Putting Good into Practice

A public dialogue on making public benefit assessments when using health and care data

A Findings Report
Hopkins Van Mil
April 2021

Creating Connections
Hopkins Van Mil

NDG National Data Guardian for health and social care

Understanding Patient Data

sciencewise

UK Research and Innovation

Annex

This annex accompanies the Putting Good into Practice report and contains the following documents:

Annex 1. Desk research document list

Number	Document title	Date	Category
001	BMC medical ethics: Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies	2016	Public attitudes
002	CQC: The state of health care and adult social care in England 2017/18	2018	Health/ social care reporting
003	CQC: The state of health care and adult social care in England 2018/19: Summary	2019	Health/ social care reporting
004	CQC: The state of health care and adult social care in England 2018/19: Full Report	2019	Health/ social care reporting
005	Wellcome: Ensuring effective use of patient data	2015	Data use
006	HVM: Foundations of fairness: views on uses of NHS patients' data and NHS operational data	2020	Data use
007	FCC: Taking Next Steps to Harness the Value of Health and Care Data	2018	Data use
008	FCC: Auditing demand for health and care data	2019	Data use
009	HRA: guidance for CAG applicants	2020	Codes & frameworks
010	HRA/ University of Sheffield: Public views on sharing anonymised patient-level data where there is a mixed public and private benefit	2019	Public attitudes
011	Imperial: Ensuring that the NHS receives fair financial value for its data	2019	Data use
012	Ipsos Mori: Commercial access to health data	2016	Public/ stakeholder attitudes
013	Ipsos Mori: Commercial access to health data	2016	Public/ stakeholder attitudes
014	Wellcome: Summary of the Commercial access report	2016	Public/ stakeholder attitudes
015	Ipsos Mori: Future data-driven technologies and the implications for use of patient data	2018	Public/ stakeholder attitudes
016	NAO: Adult social care at a glance	2018	Social care stats & analysis
017	NDG poll findings: public attitudes to organisations innovating with NHS data	2019	Public attitudes
018	NDG: A report of a citizens' jury designed to explore when it is reasonable for patients to expect patient data to be shared	2018	Public attitudes
019	NDG: Roundtable briefing on what we already know about public attitudes and values	2019	Public attitudes

020	NDG: Summary and briefing paper for roundtable including previous public dialogue programmes	2019	Public attitudes
021	NDG: Response to consultation giving feedback on NDG work priorities	2019	Data use
022	UPD: New Technologies Using Patient Data for Healthcare	2019	Data use
023	One London: Understanding public expectations of the use of health and care data	2019	Public attitudes
024	Reform: Making NHS data work for everyone	2018	Data use
025	UPD: What do we mean by public benefit?	2017	Definitions
026	UPD: Patient Data: Finding the best set of words to use	2017	Definitions
027	Wellcome funded: systematic review use of patient data	2019	Data use
028	CQC Driving improvement through technology	2020	Innovation
029	FCC: Intelligent sharing: unleashing the potential of health and care data in the UK to transform outcome	2017	Data use
030	The Department of Health and Social Care (DHSC) Code of Conduct for Data-driven Health and Care Technologies,	2019	Codes & frameworks
031	HMT UK Gov: Getting smart about intellectual property and other intangibles in the public sector	2018	Codes & frameworks
032	Wired Mag: China's hackers are ransacking databases for your health data	2019	Problems
033	Sharing is caring - data sharing initiatives	2019	Data use
034	Genomics England/Ipsos Mori: A public dialogue on genomic medicine: time for a new social contract?	2019	Public attitudes
035	Connected Health Cities Impact Summary	2020	Data use
036	Data sharing in the era of COVID-19	2020	Data use
037	UK patients and the NHS to benefit from new health data initiatives that will address major health challenges - HDR UK	2020	Data use
038	The Power of Data in a Pandemic	2020	Data use
039	HDR UK/ Health Research catalyst projects	2020	Data use
040	Nuffield Council on Bioethics: The collection, linking and use of data in biomedical research and health care: ethical issues	2015	Data use
041	UK Health Data Research Alliance: Trusted Research Environments (TRE) - A strategy to build public trust and meet changing health data science needs	2020	Data use
042	Revealed: how drugs giants can access your health records | Data protection | The Guardian	2020	Data use
043	New Zealand Data Commons Project	2016-2020	Data use

Annex 2. Process plans

The following process plans relate to the facilitated workshops for the group based in Reading and surrounds as a sample of the process used in each dialogue location.

Process Plan: Webinar

Putting good into practice: making public benefit assessments when using health and care data
Contextual **webinar**, setting the scene for dialogue deliberations. One hour on Zoom. Hard copy participant pack sent to all participants in advance of the webinar.

Purpose:
Introducing the dialogue through a vox pop films from commissioning bodies and stakeholders and other introductory material.

Time	Agenda	Process	Expected Outcomes
5.50-6.00	Check-in	Participant check in – test connection, chat function, go to Menti.com on phones. Explain why microphones are off for this discussion.	
6:00-6:10	Introductions & webinar purpose	Lead Facilitator: Warmly welcomes participants. Explanation that this is an introductory webinar to get us in the space to discuss topics related to making public benefit assessments when using health and care data. It will not run in the same way as a public dialogue session – these are interactive and give lots of space for discussion in small groups and time to listen to specialists in the room. This session provides you with the initial information you need to get us thinking about the issues. • NDG and HVM team members to introduce themselves	Participants know the purpose and format of the webinar

Time	Agenda	Process	Expected Outcomes
		- Notes participation from each event location - Shares timings for the session. Invite questions/comments: as many of these as possible will be put to the commissioning team, some may need to be followed up for the first online workshop.	
6:10-6:15 (5 mins)	Menti.com	**Q1: What comes to your mind when you think about health and care data or information?** Lead facilitator summarises what's coming on screen as it appears.	Understand where participants are in their thinking
6:15-6:30 (15 mins)	What is public dialogue & aims and objectives of this dialogue	Comments throughout collected in the chat and encouraged. Lead facilitator: Make it clear we'll have a discussion after this drawing on all the questions in the chat so please add questions you have there as we go along. 1. Summary of why this programme of work is different from other research activities participants may have been involved in/ heard about: - Time to reflect in/ in-between workshops - Interaction with specialists in the area under discussion - Working towards a practical outcome with a policy impact 1. Show **vox pop film** introducing the dialogue, the issues, touching on the dilemmas and explaining why it is important to hear the views of citizens on these. 2. **Presentation from NDG/UPD** picking up the detail of the aims and objectives of this dialogue to support what has been said in the film Objective visual on screen and participant packs.	Stresses the importance of what participants are doing & takin part in all of it. Stressing the practical purpose of this dialogue.
6:30-6:40 (10 mins)	Reflections, comments & questions	Drawing on the questions/ comments in the Chat. **NDG** and **UPD** answering the questions where possible.	Clarity on purpose for all participants.

Time	Agenda	Process	Expected Outcomes
		Lead facilitator explains how the answers to others which can't be answered this evening will be provided or form part of our discussions over the course of the workshops.	Initial questions answered.
6:40-6:45 (5 mins)		Comments throughout collected in the chat and encouraged. Lead facilitator: Make it clear we'll have a discussion after this drawing on all the questions in the chat. So please add questions you have there as we go along. Emphasise - we are talking about: • Health data AND • Social care data • Data used for purposes other than our individual care • We'll explain in the next session that the collection and use of social care data is less developed than health data for these purposes which are more than our individual care (research, planning, innovation) • Large amounts of data and information which is, *for the most part*, de-personalised or anonymous – show UP spectrum of identifiability. UPD films to support the understanding of patient data The Bigger Picture And finally – jargon busting: film with Kirsty Irvine/ Natalie Banner + introduction of the jargon busting handout in packs which participants can review while watching.	Making it clear what the practical purpose of this dialogue is De-mystifying terms and ideas.
6:45-6:55 (10 mins)	Reflections, comments, questions	Brief opportunity for questions – drawn from the chat. **NDG** and **UPD** answering the questions where possible. LF explains how the answers to others which can't be answered this evening will be provided or form part of our discussions over the course of round 2.	Clarity on purpose for all participants. Initial questions answered.

Time	Agenda	Process	Expected Outcomes
6:55-6:57	Recollective and participant pack	LF introduces the online space for individual tasks, demonstrating that the materials from tonight's webinar are there and can be reviewed again whenever participants wish to. Explaining the participants' pack and that this is arriving in hard copy so it can be used to make notes, as a prompt to their own thinking and as a resource for keeping all the materials used in the sessions.	
6:57-7:00	Menti.com	**Q1: One point you will take from this evening into our first workshop** **Q2: One thing you hope for the public dialogue** Lead facilitator: Highlight next steps including longer-term opportunity in the follow-up workshop.	Feedback on what was most helpful. Looking forward to next steps.

Recollective Homework task
Review webinar materials. Add in further questions you have about either the purpose of the dialogues or the public benefit assessments when using health and social care data.

Process Plan: Workshop 1

Putting good into practice: making public benefit assessments when using health and care data
Online workshop 1: context and deliberation. 2 hour online workshop.

Purpose:

a) Providing contextual information to support deliberations.
b) Initial considerations of the subject.

Time	Agenda	Process	Expected outcomes
5.30-6:00 (30 mins)	Participant Check-in	Participants who want to test their learning from the tech-try outs are encouraged to join the zoom session early to check-in and check their video/mic. Open www.menti.com on smart phones/ tab on their computer. Participants encouraged to get a pen and paper and have their participant pack with them. Tech support to run a register as people join and changed screen names as necessary.	Participants ready to go
5:50-6:00 (10 mins)	Speakers/ Observers Check-in	Speakers to check in and test mic and camera	
6:00-6:05 (5 mins)	Welcome & introductions	Warm welcome to the first workshop, setting the tone for the session. Lead facilitator: Hello and welcome to this first of four online public dialogue sessions exploring public benefit assessments when using health and care data. In a moment we will look at what to expect over the course of the workshops, but first, let's introduce the team who'll be with you. You'll get a chance to introduce yourself when we go into our small groups.	Everyone knows the facilitation team, observers and specialists in the room and why; and their roles and responsibilities in the time we are together.
6:05-6:10 (5 mins)	Process, agenda & points to help the discussion	Reminder of the overall process for this public dialogue in the form of online workshops and reflection tasks (as set out in webinar). Look at the agenda for this evening and points to help our discussions run smoothly. Lead facilitator shows PowerPoint slides that have been sent in advance to participants, setting out the overall process: key topics for each workshop and timings and reflection	Understand what is happening when and what's expected when taking part in our series of zoom workshops and in

Time	Agenda	Process	Expected outcomes
		tasks, the agenda for this workshop followed by the 2 slides giving guidance for online workshops and points to help us work well together.	the homework space on Recollective.
6:10-6:15 (5 mins)	Thinking about health and social care data	Log into www.menti.com and input code at the top of the screen. Tech support will enter information for those who can't access menti (communicated via Chat) **Q: To what extent have you thought about health and social care data/ information being used for research, planning and innovation?** • I have never thought about it • I have only thought about it occasionally • I have thought about it regularly Vote visual up on the screen. Review with the group.	Getting people in to the space. Gathering baseline data on initial thoughts.
6:15	Move to small groups		
6:15-6:35 (20 min) 6.15-6.20 (5mins) 6:20-6:30 (10 mins)	Introductions Our personal experience of health and social care data uses	**Recorder on** **Small group introductions:** Quick round of introductions: Name, where you live and one thing about you that you'd like to share with the group. Reminder: we are talking about uses of data beyond individual care. We asked you in the menti to tell us the extent to which you had thought about health/ social care data being used for research, planning and innovation as well as individual care. **Q1: Tell me more about what came to your mind – does this remind you of anything from your own experience/ something you've heard in the news?** Write your point in your pack or in the chat.	Unprompted surfacing of the key issues we are tackling to confirm the scope of the dialogue. Begin to think about the dilemmas the dialogue will tackle.

Time	Agenda	Process	Expected outcomes
6:30-6:35 (5 mins)		e.g. If I had diabetes, at some point I might think that all the data about people with diabetes around the country could help to plan for better diabetes care in the community. e.g. If my an elderly relative had a fall and as a result needed reablement support from social services, I might think that all the information gathered on the elderly having falls might be used to help prevent similar falls in the future. *Prompts:* • In your own life/ family/ friends • In things you've heard on the news • Covid (if not referenced by participants) • Or if this is news to you? Go round the group. Then whole group discusses: **Q2: What are your first thoughts on use of data for purposes beyond your care such as planning, research or new developments in health/ social care?** **Recorder off**	
6:35	Move to main space		
6:35-6:45 (10 mins)	Introduction to health and social care	1. The objective slide is shown again 2. NHS England and adult social care slide shown 3. What is social care? King's Fund 4. What is adult social care handout Lead facilitator explains: All parts of these systems collect data routinely as people are cared for. This data is treated with care, and people need to apply to those that hold the data for access to use it for research, planning and innovation. Stress differences between health & social care data collection and use.	Understanding that the system is made up of many, many parts and that NHS England and adult social care services have different models

Time	Agenda	Process	Expected outcomes
			managed differently.
6:45	Move to small groups		
6:45-6:55 (10 mins)	Exploring points	**Recorder on** Looking through the notes you made as you watched the video and heard the presentation: **Q1: To what extent did you hear things that were important/ improved your knowledge of this subject?** *Prompts:* • Do you have questions on what you've heard so far? • What surprised you or was news to you? • Why did it surprise you? **Recorder off**	Participants explore anything that was unclear, develop their understanding of a complex system
6:55 – 7:05	Break		
7:05-7:30 (25 mins)	The data assessment perspective	Comments throughout collected in the chat and encouraged. Lead facilitator: Make it clear we'll have a discussion after this drawing on all the questions in the chat. So please make sure you add at least one comment, question or thought you have in the chat as we go along. The Data Assessor – the how and why of how data is assessed currently: **1. Video: Kirsty Irvine**, IGARD	Understanding how data is assessed currently.

Time	Agenda	Process	Expected outcomes
		2. Video: Janet Valentine, Director, Clinical Practice Research Datalink (CPRD) – How CPRD assessment **3. Live presentation: Peter Short,** Clinical lead for GP data at NHS Digital Answers given by speakers/ observers where possible. Lead facilitator makes it clear that the answers to questions that can't be answered this evening will be shared in homework space.	
7:35	Move to small groups		
7:30-7:55 (25 mins) 7:30-7:31 (1 min) 7:31-7:40 (9 mins) 7:40-7:50 (10 mins)	Exploration of the points	**Recorder on** Please take one minute to think by yourself. Note in your pack one thing from the videos/ presentation you feel is important about how decisions are made about public benefit. Thinking through what we've heard so far… **1. What are your initial thoughts on the benefits of using data for research, planning innovation?** *Prompts:* • Think about health *and* social care data • What do you think about the benefits when the data is released to a university? (we heard about the Oxford University vaccine request in the first film we saw) • What do you think about the benefits when the data is released to a commercial organisation? The commercial arm of a charity or a pharmaceutical company? **2. What are your initial thoughts on the dilemmas/ challenges raised by using data for research, planning and innovation?** *Prompts:* • Think about health *and* social care data	First thoughts on benefits/ dilemmas.

Time	Agenda	Process	Expected outcomes
7:50-7:55 (5 mins)		- What do you think the dilemmas/ challenges might be about releasing data **Note:** data assessors will never release data if they think data breaches are a risk. **3. Group to summarise three main points** from their discussions so far. These will be shared on the homework space so you can see what other groups have said before the next workshop. This is just the start of our reflections on this. We will be continuing with these questions in our next session. **Recorder off**	
7:55-8:00 **(5 mins)**	Menti.com Explain the homework task: individual thinking time between activities	**Q1: Tell us one thing you will take from this evening into the next discussions we have** Word cloud will appear. Review with the group We will be on Zoom for a few more minutes if you have any questions about these workshops. **3KQ** to Explain the evaluation process.	Know what's expected of reflection tasks
8:00	Close		
8:00-8:05 **(5 mins)**		Time for participants to ask any follow up questions about the process or the evening.	Informal check-in as necessary

Recollective Homework task

1. Review workshop 1 materials. Add in further questions you have about either the purpose of the dialogues or the public benefit assessments when using health and social care data.

2. Review the 3 main points from the other groups in our location and note down one thing that you noted that is different/ very similar to your own group's discussions.
3. Review uses of health and social care data charts.

Process Plan: Workshop 2

Putting good into practice: making public benefit assessments when using health and care data
Online workshop 2: context and deliberation. 2 hour online workshop.

Purpose:
Initial explorations of scope area 6: Explore how people weight benefit and disbenefit of the use of data generated from publicly funded health and care given various factors.

Time	Agenda	Process	Expected outcomes
5:30-6:00 (30 mins)	Participant Check-in	Participants who want to test their learning from the tech-try outs are encouraged to join the zoom session early to check-in and check their video/mic. Open www.menti.com on smart phones/ tab on their computer. Participants encouraged to get a pen and paper and have their participant pack with them. Tech support to run a register as people join and changed screen names as necessary.	Participants ready to go
5:50-6:00 (10 mins)	Speakers/ Observers Check-in	Speakers to check in and test mic and camera	
6:00-6:05 (5 mins)	Welcome & introductions	Warm welcome to the workshop, setting the tone for the session:	Everyone knows the facilitation

Time	Agenda	Process	Expected outcomes
		Lead facilitator: Hello and welcome to this second of four online public dialogue sessions exploring public benefit assessments when using health and care data. In a moment we will look at what to expect this evening. The team of facilitators from HVM is the same as the previous workshop but we do have new speakers/ observers with us. Let's introduce the team who'll be with you. You'll be working in the same small groups as before. Reminder of the overall process for this public dialogue and the stage we are at. Look at the agenda for this evening and points to help our discussions run smoothly. • Reminder of all points to help the discussion • Stress recording – for our own notes, comments won't be attributed to any named individuals in our reports • Slide which shows us where we are in the process and where we are moving on to • Agenda for this evening • Reminder of the aim of the public dialogue	team, observers and specialists in the room and why; and their roles and responsibilities in the time we are together. Understand what's happening this evening & where we are in the process
6:05-6:10 (5 mins)	Thinking about health and social care data	Log into www.menti.com and input code at the top of the screen. Tech support will enter information for those who can't access menti (communicated via Chat) Vote visual up on the screen. **Q5: What's the main thing you remember about our last discussion?** You can add up to three words. Flowing discussion boxes appear.	Getting people in to the space. Gathering baseline data on initial thoughts.
6:10	Move to small groups		

Time	Agenda	Process	Expected outcomes
6:10-6:30 (20 min) 6:10-6:15 (5 mins) 6:15-6:25 (10 mins)	Reflections on public benefit	**Recorder on** Reminder: we are talking about uses of data collected every day in the NHS and adult social care for more than individual care. In your homework you looked at uses of data. We are drawing on that here. Facilitators to show the aim screen again. **Q5: Who do you think will benefit from the use of health and social care data for purposes beyond our individual care?** *Prompts (only add in gradually – allow participants to define) – to what extent will the following benefit?:* • Patients • Families • NHS organisations • Social care organisations • Data assessors • Universities • Businesses • Government • UK economy/employment Discuss as a small group. **Q6: How do you think these people/ organisations will benefit?** *Prompts:* • Create a list of the ways you think these people/ organisations will benefits • Why do you think this?	Unprompted surfacing of the key issues we are tackling to confirm the scope of the dialogue. Begin to think about the dilemmas the dialogue will tackle.

Time	Agenda	Process	Expected outcomes
6:25-6:30 (5 mins)		**Q7: Which, of any, of these things that we've listed feel like public benefits to you?** **Recorder off**	
6:30	Move to main space		
6:30-6:45 (15 mins)	Perspective from the data applicant – where benefits are clear	1. Social care: UCL Vivaldi study into COVID-19 in care homes. 2. Retinal scan and link to Alzheimer's 3. Cancer Care Registry + film Case studies shown *without* the What-ifs.	Understanding of examples when the benefits are clear.
6:45	Move to small groups		
6:45-7:10 (25 mins)	Exploring points	**Recorder on** We are going to look through the What Ifs for each case study (reminder these are in their packs). Run through each of the What if slides – one for each case study. Return to this as necessary in the discussion. These ask you to think about: **Q5: What impact would each of these 'what ifs' have on decisions about public benefit in your view?** *Prompts – to be used if helpful - What if:* • Data is used to make funding/ allocation of resources decisions?	Participants explore anything that was unclear, develop their understanding of a complex system.

Time	Agenda	Process	Expected outcomes

		- EU: Sharing: why is this a concern? e.g. data sovereignty or is it a national security issue?
		- Not everybody benefits (identity)
		- Lots of people benefit but in different ways (identity):
		  ○ A commercial firm makes a profit
		  ○ Patients get new treatments for a disease
		  ○ A local authority plans better for social care provision
		- Does the size of the study matter?
		- The expected outcome isn't found?
		- Another outcome is found?
		- Data is used as a predictive tool (linked to genome sequencing)?
		- Other countries use the data
		- Planning for mental health service provision
		
		Thinking about your homework on uses and what you have just seen,
		Q6: What do you feel about the purpose of the data access request in each case?
		
		Recorder off	

7:10-7:20	Break		
7:20-7:35 (15 mins)	Perspective from the data applicant – where benefits are not clear cut	**1. The Health Foundation** Richard Brine - The Health Foundation – the process of applying for data release. What's needed? How is public benefit explained in applications? What happens when an application isn't successful? Questions/ comments and reflections in the Chat. Lead facilitator asks speaker to respond as far as possible. Other questions will be answered and responses put in homework space.	Understanding how data is assessed currently.

Time	Agenda	Process	Expected outcomes
7:35	Move to small groups		
7:35-7:55 **(20 mins)** 7:35-7:50 (15 mins) 7:50-7:55 (5 mins) Flexi task	Exploration of the points	**Recorder on** Thinking through what we've heard so far… **1. What are the opportunities/ dilemmas you've heard this evening from the case studies and the presentation?** *Prompts:* • What is the opportunity? • Why is that an opportunity and who is the opportunity for? • Are the opportunities you've raised here applicable to everyone, or only to specific sections of society? • Why? • To what extent does there feel a difference in the opportunities for health care or social care data? • Why? *Prompts:* • What is problematic/ an issue? • Are the dilemmas you've raise challenges for everyone or specific sections of society? Why? • To what extent does there feel a difference in the dilemmas for health care or social care data? • Why? **If time:** **Q: What are the 3 most important points you've heard this evening?**	

Time	Agenda	Process	Expected outcomes
		This is just the start of our reflections on this. We will be continuing with these questions in our next session. **Recorder off**	
7:55-8:00 (5 mins)	Menti.com Explaining the homework task.	**Q5: What comes to your mind when you think about health and care data given all you've heard so far** Thank you for taking part this evening. Homework task - please review the materials from tonight in your packs, they are also on Recollective. And review the case studies we'll be looking at in Workshop 3. We will be on Zoom for a few more minutes if you have any questions about these workshops.	Know what's expected of reflection tasks.
8:00	Close	Reminder to come back for Workshop 3. We look forward to seeing you then.	
8:00 – 8:05		Time for participants to ask any follow up questions about the process or the afternoon.	Allows participants space

Recollective Homework task

1. Review workshop 2 materials. Add in further questions you have about either the purpose of the dialogues or the public benefit assessments when using health and social care data. Spend a minute reviewing the materials for workshop 3 which are on Recollective and in your packs.

Process plan: Workshop 3

Putting good into practice: making public benefit assessments when using health and care data
Online workshop 3: context and deliberation. 3 hour online workshop.

Purpose:
More detailed explorations of scope area 2: Explore how people weight benefit and disbenefit of the use of data generated from publicly funded health and care given issues of identity; scale; original purpose; prospect of benefit/ disbenefit; types of data.

Time	Agenda	Process	Expected outcomes
1.30-2:00 (30 mins)	Participant Check-in	Participants who want to test their learning from the tech-try outs are encouraged to join the zoom session early to check-in and check their video/mic. Open www.menti.com on smart phones/ tab on their computer. Participants encouraged to get a pen and paper and have their participant pack with them. Tech support to run a register as people join and changed screen names as necessary.	Participants ready to go
1:50-2:00 (10 mins)	Speakers/ Observers Check-in	Speakers to check in and test mic and camera	
2:00-2:05 (5 mins)	Welcome & introductions	Warm welcome to the workshop, setting the tone for the session: Lead facilitator: Hello and welcome to this third of four online public dialogue sessions exploring public benefit assessments when using health and care data.	Everyone knows the facilitation team, observers and specialists in the room and why; and their

Time	Agenda	Process	Expected outcomes
		In a moment we will look at what to expect this afternoon, but first, let's introduce the team who'll be with you – same team and introduce speakers/ observers. Reminder of the overall process for this public dialogue and the stage we are at. Look at the agenda for this afternoon and points to help our discussions run smoothly. • Reminder of all points to help the discussion • Stress recording – for our own notes, comments won't be attributed to any named individuals in our reports • A reminder of the scope of our discussions.	roles and responsibilities in the time we are together. Understand what's happening this afternoon & where we are in the process.
2:05-2:10 (5 mins)	Thinking about health and social care data	Log into www.menti.com and input code at the top of the screen. Tech support will enter information for those who can't access menti (communicated via Chat) Vote visual up on the screen. **Q: Share a few words which sum up your view at this point on using health and social care data for planning, research and new medical and social care developments.** You can add up to three words. Word cloud will appear. Review with the group .	Getting people in to the space. Gathering baseline data on initial thoughts.
2:10-2:35 (25 mins)	Case study presentations	Comments throughout collected in the chat and encouraged. Lead facilitator: Make it clear we'll have a discussion after this drawing on all the questions in the chat. So please make sure you add at least one comment, question or thought you have in the chat as we go along. 1. Health: National COVID-19 Chest Imaging Database (NCCID) - **Dominic Cushnan** NHSX AI Lab	Gain a clearer understanding of data assessment from the applicant's perspective and in relation to adult social care specifically.

Time	Agenda	Process	Expected outcomes
		2. Housing conditions impacts – **Sarah Dougan**, Chief Analytical Officer at London Borough of Islington 3. **Ian Turner**, Executive Chair, Registered Nursing Home Association	
2:35-2:55 (20 mins)	Whole group reflection discussion	Are there points which need clarifying? Are there points you'd like to explore further? Answers given by speakers/ observers where possible. Lead facilitator makes it clear that the answers to questions that can't be answered this afternoon will be shared in homework space.	Clarity on the above.
2:55-3:00 (5 mins)	Case study presentations	Developing on from the presentations heard previously we're going to look at three case studies that you looked at in your packs as your homework and that the speakers mentioned. LF goes through each of the case studies – picking up points that weren't perhaps clear from the presentations. Include the 'What-ifs'. 1. Chest imaging database 2. Housing conditions impacts on health 3. Long-term planning for social care Groups encouraged to make notes in their packs to bring in to the discussion.	Participants explore anything that was unclear, develop their understanding of a complex system.
3.00-3.25 3.00-3.20 (20mins)	Case study discussions	**Recorder on** **Q1: What impact would each of these 'what ifs' have on decisions about public benefit in your view?** *Prompts – to be used if helpful - What if:* • The research is exploratory, without a clear purpose at first?	Quick reflections on purpose will help to understand where scepticism lies.

Time	Agenda	Process	Expected outcomes
3.20-3.25 (5mins)		- Scans or data from them are not used for their original purpose? - Access to data is given to those outside the UK? - A profit is made? - The experience of using the data is used for promotion/ marketing? - Funding decisions/ resource allocations are made as a result of the research? - Other findings (child at risk of harm) are found from linking the data to other sources of information? - Data informs planning in other parts of the country? **Q2: What do you feel about the purpose of the data access request in each case?** **Recorder off**	
3:25-3:45 (20 mins)	Break		
3:45	Move to small groups		
3:45-4:50 (65 mins) 3:45-3:50 (5 mins) 3:50-4:00 (10 mins)	Drilling into the detail of public benefit	**Recorder on** Reminder: we are talking about uses of data collected every day in the NHS and adult social care for more than individual care. Facilitators to go back through the packs and remind themselves of the case studies they've heard about so far. Given what you have heard so far this afternoon, and in the previous workshops (refer to your packs as a reminder): **Q3: How does all you have heard so far affect what you think about the decisions that have to be made about public benefit?** - What are the key things that affect public benefit for you?	Tracking down in to the detail.

Time	Agenda	Process	Expected outcomes
4:00-4:10 (10 mins) 4:10-4:40 (30 mins)		Facilitators to work with the group to draw up a quick list of everything that affects public benefit decisions in their view. **Q4: To what extent are these factors important/ unimportant?** • The identity of those who benefit or are disadvantaged • The scale of any benefit and disadvantage • How close the benefit should be to the original purpose of the data collection • The likely prospect (likelihood) of the benefit or disadvantage • The impacts of the type of data used on public benefit assessment **Q5: Why do you feel as you do about what is important/ unimportant in public benefit decisions?** Go through each of the factors: • Identity – *e.g. use of data from housing and health identifies an adult with a drug problem but also a child at risk of harm – meaning a parent could lose custody of a child. Or the healthcare/social care organisation is the main beneficiary through access to cleaned up data to use for other research/planning projects?* • Scale – *e.g. what if it's a large scale research study using hundreds of thousands of people's data but only a few people benefit?* • Closeness – *e.g. if Chest scan data collected for COVID-19 was also used to identify rare genetic lung conditions earlier. If data collected on length of homecare visits to assess nutrition/weight in the elderly was also used to assess impacts on mental health?*	

Time	Agenda	Process	Expected outcomes
4:40-4:50 (10 mins)		• Prospect – *e.g. what about exploratory research? Researchers want to explore data on a condition for insights/patterns but don't have a specific outcome in mind? E.g. brain scans of everyone between 20-30 who had a stroke.* • Impacts of the type of data used: *e.g. linking data on mobile phone usage (call duration/frequency) with data on mental health crises to help identify crises earlier?* • Why do you feel this? What matters/ doesn't matter about each of them? **Create a summary sheet of the three main points discussed. We'll be sharing these on Recollective.** **Recorder off**	
4:50	Move to main space		
4.50-4.55 (5mins)	Sharing three main points	Each group to take **no more than 1 minute** to share their three key points. Facilitators to share their screen so that participant volunteers can read from it.	
4:55-5:00 (5 mins)	Menti.com	Show the objective of the session slide again. **What will it be important for us to consider in our next workshop when thinking about how decisions about public benefit should be made?** This time we'd like you to review the findings from the three groups so far this afternoon and think through your own reflections on the dilemmas here. The instructions are on Recollective. It's important that you do this as we'll be discussing it at our next session. Thank you for taking part this afternoon. We will be on Zoom for a few more minutes if you have any questions about these workshops.	Know what's expected of reflection tasks.
5:00	Close	Reminder to come back for Workshop 4. We look forward to seeing you then.	

Time	Agenda	Process	Expected outcomes
5:00-5:05 (5 mins)		Time for participants to ask any follow up questions about the process or the afternoon.	Allows participants space

Recollective Homework task
1. Review workshop 3 materials. Add in further questions you have about either the purpose of the dialogues or the public benefit assessments when using health and social care data.
2. Spend a minute reviewing the summaries from the other groups. Where to points seem similar/ different from what was discussed in your group?

Process Plan: Workshop 4

Putting good into practice: making public benefit assessments when using health and care data
Online workshop 4: Concluding deliberation. 2 hour online workshop.

Purpose:
More detailed explorations of scope area 3: Explore how far attitudes vary on 1 and 2 when social care data is being used.

Time	Agenda	Process	Expected outcomes
5.45-5:00 (15 mins)	Participant Check-in	Participants who want to test their learning from the tech-try outs are encouraged to join the zoom session early to check-in and check their video/mic. Open www.menti.com on smart phones/ tab on their computer.	Participants ready to go

Time	Agenda	Process	Expected outcomes
		Participants encouraged to get a pen and paper and have their participant pack with them. Tech support to run a register as people join and changed screen names as necessary.	
5:50-6:00 (10 mins)	Speakers/ Observers Check-in	Speakers to check in and test mic and camera	
6:00-6:05 (5 mins)	Welcome & introductions	Warm welcome to the workshop, setting the tone for the session: Lead faciliator: Hello and welcome to this fourth and final online public dialogue sessions exploring public benefit assessments when using health and care data. **It is really important that by the end of this evening we have arrived at some practical suggestions for what should be included in the guidance to data assessors being prepared by the National Data Guardian.** In a moment we will look at what to expect this evening, but first, let's introduce the team who'll be with you – same team and introduce speakers/ observers. Reminder of the overall process for this public dialogue and the stage we are at. Look at the agenda for this evening and points to help our discussions run smoothly. • Reminder of all points to help the discussion • Stress recording – for our own notes, comments won't be attributed to any named individuals in our reports • A reminder of the scope of our discussions.	Everyone knows the facilitation team, observers and specialists in the room and why; and their roles and responsibilities in the time we are together. Understand what's happening this evening & where we are in the process
6:05-6:10 (5 mins)	Thinking about health and social care data	Log into www.menti.com and input code at the top of the screen. Tech support will enter information for those who can't access menti (communicated via Chat) Vote visual up on the screen.	Getting people in to the space. Gathering

Time	Agenda	Process	Expected outcomes
		Q1: Share a few words which sum up your view at this point on using health and social care data for planning, research and innovation.	baseline data on initial thoughts.
6:10-6:20 (10 mins)	Presentation on headline findings so far	A top-line presentation on what we've heard (main stimulus reminders/ homework tasks), where we are (3 key points from last session) and what is expected by the end to inform the concluding deliberations tonight. Highlight where the findings seem to be heading towards a practical output/ suggestion/ consideration e.g. ensuring there is transparency in the process by sharing interim and final findings of research publicly. Quick summary of all the case studies/ presentations.	Understand where we've got so far and how this session will lead us to our outcome. Avoiding recency.
6:20	Move to small groups		
6:20-6:50 (30 min) 6:20-6:40 (20 mins)	Making a data application in the future	**Recorder on** **Q1: What are the issues raised in exploring key uses of health and social care data?** *Think about:* • Speculative research (no clear outcome in mind) • Potential harms to groups – use of the data *and* whose data is not represented? E.g. CPRD voluntary for GPs to submit data • Other uses than the original purpose • Big data – but only a few people benefit *Prompts:* • What feels comfortable • What feels worthwhile – where is something uncomfortable but also worthwhile? • What are the clear benefits in the examples we've seen? Treatments/ innovations/ planning/ new research areas/cleaned data? • What's the scale of opportunity you have seen?	Comparisons can be made between findings on health and findings on social care. Leads us in to principle development.

Time	Agenda	Process	Expected outcomes
6:40-6:50 (10 mins)		Reminder: we are talking data collected every day in the health and adult social care for individual care – which is then (and this is the important bit) used for purposes beyond that e.g. research, planning, new developments **Q4: To what extent are the key issues the same/ different if:** 1. It was November 2019 and we had never heard of Covid-19? 2. It was November 2025 and the Covid crisis was in the past? **Recorder off**	
6:50 – 7:00	Break		
7:00-7:45 **(45 mins)** 7:00-7:10 (10 mins) 7:10-7:45 (35 mins)	What we need to be in the policy guidance/ advice	**Recorder on** Discussion on the principles that we would recommend for the policy guidance. Group develop their own set. **Q1: Given what we've learnt so far about the key issues what needs to be taken into account to assess whether there is/ is not public benefit in a data access request?** *Prompts – be specific and practical:* - What would an assessor need to know to test public benefit? - To what extent is there a difference if social care or health care data is being used? - What is sufficient public benefit? - Where do we draw the line?	Concluding deliberation.

Time	Agenda	Process	Expected outcomes
		Q2: Drawing on our long list of what needs to be taken into account - what are the specific considerations ? e.g. If a study starts somewhere but finds something else – you can press the 'reset button' and go back to those who gave the additional permissions to ask for permission for the new study. To explore other avenues. A list of all the decisions that need to be made (up to 10 decisions). *Prompts – be specific:* • If you were the data assessor what would you need to know to make a decision? • How would you define public benefit? • How would you test for public benefit? • What is the consideration to be made here? • What an applicant have to include in their application? • Which considerations are more or less important • Are there are any key principles that you'd like to include? Create a prioritised list. Volunteer(s) to share the groups top 2 considerations. **Recorder off**	
7:45	Move to main space		
7:45-7:50 (5 mins)	Groups share their decisions	**Recorder on** Each group shares findings. 1 minute each.	

Time	Agenda	Process	Expected outcomes
7:50-7:55 (5 mins)	Responses from commissioning bodies	NDG and UPD to respond to the findings that are shared. Explain next steps and how this will help those applying for / assessing health and social care data.. Lead facilitator to explain **follow up workshop next June.** **Recorder off**	
7:55-8:00 (5 mins)	Menti.com Evaluation survey	**One final piece of advice to the National Data Guardian in devising the policy advice or guidance based on these discussions.** Set by **3KQ: Facilitator to state importance of evaluation:** • Responses will go directly to the evaluators. • Feedback is anonymous unless they choose to share their details with us. • The aim is to help us learn what's working well or not so well and feed this back to the project team so they can adapt to future workshops and make them as good as possible. Thank you for taking part this evening, and in the whole public dialogue process.	
8:00	Close	Explain incentives. Thanks again.	
8:00-8:05 (5 mins)		Time for participants to ask any follow up questions about the process or the evening.	Allows participants space to raise

Annex 3. Stimulus materials

Jargon Buster

Some words and phrases that may come up in our discussions

Algorithm: A step by step method of solving a problem using a set of mathematical instructions or rules, most commonly used in processing large amounts of data using computers.

Anonymisation: The process of turning data into a form which does not identify individuals either directly or indirectly and where identification is not likely to take place. The spectrum of identifiability is relevant here.

Confidentiality: Ensuring that information is only made available or disclosed to authorised individuals, or organisations.

Controller: A term used to describe an individual or organisation who determines the purposes for which, and the ways in which, any **personally identifiable data** is or will be processed. It is the responsibility of the Controller to ensure that any processing of personally identifiable data is lawful.

Care record/ medical record/ patient record: Care records are personal records which identify an individual (whether living or dead) and which can be held electronically, in a paper file or a combination of both. They include data relating to patients' physical or mental health; social care needs and service; any counselling or assistance given by professional or voluntary organisations

Data/ patient data/ patient health information: Data that is collected about a patient whenever they go to a doctor or receive social care. It may include details about the individual's physical or mental health, such as height, weight, allergies, social care needs and services received. It may also include next of kin information. This is recorded and stored in a **care record**.

Data Protection Act (2018)[1]**:** Data protection legislation for the UK which governs the handling and protection of **personally identifiable data** relating to living people. It includes specific rights for individuals, such as rights to know and correct what data is held. It supersedes the Data Protection Act (1998) and stipulates additional legal obligations under the European Union's **GDPR**.

Data Protection Officer: An independent officer responsible for advising an organisation on how to ensure they comply with the Data Protection Act 2018 and meeting the individual's rights.

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[1] http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted

Data security: Protecting data and information systems from unauthorised access, use, disclosure, disruption, modification or destruction.

Data Use/ Sharing Contracts and Agreements: a group of documents that sets out the common set of rules to be adopted by the various organisations involved in using health data. They establish the rules that will apply to the processing of any data by partner organisations.

Depersonalised data: Also called anonymised or **pseudonymised** - this is information that does not identify an individual, because **identifiers** or identifiable data have been scrambled or removed from the non-identifiable information about the person it relates to.

Duty of Confidentiality: A duty of confidentiality (or confidence) arises when one person discloses information to another (e.g. patient to clinician) in circumstances where it is reasonable to expect that the information will be held in confidence.

Explicit consent: a freely given, specific, informed and unambiguous indication of the individual's wishes e.g. regarding data use. There must be some form of clear affirmative action – or in other words, a positive opt-in. Explicit consent cannot be inferred from silence, pre-ticked boxes or inactivity.

General Data Protection Regulation (GDPR)[2]**:** The General Data Protection Regulation 2016/679 is a regulation in EU law on data protection and privacy for all individuals within the European Union and the European Economic Area. It also addresses the export of personal data outside the EU and EEA areas and all personal data processed by organisations established in the EU.

Identifier: An item of data, which by itself or in combination with other data, enables an individual to be identified.

Linkage: The merging of information or data from two or more sources, with the object of combining facts concerning an individual or an event, which are not available in any separate record.

Personally identifiable/ confidential patient data: This term describes personal information about identified or identifiable individuals, which should be kept private or secret. It includes the definition of personal data in the Data Protection Act, but also includes data relating to people who have died and information given in confidence under the Duty of Confidentiality.

Personal data: According to the Data Protection Act, this is data that relates to a living individual who can be identified from this data, or from a combination of this data and other data which is in the possession of, or is likely to come into the possession of, the **controller**.

Population level data: data which helps the NHS better understand health trends and patterns within a community, a region of or the whole country.

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[2] https://gdpr-info.eu/

Pseudonymisation: A procedure by which personalised data, such as name and address within a **data set** are replaced by one or more artificial identifiers, or pseudonyms.

Routine data: Patient health information and NHS operational information collected as part of the everyday running of the NHS. Routine data is used by NHS organisations to understand the health needs of local and national populations, to monitor and manage services, and for research.

Social care data: information collected about people who use social care services. We are focusing on the information collected by adults who are using public sector social care services in our dialogue discussions.

Case Study: UCL Vivaldi study into COVID-19 in care homes

National study to find out about COVID-19 infections in care homes

What data?

COVID-19 test data from 6500 staff and 5000 residents in over 100 care homes across England.
Symptoms data from those infected.
Data will be linked to hospital admissions & deaths.
Identifying information e.g. name & address is removed

Do what with the data?

Test and symptoms data will be linked to hospital admissions and deaths data to understand how COVID-19 spreads in care homes, how long the antibody response lasts and if this helps to prevent re-infection with the virus.

What next?

Add to the data in-depth interviews with care home staff to understand how the pandemic has affected working conditions and measures to prevent infections in care homes

National study to find out about COVID-19 infections in care homes

Department of Health & Social Care

UCL

Who is applying to use the data?

'Vivaldi' is the project name for a collaboration between University College London researchers, the Dept. of Health & Social Care and Four Seasons Care Homes. University of Birmingham researchers conduct the in-depth interviews

vivaldi

Preventing COVID-19 in care homes

Why they said they wanted the data

- To use this data to inform the national pandemic response to COVID-19 in care homes
- To protect residents and staff from future waves of infection

What if…

1. The data was used to decide which care homes got additional support?

2. The data was shared with other researchers in the EU looking at the impact of COVID-19?

3. The data was used make care homes bring in new working practices which they might not be able to afford and the home closed as a result.

What impact would that have on decisions about public benefit?

Case Study: Retinal scan and link to Alzheimer's

Retina scanning using Artificial Intelligence (AI) to detect early signs of Alzheimer's

What data?

Eye scans of 300,000 patients aged 40+ who visited eye doctors between 2008 and 2018 linked to the patients' other hospital data - identifying information e.g. name/ address removed

Do what with the data?

Searching for patterns in the eye that could indicate the presence of disease elsewhere in the body. First study will be for Alzheimer's. Future studies could look at Stroke and heart disease.

What next?

Linking the eye scan data with other hospital data to examine changes to patients' eyes within the ten-year period.
Look for the development of Alzheimer's disease in the same patient.
The researchers hope to identify a reliable test using eye scans to diagnose Alzheimer's disease earlier.

Retina scanning using Artificial Intelligence (AI) to detect early signs of Alzheimer's

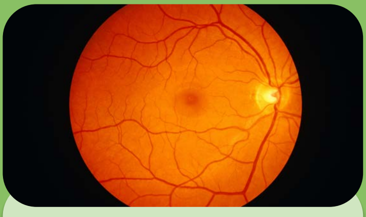
Who's involved?

Doctors and researchers in universities and hospitals specializing in eye disease, collaborating with a multi-national tech company which has developed an artificial intelligence tool

What is being said about this research?

- There is some evidence that the back of the eye changes as a person develops Alzheimer's.
- The changes may be too small to diagnose the disease.
- 50% to 80% of Alzheimer's cases currently go undiagnosed.
- If the technique does not work for Alzheimer's, it might work for something else.

What if…



1. Not all the people who were included in the study benefited from it in terms of early diagnosis?
2. The study was much smaller in scale?

3. In the longer-term this study finds no link between changes in the eye and an Alzheimer's diagnosis?
4. The data is found to be important in diagnosing other diseases such as Stroke and heart disease, but not Alzheimer's?

What impact would that have on decisions about public benefit?

Case Study: Cancer Care Registry

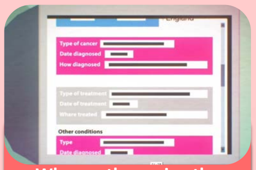
National Cancer Registry to plan cancer services

What data?

When a person is diagnosed with cancer in the UK they are automatically included in the registry. Data includes:
Type of cancer
Diagnosis date
How diagnosed
Type of treatment & where
Other health conditions
Outcomes
Identifying information: name & address removed

Do what with the data?

Follow patients' progress for the rest of their lives and study the affect of their treatment, their other health conditions and other lifestyle factors



Why are they using the data?

Measure the effectiveness of new drugs & treatments
Plan cancer services
Measure how the UK is performing vs other countries

National Cancer Registry to plan cancer services

NHS CANCER RESEARCH UK

Who is using the data?

The NHS, Charities, university researchers, pharmaceutical and health care companies

What is registry saying that its doing with the data

Data from the registry is being used to:
- Measure the benefits of a new treatment for lung cancer
- Identify women at higher risk of breast cancer in later years
- Measure the affect of the 'Be Clear on Cancer' campaign

What if…

1. Data is linked to genome sequencing to help predict who will go on to develop more aggressive cancers
2. Other countries pay for access to plan cancer services in their nations.

3. Data is used to predict suicide risk after cancer diagnosis and plan services to help design appropriate mental health support.

What impact would that have on decisions about public benefit?

Case Study: National COVID-19 Chest Imaging Database

National COVID-19 Chest Imaging Database

What data?

A centralised UK database containing chest X-Ray, CT and MRI images from hospital patients across the country + clinical data, identifying information e.g. name/ address removed

Do what with the data?

Use the images to train artificial intelligence to look for patterns that are telltale signs of COVID-19

Why are they using the data?

Artificial intelligence could make it quicker to analyse the effect of COVID-19 on our bodies and identify the best ways to treat patients in hospital

National COVID-19 Chest Imaging Database

Who is using the data?

NHSX

faculty

Artificial intelligence made real

NHS Royal Surrey NHS Foundation Trust

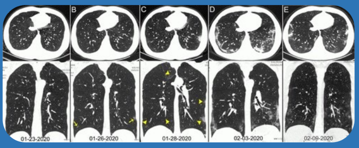
BSTI The British Society of Thoracic Imaging

Joint project by NHSX, the British Society of Thoracic Imaging (BSTI), Royal Surrey NHS Foundation Trust and technology company Faculty

Why they wanted the data?

- Assess patients faster in A&E
- Save Radiologists' time
- Increase the safety and consistency of care across the country
- To make data available to researchers, clinicians, tech companies wanting to investigate the disease and support the treatment and recovery COVID-19 patients

What if…



1. The data is explored without a clear purpose at first, to see what other interesting and useful findings about Covid-19 or other diseases can be discovered?
2. The scans or the data which come from them are used for research not related to Covid-19 further down the line?
3. Access to the data is granted to a research organisation outside the UK?
4. A research company, such as a University spin-off, makes a profit from the research they have carried out using the data?

What impact would that have on decisions about public benefit?

Case Study: Housing conditions impacts

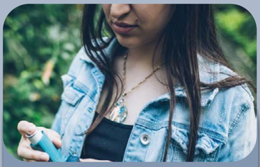
Study to find out the impact of housing conditions on health

What data?

Health data from hospitals, mental health, GP and community services linked with unique property reference numbers – collected by local councils and by the NHS. Identifying information: names & addresses removed

Do what with the data?

Link health data records on health conditions and use of health care services with the type and condition of homes



What next?

Use the data to find out which kinds of homes in which areas are linked to the most cases of health conditions such as asthma or mental health crisis

Study to find out the impact of housing conditions on health

NHS

LOCAL COUNCIL

Who is applying to use the data?

A London Council working with its local NHS commissioners and a US-owned population data management company.

Why they said they wanted the data

- Health can be affected by the environment, housing, education, nutrition and wealth
- The Council want to answer questions such as ‘how does living in a damp house affect a child’s health’
- They will use the data to better target services such as housing maintenance

What if…

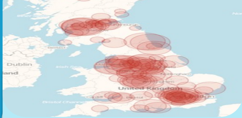
1. The population data management company uses the experience from this project to help promote their services to other councils and NHS organisations?
2. The data was used by the council to increase investment in some services and decrease investment in others?

3. Linking the housing and health data (e.g. drug/alcohol abuse) revealed a child not currently identified by social services could be at risk of harm?

What impact would that have on decisions about public benefit?

Case Study: Long-term planning for improved social care

Long-term planning for improved social care



What data?

Combining data from several local councils across the country on the availability of adult social care services with the number and type of requests for adult social care support

Do what with the data?

Data visuals are used to show:

1. Where care is currently being delivered
2. Requests for care that have not yet been met
3. Reveal where adult social care demand is clustered

Why are they using the data?

The data is used to help local councils organise their social care services better and plan for different types of services in the future

Long-term planning for improved health and social care

Who is using the data?

Local councils, providers of adult social care services and NHS Digital working with a data visualisation/ AI technology company

Why they said the wanted this data

Use big data from health and social care to:

- Help to meet the growing demand for social care services.
- Help to better understand current demand,
- Help to predict and prevent future demand
- Allow care homes and home care organisations to identify key areas of need

What if…

1. The data is used to plan for the closure of some services in order to fund others which are more effective overall?

2. The data is used by care companies to model their business plans and market their services?

3. The data is used to make plans for the need/delivery of adult social care services in other parts of the country?

What impact would that have on decisions about public benefit?