Results from Group Work at 10 March Workshop

Results from group tables tackling question 1: Organisations and value judgements

Group work 1a: Does your organisation make judgements that rely on values as well as evidence? [Select only one of the following]	Votes	%
Yes, mostly explicit, they publish their values and/or normative reasoning (like NICE)	11	37%
Yes, mostly implicit	17	57%
No	2	7%
I don't know	0	0%

Group work Q1b: How does your organisation learn about the public's values and priorities?	Votes	%
Privacy impact assessments	7	37%
Published statements of social values that we pursue	9	47%
Consulting patients and public through surveys	9	47%
Consulting patients and public through focus groups / short events	14	74%
Formal public consultation of draft policies	12	63%
In-depth research into social values such as citizens' juries	6	32%
Other	4	21%
It rarely does any of these	1	5%

Group work Q1c: Can you use what you heard this morning about the citizens' juries and the Wellcome Trust research to inform your values, and if so how?	Submitted by
The findings and the way they have been presented has been genuinely informative. The key question is whether it can be adopted by other organisations and scaled? It can be adopted, but can it be scaled? Using different methodologies for identifying values can be really helpful for triangulating findings and giving reassurance that what you are hearing from one methodology is replicated by others. It'll be really helpful to be using the Wellcome and citizen jury examples and case studies to inform a future dialogue to identify where the public's lines are in releasing types of data. The wider research shows how little the public understands, and the jury helps to understand how the public's views change on basis of being better informed. The movement between start and end on various questions shows that it may be important to run more than one. In end, take home from this is that juries will be helpful to inform the types of questions that might be used more widely.	a Q1 group table
Privacy impact assessment (PIA) - in depth and inward or iterative with outward consultation / gathering public view then privacy by design, vs. here is a decision and what do you think of it Similar but more limited than Citizen Jury e.g. Administrative Data Research Network to support access to linked administrative data in secure settings - everything is transparent - data is effectively anonymised once accesses (rich, disclosive and maintained within controlled environment) - good preparation but still exposed to the risk of ridicule / horror story limitation to numbers of citizen jury / consultation that can be sustained complexity is inevitable and that is the challenge of any consultation damage of the data set of opt out event at all	a Q1 group table
Answers to how we would use the evidence from this morning: a. From the jury, the more transparent you are and if trustworthy and responsible, the more buy in you will get. b. This is only the beginning of the journey, not a done deal, engagement with the public must continue. c. Disseminating information about what we do is badly done. d. The framework of why, who, how is data being disseminated is good to think about how to do fair processing communication. Public benefit is an important element of communicating the why. More understanding of how data allows the NHS to be more efficient - how many hip prostheses will be needed next year.	a Q1 group table

Group work Q1c: Can you use what you heard this morning about the citizens' juries and the Wellcome Trust research to inform your values, and if so how?	Submitted by
e. Interested in public response to the sharing of data with commercial organisations - how do the public feel about with commercial organisations working for public benefit f. Juror felt empowered by the extra understanding they gained in the process - how does this inform the 3 minutes for members of the public. g. How do you foster public trust? Publishing audit results. Prove it is only used within the parameters agreed for dissemination. h. The gap between publishing data analysis in a research publication and make the results accessible to the public. i. Dichotomy of two views of this question - need to get the public to agree to what we want to do and to do only what the pubic will generally agree to. j. Public access to the data held that is identifiable and what it is being and has been used for and their consents and objects. May be through the Patient Online portal. k. Data quality is poorer in certain datasets, e.g. foreign name. Also there are social differences between people who are likely to opt out. From the jury, the more transparent you are and if trustworthy and responsible, the more buy in you will get. 1) This is only the beginning of the journey, not a done deal, engagement with the public must continue. 2) Disseminating information about what we do is badly done. 3) The framework of why, who, how is data being disseminated is good to think about how to do fair processing communication 4) Public benefit is an important element of communicating the why 5) Interested in public response to the sharing of data with commercial organisations - how do the public feel about with commercial organisations working for public benefit 6) More understanding of how data allows the NHS to be more efficient - how many hip prostheses will be needed next year. 7) It is like 360 degree appraisal, it needs to show what was done with the data and the public benefit. Give examples of benefit. 8) Juror felt empowered by the extra understanding they gained in the process - how does this inform the 3 minutes for members of the public. 9)How do you foster public trust? Publishing audit results. Prove it is only used within the parameters agreed for dissemination. The gap between publishing data analysis in a research publication and make the results accessible to the public. Dichotomy of two views of this question - need to get the public to agree to what we want to do and to do only what the pubic will generally agree to. Public access to the data held that is identifiable and what it is being and has been used for and their consents and objects. May be through the Patient Online portal. Data quality is poorer in certain datasets, e.g. foreign name. Also there are social differences between people who are likely to opt out.	

Group work Q1c: Can you use what you heard this morning about the citizens' juries and the Wellcome Trust research to inform your values, and if so how?	Submitted by
Yes. In thinking about how to engage different groups of public.	an individual's response
My values? No. However it is helpful for informing the ongoing discussion over how to best capture people's attitudes to data sharing.	an individual's response

Responses from group tables tackling question 2: Risks of a public debate

Group work Q2a: Is there a risk that when the public hears more about sharing health records, they will get more concerned about the risks of sharing? [Select only one of the following]	Votes	%
Yes, a significant risk	12	43%
Yes, a small risk	14	50%
Don't know	1	4%
No, I don't think so	1	4%
No, I am sure there is no risk	0	0%

Group work Q2b: Is this a good reason not to engage in a public debate? [Select only one of the following]	Votes	%
Yes	2	7%
No	11	41%
No, but it makes it more challenging	14	52%
Don't know	0	0%

Group work Q2c: What can be done to address this risk?	Submitted by
Manner of communication • Being open and honest from the beginning about what you doing/proposing necessary to build trust Form of communication • If it's a two way conversation, people will feel that they are less powerless • Ongoing to keep people on board, not a big bang approach • Put particular effort into hard to reach groups Content of communication • Important to clearly articulate benefits to people and their families • Layered information, with general principles communicated and with more detail available for people to seek out more detail if they wish Source of communication • Discussion about who should deliver information – eg local healthcare provider, in school citizenship class, probably many	a Q2 group table

Group work Q2c: What can be done to address this risk?	Submitted by
Give the messages at the right time and right place, right persons. Local engagement is important, with clear national messages. Need local contacts – real people. Could this person be someone independent, or at least without a vested interest in you giving a particular answer? PALS, GP, Healthwatch Different messages at different times with different groups, some of who might have special groups. Patients being able to access their own records to be reassured. You don't even need to access it yourself. Being able to see who has accessed your record. Good clear mechanisms for opt in and opt out, with outreach to dfferent groups, languages, media. Open, honest and simple. Clear about what we don't know.	a Q2 group table
Provide information in multiple and creative ways. This issue is now in the public domain, so we need to overcome worries about the risk. Citizens' juries provide evidence that the public can be informed and can consider and deal with difficult issues. The cost of this is a matter of concern, but more cost-effective methods of data dissemination can be developed. Consider concentrating on making the information 2 way.	a Q2 group table
• Social contract as a concept is attractive – "you engage with it by receiving the service" but organisation needs to constantly interpret what that means in practice • Local Government as a vehicle to be explored as able to "speak for the people" more effectively than Parliament – could be used	more from a Q2 group table
Make it mandatory for GPs, MPs & public officials to opt-in, permanently. And have them trial the system exclusively for 6 months prior to a public launch. This should ensure that the system is safe before engaging and risking the whole population's privacy.	an individual's response
Inform and educate citizens	an individual's response
More transparency of purpose and better sharing of information on outcomes of data uses	an individual's response