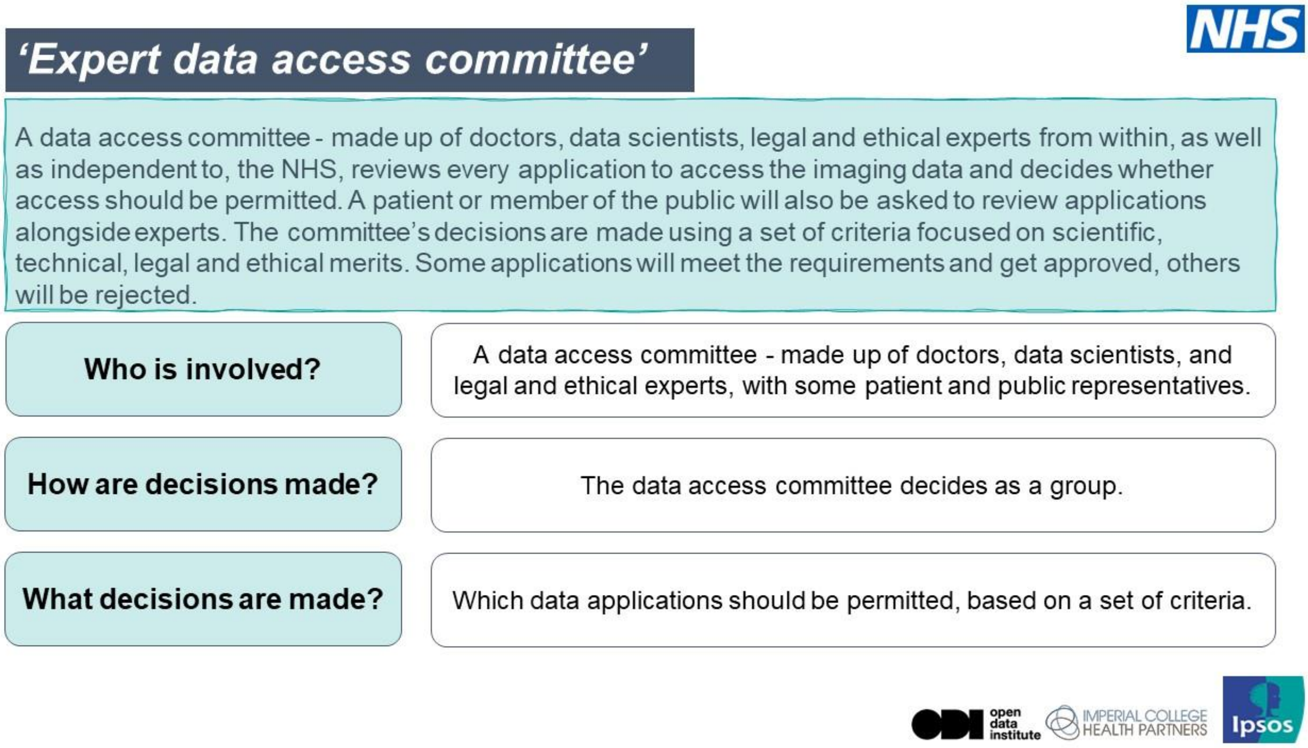
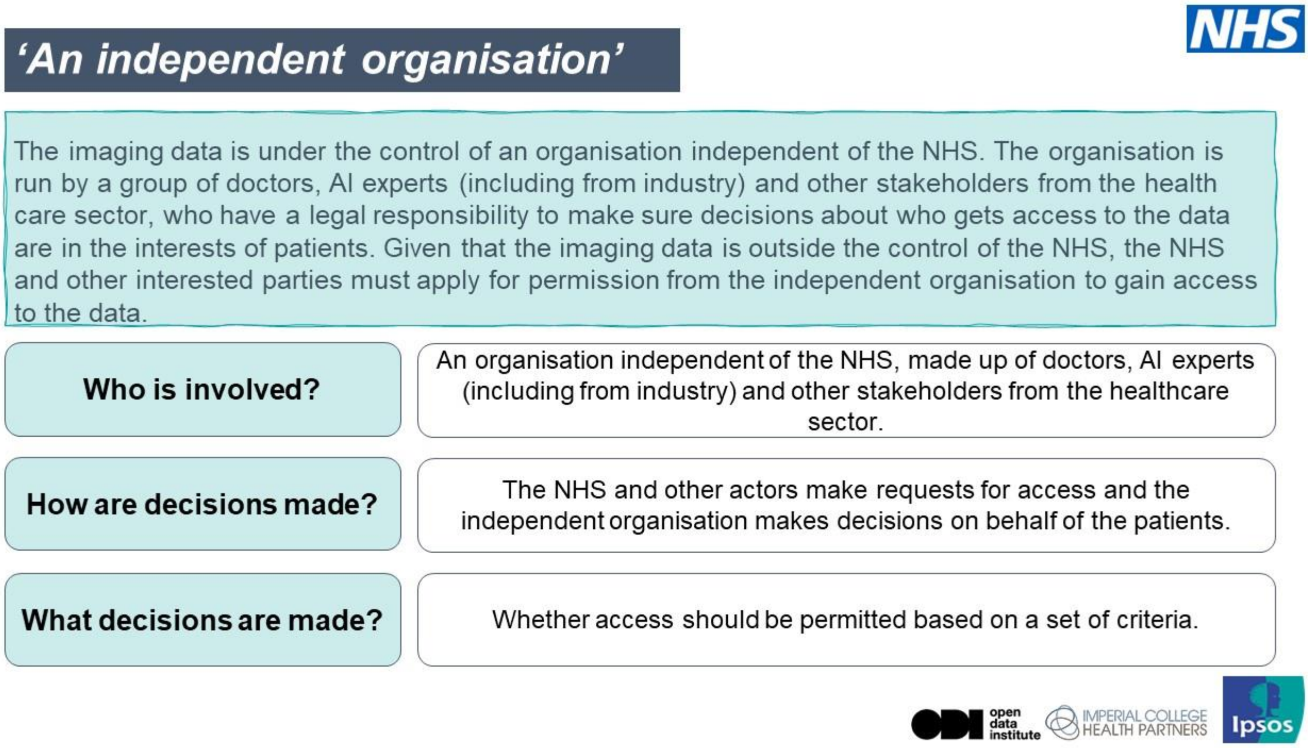
- In a health data context, this could be an ethics board of data experts, NHS doctors and the public deciding who can access and use data about a group of patients.



‘Expert data access committee’

A data access committee - made up of doctors, data scientists, legal and ethical experts from within, as well as independent to, the NHS, reviews every application to access the imaging data and decides whether access should be permitted. A patient or member of the public will also be asked to review applications alongside experts. The committee’s decisions are made using a set of criteria focused on scientific, technical, legal and ethical merits. Some applications will meet the requirements and get approved, others will be rejected.

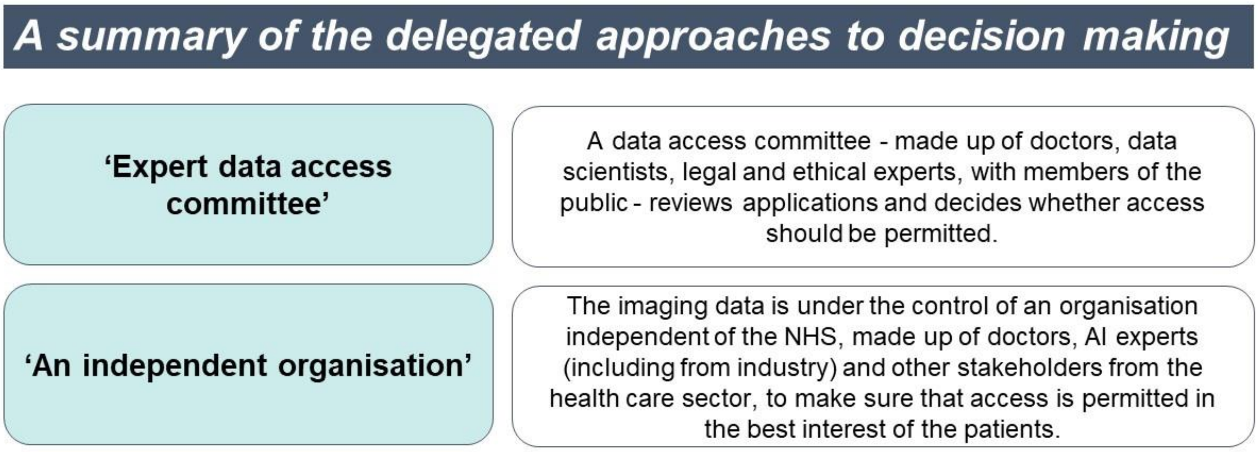
Who is involved?	A data access committee - made up of doctors, data scientists, and legal and ethical experts, with some patient and public representatives.
How are decisions made?	The data access committee decides as a group.
What decisions are made?	Which data applications should be permitted, based on a set of criteria.



‘An independent organisation’

The imaging data is under the control of an organisation independent of the NHS. The organisation is run by a group of doctors, AI experts (including from industry) and other stakeholders from the health care sector, who have a legal responsibility to make sure decisions about who gets access to the data are in the interests of patients. Given that the imaging data is outside the control of the NHS, the NHS and other interested parties must apply for permission from the independent organisation to gain access to the data.

Who is involved?	An organisation independent of the NHS, made up of doctors, AI experts (including from industry) and other stakeholders from the healthcare sector.
How are decisions made?	The NHS and other actors make requests for access and the independent organisation makes decisions on behalf of the patients.
What decisions are made?	Whether access should be permitted based on a set of criteria.



A summary of the delegated approaches to decision making

'Expert data access committee'	A data access committee - made up of doctors, data scientists, legal and ethical experts, with members of the public - reviews applications and decides whether access should be permitted.
'An independent organisation'	The imaging data is under the control of an organisation independent of the NHS, made up of doctors, AI experts (including from industry) and other stakeholders from the health care sector, to make sure that access is permitted in the best interest of the patients.

Workshop 2 – Discussion guide

Saturday 9th July 10.00-13.00pm

DISCUSSION GUIDE

Time	Discussion structure	Process, Questions and materials
9.30-9.55	**Set-up: Facilitators check in** **25 mins**	● Test link, mic and camera. ● Test who has the host/co-host function and ensure it is allocated to the right team member(s) for recording break out rooms. Make all moderators Co-hosts. ● Change screen name to NAME – Org – Chair/Moderator. ● Check everyone is on the WhatsApp group for facilitation team to be able to ask questions etc ● Meanwhile tech support is assigning participants who are in the waiting room, notes takers, moderators, experts and observers to break-out rooms.
9.55-10.05	**Participant Check-in** **10 mins**	**Participants log into the online session** ● Participants encouraged to join the zoom session early to check-in and check their video/mic. ● Participants encouraged to get a pen and paper and have their participant pack with them. ● Register as people join and change screen names as necessary to First name and first initial of surname (i.e. John H).
10.05-10.10	**Introduction and scene setting** **Plenary 1** **5 mins**	**Ipsos Chair to give a warm welcome to the second of four online workshop (<u>5 mins</u>):** ● Introduce Consortium (Ipsos, ODI, ICHP), NHS AI Lab and Sciencewise (SLIDE 1) ● Chair to explain why we are here: expert commentators, any observers, and facilitators and note takers (SLIDE 2) ● Chair to explain that a lot of information will be provided to participants over the course of four workshops, and to always ask or note down any questions/ queries and ask for clarification when needed. ● There will be a lot of quite technical information. If you have questions, raise these with your facilitator and we will either respond there and then or come back to you with a response ● We may cover topics (for example diseases) which people might have personal experience of. If anything that we do cover is triggering, feel free to take a break or come and talk to me (Chair) ● Chair also reintroduce and cover ground rules and additionally…(SLIDE 3) ○ We will be going in to break out rooms -we've set these up so you don't need to do anything – just let it happen ○ If we lose connection to you at any point in the session [INSERT NAME] will call you to see if we can help bring you back in again ○ We'll be capturing discussions live for our own notes. ○ Confidentiality: we are interested in what you say not who said what. Your comments will not be attributed back to you in our report. ○ We have shared materials with you, but please respect that these have been designed for the purpose of this exercise, and please don't post photos or content from these on social media or share otherwise. ● Chair to remind participants of the Five Safes Framework (SLIDE 4)

10.10-10.20	**Introduction to approaches to data stewardship** **Plenary 2** **10mins**	**Presentation (Kira Allman) to introduce approaches to Data Stewardship (SLIDES 5-14)** Before Ipsos chair introduces the speaker, to explain to participants that they might want to jot things down throughout the presentation but also that they have these slides in their packs. - What is data stewardship, with a particular focus on which part of stewardship this dialogue is focused on (SLIDE 6) - How can decisions about access to data be made (SLIDE 7) - Delegated decision making (SLIDES 8 AND 9) - Collective decision making (SLIDES 10 AND 11) - Individual decision making (SLIDES 12 AND 13) - Summary of how decisions about data access can be made (SLIDE 14)
10.20-10.35	**Reflections on approaches to data stewardship** **Breakout 1** **15 mins**	**Facilitators to welcome people, quick intros, and to explain that we have some time to digest, as a group, the information we have just received and think about any immediate questions this raises for us. Remind them that they have this information in their packs to refer to.** READ OUT: We are going to have the opportunity to discuss the three approaches (or buckets) throughout the first part of this morning in more depth, but for now we need to make sure that as a group we understand these and also the differences between them. ▪ How did you find the information in the presentation just now? ▪ To what extent are the differences between delegated, collective, and individual decision-making approaches clear to you? ASK A PARTICIPANT WHO SAYS IT'S CLEAR TO HAVE A GO AT EXPLAINING IT IN THEIR OWN WORDS. ALSO USE SLIDE 14 (SUMMARY) TO TRY AND HELP PEOPLE RECOGNISE THE DIFFERENCES. ▪ What questions, if any, does this information raise for you? *Facilitator to agree with the group which one question they will ask on their behalf and then have a few back up questions in case this is asked by another group.*
10.35-10.45	**Expert Q&A** **Plenary 3** **10 mins**	**Chair to welcome everyone back and to open the floor to questions from each of the eight breakout rooms, emphasising that it is likely that we will only be able to cover one question per group.** *Facilitators to ask one question on behalf of their group, avoiding those questions which have already been asked and answered by other groups.*
10.45-10.55	**BREAK**	*Facilitators to explain to participants that they must be back promptly for a 10.55 start. That they can turn off their cameras and their mic's during the break. Explain that just before 10.55, we will be automatically moved back into the break-out rooms.*
10.55-11.35	**Discussion about data stewardship approaches**	Facilitators to welcome their group back and to explain that we are going to spend the rest of the workshop discussing the three approaches in more detail: what we see as the benefits, what we see as the disadvantages and risks for example.

	Breakout 2 **40 mins**	Facilitator to spend 10 minutes discussing each approach (delegated, collective, individual), ensuring that they leave 10 minutes at the end to discuss the merits of each in relation to one another. **Delegated (10 mins) –** SLIDES 8 AND 9 ▪ How do you feel about this means of deciding who has access to health data for AI research? ▪ Can you think of any pros/cons to this kind of decision making? ▪ What do you think about the ‘things to consider’? ▪ How comfortable would you be if this type of decision making was in place in relation to access to health data about you for AI research? ▪ What would need to be in place for this approach to decision making to feel trustworthy? (by which we mean ‘competent, honest, and reliable)? ▪ To what extent do you feel this decision would be made competently? honestly? reliably? **Collective (10 mins) –** SLIDES 10 AND 11 ▪ How do you feel about this means of deciding who has access to health data for AI research? ▪ Can you think of any pros/cons to this kind of decision making? ▪ What do you think about the ‘things to consider’? ▪ How would you feel about being involved collectively to decide how access to health data about you is used for AI research? Would you want to be involved yourself or have other patient groups debate these? ▪ What would need to be in place for this approach to decision making to feel trustworthy? (by which we mean ‘competent, honest, and reliable)? ▪ To what extent do you feel this decision would be made competently? honestly? reliably? **Individual (10 mins)** – SLIDES 12 AND 13 ▪ How do you feel about this means of deciding who has access to health data for AI research? ▪ Can you think of any pros/cons to this kind of decision making? ▪ What do you think about the ‘things to consider’? ▪ How would you feel about making individual decisions about access to health data about you? ▪ What would need to be in place for you to trust that your decision was being respected? **Comparing and contrasting the approaches and associated trade-offs (10 mins) –** SLIDE 14 READ OUT: Now that we have discussed the merits of each approach separately, lets look at them together. ▪ Which approach do you think is most common in the NHS currently? Why? ▪ Which approach or approaches do you think *should* be used by the NHS going forward in relation to access to health data for AI research? Why? Are some approaches more suitable for different use cases/circumstances?

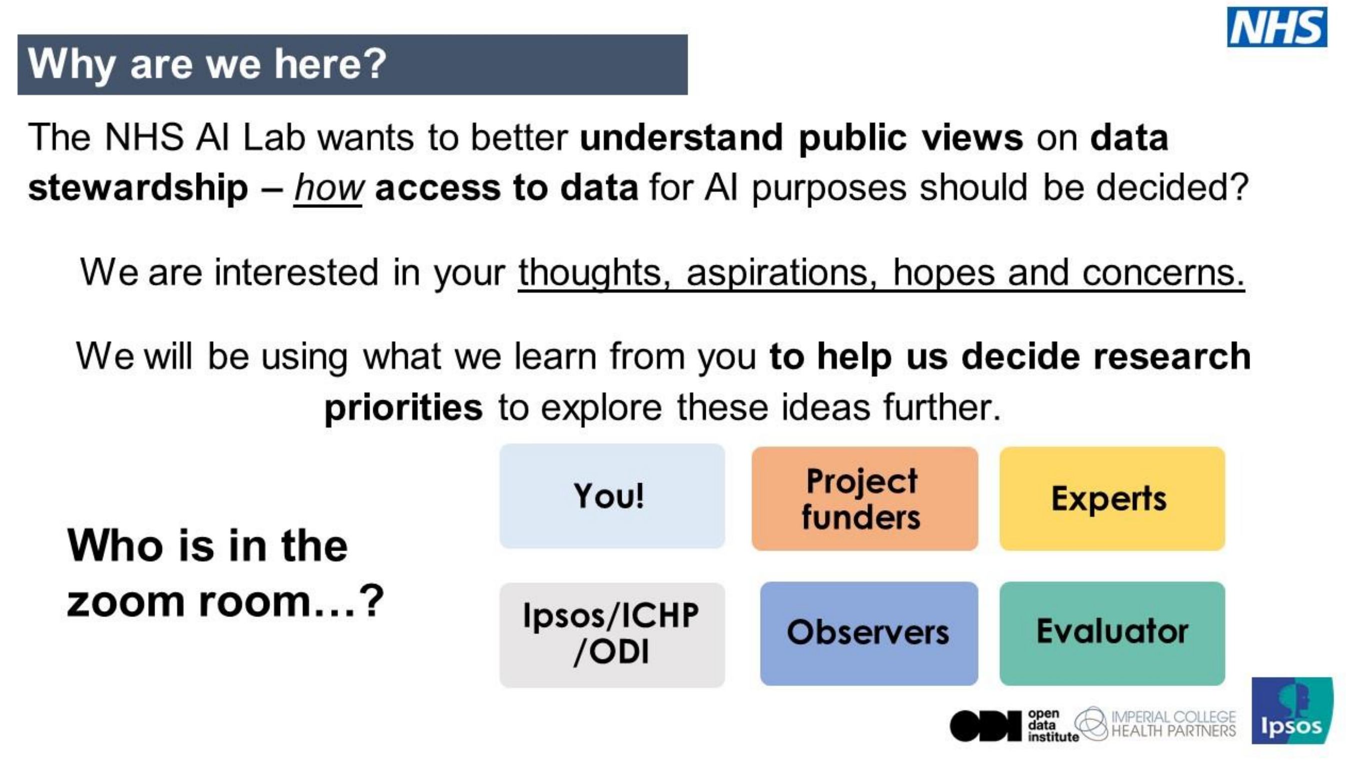
		▪ Bearing in mind the trade-offs that we have discussed, what level of involvement in decisions about access to data should patients and the public believe be offered in the NHS?
11.35-11.45	**Presentation of the NID Case Study** **Break out 3** **10 min**	**Facilitator to introduce the National Imaging Database (NID) which is the case study database that we will be using to explore these approaches to decision making around access.** - Read out SLIDES 16, 17 AND 18 - Check understanding - Invite Qs - Call on an expert should you need them to answer technical questions
11.45-11.55	**BREAK**	*Facilitators to explain to participants that they must be back promptly for a 11.55 start. That they can turn off their cameras and their mic's during the break.*
11.55-12.55	**Discussion around delegated scenarios** **Breakout 4** **60 mins**	**Facilitator to remind participants about delegated decision making (SLIDE 20) and then to introduce the first of the two delegated scenarios** *(we will rotate the order in which these are discussed across the groups)* **spending 30 minutes discussing each scenario.** **Expert data access committee (30 mins) – slide 21** ▪ What are your initial reactions to the idea of an expert data access committee? ▪ How do you feel about this approach to decision making regarding access to National Imaging Database data for AI research? ▪ What do you see to be the **advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example… o Qualified experts are making decisions on patient's behalf. o This type of committee is a common way that the NHS make decisions about data access. o There can be one or two patients or members of the public on the committee, who can share a 'lay' perspective. ▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example… o The committee may choose to give access to a project or organisation that patients are not comfortable with. o People might not feel very involved in making decisions about the data. o The impact of patient representation may be limited among the group of experts. ▪ What would need to be in place for you to trust this committee to make decisions? ▪ How do you feel about the level of involvement of patients and the public here? **An independent organisation (30 mins) – slide 22** ▪ What are your initial reactions to the idea of an independent group? ▪ How do you feel about this approach to decision making regarding access to National Imaging Database data for AI research? ▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example…

		- There is separation between the independent organisation and the NHS, so people may have more confidence that the data will be put to use effectively. - The independent organisation may allow the data to be used for other causes, beyond the NHS's priorities. - The independent organisation has a legal requirement to act in the best interest of the patients. ▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example… - The independent organisation may choose to give access to a project, or organisation, that patients are not comfortable with. - Because the organisation is independent from the NHS, the NHS no longer has control over the data. ▪ What would need to be in place for you to trust this organisation to make decisions? ▪ How do you feel about the level of involvement of patients and the public here?
20.55-21.00	Thank and close in plenary	

Workshop 3 – PowerPoint slides

NHS AI Lab Public Dialogue - Workshop 3

Thursday 14th July 2022 18.00-21.00pm



Why are we here?

The NHS AI Lab wants to better **understand public views** on **data stewardship** – ***how*** **access to data** for AI purposes should be decided?

We are interested in your thoughts, aspirations, hopes and concerns.

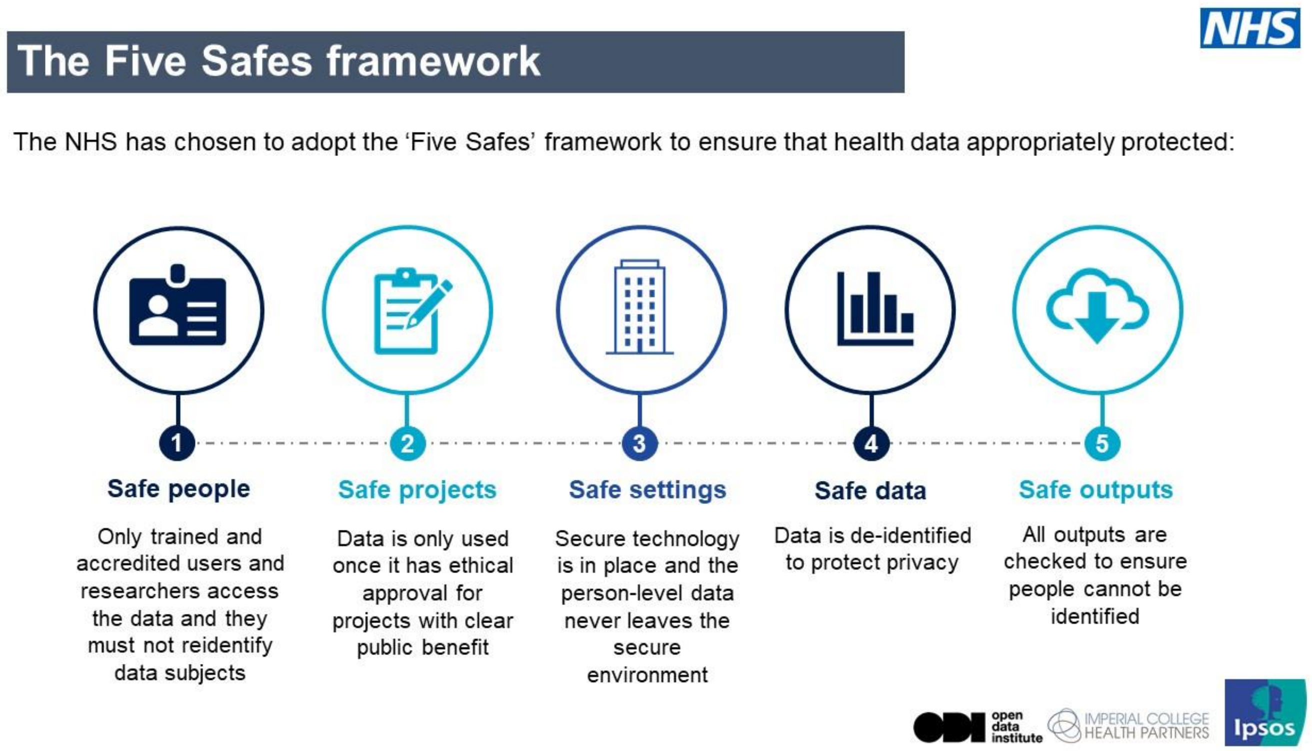
We will be using what we learn from you **to help us decide research priorities** to explore these ideas further.

Who is in the zoom room…?

- You!
- Project funders
- Experts
- Ipsos/ICHP /ODI
- Observers
- Evaluator

Ground Rules

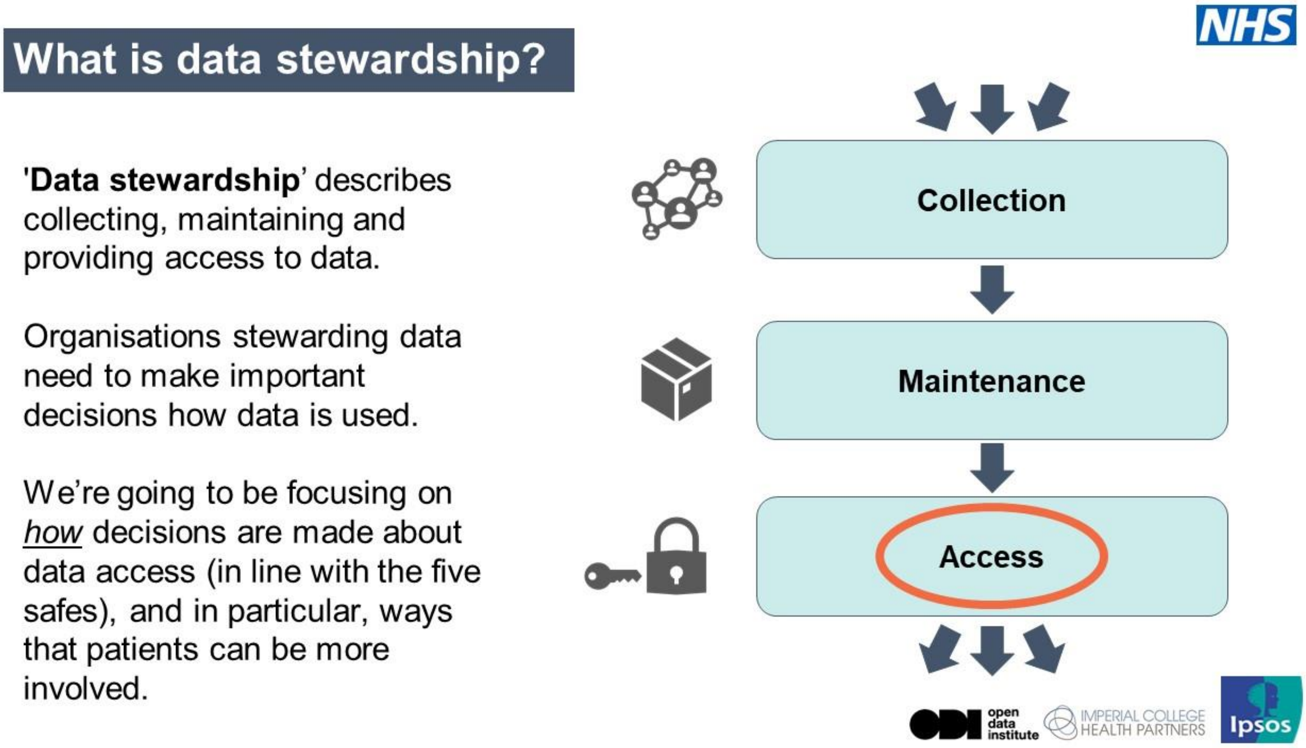
1. Listen **respectfully**, without interrupting.
2. Listen actively and with an ear to **understanding others'** views. (Don't just think about what you are going to say while someone else is talking.)
3. **Any question is a good** question.
4. Criticise ideas, **not individuals**.
5. Commit **to learning**, not debating. Comment in order to share information, not to persuade.
6. Stay on topic and **try to be concise**.
7. **Avoid** blame, speculation, and inflammatory language.
8. Allow everyone the **chance to speak.**
9. **Avoid assumptions** about any member of the group or generalisations about social groups. Do not ask individuals to speak for their (perceived) social group.
10. Keep **distractions to a minimum** (phone on silent, don't multitask)
11. **Be patient** with other participants and the team – we have a lot of information to get through.
12. Feel free to share your thoughts about this event with **friends and family**.
13. If posting **about this event on social media** please do not share any detail of the discussions.
14. Think and act as **citizens,** not just as individuals.



The Five Safes framework

The NHS has chosen to adopt the 'Five Safes' framework to ensure that health data appropriately protected:

1. **Safe people**
   Only trained and accredited users and researchers access the data and they must not reidentify data subjects
2. **Safe projects**
   Data is only used once it has ethical approval for projects with clear public benefit
3. **Safe settings**
   Secure technology is in place and the person-level data never leaves the secure environment
4. **Safe data**
   Data is de-identified to protect privacy
5. **Safe outputs**
   All outputs are checked to ensure people cannot be identified



What is data stewardship?

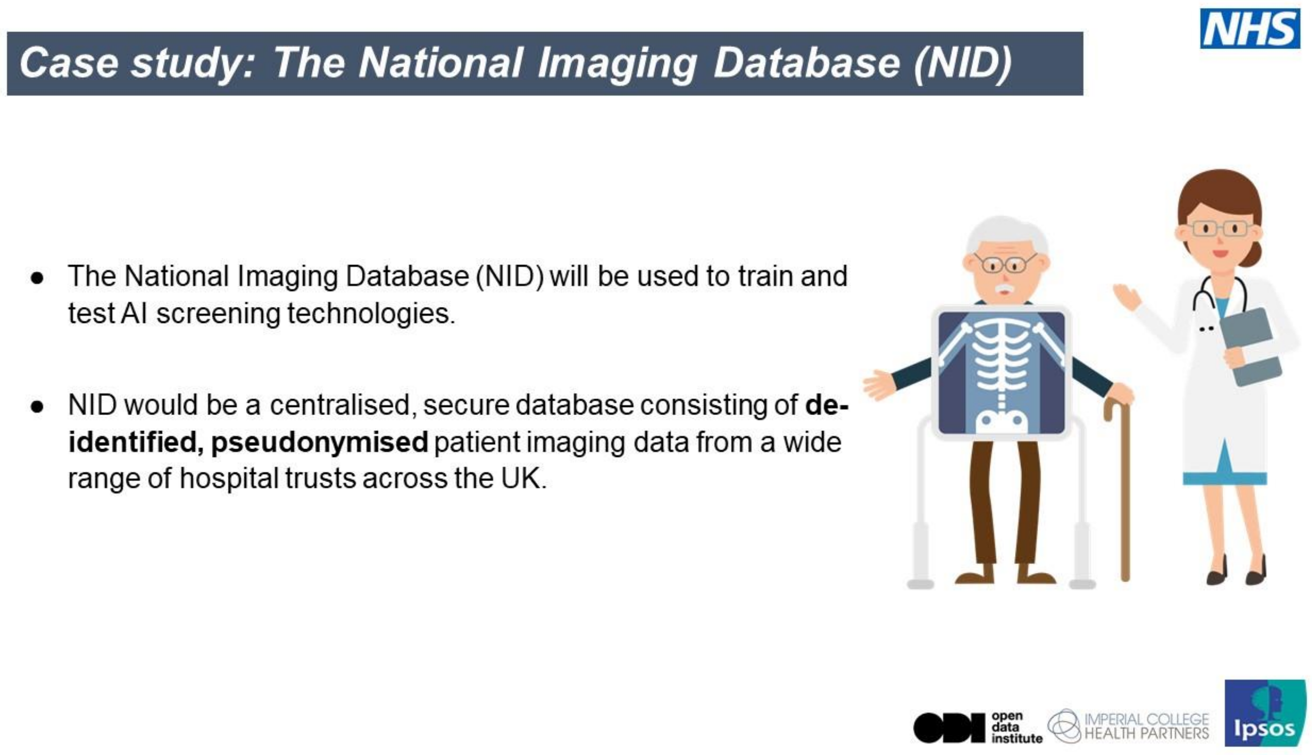
'**Data stewardship**' describes collecting, maintaining and providing access to data.

Organisations stewarding data need to make important decisions how data is used.

We're going to be focusing on *how* decisions are made about data access (in line with the five safes), and in particular, ways that patients can be more involved.

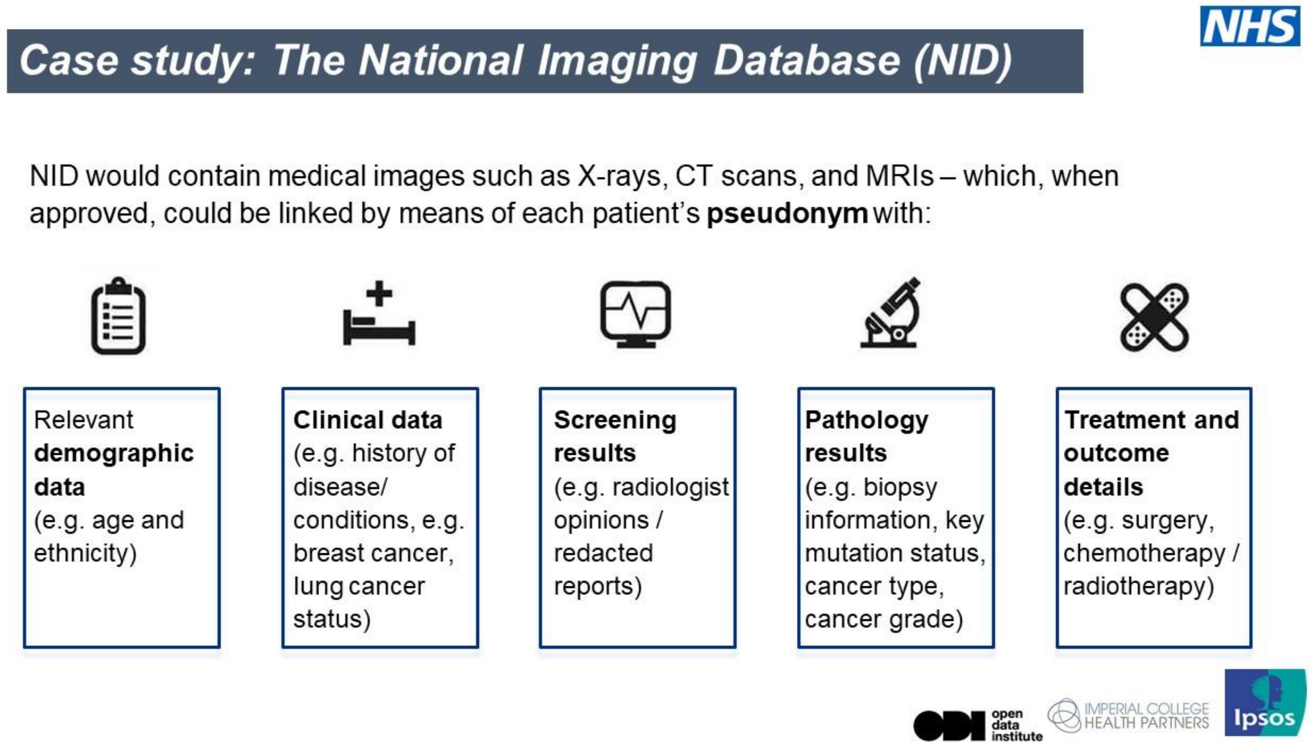
How can decisions about data access be made?

Delegated	Someone making decisions on your behalf and for other people like you.
Collective	People making decisions as part of a larger group.
Individual	People making decisions for themselves or on behalf of someone they care for.



Case study: The National Imaging Database (NID)

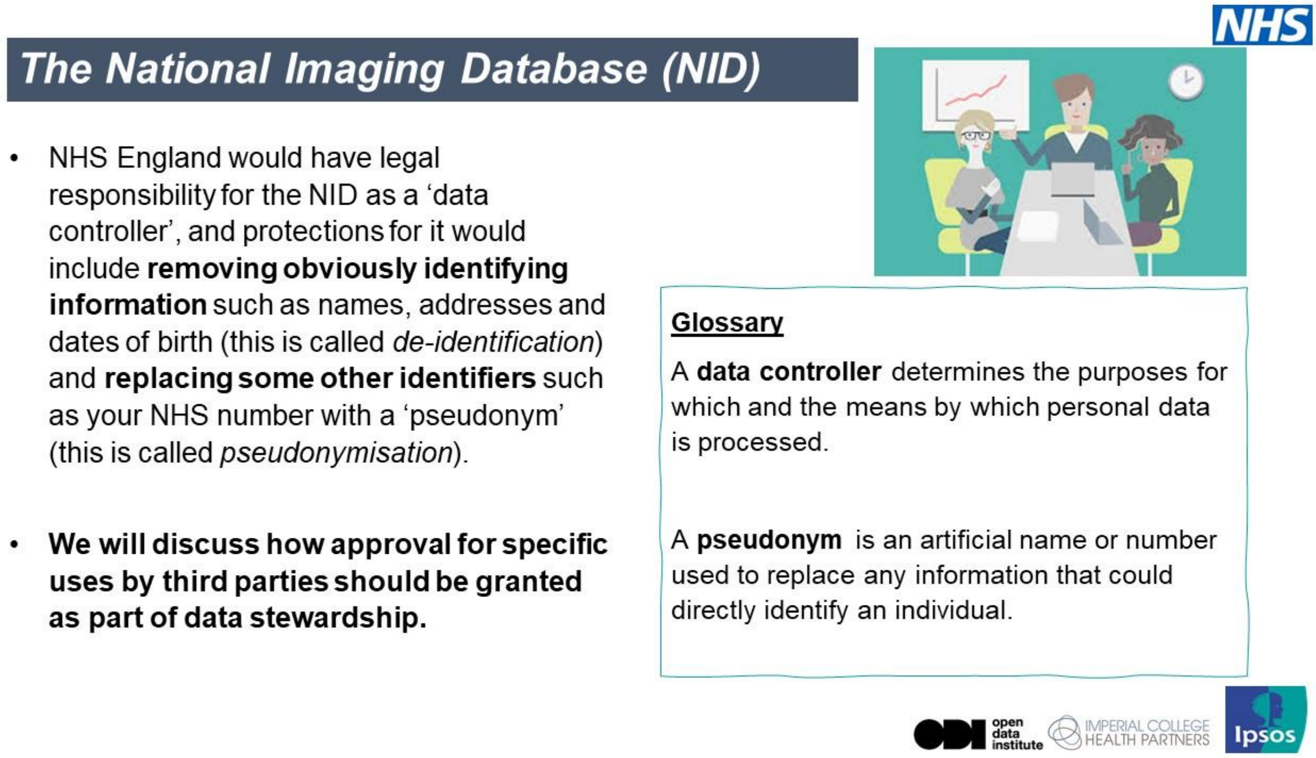
- The National Imaging Database (NID) will be used to train and test AI screening technologies.
- NID would be a centralised, secure database consisting of **de-identified, pseudonymised** patient imaging data from a wide range of hospital trusts across the UK.



Case study: The National Imaging Database (NID)

NID would contain medical images such as X-rays, CT scans, and MRIs – which, when approved, could be linked by means of each patient's **pseudonym** with:

- Relevant **demographic data** (e.g. age and ethnicity)
- **Clinical data** (e.g. history of disease/ conditions, e.g. breast cancer, lung cancer status)
- **Screening results** (e.g. radiologist opinions / redacted reports)
- **Pathology results** (e.g. biopsy information, key mutation status, cancer type, cancer grade)
- **Treatment and outcome details** (e.g. surgery, chemotherapy / radiotherapy)



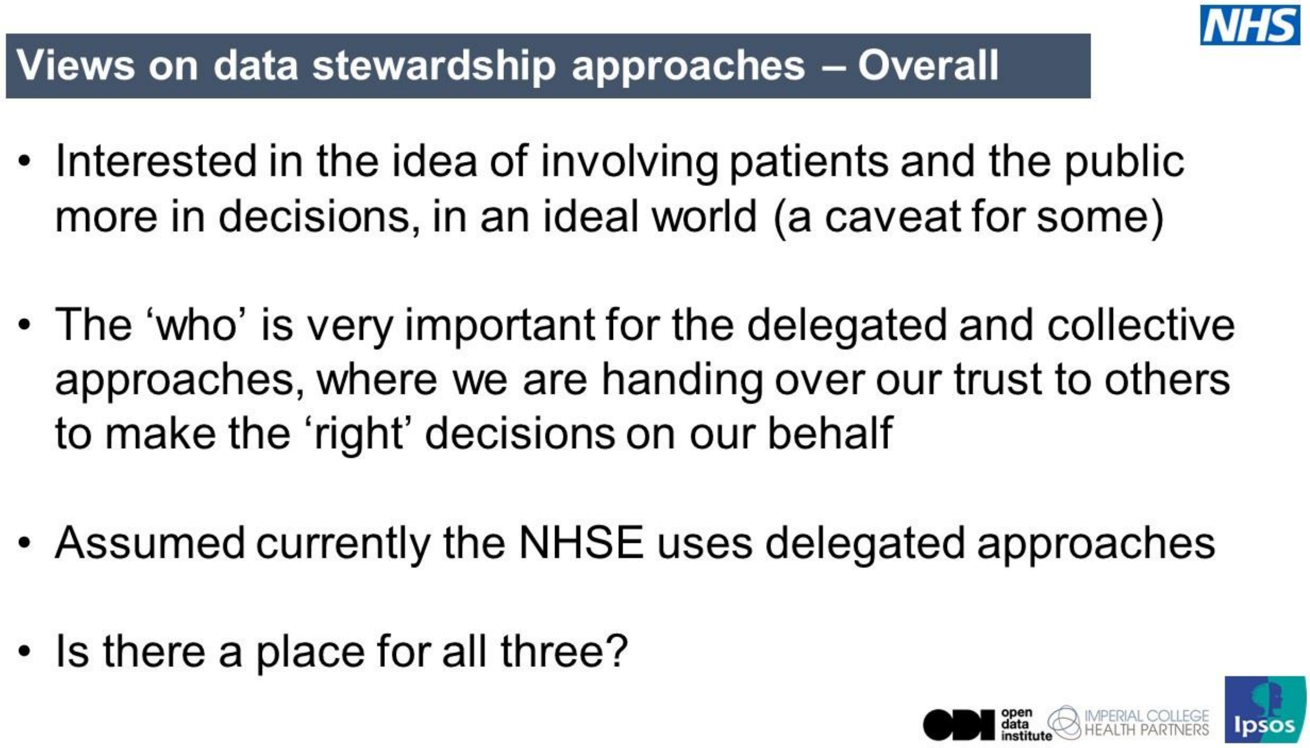
The National Imaging Database (NID)

- NHS England would have legal responsibility for the NID as a ‘data controller’, and protections for it would include **removing obviously identifying information** such as names, addresses and dates of birth (this is called *de-identification*) and **replacing some other identifiers** such as your NHS number with a ‘pseudonym’ (this is called *pseudonymisation*).
- **We will discuss how approval for specific uses by third parties should be granted as part of data stewardship.**

Glossary

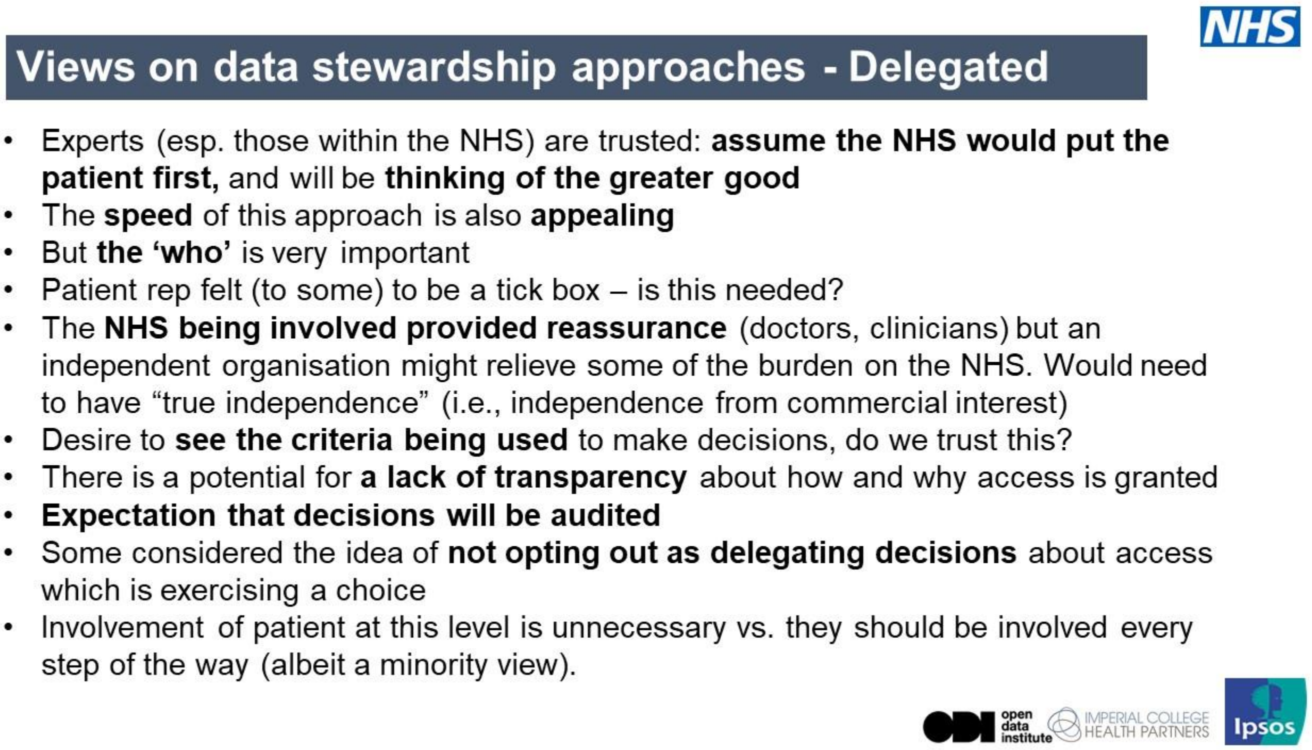
A **data controller** determines the purposes for which and the means by which personal data is processed.

A **pseudonym** is an artificial name or number used to replace any information that could directly identify an individual.



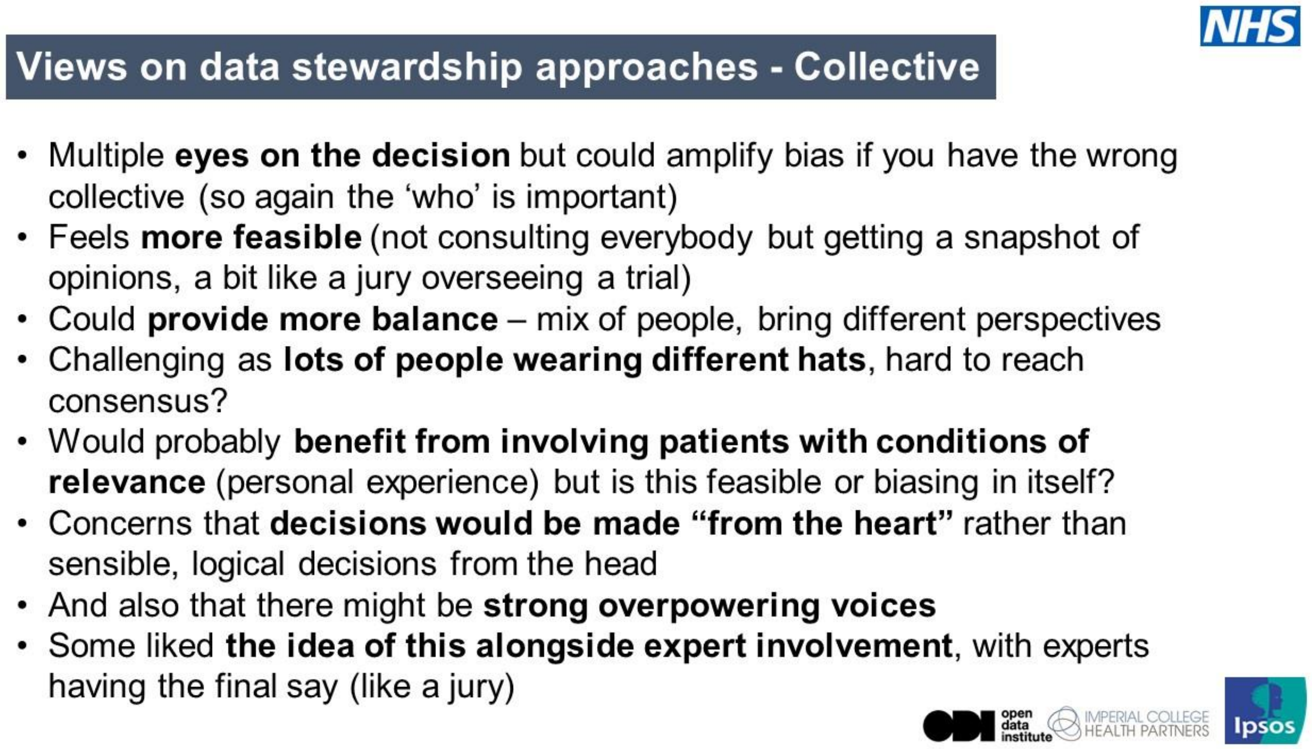
Views on data stewardship approaches – Overall

- Interested in the idea of involving patients and the public more in decisions, in an ideal world (a caveat for some)
- The ‘who’ is very important for the delegated and collective approaches, where we are handing over our trust to others to make the ‘right’ decisions on our behalf
- Assumed currently the NHSE uses delegated approaches
- Is there a place for all three?



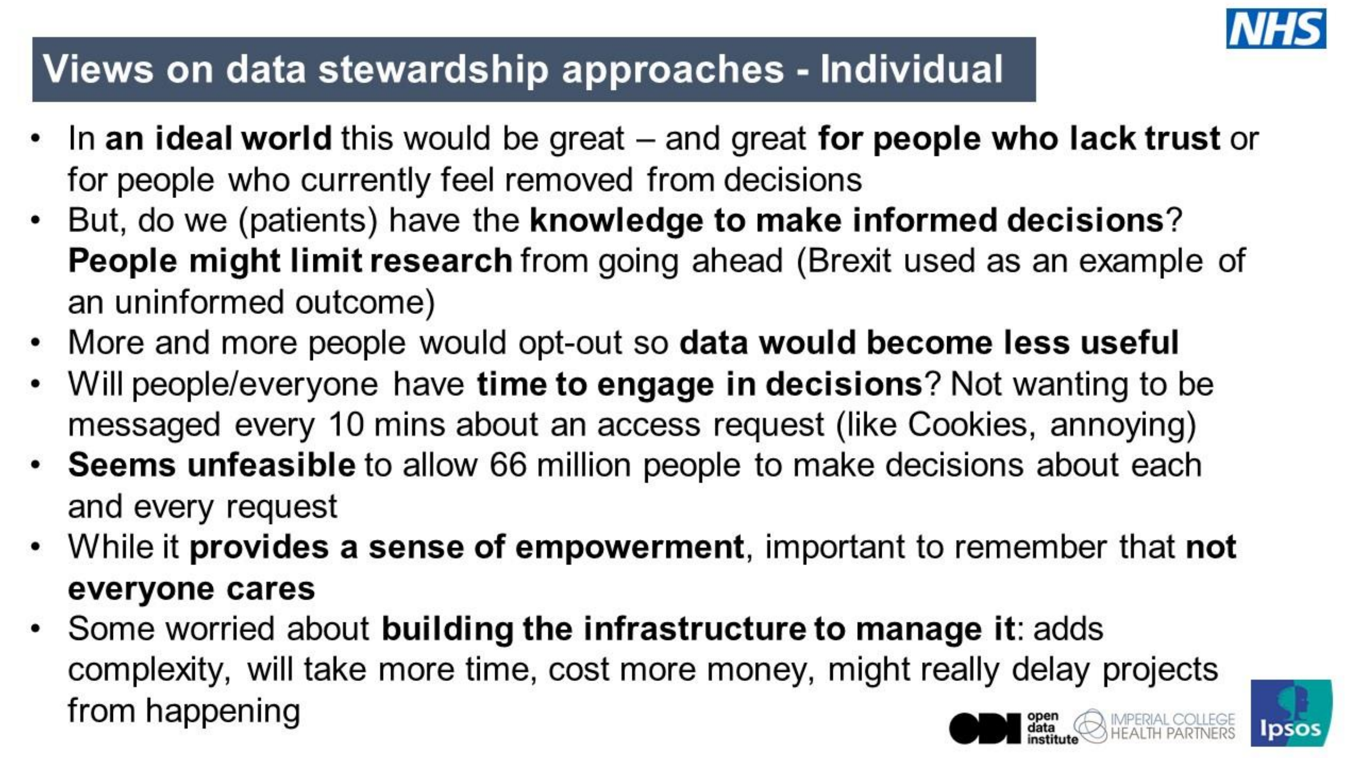
Views on data stewardship approaches - Delegated

- Experts (esp. those within the NHS) are trusted: **assume the NHS would put the patient first,** and will be **thinking of the greater good**
- The **speed** of this approach is also **appealing**
- But **the 'who'** is very important
- Patient rep felt (to some) to be a tick box – is this needed?
- The **NHS being involved provided reassurance** (doctors, clinicians) but an independent organisation might relieve some of the burden on the NHS. Would need to have "true independence" (i.e., independence from commercial interest)
- Desire to **see the criteria being used** to make decisions, do we trust this?
- There is a potential for **a lack of transparency** about how and why access is granted
- **Expectation that decisions will be audited**
- Some considered the idea of **not opting out as delegating decisions** about access which is exercising a choice
- Involvement of patient at this level is unnecessary vs. they should be involved every step of the way (albeit a minority view).



Views on data stewardship approaches - Collective

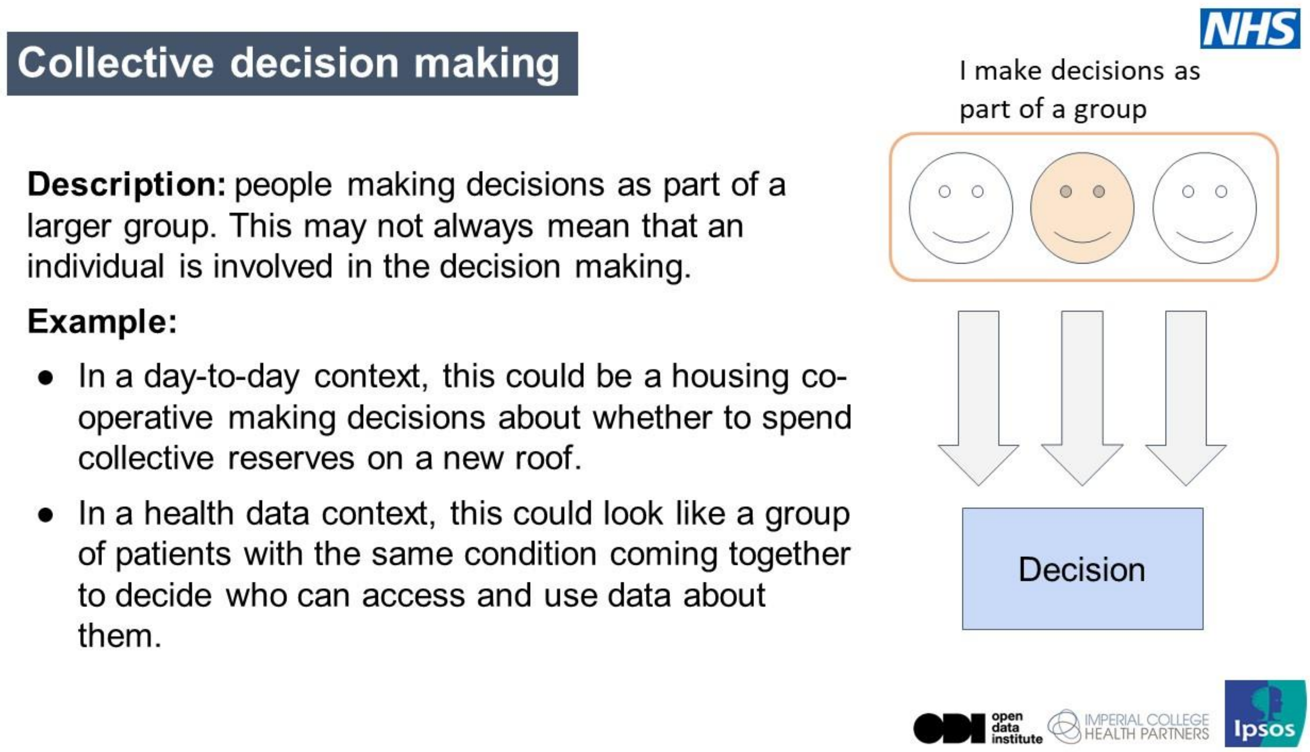
- Multiple **eyes on the decision** but could amplify bias if you have the wrong collective (so again the 'who' is important)
- Feels **more feasible** (not consulting everybody but getting a snapshot of opinions, a bit like a jury overseeing a trial)
- Could **provide more balance** – mix of people, bring different perspectives
- Challenging as **lots of people wearing different hats**, hard to reach consensus?
- Would probably **benefit from involving patients with conditions of relevance** (personal experience) but is this feasible or biasing in itself?
- Concerns that **decisions would be made "from the heart"** rather than sensible, logical decisions from the head
- And also that there might be **strong overpowering voices**
- Some liked **the idea of this alongside expert involvement**, with experts having the final say (like a jury)



Views on data stewardship approaches - Individual

- In **an ideal world** this would be great – and great **for people who lack trust** or for people who currently feel removed from decisions
- But, do we (patients) have the **knowledge to make informed decisions**? **People might limit research** from going ahead (Brexit used as an example of an uninformed outcome)
- More and more people would opt-out so **data would become less useful**
- Will people/everyone have **time to engage in decisions**? Not wanting to be messaged every 10 mins about an access request (like Cookies, annoying)
- **Seems unfeasible** to allow 66 million people to make decisions about each and every request
- While it **provides a sense of empowerment**, important to remember that **not everyone cares**
- Some worried about **building the infrastructure to manage it**: adds complexity, will take more time, cost more money, might really delay projects from happening

Collective Scenarios



Collective decision making

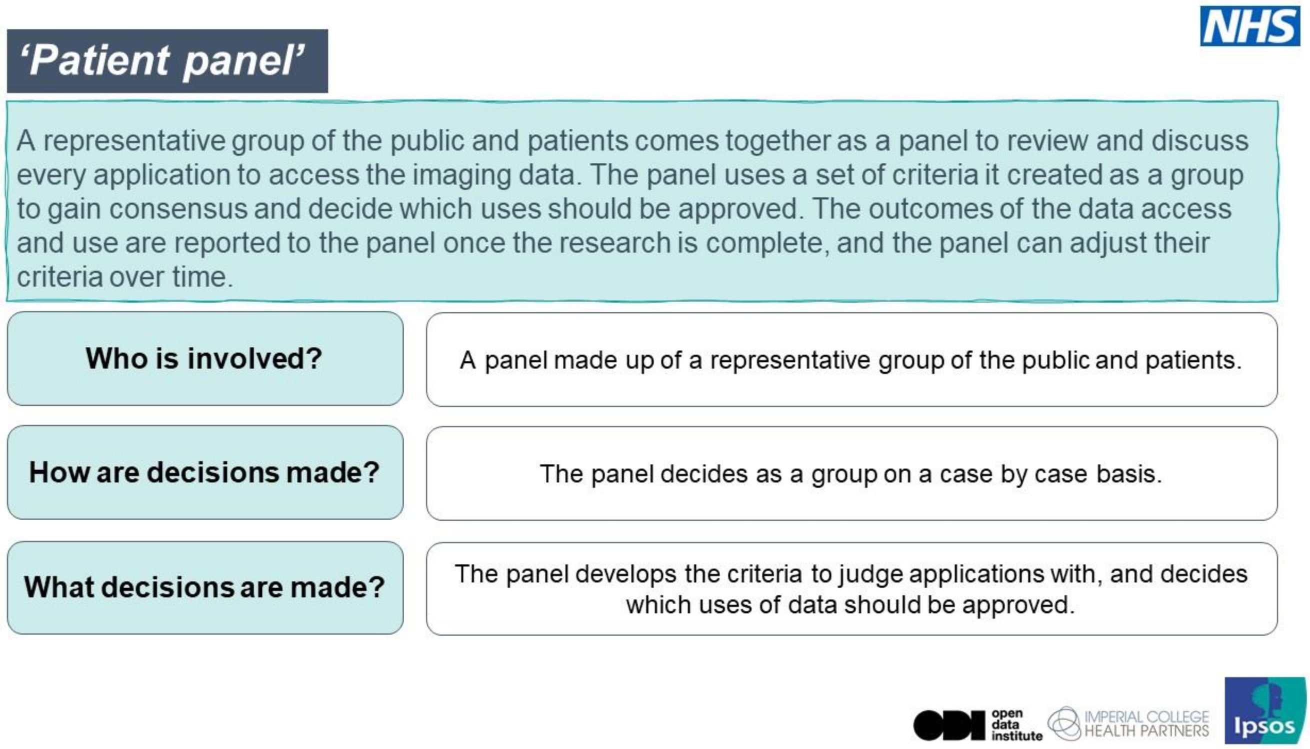
Description: people making decisions as part of a larger group. This may not always mean that an individual is involved in the decision making.

Example:

- In a day-to-day context, this could be a housing co-operative making decisions about whether to spend collective reserves on a new roof.
- In a health data context, this could look like a group of patients with the same condition coming together to decide who can access and use data about them.

I make decisions as part of a group

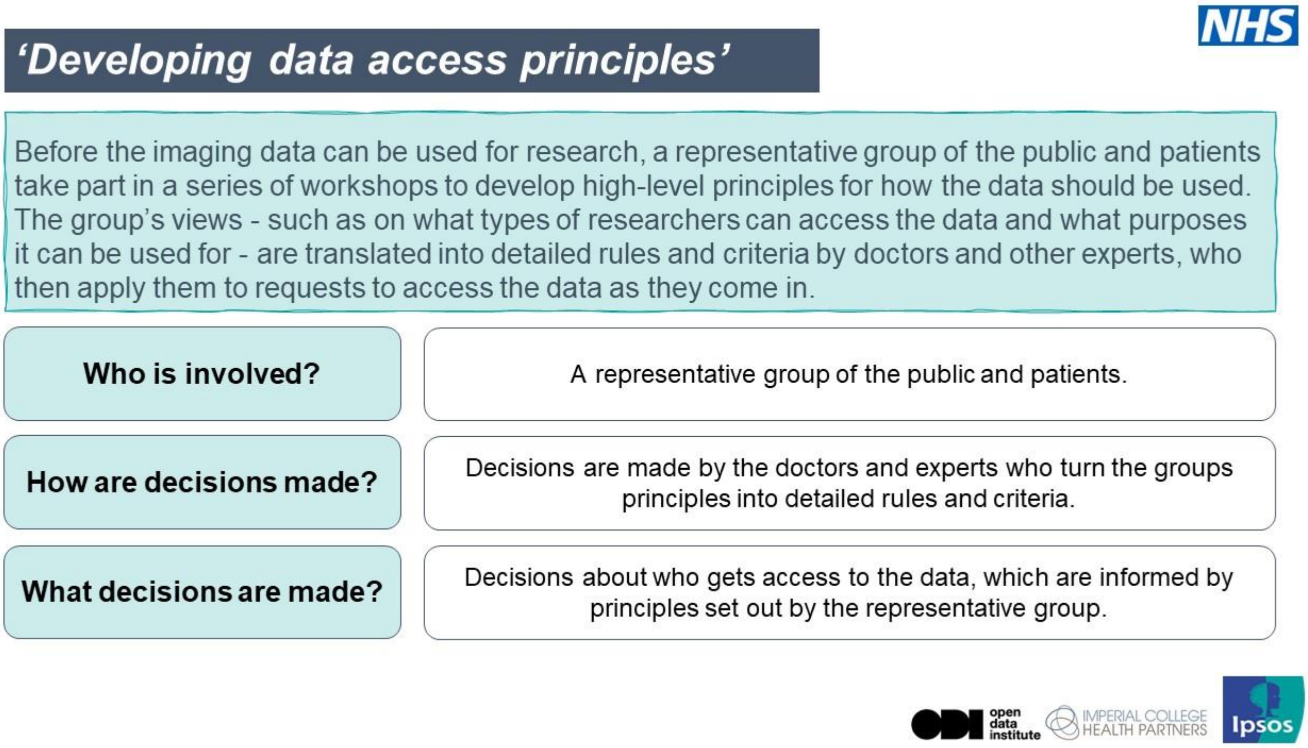
Decision



‘Patient panel’

A representative group of the public and patients comes together as a panel to review and discuss every application to access the imaging data. The panel uses a set of criteria it created as a group to gain consensus and decide which uses should be approved. The outcomes of the data access and use are reported to the panel once the research is complete, and the panel can adjust their criteria over time.

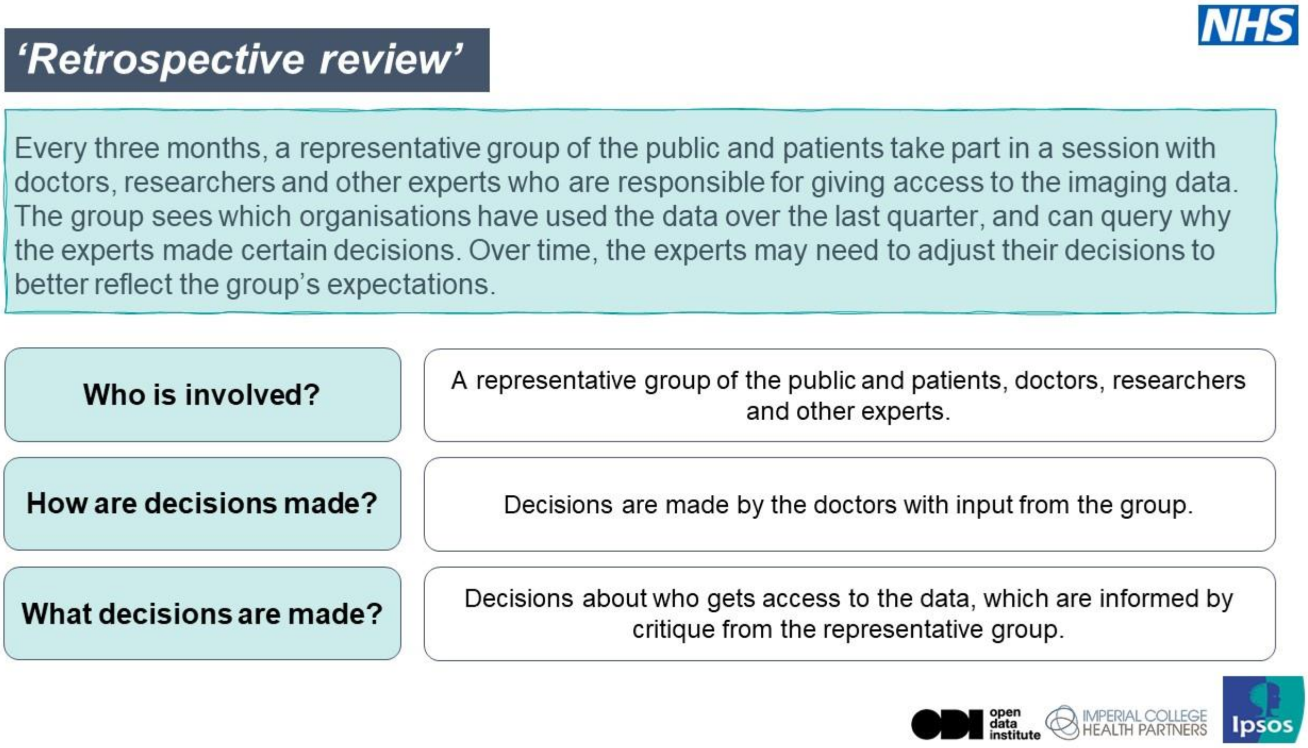
Who is involved?	A panel made up of a representative group of the public and patients.
How are decisions made?	The panel decides as a group on a case by case basis.
What decisions are made?	The panel develops the criteria to judge applications with, and decides which uses of data should be approved.



‘Developing data access principles’

Before the imaging data can be used for research, a representative group of the public and patients take part in a series of workshops to develop high-level principles for how the data should be used. The group’s views - such as on what types of researchers can access the data and what purposes it can be used for - are translated into detailed rules and criteria by doctors and other experts, who then apply them to requests to access the data as they come in.

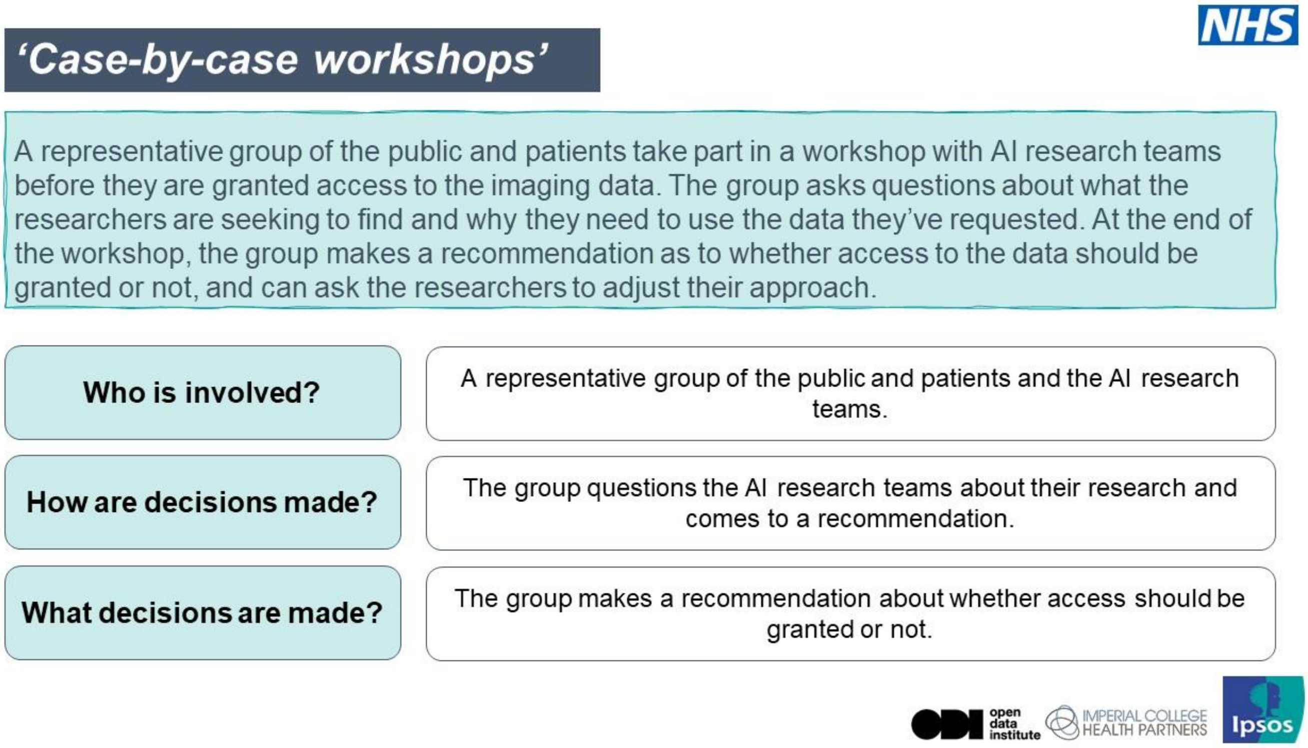
Who is involved?	A representative group of the public and patients.
How are decisions made?	Decisions are made by the doctors and experts who turn the groups principles into detailed rules and criteria.
What decisions are made?	Decisions about who gets access to the data, which are informed by principles set out by the representative group.



‘Retrospective review’

Every three months, a representative group of the public and patients take part in a session with doctors, researchers and other experts who are responsible for giving access to the imaging data. The group sees which organisations have used the data over the last quarter, and can query why the experts made certain decisions. Over time, the experts may need to adjust their decisions to better reflect the group’s expectations.

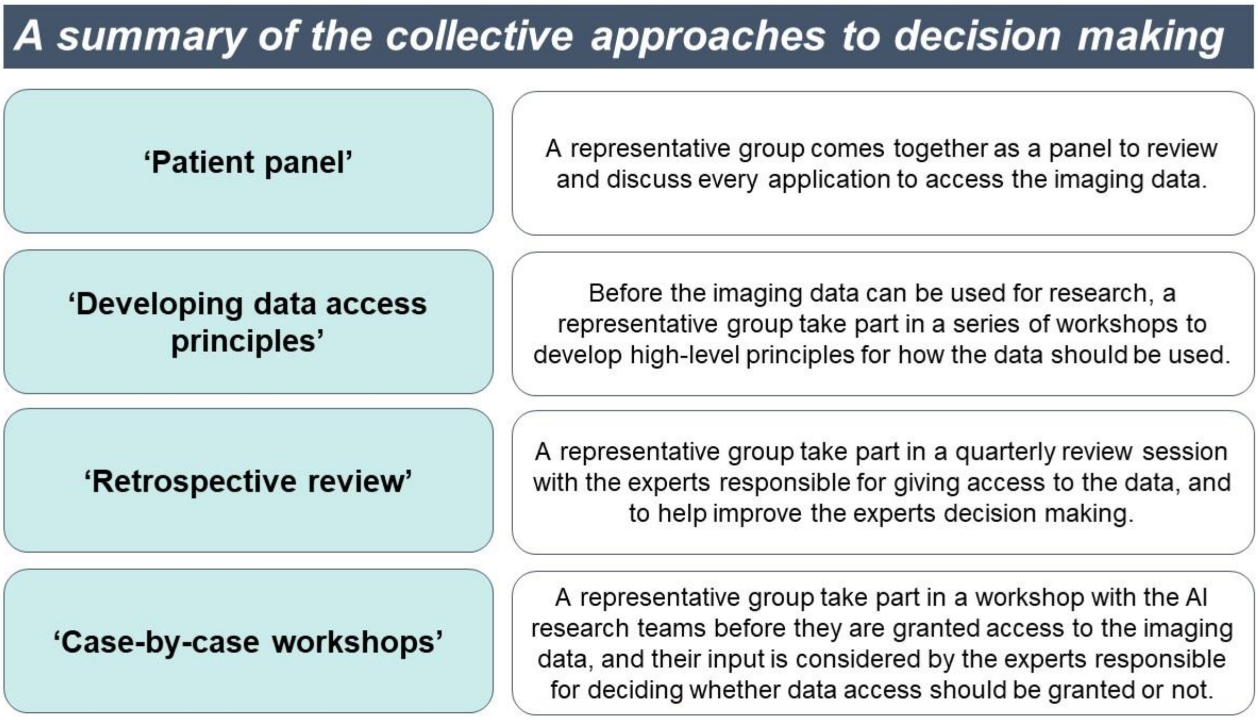
Who is involved?	A representative group of the public and patients, doctors, researchers and other experts.
How are decisions made?	Decisions are made by the doctors with input from the group.
What decisions are made?	Decisions about who gets access to the data, which are informed by critique from the representative group.



‘Case-by-case workshops’

A representative group of the public and patients take part in a workshop with AI research teams before they are granted access to the imaging data. The group asks questions about what the researchers are seeking to find and why they need to use the data they’ve requested. At the end of the workshop, the group makes a recommendation as to whether access to the data should be granted or not, and can ask the researchers to adjust their approach.

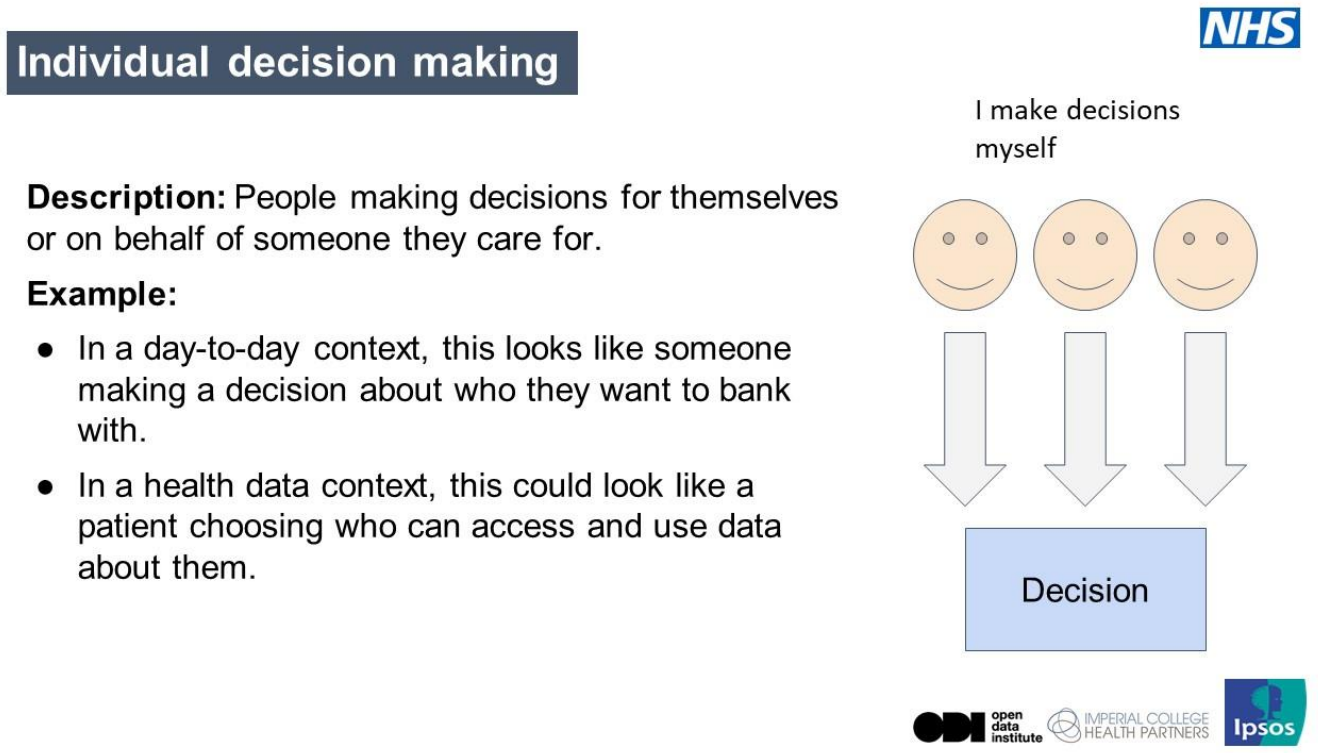
Who is involved?	A representative group of the public and patients and the AI research teams.
How are decisions made?	The group questions the AI research teams about their research and comes to a recommendation.
What decisions are made?	The group makes a recommendation about whether access should be granted or not.



A summary of the collective approaches to decision making

‘Patient panel’	A representative group comes together as a panel to review and discuss every application to access the imaging data.
‘Developing data access principles’	Before the imaging data can be used for research, a representative group take part in a series of workshops to develop high-level principles for how the data should be used.
‘Retrospective review’	A representative group take part in a quarterly review session with the experts responsible for giving access to the data, and to help improve the experts decision making.
‘Case-by-case workshops’	A representative group take part in a workshop with the AI research teams before they are granted access to the imaging data, and their input is considered by the experts responsible for deciding whether data access should be granted or not.

Individual Scenarios



Individual decision making

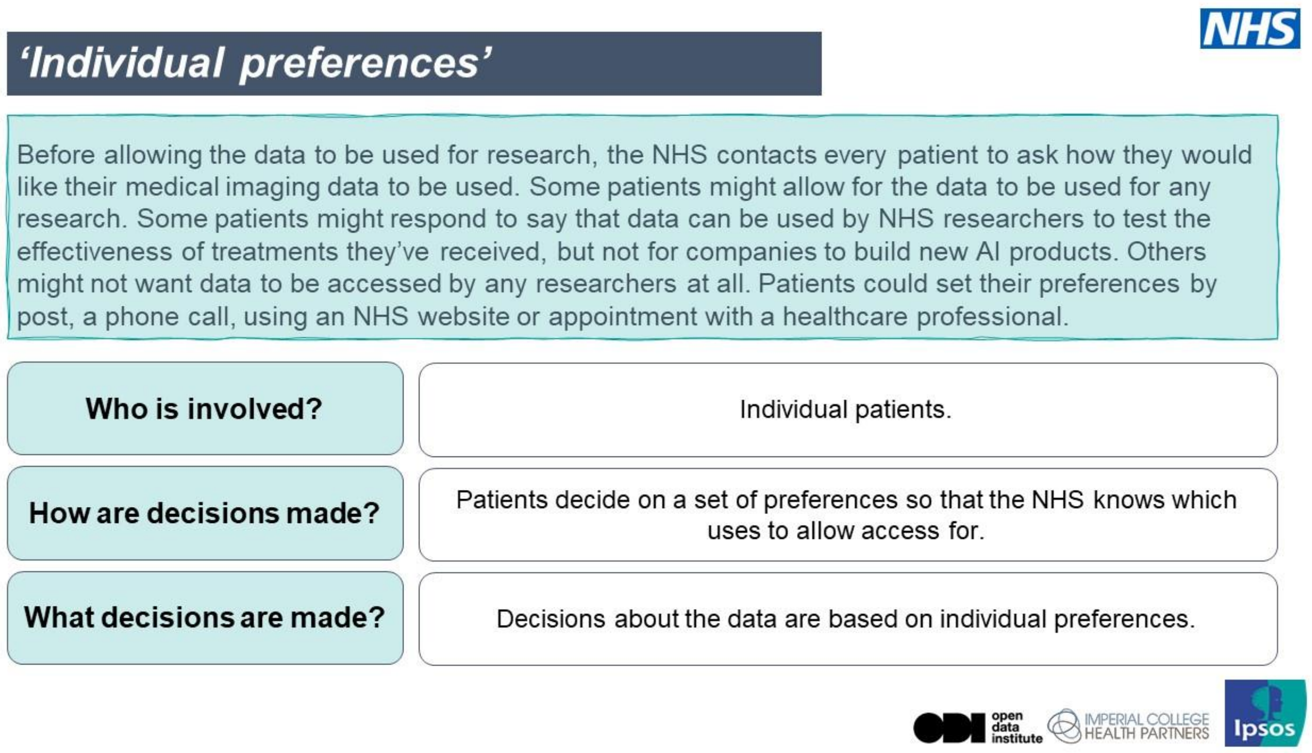
Description: People making decisions for themselves or on behalf of someone they care for.

Example:

- In a day-to-day context, this looks like someone making a decision about who they want to bank with.
- In a health data context, this could look like a patient choosing who can access and use data about them.

I make decisions myself

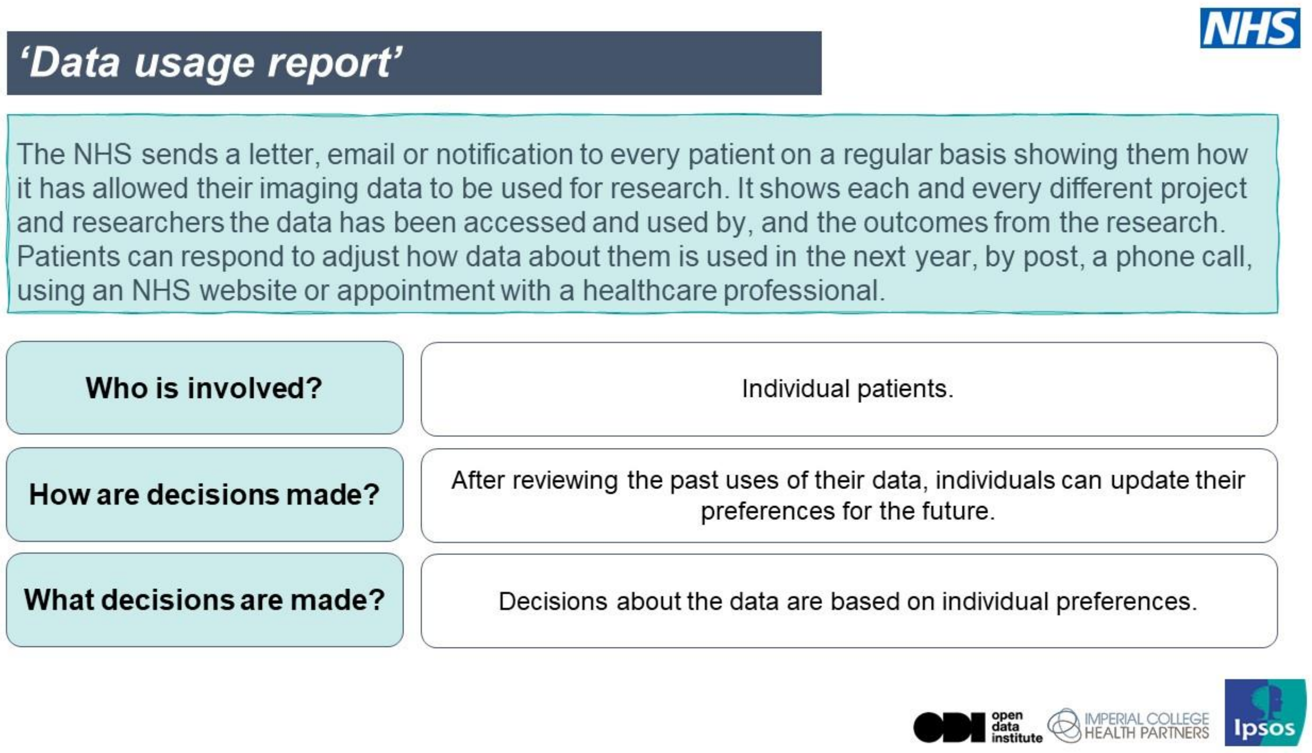
Decision



‘Individual preferences’

Before allowing the data to be used for research, the NHS contacts every patient to ask how they would like their medical imaging data to be used. Some patients might allow for the data to be used for any research. Some patients might respond to say that data can be used by NHS researchers to test the effectiveness of treatments they’ve received, but not for companies to build new AI products. Others might not want data to be accessed by any researchers at all. Patients could set their preferences by post, a phone call, using an NHS website or appointment with a healthcare professional.

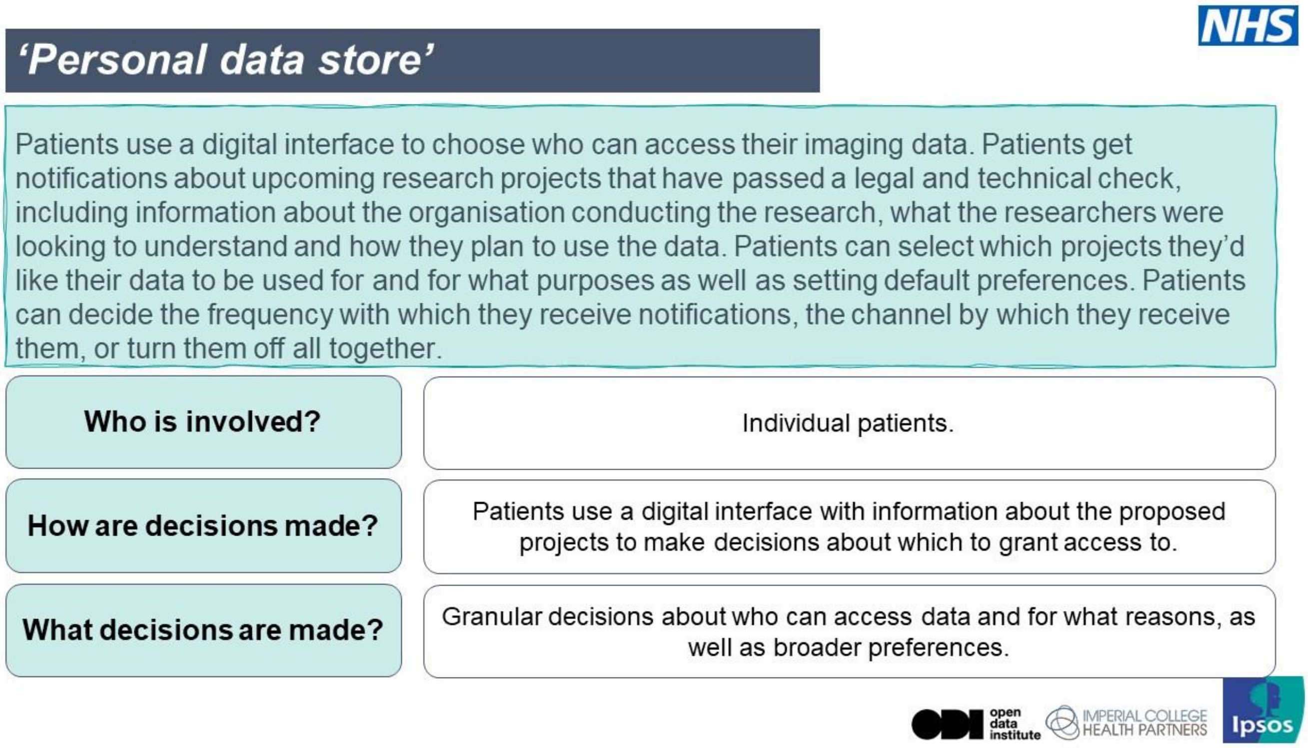
Who is involved?	Individual patients.
How are decisions made?	Patients decide on a set of preferences so that the NHS knows which uses to allow access for.
What decisions are made?	Decisions about the data are based on individual preferences.



‘Data usage report’

The NHS sends a letter, email or notification to every patient on a regular basis showing them how it has allowed their imaging data to be used for research. It shows each and every different project and researchers the data has been accessed and used by, and the outcomes from the research. Patients can respond to adjust how data about them is used in the next year, by post, a phone call, using an NHS website or appointment with a healthcare professional.

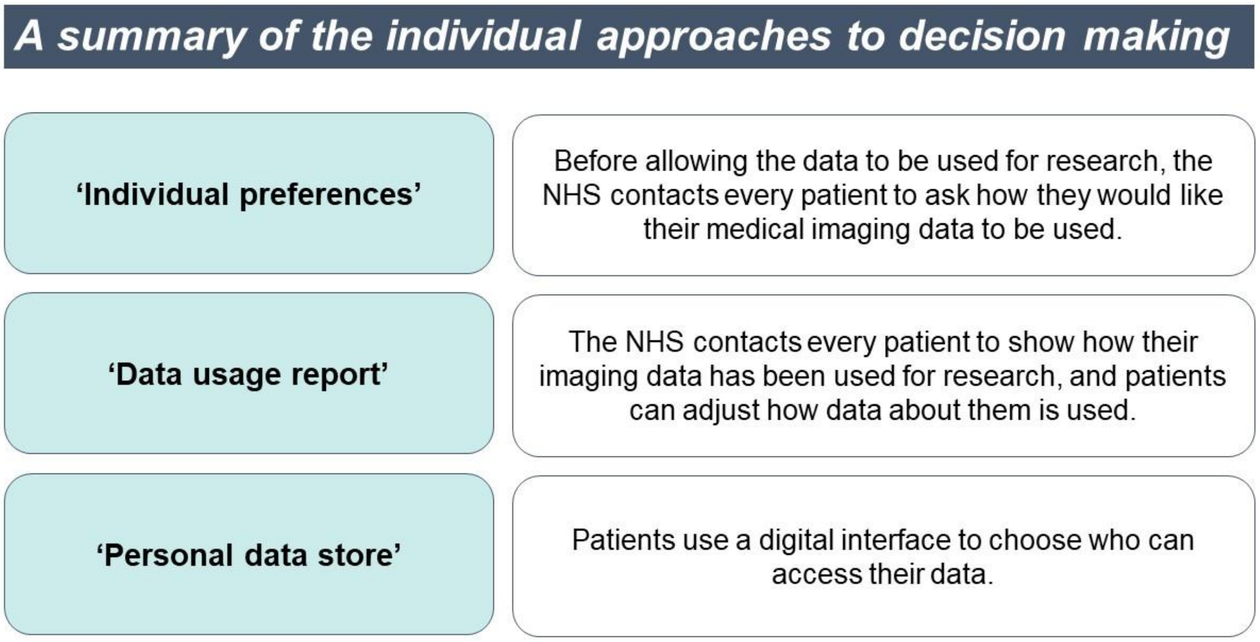
Who is involved?	Individual patients.
How are decisions made?	After reviewing the past uses of their data, individuals can update their preferences for the future.
What decisions are made?	Decisions about the data are based on individual preferences.



‘Personal data store’

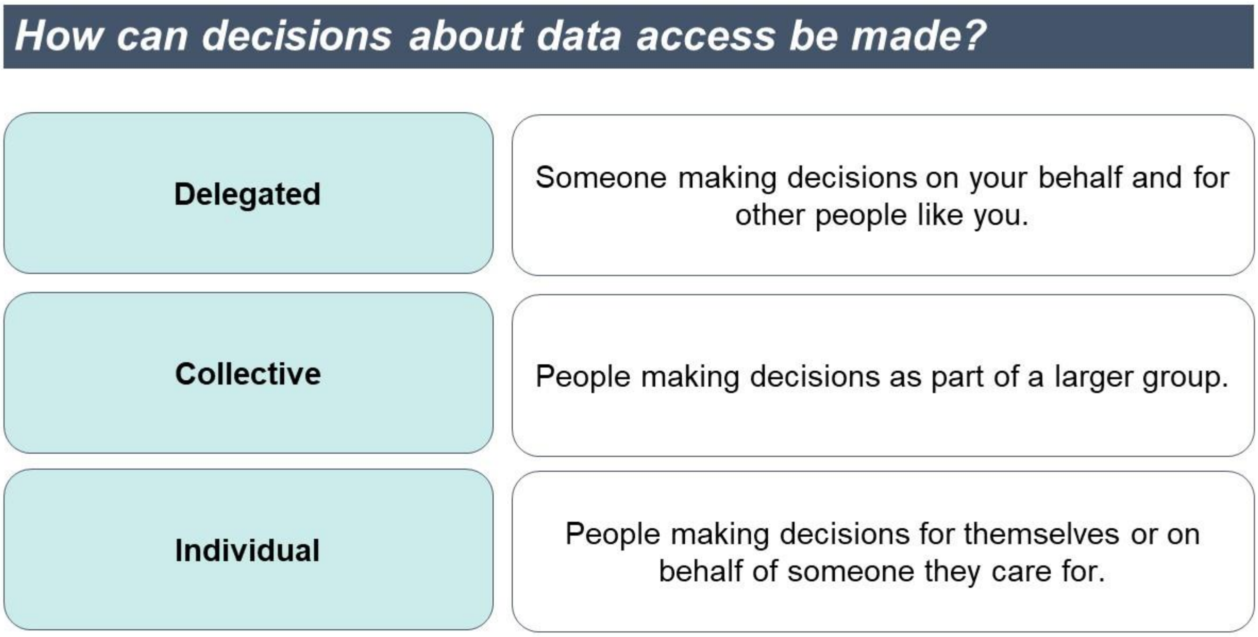
Patients use a digital interface to choose who can access their imaging data. Patients get notifications about upcoming research projects that have passed a legal and technical check, including information about the organisation conducting the research, what the researchers were looking to understand and how they plan to use the data. Patients can select which projects they’d like their data to be used for and for what purposes as well as setting default preferences. Patients can decide the frequency with which they receive notifications, the channel by which they receive them, or turn them off all together.

Who is involved?	Individual patients.
How are decisions made?	Patients use a digital interface with information about the proposed projects to make decisions about which to grant access to.
What decisions are made?	Granular decisions about who can access data and for what reasons, as well as broader preferences.



A summary of the individual approaches to decision making

‘Individual preferences’	Before allowing the data to be used for research, the NHS contacts every patient to ask how they would like their medical imaging data to be used.
‘Data usage report’	The NHS contacts every patient to show how their imaging data has been used for research, and patients can adjust how data about them is used.
‘Personal data store’	Patients use a digital interface to choose who can access their data.



How can decisions about data access be made?

Delegated	Someone making decisions on your behalf and for other people like you.
Collective	People making decisions as part of a larger group.
Individual	People making decisions for themselves or on behalf of someone they care for.

Workshop 3 – Discussion guide

Thursday 14th July 18.00-21.00pm

DISCUSSION GUIDE

Time	Discussion structure	Process, Questions and materials
17.30-17.55	**Set-up: Facilitators check in** **25 mins**	● Test link, mic and camera. ● Test who has the host/co-host function and ensure it is allocated to the right team member(s) for recording break out rooms. Make all moderators Co-hosts. ● Change screen name to NAME – Org – Chair/Moderator. ● Check everyone is on the WhatsApp group for facilitation team to be able to ask questions etc ● Meanwhile tech support is assigning participants who are in the waiting room, notes takers, moderators, experts and observers to break-out rooms.
17.55-18.05	**Participant Check-in** **10 mins**	**Participants log into the online session** ● Participants encouraged to join the zoom session early to check-in and check their video/mic. ● Participants encouraged to get a pen and paper and have their participant pack with them. ● Register as people join and change screen names as necessary to First name and first initial of surname (i.e. John H).
18.05-18.15	**Introduction and scene setting** **Plenary 1** **10 mins**	**Ipsos Chair to give a warm welcome to the third of four online workshop (<u>10 mins</u>):** ● Introduce Consortium (Ipsos, ODI, ICHP), NHS AI Lab and Sciencewise (SLIDE 1) ● Chair to explain why we are here: expert commentators, any observers, and facilitators and note takers (SLIDE 2) ● Chair to explain that a lot of information will be provided to participants over the course of four workshops, and to always ask or note down any questions/ queries and ask for clarification when needed. ● There will be a lot of quite technical information. If you have questions, raise these with your facilitator and we will either respond there and then or come back to you with a response ● We may cover topics (for example diseases) which people might have personal experience of. If anything that we do cover is triggering, feel free to take a break or come and talk to me (Chair) ● Chair also reintroduce and cover ground rules and additionally…(SLIDE 3) ○ We will be going in to break out rooms -we've set these up so you don't need to do anything – just let it happen ○ If we lose connection to you at any point in the session [INSERT NAME] will call you to see if we can help bring you back in again ○ We'll be capturing discussions live for our own notes. ○ Confidentiality: we are interested in what you say not who said what. Your comments will not be attributed back to you in our report. ○ We have shared materials with you, but please respect that these have been designed for the purpose of this exercise, and please don't post photos or content from these on social media or share otherwise. ● Chair to remind participants of the Five Safes Framework (SLIDE 4) ● Chair to remind participants what we mean by data stewardship (SLIDE 5)

		● Chair to remind participants about the three approaches to decision making about access to data (SLIDE 6) ● Chair to remind participants about the NID case study (SLIDES 7-9) ● Chair to play back a summary of the key points from the previous discussions in workshop 2
18.15-18.45	**Discussion around collective scenarios** **Breakout 1** **30 mins**	**Facilitator to remind participants about collective decision making (SLIDE 11) and then to introduce the first of the four collective scenarios** *(we will rotate the order in which these are discussed across the groups)* **spending 15 minutes discussing each scenario.** **Patient panel (15 mins)** SLIDE 12 ▪ What are your initial reactions to the idea of a patient panel? ▪ How do you feel about this approach to decision making regarding access to data from the National Imaging Database for AI research? ▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example… o The panel directly sets the criteria of data access, reflecting their views and priorities. o The panel sees every application, so there's a low chance that any access is granted that they disagree with. o Other patients may feel comfortable that people like them are involving in the decision-making. ▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example… o The panel may not have anyone with health or data experience or expertise on it. o Depending on who is on the panel, the criteria and reviews might be biased towards particular viewpoints. o The process of reviewing the applications takes up a lot of people's time, and may slow down research. ▪ How do you feel about the level of involvement of patients and the public here? **Developing data access principles (15 mins) –** SLIDE 13 ▪ What are your initial reactions to the idea of a developing data access principles? ▪ How do you feel about this approach to decision making regarding access to data from the National Imaging Database for AI research? ▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example… o The group sets guiding parameters for how data can be accessed and used. o The group doesn't need to look at all applications for access to the data, which will not slow down research. o Other patients may feel comfortable that people like them are involving in the decision-making. ▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example… o The panel may not have anyone with health or data experience or expertise on it. o Depending on who is on the panel, the criteria and reviews might be biased towards particular viewpoints. o The process of reviewing the applications takes up a lot of people's time, and may slow down research. ▪ How do you feel about the level of involvement of patients and the public here? ▪ What would need to be in place for you to trust this group to make decisions?

18.45-18.55	**BREAK**	*Facilitators to explain to participants that they must be back promptly for a 18.55 start. That they can turn off their cameras and their mic's during the break..*
18.55-19.25	**Discussion around collective scenarios** **Breakout 2** **30 mins**	**Retrospective review (15 mins)** SLIDE 14 ▪ What are your initial reactions to the idea of a retrospective review? ▪ How do you feel about this approach to decision making regarding access to National Imaging Database data for AI research? ▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example… o The group gets to directly engage with and scrutinise the decisions made by doctors and other experts. o Other patients may feel comfortable that people like them are involving in the decision-making. o The sessions don't slow down applications to access the data. ▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example… o The group may develop principles that run counter to individual patients' views and preferences. o Depending on who attends the workshops, the principles might be biased towards particular viewpoints. o The application of the principles by doctors and other experts may mean that they allow access to projects the group intended not to happen. ▪ How do you feel about the level of involvement of patients and the public here? **Case by case workshops (15 mins)** SLIDE 15 ▪ What are your initial reactions to the idea of case-by-case workshops? ▪ How do you feel about this approach to decision making regarding access to National Imaging Database data for AI research? ▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example… o The group develops a deeper understanding of prospective research and exactly how the data will be used. o The approach allows for exchange between the public and patients and people using the data for research. o Other patients may feel comfortable that people like them are involved in the decision-making. ▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example… o Depending on who is on the group, the reviews might be biased towards particular viewpoints. o The process of running workshops will take up a lot of people's time, and may slow down research. o The group may not feel informed enough to engage and ask questions. ▪ How do you feel about the level of involvement of patients and the public here? ▪ What would need to be in place for you to trust this group to make decisions?
19.25-19.45	**Discussion around individual scenarios**	**Facilitator to remind participants about individual decision making (SLIDE 18) and then to introduce the first of the two individual scenarios** *(we will rotate the order in which these are discussed across the groups)* **spending 20 minutes discussing each scenario.** **Individual preferences (20 mins)** SLIDE 19

	Breakout 3
	20 mins
		▪ What are your initial reactions to the idea of individual preferences?
		▪ How do you feel about this approach to decision making regarding access to National Imaging Database data for AI research?
		▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example…
		  o People can shape how data should be accessed, without compromising on their views.
		  o People don't need to make lots of individual decisions, but instead set their preferences once.
		  o People don't have to trust others to make the decisions on their behalf.
		▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example…
		  o It may not produce the quantity of data required for AI research, and may skew towards certain demographics of people.
		  o People may not feel like they have enough information or the expertise to make informed decisions.
		▪ What would need to be in place to give you the confidence to input here?
		▪ How do you feel about the level of involvement of patients and the public here?

19.45-19.55	**BREAK**	*Facilitators to explain to participants that they must be back promptly for a 19.55 start. That they can turn off their cameras and their mic's during the break.*

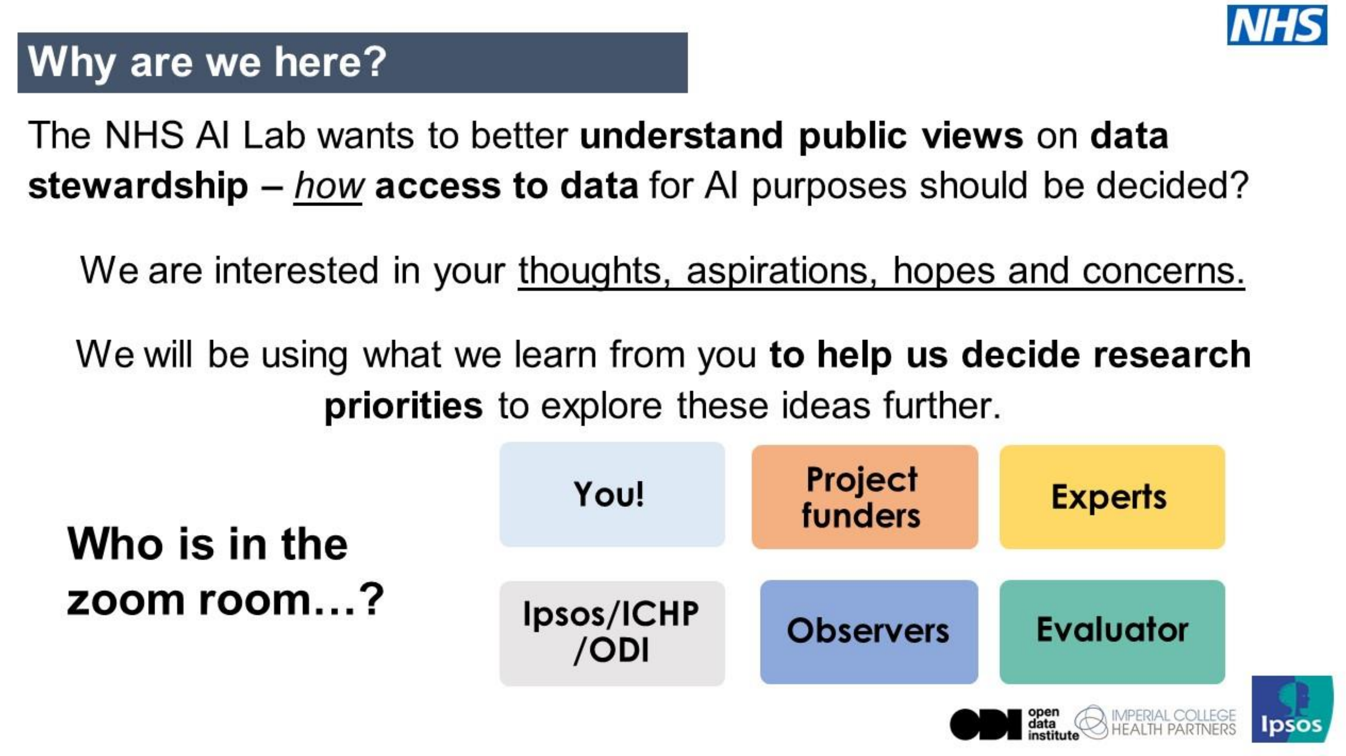
19.55-20.55	**Discussion around individual scenarios**
	Breakout 4
	60 mins
		Data usage report (20 mins) SLIDE 20
		▪ What are your initial reactions to the idea of a data usage report?
		▪ How do you feel about this approach to decision making regarding access to National Imaging Database data for AI research?
		▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example…
		  o People can set whether data can be accessed, without compromising on their views.
		  o There would be more transparency about how the data is accessed and used.
		  o People could make more informed decisions about data access once if they can see how it's been used.
		▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example…
		  o It may not produce the quantity of data required for AI research, and may skew towards certain demographics of people.
		  o People may not feel like they have enough information or the expertise to make informed decisions.
		  o Updating settings annually may not be frequent enough for people.
		  o The NHS would have to put in place centralised data repositories to be able to track who has used what/where. This is not impossible but could be costly / take up resource
		▪ What would need to be in place to give you the confidence to input here?
		▪ How do you feel about the level of involvement of patients and the public here?
		Personal data store (20 mins) SLIDE 21

		▪ What are your initial reactions to the idea of a personal data store? ▪ How do you feel about this approach to decision making regarding access to National Imaging Database data for AI research? ▪ What do you see to be **the advantages of this approach** to decision making? PROMPT IF NOT MENTIONED: For example… o People don't have to trust others to make the decisions on their behalf. o People can make decisions in real-time, and change their preferences on a more regular basis. o Patients can see exactly what data is stored about them, eg. they could view the scans themselves. ▪ And what do you see as **the disadvantages**? PROMPT IF NOT MENTIONED: For example… o The process could take up a lot of people's time, especially among other commitments and priorities. o People may not feel like they have enough information or the expertise to make informed decisions. o It may not produce the quantity of data required for Machine Learning, and may skew towards certain demographics of people. o Some people may not be able to access a digital interface. ▪ What would need to be in place to give you the confidence to input here? ▪ How do you feel about the level of involvement of patients and the public here? **Closing discussion (20 mins)** ▪ Based on everything that we have discussed over the last workshop and this evening, how are you feeling about how decisions are made about access to health data for AI research? ▪ What approaches/scenarios did you like best and why? ▪ Bearing in mind the pros and cons that we have discussed, which type of approach or approaches do you believe the NHS should prioritise for further research? Why?
20.55-21.00	Thank and close in plenary	

Workshop 4 – PowerPoint slides

NHS AI Lab Public Dialogue - Workshop 4

Wednesday 20th July 18.00-21.00pm



Why are we here?

The NHS AI Lab wants to better **understand public views** on **data stewardship** – *how* **access to data** for AI purposes should be decided?

We are interested in your thoughts, aspirations, hopes and concerns.

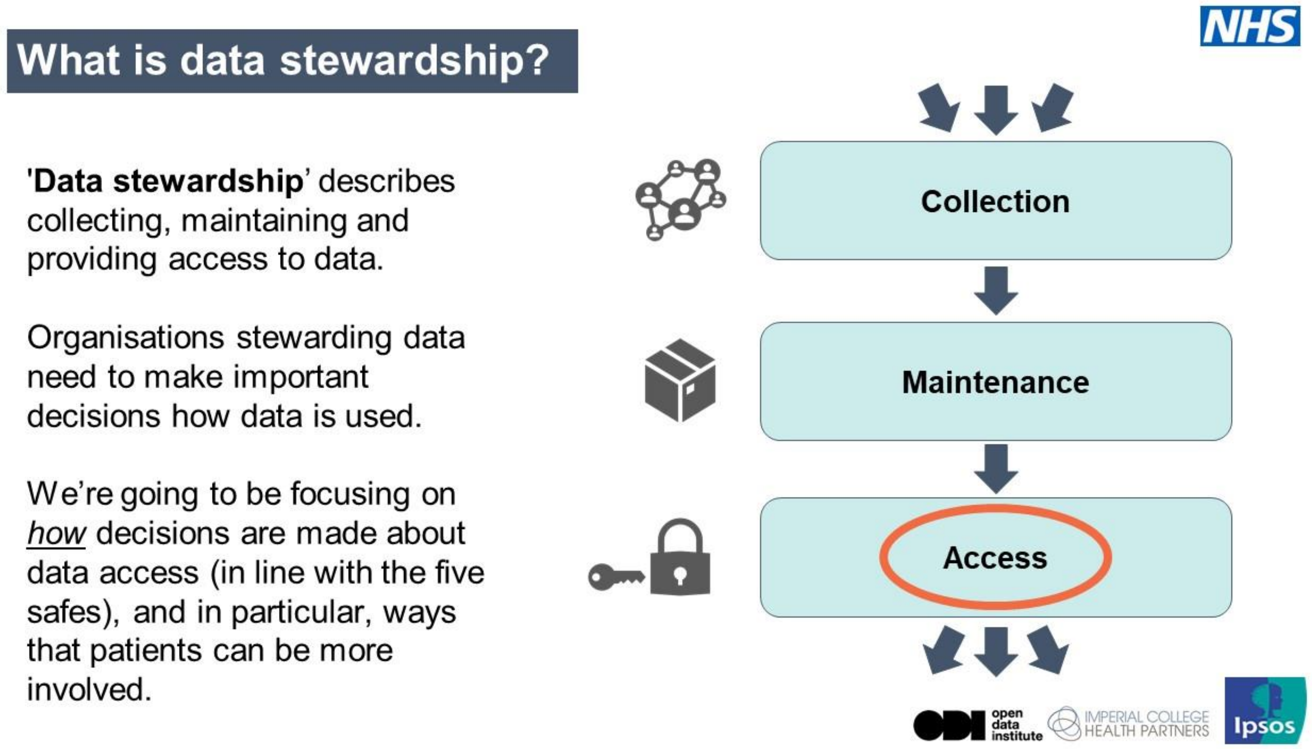
We will be using what we learn from you **to help us decide research priorities** to explore these ideas further.

Who is in the zoom room…?

- You!
- Project funders
- Experts
- Ipsos/ICHP /ODI
- Observers
- Evaluator

Ground Rules

1. Listen **respectfully**, without interrupting.
2. Listen actively and with an ear to **understanding others'** views. (Don't just think about what you are going to say while someone else is talking.)
3. **Any question is a good** question.
4. Criticise ideas, **not individuals**.
5. Commit **to learning**, not debating. Comment in order to share information, not to persuade.
6. Stay on topic and **try to be concise**.
7. **Avoid** blame, speculation, and inflammatory language.
8. Allow everyone the **chance to speak.**
9. **Avoid assumptions** about any member of the group or generalisations about social groups. Do not ask individuals to speak for their (perceived) social group.
10. Keep **distractions to a minimum** (phone on silent, don't multitask)
11. **Be patient** with other participants and the team – we have a lot of information to get through.
12. Feel free to share your thoughts about this event with **friends and family**.
13. If posting **about this event on social media** please do not share any detail of the discussions.
14. Think and act as **citizens,** not just as individuals.



What is data stewardship?

'**Data stewardship**' describes collecting, maintaining and providing access to data.

Organisations stewarding data need to make important decisions how data is used.

We're going to be focusing on *how* decisions are made about data access (in line with the five safes), and in particular, ways that patients can be more involved.

Collection

Maintenance

Access

How can decisions about data access be made?

Delegated	Someone making decisions on your behalf and for other people like you.
Collective	People making decisions as part of a larger group.
Individual	People making decisions for themselves or on behalf of someone they care for.

NHS

Case study: The National Imaging Database (NID)

- The National Imaging Database (NID) will be used to train and test AI screening technologies.
- NID would be a centralised, secure database consisting of **de-identified, pseudonymised** patient imaging data from a wide range of hospital trusts across the UK.

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Case study: The National Imaging Database (NID)

NID would contain medical images such as X-rays, CT scans, and MRIs – which, when approved, could be linked by means of each patient's **pseudonym** with:

Relevant **demographic data** (e.g. age and ethnicity)

Clinical data (e.g. history of disease/ conditions, e.g. breast cancer, lung cancer status)

Screening results (e.g. radiologist opinions / redacted reports)

Pathology results (e.g. biopsy information, key mutation status, cancer type, cancer grade)

Treatment and outcome details (e.g. surgery, chemotherapy / radiotherapy)

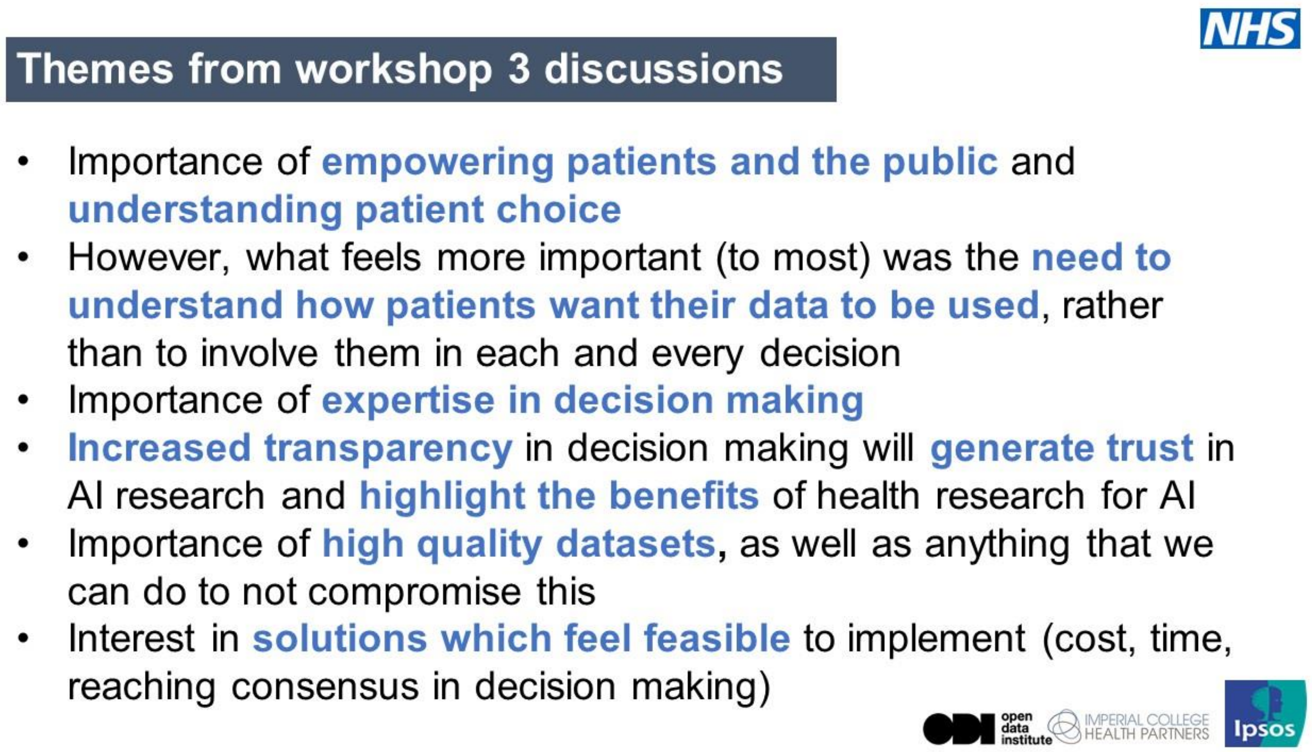
The National Imaging Database (NID)

- NHS England would have legal responsibility for the NID as a 'data controller', and protections for it would include **removing obviously identifying information** such as names, addresses and dates of birth (this is called *de-identification*) and **replacing some other identifiers** such as your NHS number with a 'pseudonym' (this is called *pseudonymisation*).
- **We will discuss how approval for specific uses by third parties should be granted as part of data stewardship.**

Glossary

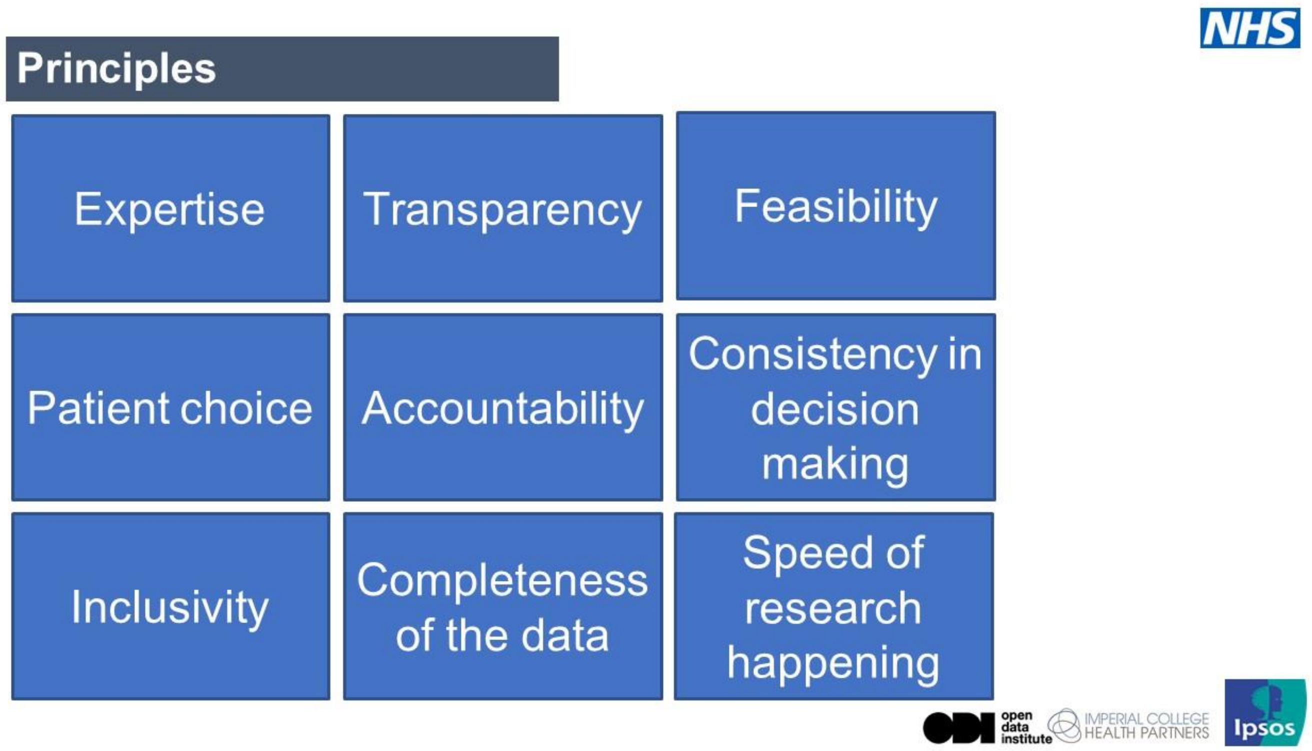
A **data controller** determines the purposes for which and the means by which personal data is processed.

A **pseudonym** is an artificial name or number used to replace any information that could directly identify an individual.



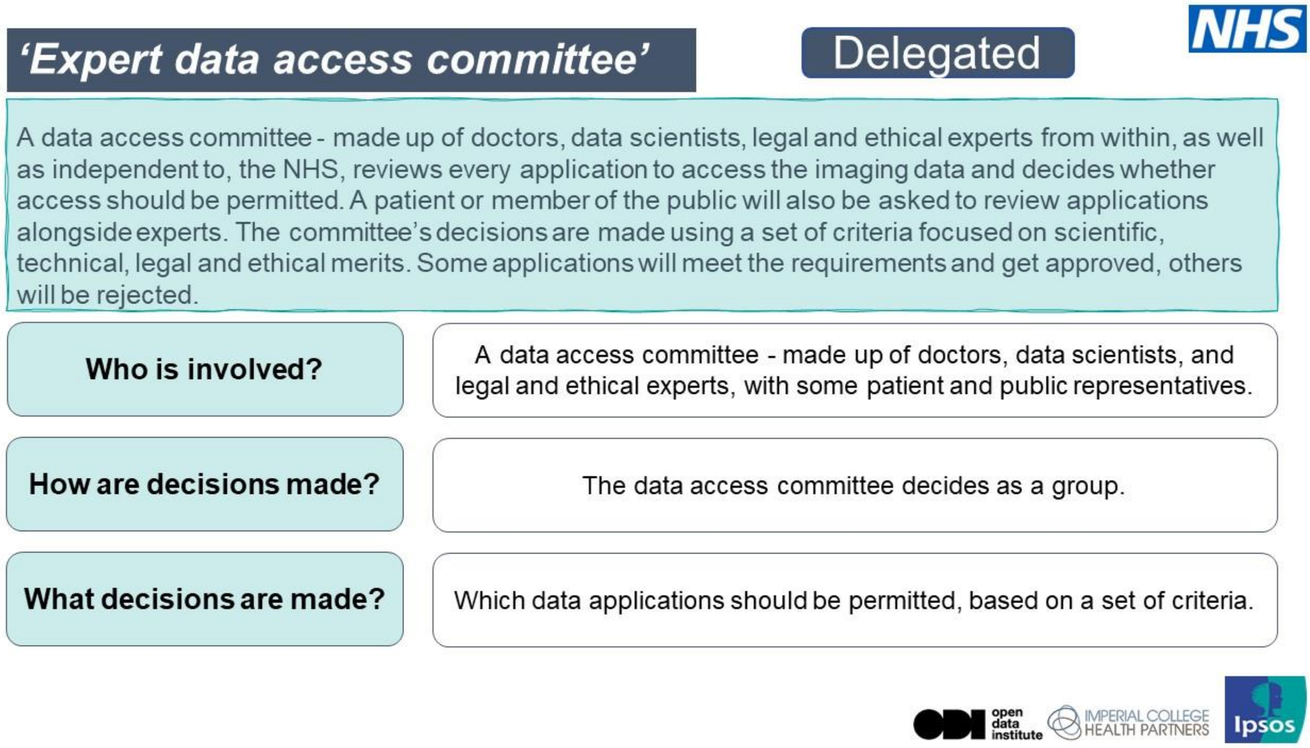
Themes from workshop 3 discussions

- Importance of **empowering patients and the public** and **understanding patient choice**
- However, what feels more important (to most) was the **need to understand how patients want their data to be used**, rather than to involve them in each and every decision
- Importance of **expertise in decision making**
- **Increased transparency** in decision making will **generate trust** in AI research and **highlight the benefits** of health research for AI
- Importance of **high quality datasets**, as well as anything that we can do to not compromise this
- Interest in **solutions which feel feasible** to implement (cost, time, reaching consensus in decision making)



Principles

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

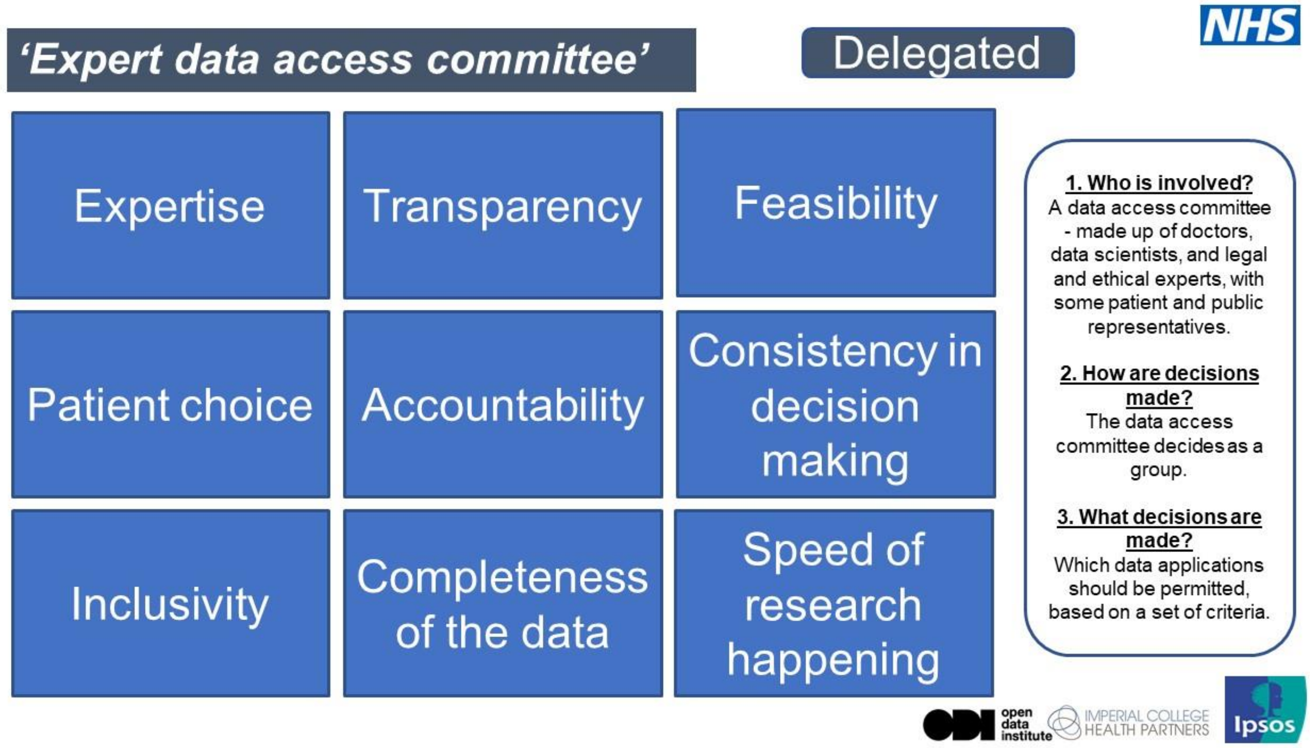


‘Expert data access committee’

Delegated

A data access committee - made up of doctors, data scientists, legal and ethical experts from within, as well as independent to, the NHS, reviews every application to access the imaging data and decides whether access should be permitted. A patient or member of the public will also be asked to review applications alongside experts. The committee’s decisions are made using a set of criteria focused on scientific, technical, legal and ethical merits. Some applications will meet the requirements and get approved, others will be rejected.

Who is involved?	A data access committee - made up of doctors, data scientists, and legal and ethical experts, with some patient and public representatives.
How are decisions made?	The data access committee decides as a group.
What decisions are made?	Which data applications should be permitted, based on a set of criteria.



‘Expert data access committee’

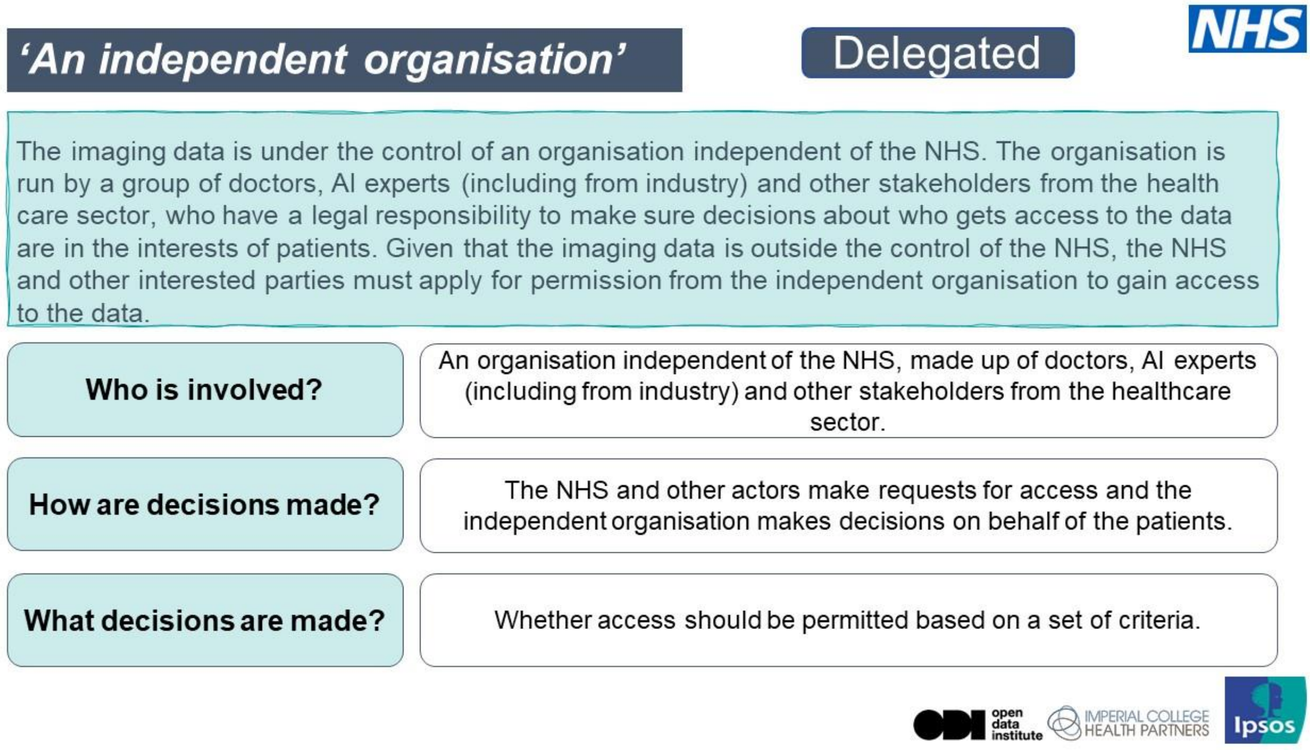
Delegated

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
A data access committee - made up of doctors, data scientists, and legal and ethical experts, with some patient and public representatives.

2. How are decisions made?
The data access committee decides as a group.

3. What decisions are made?
Which data applications should be permitted, based on a set of criteria.

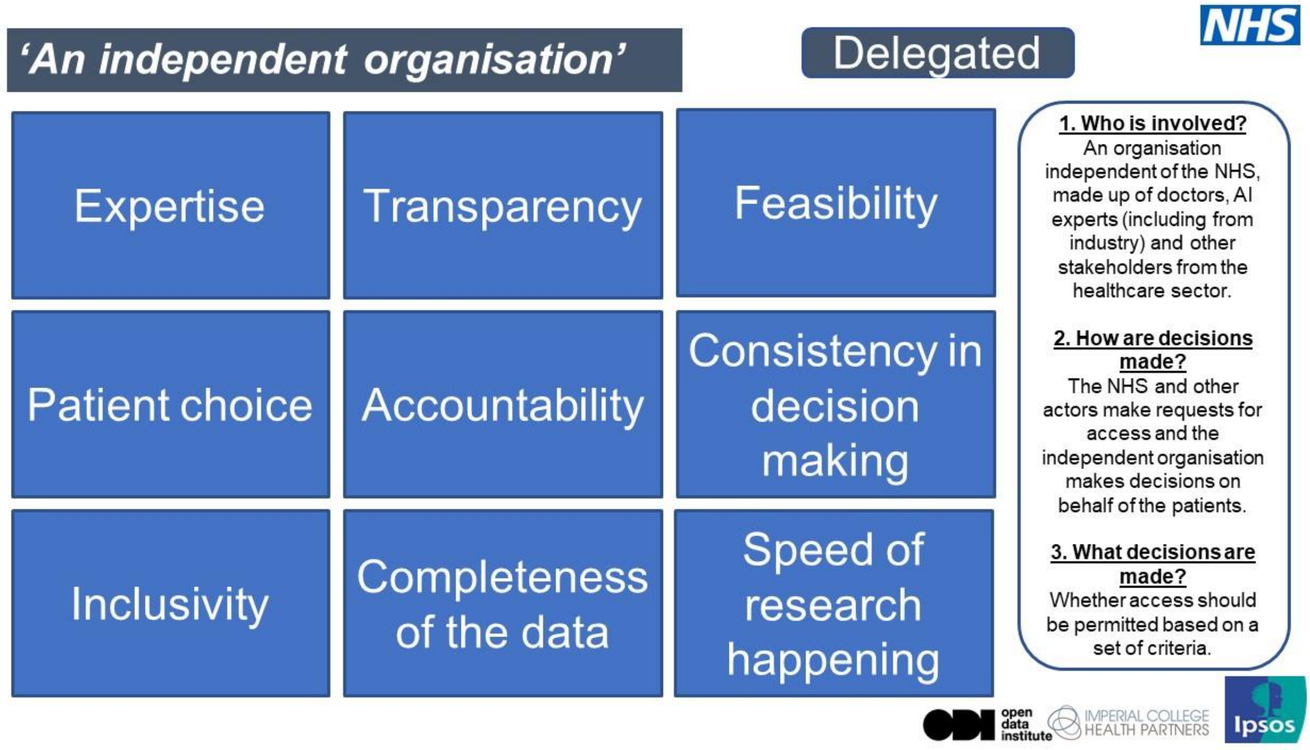


‘An independent organisation’

Delegated

The imaging data is under the control of an organisation independent of the NHS. The organisation is run by a group of doctors, AI experts (including from industry) and other stakeholders from the health care sector, who have a legal responsibility to make sure decisions about who gets access to the data are in the interests of patients. Given that the imaging data is outside the control of the NHS, the NHS and other interested parties must apply for permission from the independent organisation to gain access to the data.

Who is involved?	An organisation independent of the NHS, made up of doctors, AI experts (including from industry) and other stakeholders from the healthcare sector.
How are decisions made?	The NHS and other actors make requests for access and the independent organisation makes decisions on behalf of the patients.
What decisions are made?	Whether access should be permitted based on a set of criteria.



‘An independent organisation’

Delegated

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
An organisation independent of the NHS, made up of doctors, AI experts (including from industry) and other stakeholders from the healthcare sector.

2. How are decisions made?
The NHS and other actors make requests for access and the independent organisation makes decisions on behalf of the patients.

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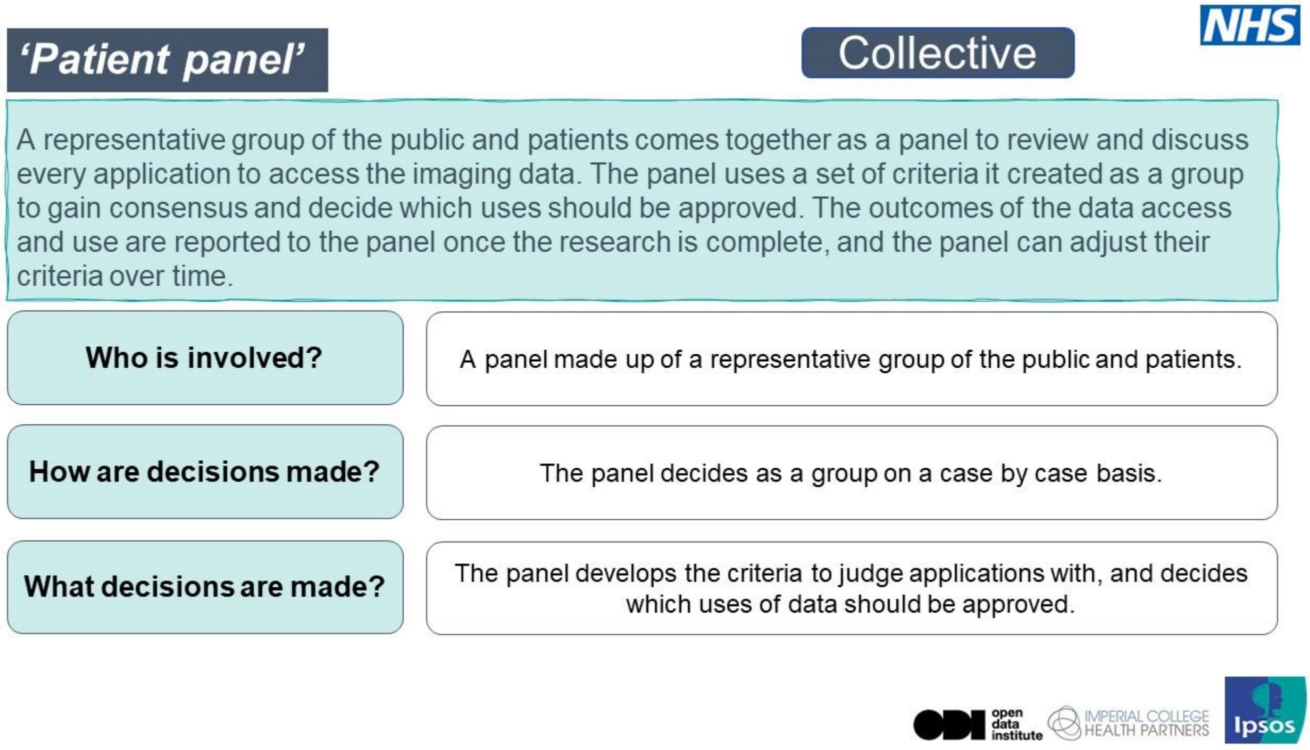
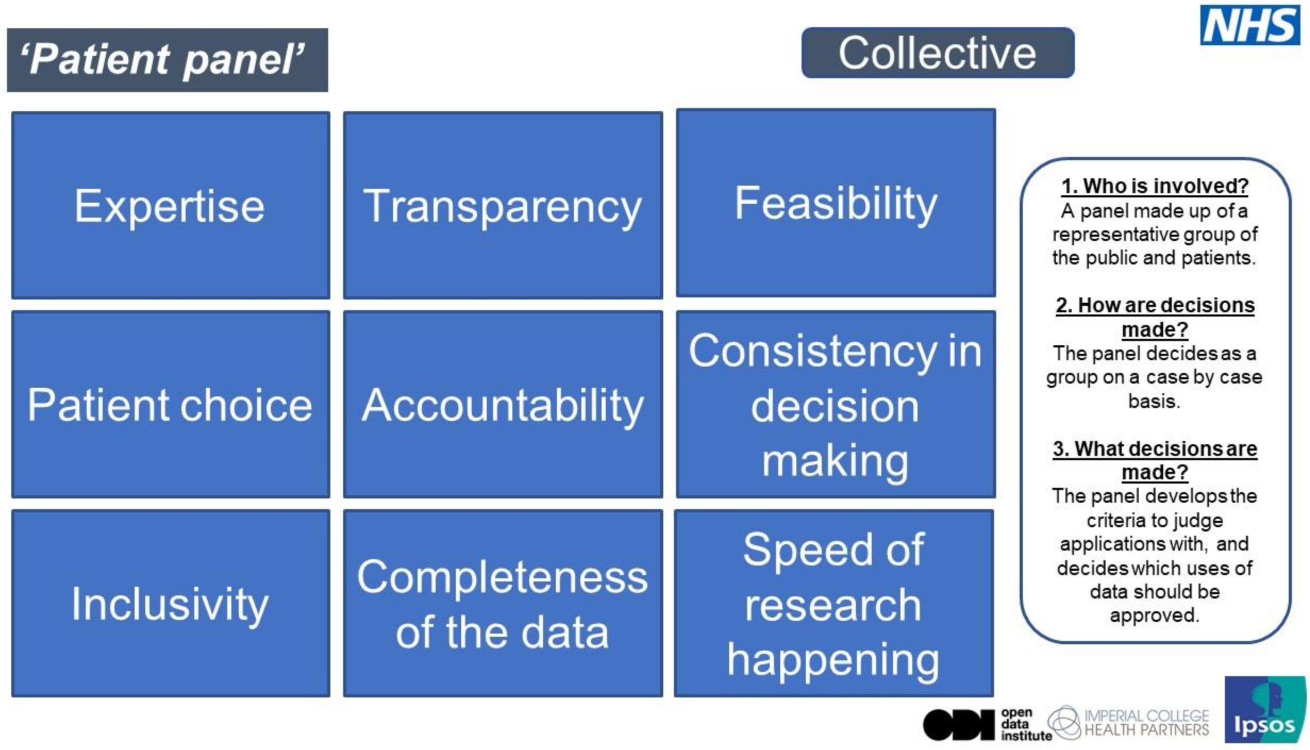


‘Patient panel’

Collective

A representative group of the public and patients comes together as a panel to review and discuss every application to access the imaging data. The panel uses a set of criteria it created as a group to gain consensus and decide which uses should be approved. The outcomes of the data access and use are reported to the panel once the research is complete, and the panel can adjust their criteria over time.

Who is involved?	A panel made up of a representative group of the public and patients.
How are decisions made?	The panel decides as a group on a case by case basis.
What decisions are made?	The panel develops the criteria to judge applications with, and decides which uses of data should be approved.



‘Patient panel’

Collective

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
A panel made up of a representative group of the public and patients.

2. How are decisions made?
The panel decides as a group on a case by case basis.

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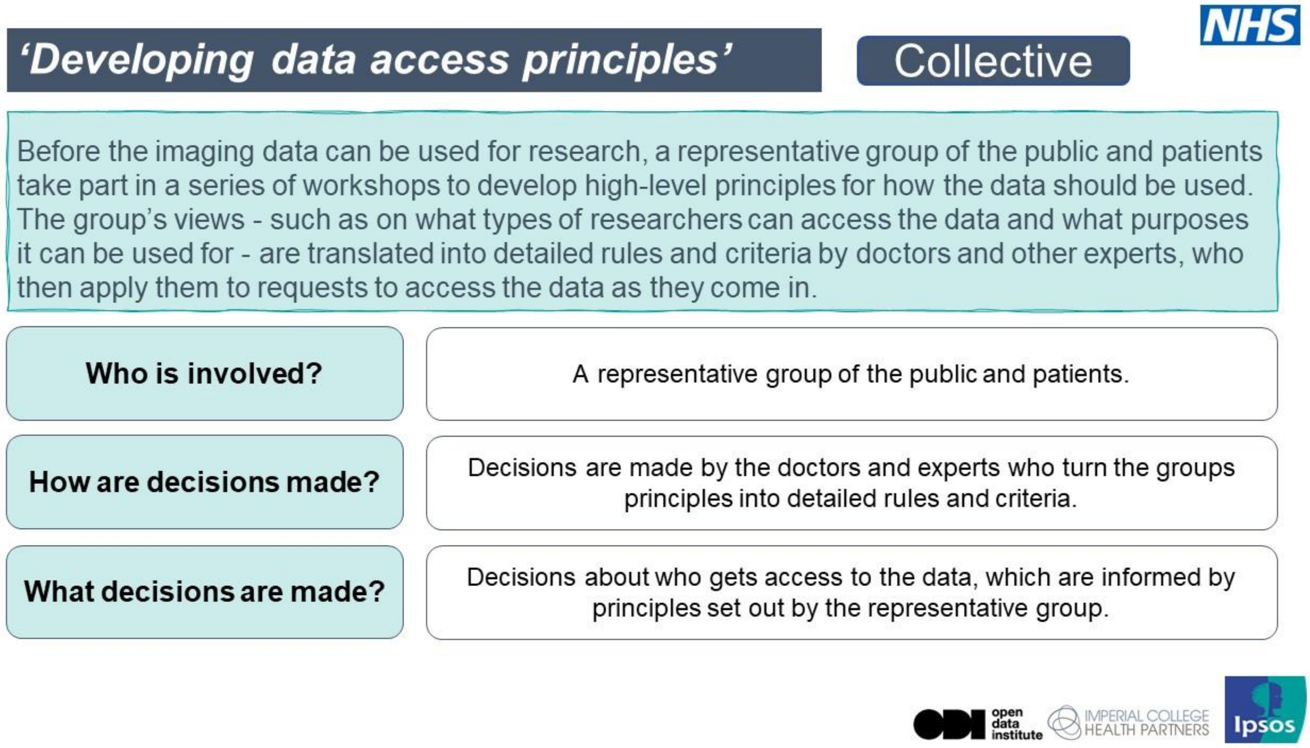
The panel develops the criteria to judge applications with, and decides which uses of data should be approved.

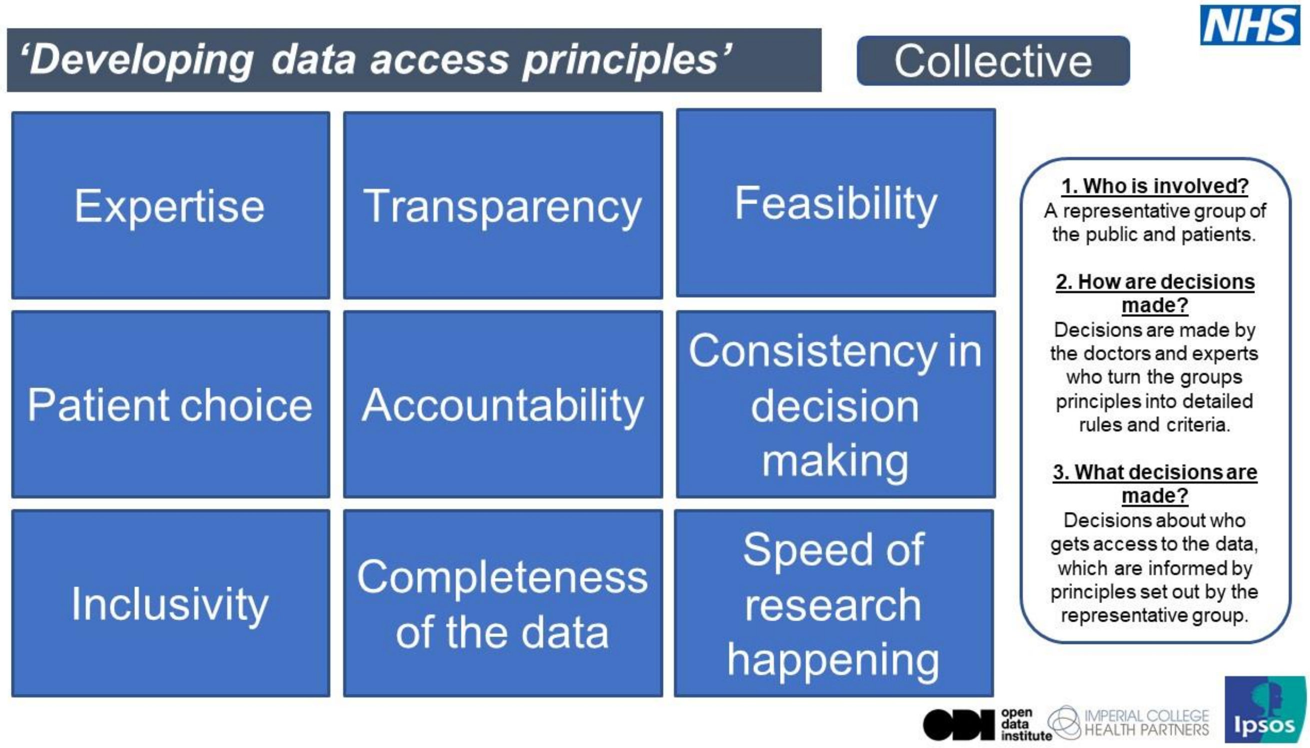


‘Developing data access principles’

Collective

Before the imaging data can be used for research, a representative group of the public and patients take part in a series of workshops to develop high-level principles for how the data should be used. The group’s views - such as on what types of researchers can access the data and what purposes it can be used for - are translated into detailed rules and criteria by doctors and other experts, who then apply them to requests to access the data as they come in.

Who is involved?	A representative group of the public and patients.
How are decisions made?	Decisions are made by the doctors and experts who turn the groups principles into detailed rules and criteria.
What decisions are made?	Decisions about who gets access to the data, which are informed by principles set out by the representative group.



‘Developing data access principles’

Collective

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
A representative group of the public and patients.

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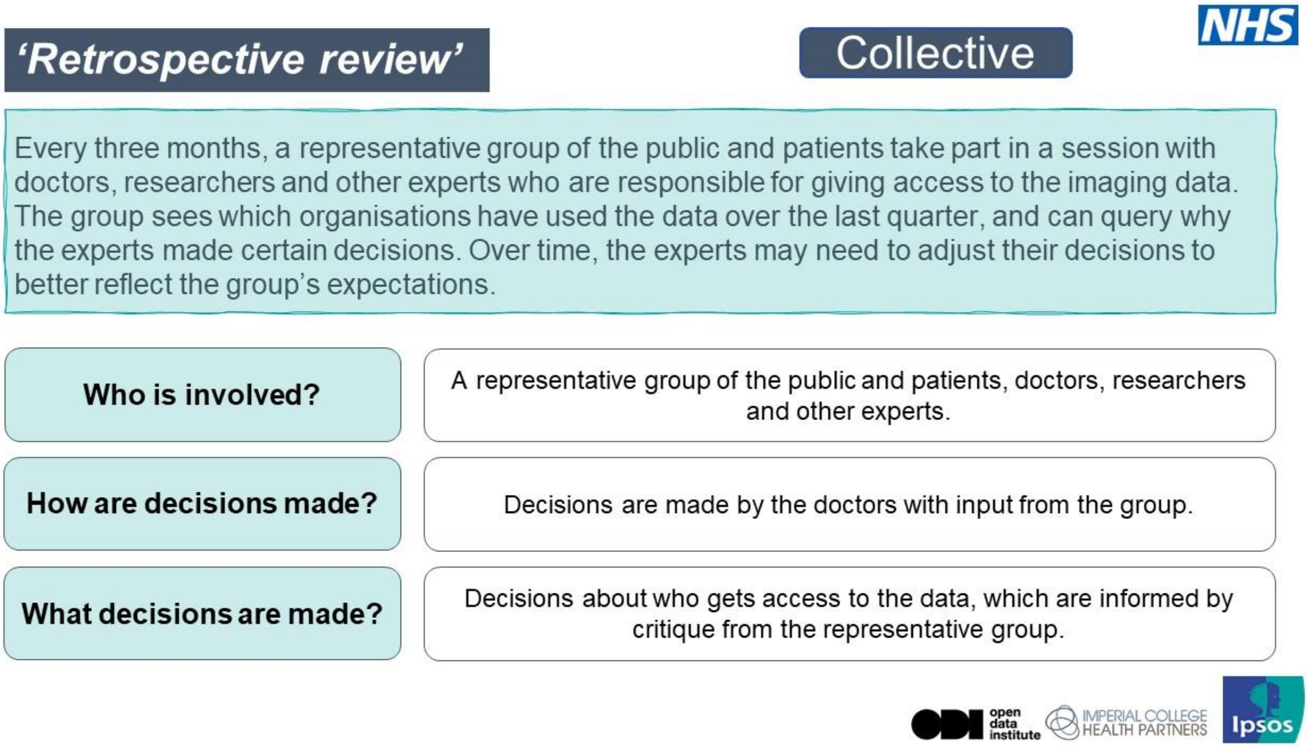


‘Retrospective review’

Collective

Every three months, a representative group of the public and patients take part in a session with doctors, researchers and other experts who are responsible for giving access to the imaging data. The group sees which organisations have used the data over the last quarter, and can query why the experts made certain decisions. Over time, the experts may need to adjust their decisions to better reflect the group’s expectations.

Who is involved?	A representative group of the public and patients, doctors, researchers and other experts.
How are decisions made?	Decisions are made by the doctors with input from the group.
What decisions are made?	Decisions about who gets access to the data, which are informed by critique from the representative group.

‘Retrospective review’

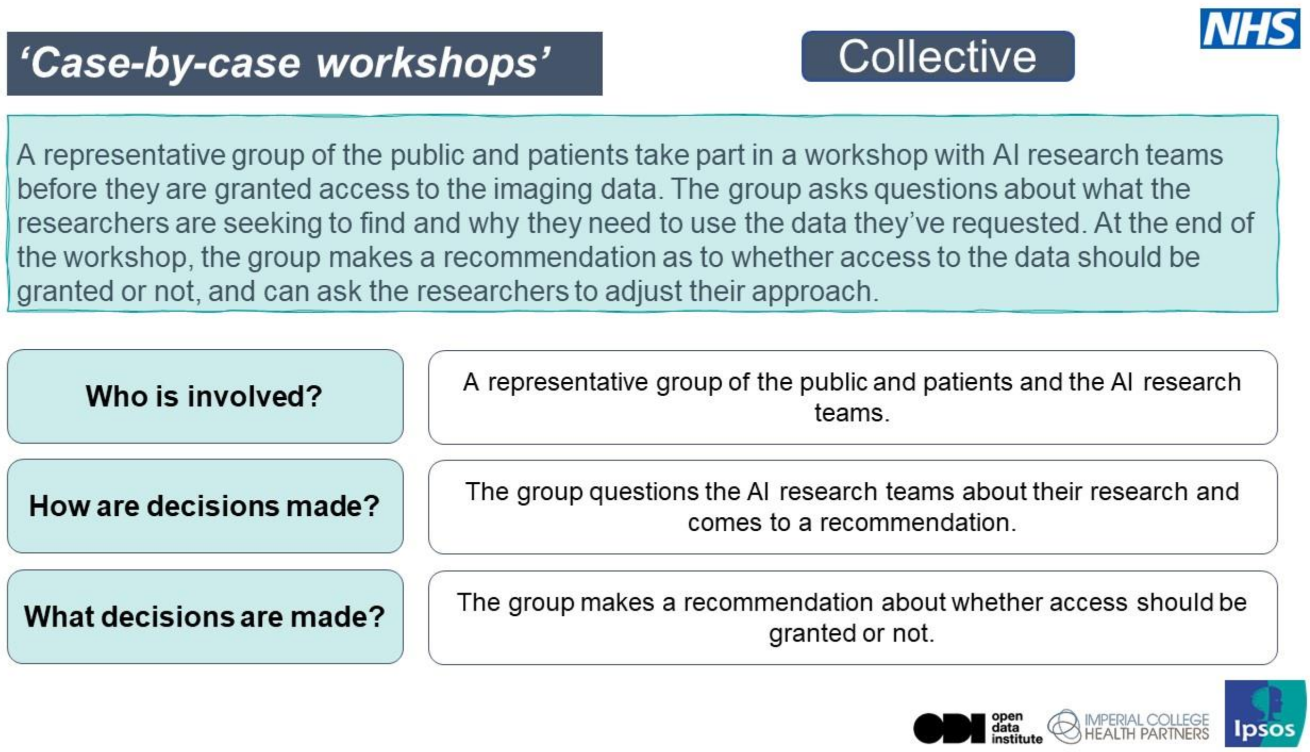
Collective

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
A representative group of the public and patients, doctors, researchers and other experts.

2. How are decisions made?
Decisions are made by the doctors with input from the group.

3. What decisions are made?
Decisions about who gets access to the data, which are informed by critique from the representative group.



‘Case-by-case workshops’

Collective

A representative group of the public and patients take part in a workshop with AI research teams before they are granted access to the imaging data. The group asks questions about what the researchers are seeking to find and why they need to use the data they’ve requested. At the end of the workshop, the group makes a recommendation as to whether access to the data should be granted or not, and can ask the researchers to adjust their approach.

Who is involved?	A representative group of the public and patients and the AI research teams.
How are decisions made?	The group questions the AI research teams about their research and comes to a recommendation.
What decisions are made?	The group makes a recommendation about whether access should be granted or not.

‘Case-by-case workshops’

Collective

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
A representative group of the public and patients and the AI research teams.

2. How are decisions made?
The group questions the AI research teams about their research and comes to a recommendation.

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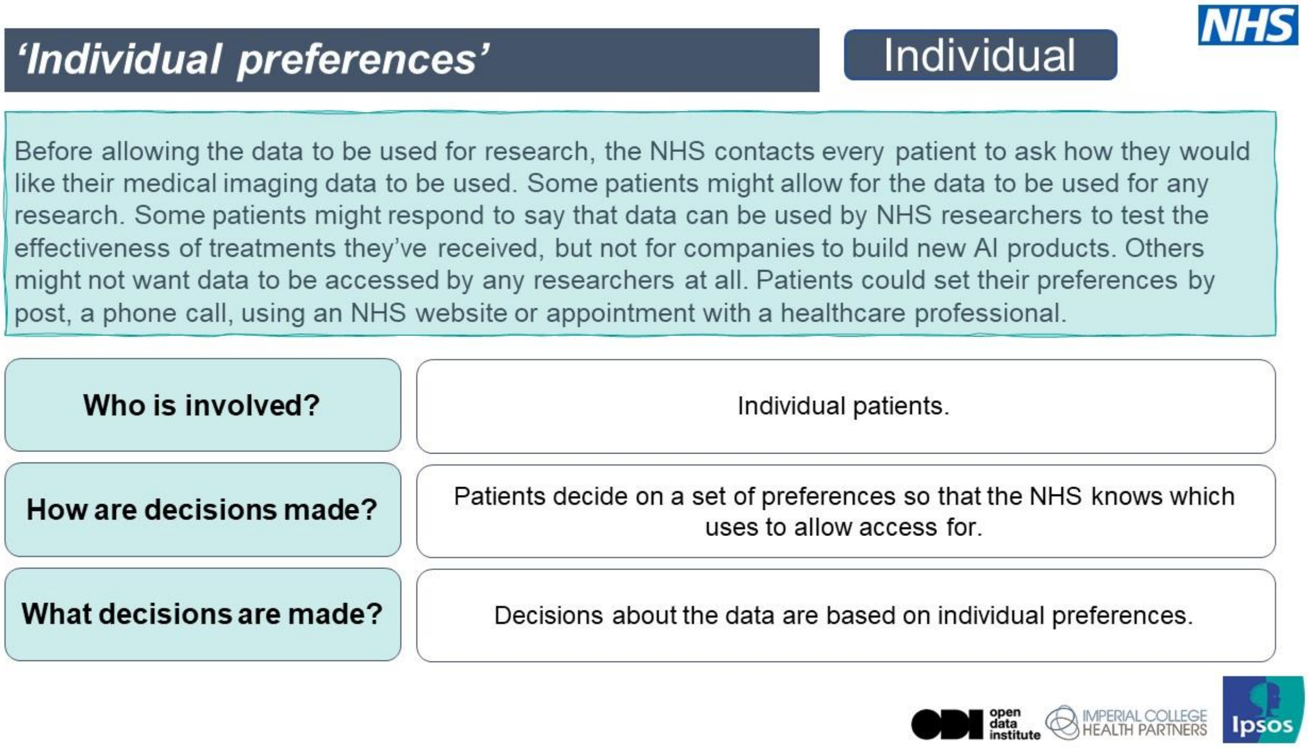
The group makes a recommendation about whether access should be granted or not.

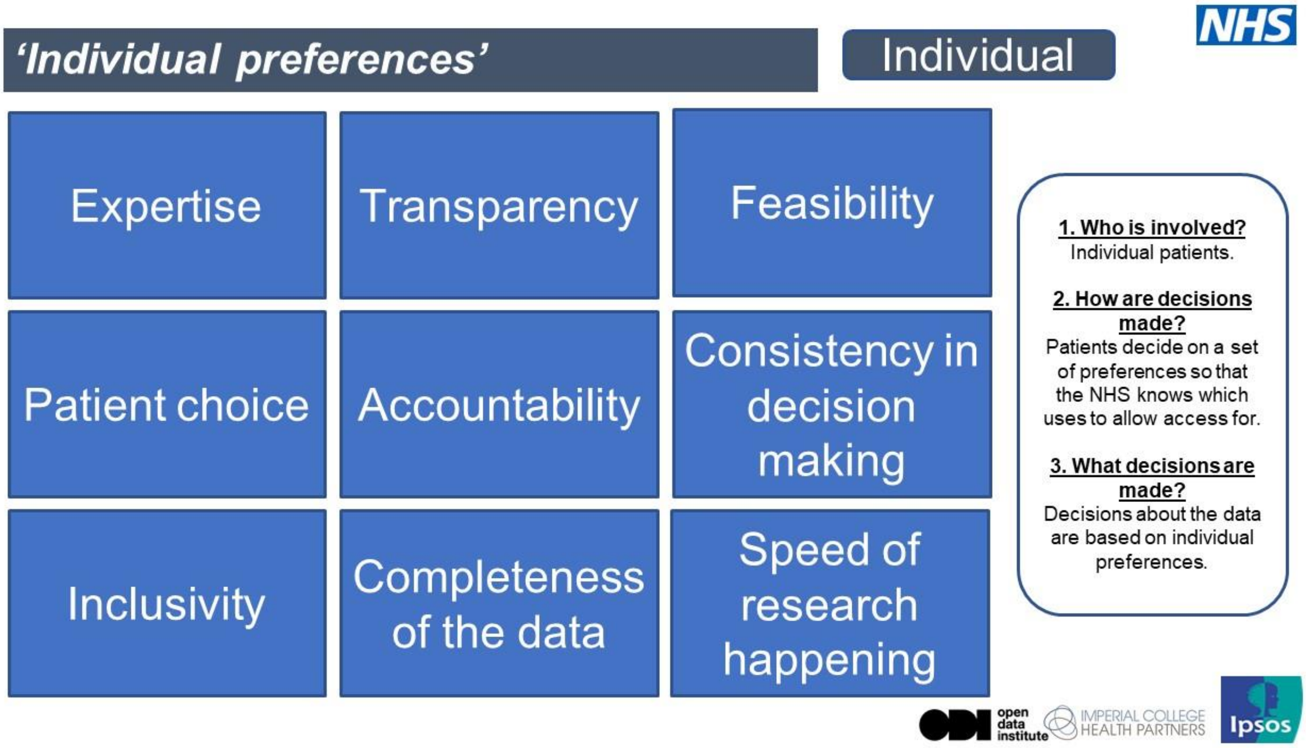


'Individual preferences'

Individual

Before allowing the data to be used for research, the NHS contacts every patient to ask how they would like their medical imaging data to be used. Some patients might allow for the data to be used for any research. Some patients might respond to say that data can be used by NHS researchers to test the effectiveness of treatments they've received, but not for companies to build new AI products. Others might not want data to be accessed by any researchers at all. Patients could set their preferences by post, a phone call, using an NHS website or appointment with a healthcare professional.

Who is involved?	Individual patients.
How are decisions made?	Patients decide on a set of preferences so that the NHS knows which uses to allow access for.
What decisions are made?	Decisions about the data are based on individual preferences.



'Individual preferences'

Individual

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
Individual patients.

2. How are decisions made?
Patients decide on a set of preferences so that the NHS knows which uses to allow access for.

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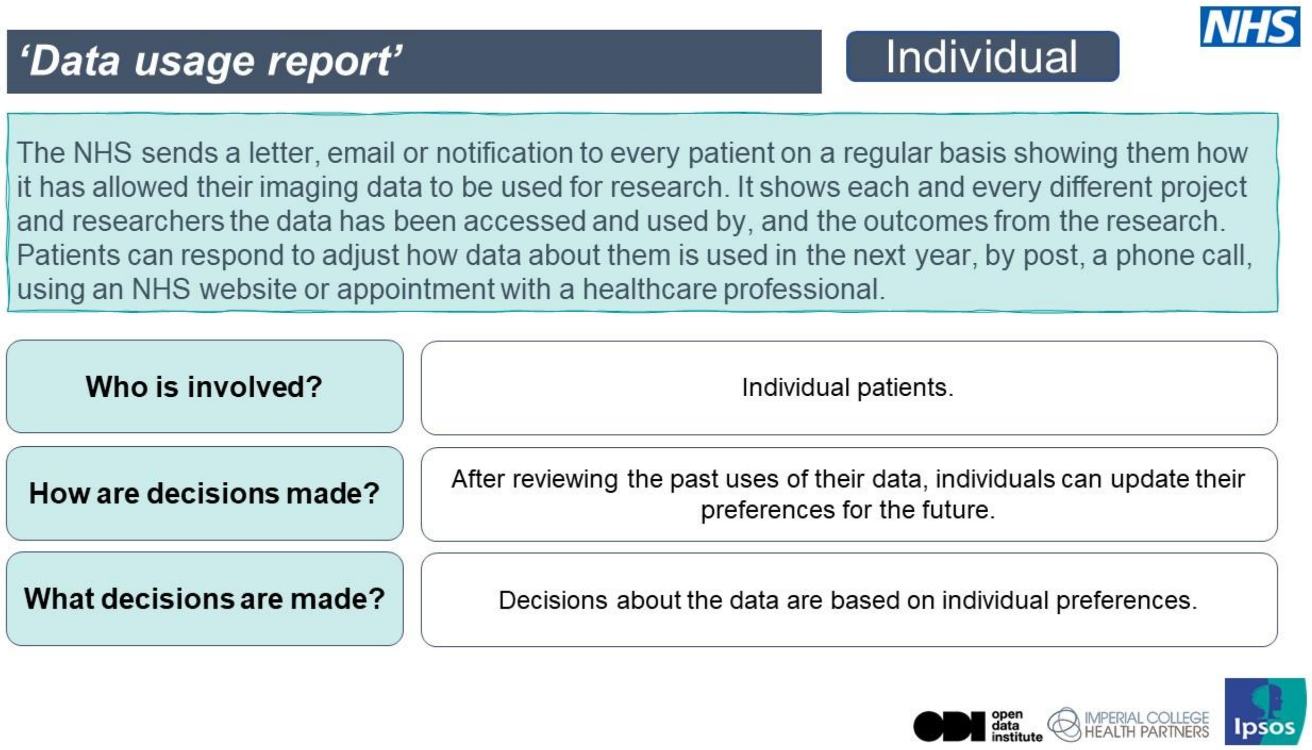

'Data usage report'

Individual

NHS

The NHS sends a letter, email or notification to every patient on a regular basis showing them how it has allowed their imaging data to be used for research. It shows each and every different project and researchers the data has been accessed and used by, and the outcomes from the research. Patients can respond to adjust how data about them is used in the next year, by post, a phone call, using an NHS website or appointment with a healthcare professional.

Who is involved?	Individual patients.
How are decisions made?	After reviewing the past uses of their data, individuals can update their preferences for the future.
What decisions are made?	Decisions about the data are based on individual preferences.

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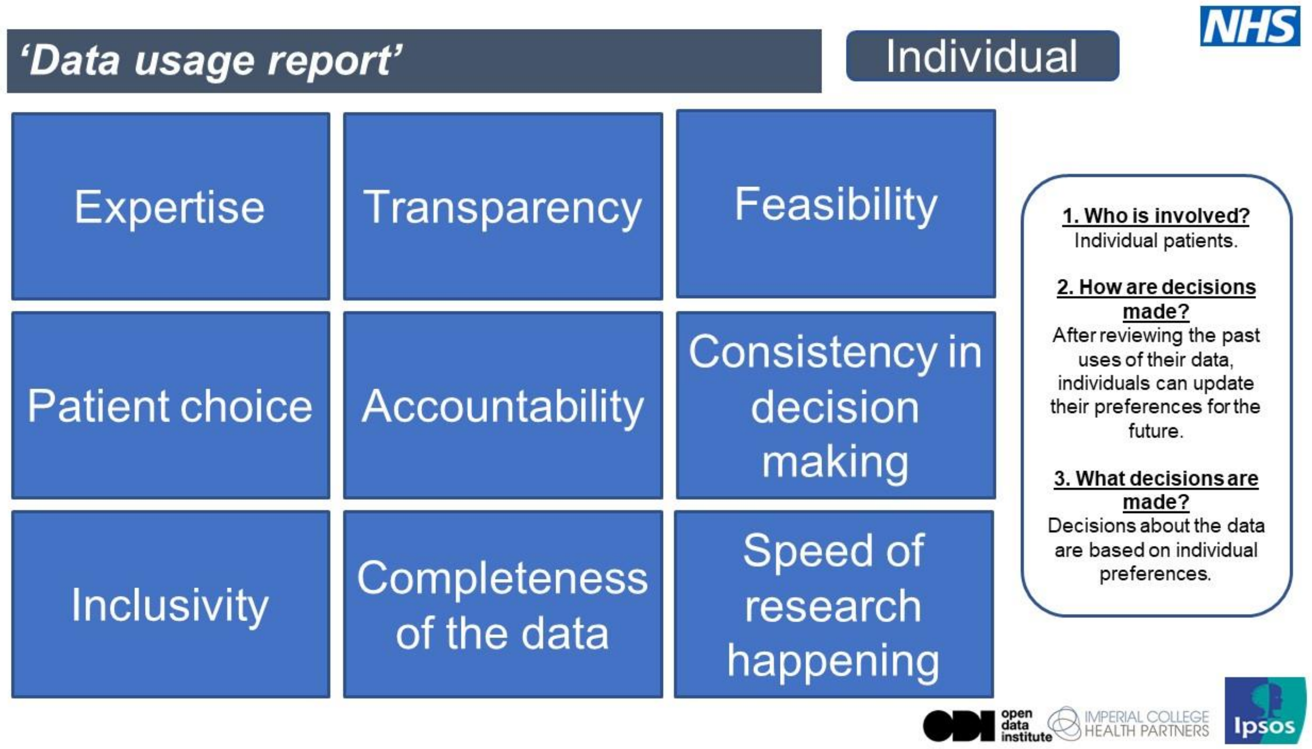

'Data usage report'

Individual

NHS

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
Individual patients.

2. How are decisions made?
After reviewing the past uses of their data, individuals can update their preferences for the future.

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Decisions about the data are based on individual preferences.

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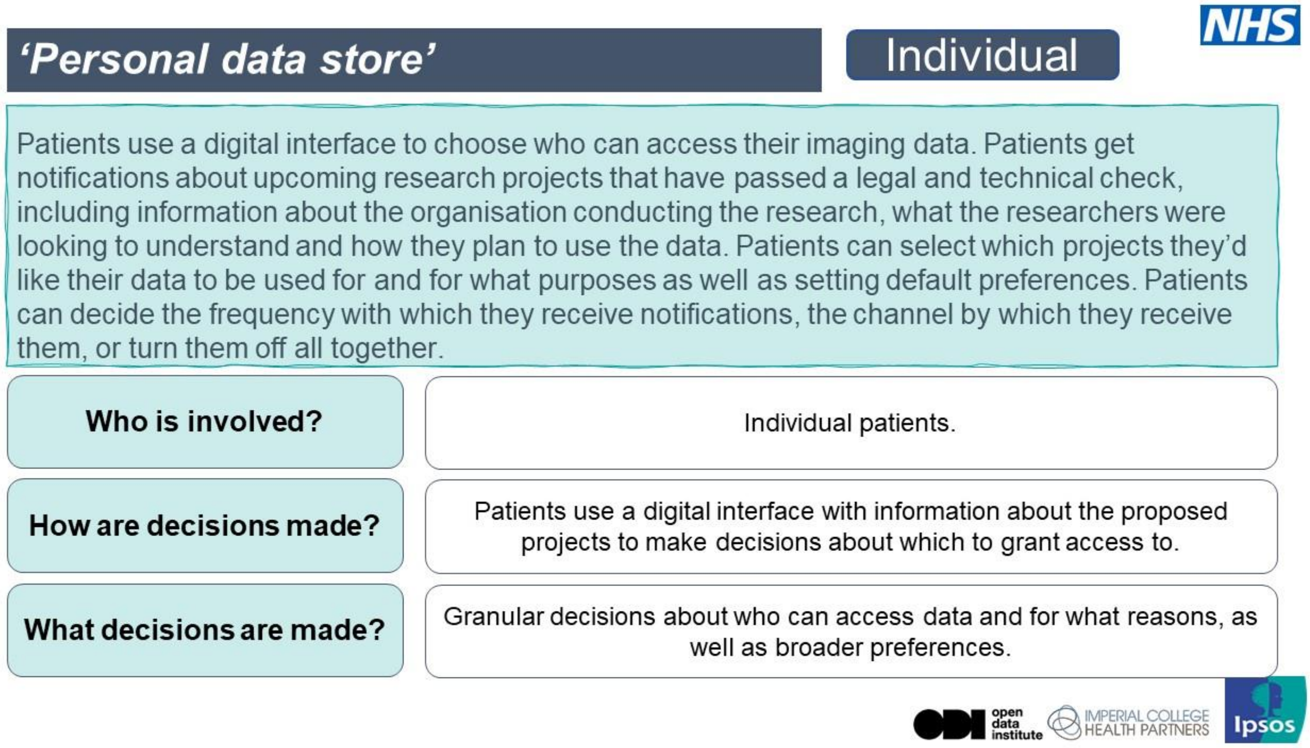
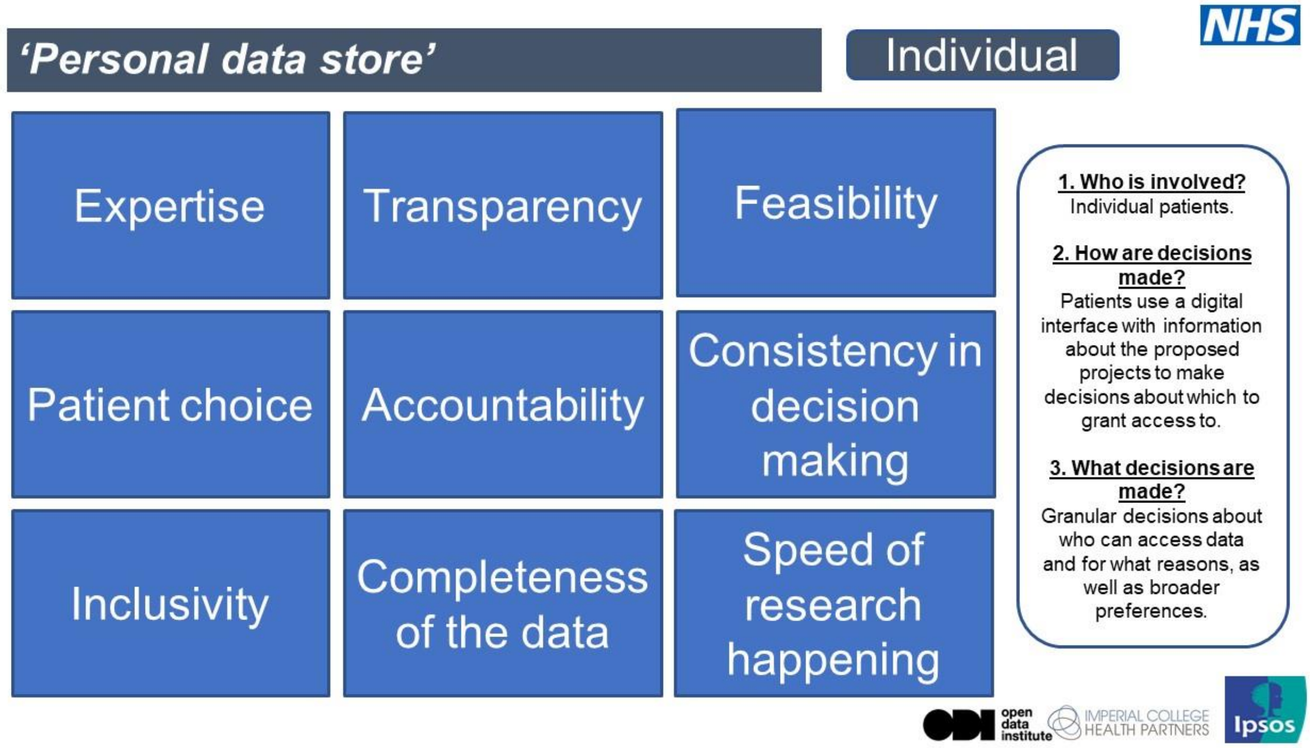


‘Personal data store’

Individual

Patients use a digital interface to choose who can access their imaging data. Patients get notifications about upcoming research projects that have passed a legal and technical check, including information about the organisation conducting the research, what the researchers were looking to understand and how they plan to use the data. Patients can select which projects they’d like their data to be used for and for what purposes as well as setting default preferences. Patients can decide the frequency with which they receive notifications, the channel by which they receive them, or turn them off all together.

Who is involved?	Individual patients.
How are decisions made?	Patients use a digital interface with information about the proposed projects to make decisions about which to grant access to.
What decisions are made?	Granular decisions about who can access data and for what reasons, as well as broader preferences.



‘Personal data store’

Individual

Expertise	Transparency	Feasibility
Patient choice	Accountability	Consistency in decision making
Inclusivity	Completeness of the data	Speed of research happening

1. Who is involved?
Individual patients.

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Patients use a digital interface with information about the proposed projects to make decisions about which to grant access to.

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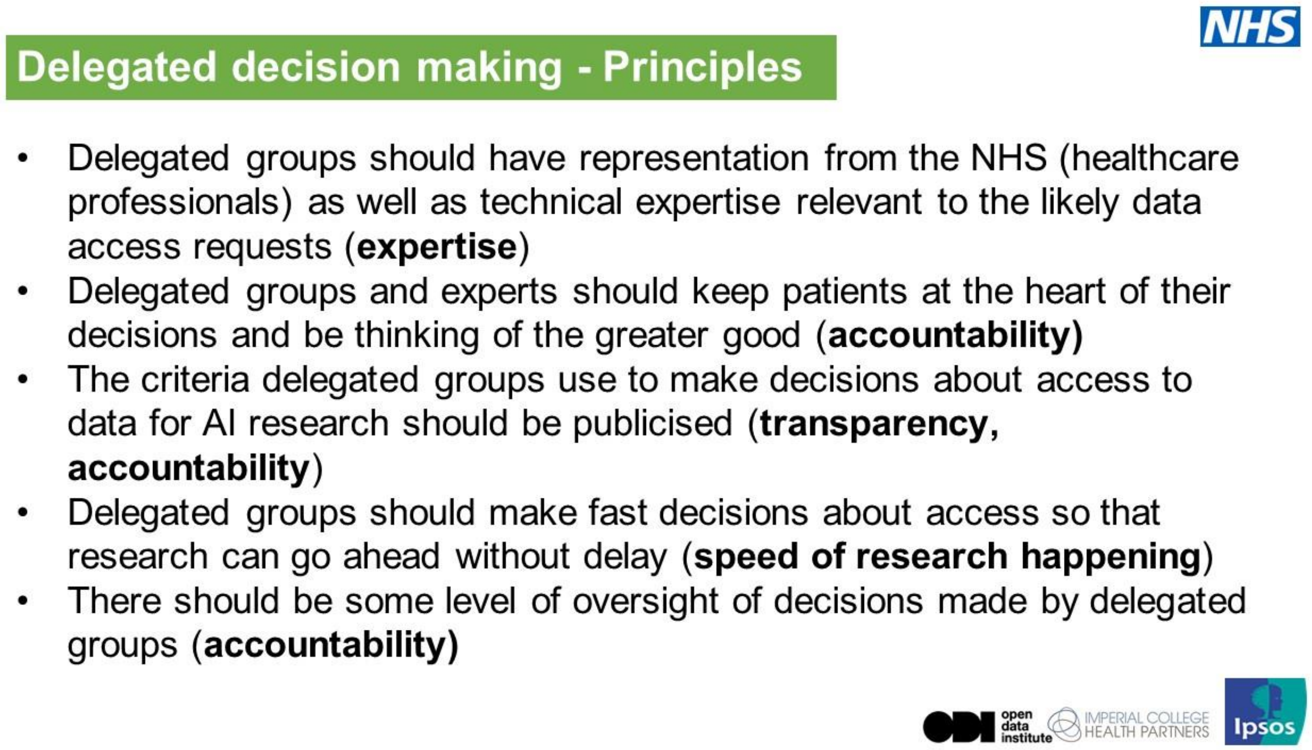
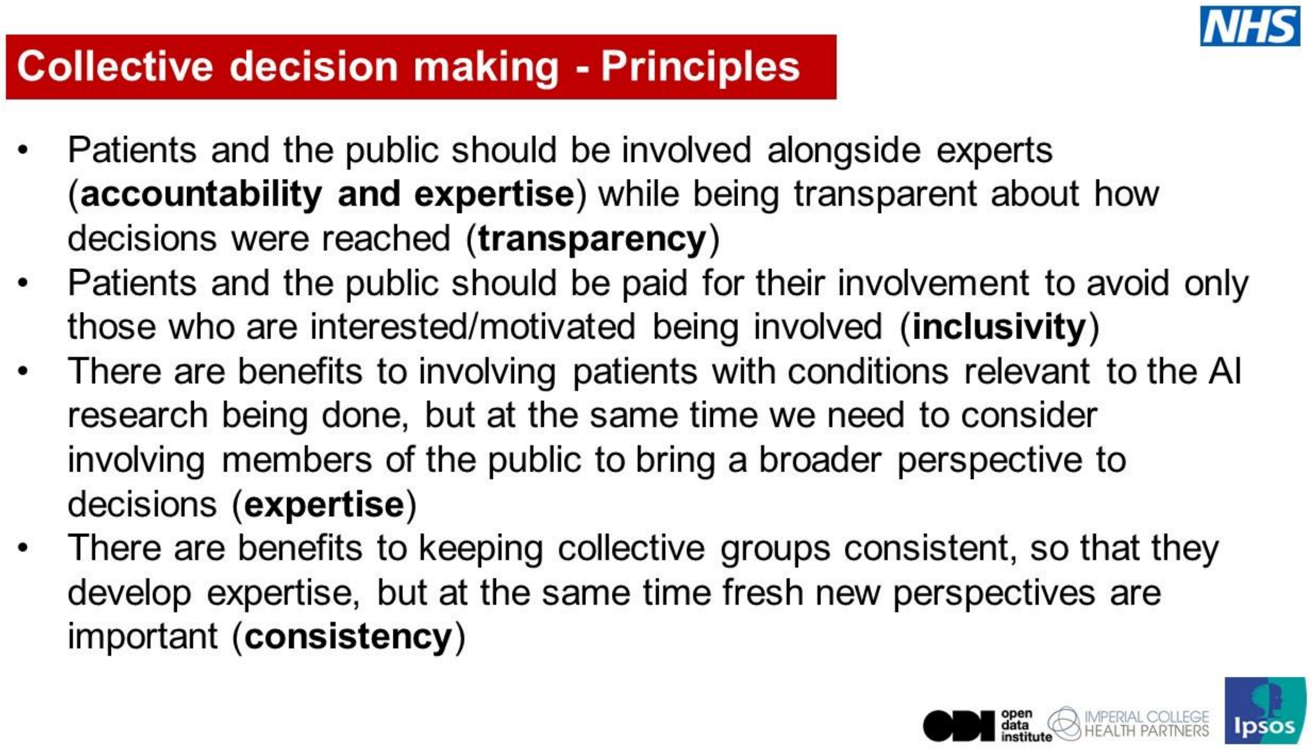


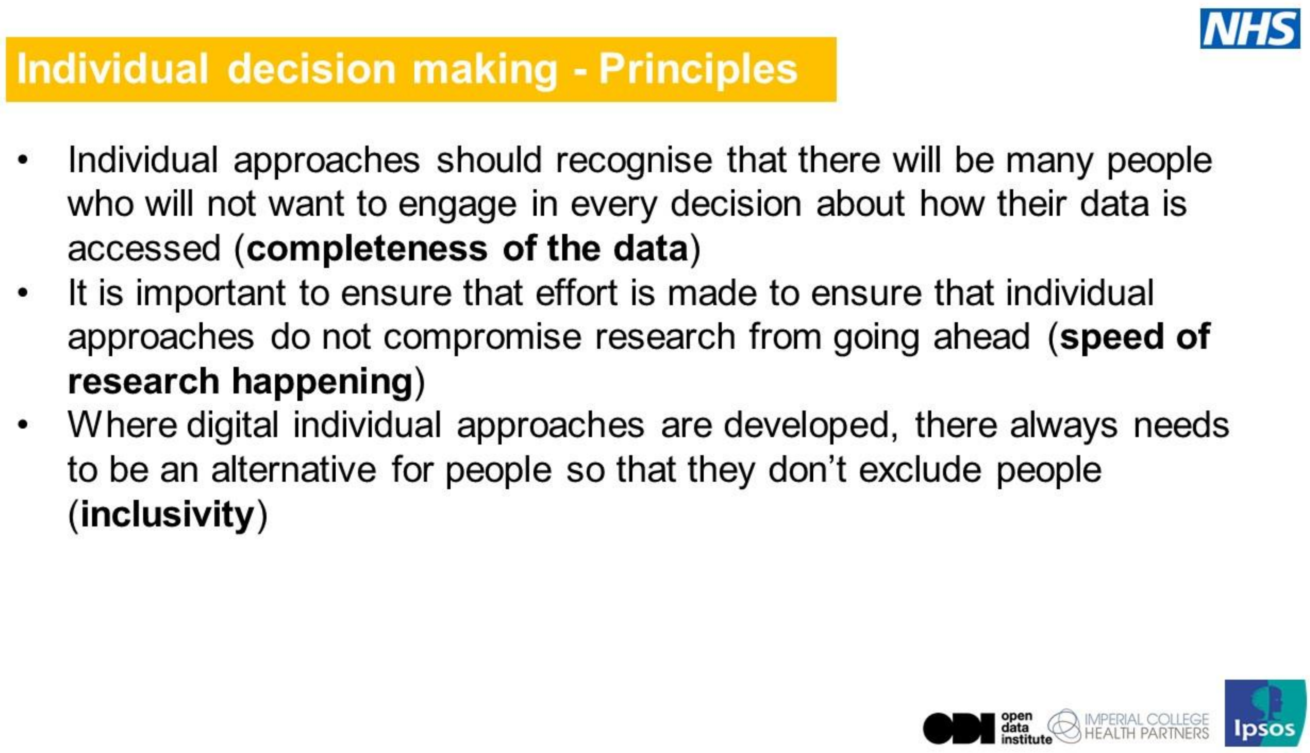
Delegated decision making - Principles

- Delegated groups should have representation from the NHS (healthcare professionals) as well as technical expertise relevant to the likely data access requests (**expertise**)
- Delegated groups and experts should keep patients at the heart of their decisions and be thinking of the greater good (**accountability)**
- The criteria delegated groups use to make decisions about access to data for AI research should be publicised (**transparency, accountability**)
- Delegated groups should make fast decisions about access so that research can go ahead without delay (**speed of research happening**)
- There should be some level of oversight of decisions made by delegated groups (**accountability)**



Collective decision making - Principles

- Patients and the public should be involved alongside experts (**accountability and expertise**) while being transparent about how decisions were reached (**transparency**)
- Patients and the public should be paid for their involvement to avoid only those who are interested/motivated being involved (**inclusivity**)
- There are benefits to involving patients with conditions relevant to the AI research being done, but at the same time we need to consider involving members of the public to bring a broader perspective to decisions (**expertise**)
- There are benefits to keeping collective groups consistent, so that they develop expertise, but at the same time fresh new perspectives are important (**consistency**)



Individual decision making - Principles

- Individual approaches should recognise that there will be many people who will not want to engage in every decision about how their data is accessed (**completeness of the data**)
- It is important to ensure that effort is made to ensure that individual approaches do not compromise research from going ahead (**speed of research happening**)
- Where digital individual approaches are developed, there always needs to be an alternative for people so that they don't exclude people (**inclusivity**)

Workshop 4 – Discussion guide

Workshop 4: Wednesday 20th July, 18.00-21.00

Time	Activity	Questions and materials
17.30-17.55	**Set-up: Facilitators check in** **25 mins**	• Test link, mic and camera. • Test who has the host/co-host function and ensure it is allocated to the right team member(s) for recording break out rooms. Make all moderators Co-hosts. • Change screen name to NAME – Org – Chair/Moderator. • Check everyone is on the WhatsApp group for facilitation team to be able to ask questions etc • Meanwhile tech support is assigning participants who are in the waiting room, notes takers, moderators, experts and observers to break-out rooms.
17.55-18.05	**Participant Check-in** **10 mins**	**Participants log into the online session** • Participants encouraged to join the zoom session early to check-in and check their video/mic. • Participants encouraged to get a pen and paper and have their participant pack with them. • Register as people join and change screen names as necessary to First name and first initial of surname (i.e. John H).
18.05-18.20	**Introduction and scene setting and presenting the cross-cutting findings** **Plenary 1** **15 mins**	**Ipsos Chair to give a warm welcome to the fourth online workshop (10 mins):** ● Introduce Consortium (Ipsos, ODI, ICHP), NHS AI Lab and Sciencewise (SLIDE 1) ● Chair to explain why we are here: expert commentators, any observers, and facilitators and note takers (SLIDE 2) ● Chair also reintroduce and cover ground rules and additionally…(SLIDE 3) ○ We will be going in to break out rooms -we've set these up so you don't need to do anything – just let it happen ○ If we lose connection to you at any point in the session [INSERT NAME] will call you to see if we can help bring you back in again ○ We'll be capturing discussions live for our own notes. ○ Confidentiality: we are interested in what you say not who said what. Your comments will not be attributed back to you in our report. ● Chair to remind participants what data stewardship is (Slide 4) and the approaches to making decisions (Slide 5), as well as the hypothetical case study we have been thinking about (Slides 6-8) ● Chair to present a summary analysis of cross cutting findings from across workshops 2-3 (Slide 9) ● Chair to present high level principles (Slide 10)
18.20-18.35	**Breakout room introductions and reflections on cross cutting themes from workshop 3** **Breakout 1** **15 mins**	**Introductions (5 mins)** • *Facilitator introduces themselves and the groups notetaker, and thanks everyone for joining this evening.* • *Check they have everyone's permission to audio record the discussion (reiterating that nothing is made attributable to an individual when writing up findings)* • *Quick Introductions – let's go round the zoom room and introduce ourselves:* ○ *Name* ○ *One thing they have learnt (if at all) throughout the workshops and one thing that stood out to them most about what we have been discussing (decisions about access to health data for AI research).*

		Facilitators to probe on participant reactions to the summary provided by Michelle and high level principles (10 mins) • What did you think of the high-level summary of workshop 3? • To what extent did it capture the discussions that you have been a part of? • What did you think about the principles? • Are there any that are missing?
18.35-18.45	**Assessing the scenarios against the principles** **Breakout 2** **10 mins**	Facilitator to welcome the group back and to explain that we will revisit the nine scenarios that we looked at in workshops 2 and 3, this time through the lens of the principles (rather than more generally what we liked/didn't like about them). **Facilitator to work through <u>one</u> scenario before the break** *Breakout rooms to follow rotation guide so that across the rooms, the scenarios are assessed in different orders.* Facilitators to use the principles slide (Slide 10) and the following prompts to explore the extent to which each scenario sits in line with these. **Facilitators to spend roughly <u>7-10 minutes</u> on each scenario**: "We are going to revisit those nine scenarios and look at these through the lens of these principles (i.e. what appears to be important to people across the whole group). For example, if we feel that all of these principles apply to the scenario, we have (in theory) the perfect means for making decisions about access to health data for AI research. " <u>First</u> show detailed summary of the scenario <u>Next</u> show Principle slide with summary box of the scenario • Which principles apply here? • Which principles do not apply here? • Which ones are we unsure about? Why? • (For those do not apply/unsure about) What could be done here to mitigate / resolve the fact that the principles do not apply here? Facilitator: please try and <u>explore trade-offs too</u>. For example: - **Expertise vs. Transparency**: An expert led scenario (+) might not feel very transparent (-) in terms of *how* decisions are made. Is this OK? Are we willing to trade-off transparency to ensure expertise involved? What could be done to mitigate this? - **Patient choice vs. Completeness of the data:** If patients are given choice (+) about each and every data access request, this could mean that many opt-out and this compromises the completeness of the data (-).Is this OK? Are we willing to trade-off completeness of the data to ensure patients are always given choice? What could be done to mitigate this? - **Consistency in decision making vs. Feasibility:** It might be preferable to have the same people coming together to review access requests so that there is consistency (+) as part of a collective group, but at the same time is this feasible? (-) Is this OK? Are we willing to trade-off feasibility (which is linked to cost, time etc) to ensure consistency in decision making? What could be done to mitigate this?

18.45-18.55	**Comfort break (10 mins)**	
18.55-19.50	**Assessing the scenarios against the principles** **Breakout 3** **55 mins**	**Facilitators to cover the remaining scenarios within the 55 mins (roughly 7-10 mins on each one).** Continued…
19.50-20.00	**Comfort break (10 mins)**	
20.00-20.50	**Refinement of fleshed out principles and identification of Qs for the research competition** **Breakout 3** **50 mins**	**Discussion of three sets of principles to inform the Terms of Reference for the research competition (15 mins so roughly on each bucket) – Slides 20, 21 and 22** • *Participants explore set of fleshed out principles (as above), including prompts such as:* ○ *How much do these reflect the conversations you had in your groups over the last three sessions? Is anything missing or not phrased accurately?* ○ *What would you like to add, remove, or change?* ○ *Are there any challenges with or questions about these approaches that should be explored through further research?* • *Moderator will amend the draft expectations live on the slides using red text for additions and ~~strikethrough~~ for deletions.* • *Facilitators to listen out for and probe for Qs which should be addressed through the research competition*
20.50 21.00	**Thank and close** **10 mins**	Chair to thank participants Brhmie to come in to also thank participants and explain how the principles and outputs will be used to inform the research competition.

Our standards and accreditations

Ipsos' standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Our focus on quality and continuous improvement means we have embedded a "right first time" approach throughout our organisation.

ISO 20252

This is the international market research specific standard that supersedes BS 7911/MRQSA and incorporates IQCS (Interviewer Quality Control Scheme). It covers the five stages of a Market Research project. Ipsos was the first company in the world to gain this accreditation.

Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos endorses and supports the core MRS brand values of professionalism, research excellence and business effectiveness, and commits to comply with the MRS Code of Conduct throughout the organisation. We were the first company to sign up to the requirements and self-regulation of the MRS Code. More than 350 companies have followed our lead.

ISO 9001

This is the international general company standard with a focus on continual improvement through quality management systems. In 1994, we became one of the early adopters of the ISO 9001 business standard.

ISO 27001

This is the international standard for information security, designed to ensure the selection of adequate and proportionate security controls. Ipsos was the first research company in the UK to be awarded this in August 2008.

The UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA) 2018

Ipsos is required to comply with the UK GDPR and the UK DPA. It covers the processing of personal data and the protection of privacy.

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This is a government-backed scheme and a key deliverable of the UK's National Cyber Security Programme. Ipsos was assessment-validated for Cyber Essentials certification in 2016. Cyber Essentials defines a set of controls which, when properly implemented, provide organisations with basic protection from the most prevalent forms of threat coming from the internet.

Fair Data

Ipsos is signed up as a "Fair Data" company, agreeing to adhere to 10 core principles. The principles support and complement other standards such as ISOs, and the requirements of Data Protection legislation.

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