National Data Advisory Group
Minutes

Date	07th September 2022	**Time**	13.00-14.30
Venue	MS Teams		
Chair	Jennifer Boon		
Secretary	[redacted]		

Attendance

Name	Title	Notes
Jennifer Boon **(chair)**	Deputy Director of Data Policy, NHS Transformation Directorate	
[redacted]	Digital Oversight, NHS Transformation Directorate	
[redacted]	Head of Cross-Government Data Strategy, NHS Transformation Directorate	
[redacted]	Deputy Head of Communications, NHS Transformation Directorate	
[redacted]	Senior Policy Advisor, NHS Transformation Directorate	
[redacted]	Senior Policy Advisor, NHS Transformation Directorate	
[redacted]	Senior Policy Advisor, NHS Transformation Directorate	
[redacted]	Policy Advisor, NHS Transformation Directorate	
[redacted]	Policy Advisor, NHS Transformation Directorate	
Dr Nicola Byrne	National Data Guardian for Health and Care	
Louis Holmes	Policy Manager, Care England	
Helen Wilkinson	Research & Information, Local Government Association	Deputy for Philippa Lynch
Nicola Perrin	Chief Executive, Association of Medical Research Charities	

Rachel Power	Chief Executive, Patient’s Association	
Matt Hennessey	Regional system rep, Greater Manchester Health Social Care Partnership	
Linn Philips	NHS patient and public voice partner	
Michelle Thompson	NHS patient and public voice partner	

Apologies

Name	Title
Chris Carrigan	Expert Data Adviser, Use MY Data
Philippa Lynch	Senior Data Specialist, Local Government Association
Helen Stokes-Lampard	Chair, Academy of Medical Royal Colleges
Mavis Machirori	Senior Researcher, Ada Lovelace Institute
Marc Farr	Regional system rep, East Kent Hospitals University NHS Foundation Trust
Nicola Brassington	Deputy Director for Data, Analytical Strategy and Burden Reduction, NHS Transformation Directorate

Minutes

Actions			
#	**Meeting Date**	**Action**	**Owner**
1	07/09/22	Return to meeting with overview of how this group relates to other data strategy groups	JB / Data Strategy Team
2	07/09/22	Put together more information on increasing individuals’ access to their data to share with the group.	JB / Data Strategy Team
3	07/09/22	Talk to ASC colleagues about how best to engage DLUC.	JB / Data Strategy team
4	07/09/22	Provide group with overview of timeline of key commitments in the data strategy	Data Strategy team
5	07/09/22	Reach out to Healthwatch England to engage with them on our plans for public engagement.	Data Strategy team

6	07/09/22	RP and [redacted] to discuss her work on patient partnership in design and delivery of services	RP and [redacted]
7	07/09/22	Add impact of proposed data protection reforms on the Data Strategy to agenda for next time. (DCMS Data Protection and Digital Information Bill)	Data Strategy team
8	07/09/22	DHSC, Care England and LGA to discuss data linkage with non-health data in SDEs outside of meeting.	[redacted]

Item 1) Welcome and introductions

JB opened the meeting, welcomed attendees and facilitated introductions of the group.

Item 2) Overview of the group

The group received the terms of reference (ToR) prior to the meeting. JB highlighted key points from these ToR focusing on an overview of role and responsibilities of members and highlighting that the chair will report back any decisions made to the group.

The group will be expected to adhere to Chatham House rules -speak freely but don’t attribute comments.

JB opened to the group for questions and to check understanding.

Question – What are the other groups in the system and how do they relate to this group?

Response – For the Data Strategy, the agenda next item covers governance. Additionally, specific programmes have their own stakeholder advisory groups.

Action – JB / Data Strategy team to return to meeting with overview of how this group relates to other data strategy groups

Recap: summary of the data strategy and its implementation governance

JB presented overview of the data strategy. Including context and need for the strategy, the future that the strategy aims to deliver, and importance of building and maintaining public trust and transparency in order to achieve the strategy goals. Also outlined implementation governance of the strategy – including implementation board, communications delivery group and National Data Advisory Group.

Question - empowering people (patients) to use own data doesn't seem to be one of the 7 headline goals of the strategy?

Response – Agree this is important and it falls under improving trust in the health and care system use of data (Chapter 1 of strategy). Additionally, highlighted that point that access to your (raw) data is only first step, need to think about how people are empowered to be able to use it.

Action – JB / Data Strategy team to put together more information on increasing individuals' access to their data to share with the group.

Question – ASC data reporting structures influenced by other departments. Is Department for Levelling Up, Housing and Communities (DLUC) included in any of the governance groups?

Response – ASC teams from DHSC are represented at Implementation Board but DLUC not.

Action – JB / Data Strategy team to talk to ASC colleagues about how best to engage DLUC.

Question – How do you envisage this group will give advice and comment across all issues in the data strategy. It would be helpful to understand timeframes on main issues and if/how you would like the group to comment.

Response - Aim for a co-creation approach to agenda setting for this meeting, so that it will be a combination of things that we already know would like to have advice on but also want to have the groups input on what would be good to discuss.

Action – Data Strategy team to provide group with overview of timeline of key commitments in the data strategy

Question – Important to ensure have space to test products with the public and it would be good to explore how we can co-design with public as part of this group.

Response – Completely agree that this group is a valuable way to explore how best to do public engagement.

Forward Look: national public engagement

[redacted] presented an overview of the commitments in the data strategy relating to public trust, highlighting commitments to public engagement at several levels:

- Large scale national: nationally representative groups, will be securing a supplier to set up and advise best methodology. Hope to begin Dec 22.
- Seldom heard groups: minority groups not usually meaningfully represented in main cohorts. Seek views on topics covered in national engagement but also data issues more prevalent in these communities.
- Regional engagement: working with ICS and regional leaders to design sessions that focus on their locality and issues most relevant to them.

Will be following Science Wise principles for public engagement.

Don't plan on offering full decision making but do want policies to be informed by publics views.

Will bring back to the group when plans more established.

Question – has there been any contact with Healthwatch England and Academic Health Science Network?

Answer – Yes, have been in engagement with Health Science Network but not Healthwatch England.

Action – Data Strategy team to reach out to Healthwatch England to engage with them on our plans for public engagement.

Question – Will people with a learning disability be included in the seldom heard groups? This group may have specific needs that need to be addressed e.g. ability to consent and need for easy-ready documentation.

Response – Want to base the seldom heard groups that we engage with on policy issues directly relevant to those groups, so those chosen will depend on analysis of policy issues. Will look to have a session on people with learning disabilities.

Question – Need to be very clear about exactly what trying to do and what the purpose of engagement is. Need to be clear about the differences between engagement, co-production and communications. How can people influence decisions and what is this groups role in forming the public engagement?

Response – In early planning stage, hope for this group to be closely involved. Will need all of the types of engagement for different products but agree it is important to be clear about which are being used when. Additionally, for each deliberative session will recruit an oversight group to discuss content and materials to be shared with members of the public.

[redacted] presented communications update. Noted this relates to communications across the whole of the NHS Transformation Directorate.

Currently undertaking behavioural science research to understand influence of reactive media on public perceptions. Also commissioning public qualitative research into individual programmes, public perceptions and expectations in terms of transparency. Research designed to inform information communications campaign and ensure it can be done in a measured, targeted and meaningful way. And goal to improve and increase permanent resources available to public.

Short- and long-term objectives of communications campaign:

- Short: maintain high levels of trust and minimise reactive spikes in opt-out levels.
- Long: deepened awareness and raised levels of informed support for better use of data.

Working on improving knowledge about the audience with which we are trying to communicate, and their needs and expectations. We know that largely there is stable opt-out rate but can have reactive spikes to individual news stories. Working to understand role of communications in responding to this and whether there are groups we need to speak to in a different way in order to engage them. Would also like to have more staff research.

Also starting to track and understand public perceptions of health care systems use of data. Know high levels of trust in NHS, however it is not always an informed trust but based on assumptions. Want to build understanding and support for work we're doing, so need to realise that we are starting at low base of understanding which presents a significant challenge. Timing and partnerships critical.

Keen for this group to support this work and will make sure well cited as work progresses.

Question – great to see inclusion of staff. Anyone representing in this group?

Response – Helen Stokes-Lampard (Chair, Academy of Medical Royal Colleges) a member but gave apologies for today. Would be good to have better deputisation to ensure she and her organisation are always represented.

Question – Should we also include NHS Confed? Also, note that we need to come from a place where we assume public don't trust and think about what the barriers to improving their trust might be.

Response – Representation of staff is important for the group, and additional staff voices would be valuable. We were surprised that the response regarding trust in the NHS's use of data was so positive in the monthly tracker, but agree this is just the surface detail and more granular information is needed, and hence critical focus on research piece.

Trust and Transparency Products

[redacted] presented.

3 major national trust and transparency products.

1. Standard for public engagement – consistent approach when engaging with the public and staff.
2. Transparency statement – increasing transparency important part of building public trust, currently no single place that provides information of how publicly held health and care data is used.
3. Data Pact – agreement between public and health and care system, setting out how health and care data will be used.

Discussed Data Pact in more detail and asked group for comment.

- Focus now is on how best to involve the public in co-design and co-production.

- Have been working on a draft but would welcome feedback from this group on the ideal structure for the product and what level of draft should be shared with public assemblies.

Thoughts from group:

- Love to see that it will be coproduced but why not start with asking the public what they want to see in the pact
- Get some draft ideas could be done easily with a few focus groups to start
- Advise starting by identifying what are the issues that want the pact to address and then take a blank draft to the public.
- Structure – suggested structure might only facilitate discussion about 'safe areas'. Need something that will prompt discussion about thorny issues and grey areas.
- Agree that a blank sheet and asking what people want to see a good starting point. Not least in order to find out if pact useful and what they want from it. However, concerned that if engage too early and people ask for things that are not politically feasible how would that be handled. Distinguish whether co-producing a data pact or co-producing the way data is used. Not the same.
- Highlight importance of getting terminology right before going to the public. Those in social care sector not just patients, important to use 'people' not 'patients'.
- Rather than going with a draft pact go with pointers of things that want to cover. Useful to ask if should have a data pact. If yes, then could start with 'we think should cover this, what do you think it should cover?'
- Be clear what was up for discussion and what was already decided (but could still be included in the pact)

Action – RP and [redacted] to discuss her work on patient partnership in design and delivery of services

Transition of NHS Digital to NHS England / Data Safe Haven

[redacted] presented summary of work ongoing to transition NHS Digital to NHS England. Group received paper in advance.

Working to ensure data is safe in NHS England and that people have confidence in this. Working on technical / legal basis for transfer of NHS Digital into NHS England, which includes making some alterations to the existing regulations to ensure good practices that existed in NHS Digital continue.

There are a wide range of related issues and will be consulting on this work to ensure cover areas of most interest to stakeholders.

Hoping to have concrete regulations which can be shared soon, and will have continuing consultative process as these are refined and is guidance produced.

Will need approval from DAs as some functions impact DAs and the system handles some DA data. Therefore, need consent to move NHSD to NHSE.

Question – do you envisage the regulations being a template for ICSs?

Response – agree would be a good starting point. NHSE will be expected to have suitable external scrutiny, which may well include how NHSE oversees work of ICSs in relation to data.

Question – will this impact researchers requests to access data (specifically time requests take)?

Response – The safe haven arrangements should not impede access to data, and in theory, will provide a basis for a swifter response to data requests. The transparency and external scrutiny of the data functions will enable monitoring of the effectiveness with which NHS England exercises these functions, and the increasing use of Secure Data Environments will support improved access to data for those with a legitimate research need, but whilst making the data more secure.

Question - Do any of the proposed data protection reforms have any implications for this (The Data Safa Haven), or any of the rest of the Data Strategy?

Answer – not for Safe Haven. But would be an interesting item to update group on.

Action – Data Strategy team to add impact of proposed data protection reforms on the Data Strategy to agenda for next time. (DCMS Data Protection and Digital Information Bill)

Secure Data Environments

[redacted] presented overview of SDEs, highlighting them as a commitment made in the Data Strategy and describing what SDEs will look like as well as the intended benefits to the system. Intention to have SDEs for multiple uses, including research as well as population health planning. Summary timeline for SDEs presented, with public and patient engagement points throughout, including as part of large scale public engagement committed to within the Data Strategy.

High level guidelines on approach to SDEs published 06/09.

To return to group for a deeper dive and project progresses.

Question – would be helpful in development of SDEs if could consider how linkage to non-health data sets will happen in new system and how to articulate this.

Response – Agree this is important and actively working on guidance for linking health and non-health data now. Would welcome further discussion on this.

Action – DHSC, Care England and LGA to discuss data linkage with non-health data in SDEs outside of meeting.

Group highlighted importance of clarity of language and the need to be clear on what active involvement with decision making means.

AOB and CLOSE	
	JB thanked attendees and closed the meeting. Slides and minutes will be circulated.