Sharing Data, Shaping Views: The Public Communication of Medical Data Sharing Policy

Summary report of event held on 24th March 2017
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Executive summary

On the 24th March 2017 the Sowerby eHealth Forum at the Institute of Global Health Innovation, in partnership with the Imperial College Science Communication Unit, hosted a meeting to explore how national policy on the sharing of patient data might be effectively communicated to the public.

The ‘Sharing Data, Shaping Views’ event, which brought together academics, patients, healthcare professionals, policymakers and other stakeholders, aimed to identify features that such a communication strategy should seek to include and avoid, with a view to assisting in the ongoing development of plans for national patient data sharing policy by the Department of Health, NHS England and NHS Digital. Drawing on the contribution of both panel members and the wider interdisciplinary audience, several key themes emerged during the debate:

1. When addressing the topic of data sharing, patients and the public need to know the ‘who, what, where, how and why’. A clear explanation of what data are to be shared, how, and with who is key to increasing public acceptance. The benefits of data sharing must be clearly demonstrated in a way that resonates with a range of communities, and reluctance to share data may well be overcome if the benefits to individuals and society are well understood.

2. Information should be accessible to all but adaptable to individual preferences. Simple and accessible language and transparency in the details of the policy are essential to aid public understanding and so build public trust. Information must be provided at different levels of detail to allow people to choose between a simple or a more complex understanding of the policy.

3. Early and meaningful stakeholder engagement is a must. Involving a diverse group of patient and public members to co-design the communications strategy will make the information more accessible and relevant to the public. GPs and other healthcare professionals could also have a key role to play in communicating this policy due to high levels of public trust, and should be engaged early on in the design process.

4. But effective communication cannot compensate for poor policy. The policy itself must be robust and well considered, particularly with regard to how data will be shared and opt-out options. Flaws in the policy should be addressed by altering the policy rather than using a communications strategy to minimise resistance to it.

Participants recognised that many of these areas will require further consideration if a successful strategy is to be designed. It is hoped that this event, and the accompanying report, will provide helpful guidance on the road towards this goal.
Background

The sharing of patient data for research purposes is crucial to scientific innovation and discovery, but how can national data sharing policy be effectively communicated to the public? The Sharing Data, Shaping Views forum, hosted at Imperial College London on Friday 24 March 2017, brought together experts from a range of academic and professional disciplines to explore this question in order to inform the development of a national communications strategy for patient data sharing schemes.

The event was a joint initiative of ethIC@Imperial, hosted by the Imperial College Science Communication Unit, and the Sowerby eHealth Forum at the Institute of Global Health Innovation, which is currently leading a wider research project on data sharing policy.

Four members of an inter-disciplinary expert panel opened proceedings by presenting their views on how policy for the sharing of medical data should – and should not – be publicly communicated. The panel comprised of:

- Professor David Hughes (DH) (Chair) - Director of Information & Analytics, NHS Digital
- Nicola Perrin (NP) - Wellcome Trust, Head of Understanding Patient Data Initiative
- John Norton (JN) Patient, Public and Carer Representative
- Dr Andrew Roddam (AR) - Vice President & Head of Real World Evidence and Epidemiology, GSK
- Dr James Wilson (JW) - Senior Lecturer in Philosophy, University College London

Each panel member was asked to draw on their own expertise and experience to provide a brief opening statement based on the following hypothetical scenario:

On secondment to the Department of Health, you have been presented with the task of outlining a public communication strategy for the Government’s new medical data sharing policy for secondary research purposes. Please highlight:

- One attribute that this communication strategy should definitely seek to include
- One pitfall that this communication strategy must take care to avoid
- One question that needs to be further explored if an effective communication strategy is to be designed

Audience members – drawn from a range of academic and professional disciplines – were then be invited to share their own views on the subject and offer those responsible for developing policy with evidence-based insights on how an effective communications strategy might be established. Examples of the organisations represented at the event are listed on Page 10.

The Sharing Data, Shaping Views event was a unique opportunity for a highly engaged, interactive discussion between the academic and scientific community and policy makers from the Department of Health, NHS England, and NHS Digital. This report provides a summary of these discussions in the hope that it can assist in the development of an effective communications strategy to accompany future patient data sharing policy.
AD described how patients often ask: “Why do I have to repeat the same story to every medical practitioner I see?” This, he said, demonstrates how, from a patient perspective, data sharing is important for the quality of care and patient experience. AD considers IT to be “an enabler for transforming the patient experience” and discussed how data sharing can lead to a wide range of public health benefits, from significant discoveries in academia to more efficient service provision. He questioned why health is the only well-funded sector to not yet successfully use data to evaluate its own effectiveness. However, AD acknowledged that data sharing has its own challenges. These include issues such as privacy and data security. He said that in debates on data sharing, concerns about privacy are sometimes perceived to trump the public benefits of sharing information.

Following AD’s opening comments, DH introduced the speakers and welcomed the wide range of experience and viewpoints represented at the forum. DH emphasised the event’s timeliness given the release of the National Data Guardian’s review on health and social care data last year and the Department of Health’s forthcoming response, and reiterated that the time is right for a conversation about not just how patient data should be shared, but how that policy should be communicated. Referring to comments by NHS Chief Clinical Information Officer Keith McNeil, DH stressed that “data is the only game in town” and that the NHS needs to move forward with medical data sharing policies to survive. He expressed his hope that the day’s discussion would help to advance this agenda and ensure that future data sharing policy be communicated in such a way as to bring the support of patients, clinicians and the wider public.
The panel began by considering what attributes they believed a communications strategy for national patient data sharing policy should definitely seek to include. Several key factors emerged.

**Attributes of an effective data-sharing communications strategy**

The panel recognised that different people need varying levels of information to feel informed. AR pointed out that while some people want to know the whole process that their data would go through in a data-sharing system, others simply don’t care. Open floor discussion provided further examples that a ‘one-size-fits-all’ approach to communications was not appropriate, with audience members calling for more information on issues as varied as anonymity, security, and primary versus secondary care use of data. Each group must be given adequate information for their own needs, in order to build public trust in data sharing policies. Further consideration needs to be given as to how a communications strategy could adequately cater to the needs of these different levels of patient inquiry.

NP pointed to a number of studies which have found that the more information people are given, the more comfortable they are with wider uses of data. However, she explained the information being provided in these examples was delivered over hours – or even days – of discussions. NP stressed that giving patients too little information can actually raise concerns. In this context, she introduced the concept of the four-minute window – the time it takes to read a newspaper article, or a consent form – in which there is opportunity for communicating to a patient why data sharing is essential. NP discussed how this short timeframe must be used as effectively as possible to get people’s attention quickly, and provide them with adequate information on data sharing, no matter how much information they require.

The early panel discussion focussed on how clear explanations of data sharing are key to increasing public acceptance, particularly around 1) what data are to be shared, 2) how data is to be shared, and 3) with whom it is to be shared. NP explained that there is currently low public awareness of what data sharing involves, and referred to one survey which found that only one third of people felt they knew how data was used in the NHS, with even lower awareness of any other users of health data, for example academics or companies accessing the data. AR discussed similar issues, focusing on the importance of explaining what information is recorded in a health data system. He pointed out that “what is in the system, and what people think is in there are completely different”. He also emphasised the importance of explaining what that information is used for and how it is used, “otherwise you can’t bring the public along with you”.

These sentiments were reinforced during the open-floor discussion; many of the participants’ comments and questions revolved around patient understanding of what data sharing really involved, and what information was going to be shared. It was pointed out that people used to think that the NHS knew everything that their General Practitioner (GP) knew about them. Now that data sharing is faster and easier, people are starting to worry about what data are disseminated and who has access to that information. It became apparent that more thought must be given to exactly what data sharing involves, and how that process could be communicated to patients. Participants also considered how patients could be given access to their own data, as a way to help them understand what information is being stored and shared in different scenarios – for example, information on blood tests versus potentially more sensitive genetic data.
Demonstrate the benefits

It was widely acknowledged by panel members and participants that any communication strategy on medical data sharing policy should clearly explain why such a policy is needed. In particular, the strategy should demonstrate the benefits of sharing data for individual health, research and wider health policy. NP highlighted how the communication strategy should include specific examples of how health data can contribute to knowledge and understanding, for example by drawing on successes in cancer research or the development of new treatments for Parkinson’s disease. In written feedback, one audience member stressed the importance of communicating the “benefits of sharing data, with clear examples”. The participant referred to a 2016 survey prepared by Ipsos MORI for Macmillan Cancer Support and Cancer Research UK, which found that 9 in 10 cancer patients support the use of cancer data to plan cancer services. AR agreed that demonstrating the benefits was key, but suggested that further thought was needed to consider how to “crisply define the benefit” of data sharing to patients and other members of the public.

It was considered particularly important to communicate how sharing patient data with commercial organisations could lead to public benefits. AR pointed out that data underpin a great deal of work at GSK and in other areas of the commercial health sector, including the development of vaccines, drugs and other health care products: “If we couldn’t use data, we would not be able to make medicines,” he said. AR also stressed the need to demonstrate the collaboration and innovation involved in turning data into something useful, with patient groups, national health bodies, and academics. NP highlighted a recent Ipsos Mori study, commissioned by the Wellcome Trust, which showed that people were happier with the notion of sharing their data with companies if there was a public benefit.

However, it was pointed out by an audience member that while data sharing is assumed to lead to public good, there are always “winners and losers”. It was suggested that more discussion and consideration was needed in terms of how data sharing would be governed, who would be responsible and accountable for it, and who might lose out. NP suggested that these questions would need to be considered on a case-by-case basis, and that this process of governance needed to be seen by the public to foster trust.

Ensure patient, carer and public involvement and engagement throughout

Throughout the discussions, patient voice and early public engagement were identified as important elements in any communication strategy, as well as being vital components in the co-design and co-development of the data sharing policy itself. JW reiterated the importance of starting public engagement early on, to identify what the challenges are likely to be before they arise. He also stressed the need for upstream public engagement to ensure that public values are taken into account from the very beginning of the system design process. Audience participants agreed, highlighting that meaningful engagement was needed to fully understand public concerns and to ascertain “what the public think the public benefit is”. One member of the audience suggested in written comments that public engagement could utilise examples of different data-sharing scenarios “to establish what the public are happy with”.

JW also stressed that patient and public voices were key in the delivery of an effective communications strategy, and that demonstrating high levels of patient and public involvement from the start, would help build trust in data sharing and mobilise the sense of social solidarity that underlie the NHS. He suggested that community solidarity with real people could be achieved by including the voices of individuals with diseases that might be better understood via health data sharing. JN indicated that those most willing to accept data sharing policies are people with chronic or long-term illnesses, and the benefit to these groups should be communicated through individual patient voices.
Potential pitfalls

Moving onto the second question posed to them, the panel highlighted three key areas as major pitfalls which this communication strategy must take care to avoid.

Avoid using inaccessible language

All of the panel and much of the audience stressed the importance of using simple and appropriate language when communicating policy and avoiding the use of jargon or unexplained technical terms. JN proposed that the Government’s communication strategy should use the “language of inclusion” – wording that is targeted to the lay public and not to any group of specialists – and that this could be best achieved by inviting patients to co-design the communication strategy. He also proposed the use of illustrations, since “what you see is more powerful, and more memorable than what you read”. JN acknowledged that the sharing of healthcare data is a technically complex topic, and that there are both medical and legal concerns that may need to be considered. However, he asserted that the patient does not share an interest in “legal nonsense”, and so the communication strategy should contain as little of the legal argument as possible while maintaining transparency and access to more information for those who want it.

NP considered the language used to describe differing levels of patient identifiability as particularly confusing, given that there are no clear definitions for apparently technical language such as “anonymised” or “de-identified” data, leading different people use these words in different ways. This lack of consistency was also noted by members of the audience. NP argued that the current debate about anonymisation, in particular, is not being had in a way that people can understand and so we need to develop better language to explain data sharing. She highlighted that the Wellcome Trust’s ‘Understanding Patient Data’ study looked specifically at language that is both accurate and meaningful to the general public in this area, and that the Government’s communication strategy should take on board the results from that investigation.

Maintain transparency to avoid loss of trust

A potential pitfall that was widely referenced throughout the meeting was the loss of public trust in healthcare data sharing policies. AR suggested that this could be brought about through a lack of transparency in the details of the policy. Based on his experience using patient data, he underlined that “defining what you are doing with the data is essential”, and that any lack of transparency will lead to questions about why the NHS has patient data and what it plans to do with it. He argued that a transparent and clearly communicated policy which clearly defines the benefit to the individual and to society (rather than the benefit to companies) will help to generate trust from patients. He drew a parallel with the data generated through clinical trials, which have become more transparent in recent years and have fostered increased patient and public trust as a result. NP also stressed the importance of transparency, describing how providing too little information risked “opening Pandora’s box” and generating public suspicion of the policy rather than public support.

JW further discussed the importance of maintaining patients’ trust. He described how commercial use of NHS data is a highly sensitive area and that the NHS must not violate the expectations of patients and the general public, lest they lose faith in the concept of data sharing. He also supported the importance of transparency in building trust, and referred to the National Back Office Tracing Service as an example of how damaging policies perceived to be ‘secretive’ can be for levels of trust. Under a memorandum of understanding that had only become public after a Freedom of Information request, the Home Office had been using NHS Digital data to trace patients suspected of immigration offences with little oversight or commitment to making patients aware of this fact. He also briefly mentioned the well-known case of care.data, and explained some of the ways in which the project had failed to build and maintain public trust. He proposed robust and independent oversight of data and a simple opt-out procedure as other mechanisms that would help to build patient trust in this policy. JN shared these views, stating that “trust is a must.”
Ensure proper engagement with healthcare professionals

Building on the theme of trust, NP highlighted the dangers of failing to engage with healthcare professionals, in particular GPs. She described GPs as “the gatekeepers to patients and their data”, and revealed that 93% of the public trust nurses and 91% trust GPs, while trust in journalists and politicians is far lower. She stated that any effective communication strategy must get GPs on board with the policy and encourage them to make the case for data sharing to their patients. JN echoed this, stating that “nothing will ever replace a one-to-one explanation by a medical professional – normally the GP”. He proposed that careful consideration be given to how best to encourage GPs to promote data sharing to their patients. However, he also highlighted the potential difficulty in engaging GPs given that they are already very busy and often pressed for time during consultations. A form of clear written communication that could be passed on via GPs may therefore be the best option.

Ensure that the policy being communicated is acceptable

JW highlighted that a good communication strategy is of limited value if the policy that it communicates is itself poor and likely to generate public resistance. He suggested that this may have been the case with care.data, which suffered from both flawed policy and flawed communication. To avoid a repeat of this situation, JW and several other participants stressed the need to ensure proper, meaningful engagement and involvement from patients, clinicians and the public during the policy development phase, as well as during the policy communication phase.

JW added that a key part of developing an effective communications strategy is knowing and understanding the specifics of the policy to be communicated – for example, who will the data be shared with, what data will be shared and how will opt-out procedures work? Concerns about the undefined boundaries around data sharing were echoed by members of the audience. JW stated that without such information about the policy itself it is very difficult to prescribe how it can be effectively communicated, and in the absence of this detail any materials produced to help communicate the policy will likely be seen to lack transparency. Other participants added that those delivering the Government’s communication strategy – whether that be a communications agency or GPs – needed to have a good understanding of the policy in order to provide accurate information on details such as opt-out procedures and the nature and ways in which data are shared.
Concluding remarks

The session concluded with closing remarks from each of the panellists on their take-home point of the discussion. JN acknowledged the multiplicity of issues that needed to be considered but felt very strongly that patients must be involved and should be “centre stage” in helping to design any communications strategy. JW also focused on patient involvement, encouraging patient co-design of the data sharing policy itself, as well as the strategy for communicating it. NP highlighted the need to find a balance between overwhelming people with information and being seen to be withholding it, thereby undermining trust, while AR highlighted the complexity of the digital data being shared and the importance of making that data more understandable to the general public. DH summarised the difficulties of information asymmetry and the importance of giving different groups of people the right level of information.

DH brought the session to a close by thanking all the participants for their thoughtful contributions and by reiterating that we are all either “past patients, present patients or future patients”. As a result, “we are all in this together”.

Left to right: Panel members Dr. James Wilson, Dr Andrew Roddam, Nicola Perrin, John Norton and event chair, Professor David Hughes.
Acknowledgements

The “Sharing Data, Shaping Views” event was sponsored by the Peter Sowerby Foundation and the Science Communication Unit at Imperial College. The organising committee comprised of Stephen Webster (Imperial College), Dilkushi Poovendran (Imperial College), Victoria Charlton (King’s College London), Anna Lawrence-Jones (Imperial College). The report was written by Kate Smith (Imperial College) and Aran Shaunak (Imperial College).

We thank delegates from the following organisations for their participation in the event:

- Academy of Medical Sciences
- Brunswick Group
- Cancer Research UK
- CLAHRC
- Clinical Practice Research Datalink (CPRD)
- DeepMind
- Doctors.net.uk
- Farr Institute
- Genomics England
- GSK
- Imperial College Health Partners
- Imperial College Healthcare Charity
- Imperial College London
- Intel
- International SOS
- Involve
- King’s College London
- Kyoto University Centre
- London School of Economics
## Agenda

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<td>Chair, Professor David Hughes, Director of Information &amp; Analytics, NHS Digital</td>
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<td>12.40-13.10</td>
<td>Opening remarks</td>
<td>Nicola Perrin, Wellcome Trust, Understanding Patient Data Initiative</td>
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<td>John Norton, Patient and Public Representative</td>
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<td>Andrew Roddam, Vice President &amp; Head of Real World Evidence and Epidemiology, GSK</td>
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<td>Dr James Wilson, Senior Lecturer in Philosophy, University College London</td>
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<td>13.45-13.50</td>
<td>Closing remarks</td>
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