

Reasonable expectations: supporting health and care professionals to share data in line with patient expectations

October 2017 - report

Background

This is a report of the second seminar exploring how health and care professionals may share personal data in line with patients' reasonable expectations. It was held at the King's Fund in London on 10 October 2017, jointly hosted by the National Data Guardian (NDG) and Sheffield Solutions, part of the University of Sheffield.

The invited group of more than 40 seminar participants included doctors, nurses, social care professionals, medico-legal advisers, lawyers, information governance professionals and others with a wide range of relevant expertise. This audience came together to discuss the approaches to ensuring patient data to support direct care is shared on an appropriate legal basis, bringing their professional experience of data sharing, its potential benefits and pitfalls. The benefits cited were improved safety and quality of care for patients and service users. Potential pitfalls mentioned included failing to act within the law and running the risk of losing the trust of patients and service users who are unpleasantly surprised when they discover their data has been shared.

This event followed a first seminar on information sharing in line with reasonable expectations held in Sheffield on 17 July 2017. A report of the Sheffield seminar is available on the NDG webpages and provides useful background to the issues being considered by the NDG¹.

The second seminar was introduced by Dr Vicky Chico, lecturer in law at the University of Sheffield. She explained her department's interest in the subject and set out the ground rules for the discussion, including observance of the Chatham House rule. This allows points made by members of the invited audience to be reported, but not attributed to any individual. Dr Chico also explained

¹ <https://www.gov.uk/government/publications/sharing-data-in-line-with-patients-reasonable-expectations>

arrangements for those present to vote on a series of propositions using a voting website that attendees could access using their mobile phones.

The National Data Guardian's objectives

The objectives of the seminar were set out by **Professor Martin Severs**, a member of the NDG's Panel. He said sharing among healthcare professionals in the NHS for the purpose of direct care was often done on the basis of implied consent. A common example was when a GP referred a patient to a hospital consultant. The GP could send information about the patient to the consultant without asking for the patient's explicit consent because the patient's agreement to this information sharing could be implied by the patient's willingness to attend an appointment with the consultant. Such an appointment could not be arranged without the GP making the consultant aware of some facts about the patient. (This approach is little used in social care where it is common for people to be asked explicitly about what information may be shared, and with whom).

Prof Severs said the NDG and her Panel were asked in 2015 and 2016 to consider several cases in which organisations wanted to use implied consent to justify novel forms of data sharing across institutional boundaries. After deliberation, the Panel reaffirmed three tests for establishing the conditions under which consent can be implied, which were set out in the report of the Information Governance Review (IGR) that Dame Fiona Caldicott conducted for the Department of Health in 2013.² Relevant recommendations from the IGR are explained in more detail below in the section on implied consent.

In addition to passing the three tests, the IGR said healthcare professionals could share information about a patient on the basis of implied consent "if it is reasonable to expect the patient understands how the information will be used." The need to pay attention to the patient's reasonable expectations was underlined in two blogs posted on the NDG's website by Dr Alan Hassey, a Panel member whose thinking is further explained below.^{3 4}

² Information Governance Review, chapter 5, page 56:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf

³ <https://www.gov.uk/government/speeches/reasonable-expectations>

⁴ <https://www.gov.uk/government/speeches/exceeding-expectations>

Further work on the subject by Dr Mark Taylor, another NDG panel member, suggested that patients' reasonable expectations may have an even more important significance in determining the lawfulness of data sharing. At the first seminar in Sheffield Dr Taylor, senior lecturer in law at the University of Sheffield, suggested that sharing data in accordance with a patient's reasonable expectations may comply with the law *even in circumstances where the patient has not given explicit or implied consent*. The Sheffield seminar reached a tentative consensus that the concept of "reasonable expectations" merited further exploration to establish whether it may be useful to health and care professionals and legally robust. Dr Taylor's presentation to the second seminar is summarised below.

Prof Severs concluded his introduction by setting two key aims for the seminar:

- To test whether frontline health and care professionals perceive challenges around the use of implied consent as a legal basis for sharing data to support care.
- To test whether frontline health and care professionals believe that the legal concept of 'reasonable expectations' might help with challenges.

Implied consent: stretched to breaking point?

Dr Alan Hassey gave a brief exposition of the different aspects of the law that are relevant to information sharing. They include the Common Law Duty of Confidence, statute law on privacy (the Data Protection Act (1998) and the EU's General Data Protection Regulation (which is being brought into UK law by a Bill currently before Parliament), and Article 8 of the European Convention on Human Rights (incorporated into UK law by the Human Rights Act 1988.) He explained that any information sharing must comply with all these strands of law. Health and care professionals must also observe their professions' codes of conduct on confidentiality.

After describing this complex legal environment Dr Hassey focused specifically on implied consent. Chapter 3 of the IGR report explained how health and care professionals may rely on implied consent to share confidential information for the purpose of providing direct care. Chapter 5 of the report set three tests for establishing the conditions under which consent can be implied, all of which have to be met affirmatively:

- Is the person sharing the information a registered and regulated professional or one of their direct care team?

- Is the activity (or purpose) a type of direct care within the scope specified by the professional’s regulatory body?
- Does the professional have a legitimate relationship with the person or persons concerned?

For implied consent to be valid it is necessary that those consenting must be adequately informed. There must be transparency of purpose so that any information sharing that takes place falls within the reasonable expectations of the individuals concerned. And the consent must be implied or signalled by the individual’s behaviour.

Dr Hassey emphasised the importance of these conditions. To rely on implied consent, it is not enough that information is being shared for purposes that are deemed “direct care.” Crucially the sharing must be within the individual’s reasonable expectations.

Although it is still possible to use implied consent to justify traditional patterns of information sharing among well-defined teams of health and care professionals, it may not be suitable as a legal basis to support new models of care. Organisational boundaries are becoming blurred, shared record systems are becoming more ambitious and it is becoming harder to ensure that information collected for one purpose is not used for another. Dr Hassey asked whether the notion of implied consent is now being stretched to breaking point.

One seminar participant suggested that the solution to this problem was not to move away from reliance on implied consent. Instead there should be better understanding across the system about limiting the information sharing to what is reasonable and appropriate. This would relieve unwarranted pressure for disclosure by GPs. Several participants reported difficulties in determining the amount of information that should be shared, since it was often hard to know in advance what parts of a patient’s medical history would be relevant.

After a wide-ranging discussion Dr Hassey presented three questions for a vote. Results were as follows:

Question: Do you experience uncertainty about where you or others are able to share data for direct care on the basis of implied consent?

- Always 7%
- Often 30%

- Sometimes 52%
- Never 11%

Question: Do you believe that use of implied consent within health and care is stretching the ethical, legal and professional boundaries?

- Always 11%
- Often 15%
- Sometimes 74%
- Never 0%

Do you believe the way that implied consent is used within health and care is problematic for ... (select all that apply)?

- Patients 73%
- Frontline professionals delivering care 96%
- Information governance professionals 69%
- Policy makers 73%
- Others 19%⁵

The voting figures reflected opinion in the room and have no wider statistical significance. However they do indicate that this expert audience shared the anxieties of members of the National Data Guardian's Panel about some uses of implied consent.

Reasonable expectations - adjunct or alternative?

Dr Mark Taylor began his address with a brief description of landmark judgments in cases involving the duty of confidence and expectation of privacy. In particular he drew attention to two relatively recent judgments which emphasised the importance of the reasonable expectations of the individuals concerned.⁶

Dr Taylor had argued at the Sheffield seminar that the implication of such judgments may be that the Common Law Duty of Confidence may be abated when

⁵ After the vote participants were asked which "others" they had in mind. Commissioners and commercial third parties were mentioned.

⁶ These were: *Murray v Express Newspapers* [2008] EWCA Civ 446, Sir Anthony Clarke MR, [35][36]; and *W,X,Y and Z v SofS for Health* [2015] EWCA Civ 1034, Lord Justice Briggs MR, Court of Appeal, [44].

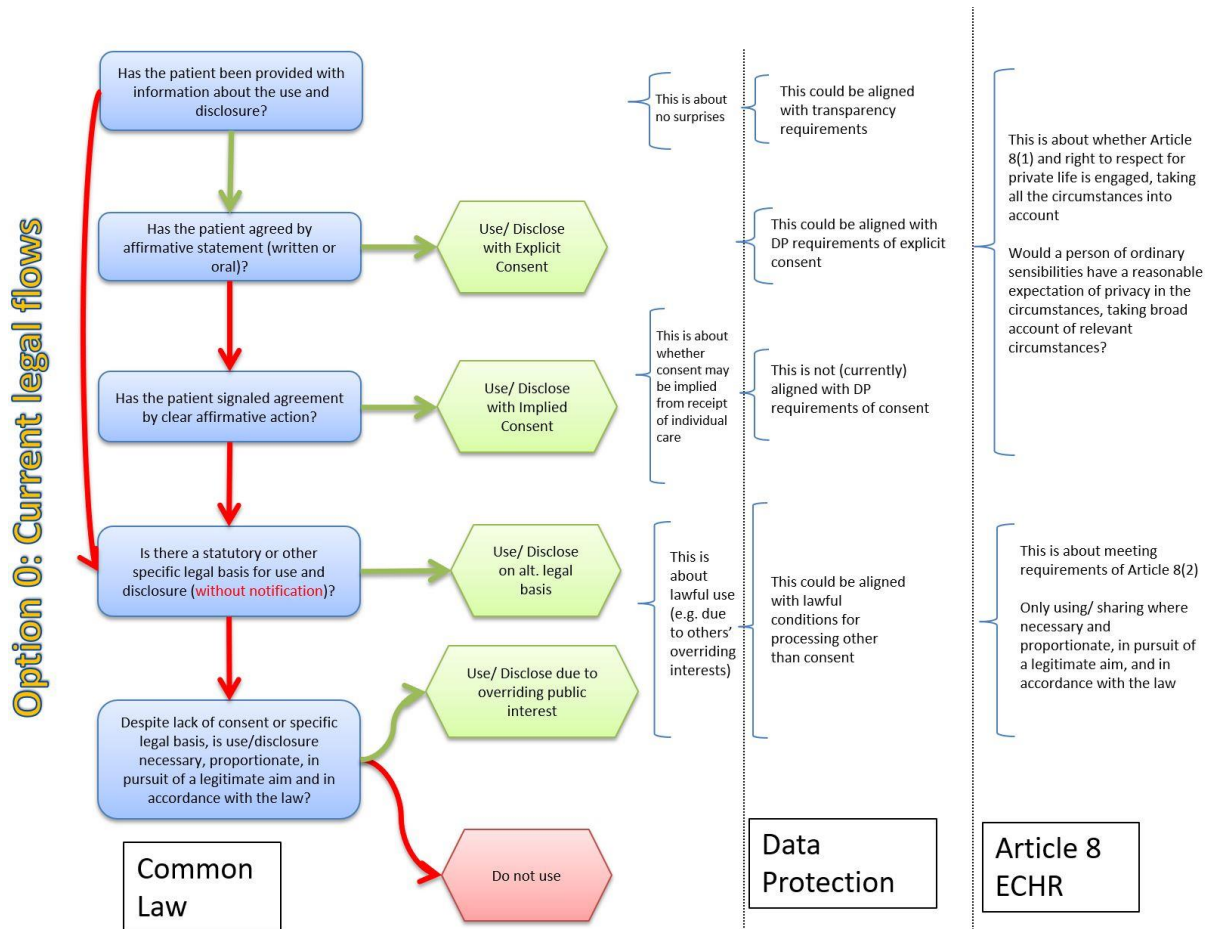
there is no (longer any) reasonable expectation of privacy in the circumstances. The effect would be to permit disclosure of information in circumstances that would otherwise be a breach of confidentiality.

Dr Taylor highlighted that the courts consistently place emphasis on a reasonable expectation test to consider whether a breach of confidence has taken place. He contrasted this with guidance for health and care professionals on the use of implied consent, which may refer to reasonable expectations or similar concepts, but tends not to emphasise the test in the same way or to the same degree as the courts.

He used the opportunity of the King's Fund seminar to present three models for determining whether information flows are lawful.

- The first model, shown in Figure 1 on the next page as Option 0, illustrates the traditional use of implied consent within health and care settings. It shows that one of the conditions for disclosure on the basis of implied consent is that the patient has signalled agreement by clear affirmative action. The central question is whether consent to the use of data necessary to deliver safe and effective care is implied by the act of receiving individual care. This model, as presented to the seminar, does not place emphasis on the patient's "reasonable expectations."

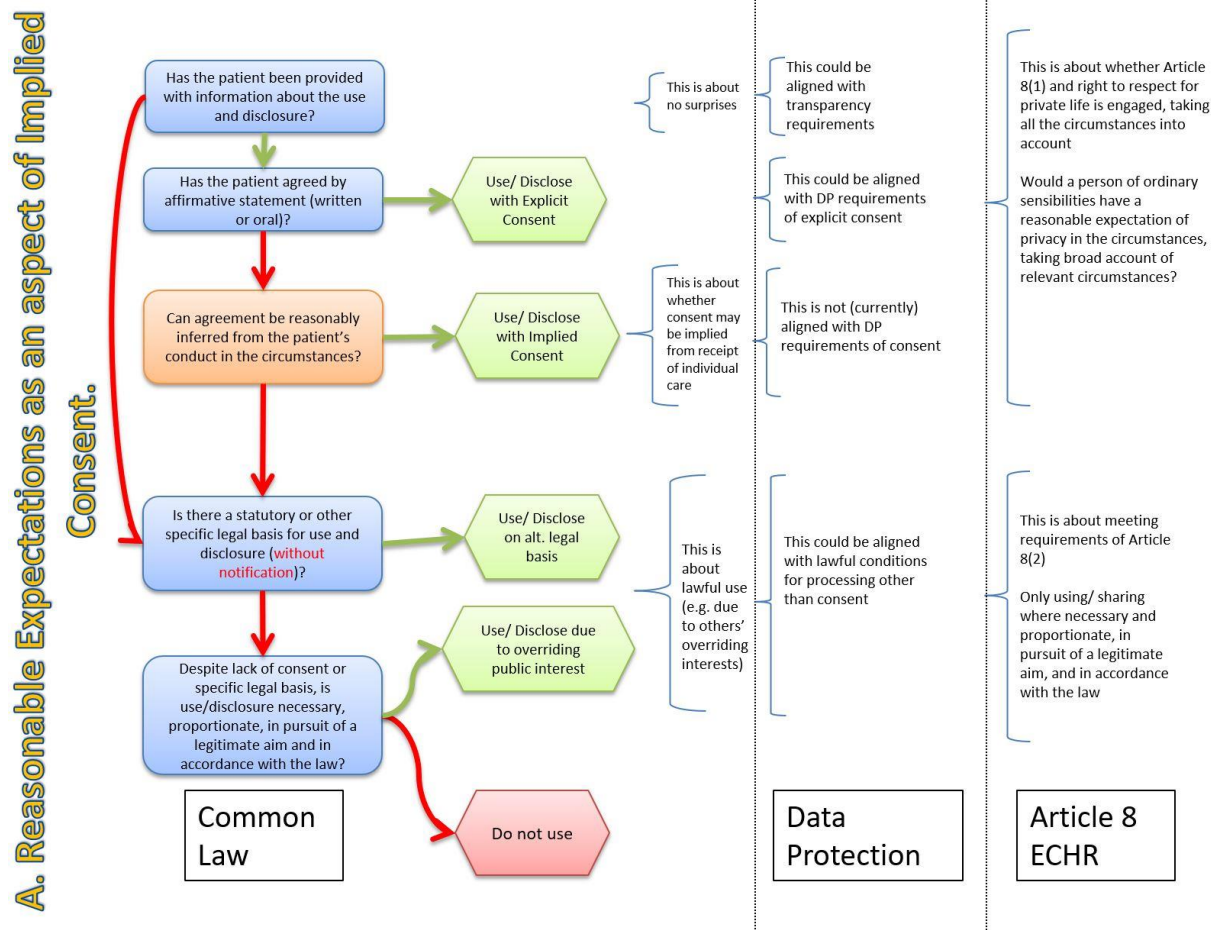
Figure 1



- The second model, shown below in Figure 2 as Option A, introduces reasonable expectations as an aspect of implied consent. As Prof Severs had noted in his introduction, the IGR said healthcare professionals could share information about a patient on the basis of implied consent “if it is reasonable to expect the patient understands how the information will be used.” However, reasonable expectations were not expressly included in the IGR’s triple test for establishing the conditions under which consent can be implied. Would it be useful to bring reasonable expectations to the foreground as shown in Option A? Instead of requiring the patient to signal

agreement by clear affirmative action, it might then be possible to consider whether the patient’s agreement could be reasonably inferred from the patient’s conduct in the circumstances. This might include inaction (rather than affirmative action) where no dissent is indicated and the use is consistent with a reasonable expectation of privacy in the circumstances.

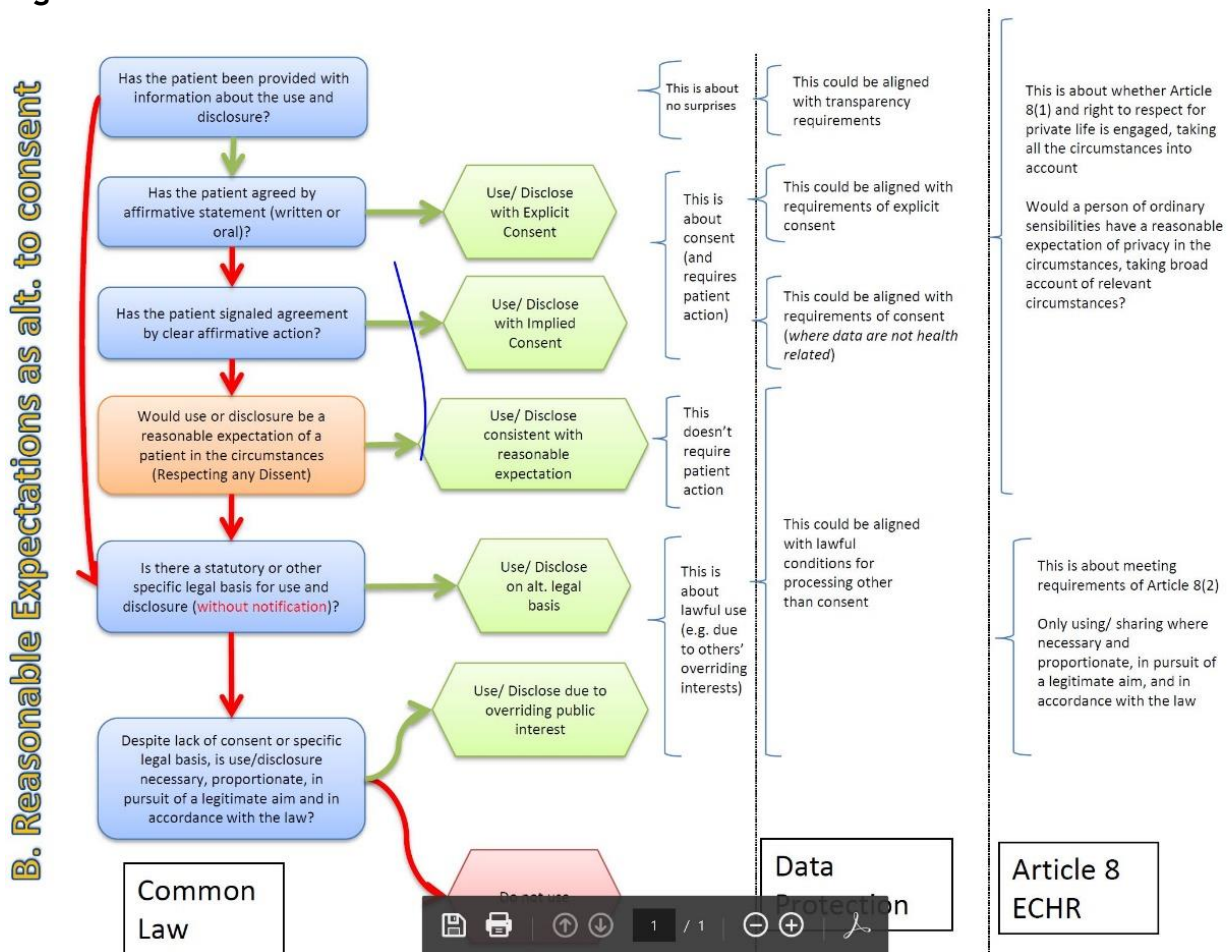
Figure 2



- The third model, shown below in Figure 3 as Option B, departs more radically from current practice by adopting reasonable expectation as an alternative to implied consent. Instead of inferring whether the patient had consented, health and care professionals (and potentially the courts) would

ask whether use or disclosure would be a reasonable expectation of a patient in the circumstances (respecting any expression of dissent.) On this basis disclosure would be justified even without the patient’s explicit or implicit consent. It was important to note that reasonable expectations referred to what might be a legitimate expectation of a person of ordinary sensibilities in the circumstances. For example, a patient might not know that an administrator would view a particular piece of information, but would consider it a legitimate use and not be surprised about that when considering the matter subsequently. In this respect the concept of reasonable expectations sat well with the doctrine of “no surprises” that has been frequently expressed by Dame Fiona Caldicott.

Figure 3



From theory to practice

At the start of the afternoon session participants reassembled into table groups to discuss which of the three options set out above would best achieve a desirable outcome for patients and service users. They tested the options against two scenarios, the first involving information sharing to create an integrated care record, and the second involving sharing of genetic data that might benefit other patients as well as the patient whose information is being shared. The tables were asked to discuss the pros and cons of using:

- Conventional implied consent (Option 0)
- Implied consent coupled with reasonable expectations (Option A)
- Reasonable expectations as a legal basis in its own right (Option B)

The two scenarios are set out below, followed by the results of votes on which option was thought by participants to be the most suitable. The reasons why participants voted as they did were not recorded at this stage, but this aspect was examined later in the seminar.

Scenario one

A county in northern England introduces an integrated care record which will link health and care information from GP practices, the two local authorities' social services departments, local hospitals and the CCG that covers the county. The intention is for home care providers and care homes to become part of the scheme at a later date.

The record is to include demographic details, diagnoses, future and past appointments, current medications, information about allergies and alerts, results of tests and investigations, referrals, care plan, letters, discharge summaries and other clinical correspondence.

Once live, the record can be accessed by staff in the participating organisations who are providing care to individuals, including doctors, nurses, social workers, care managers, trusted assessors (a person authorised to carry out a trusted assessment on behalf of others) and administrative staff supporting professionals delivering care.

In addition, an extract of the data is made which is anonymised to the Information Commissioner's Office's Anonymisation Code of Practice to be used for secondary purposes by staff within participating organisations.

Before the record goes live, information about the project is provided to people living in the county via posters in care settings, leaflets, web sites, local newsletters and newspaper adverts.

A privacy impact assessment has been completed for the programme. Each organisation has confirmed they will be individual data controllers for the programme and each has identified a legal basis for sharing data in accordance with the Data Protection Act (i.e. the sharing is fair and lawful and a schedule 2 and 3 condition has been met - another condition other than explicit consent has been used). Those partners have committed to sign an information sharing agreement.

Patients and service users can choose to opt out of having a record at the initial or any later stage. Those who choose to have a record cannot opt out of their anonymised data being used for secondary purposes.

Voting on scenario one

Question: Thinking about the shared record scheme scenario, which of the following best reflects your view?

- Conventional implied consent works best in this scenario (Option 0) 17 %
- Implied consent coupled with reasonable expectations works best in this scenario (Option A) 21 %
- Reasonable expectations as an alternative legal basis works best in this scenario (Option B) 41 %
- Any of the above 0 %
- Another legal basis would work best 21 %

Although participants' reasons for voting as they did were not recorded, it was clear from listening to debate that many did not find conventional implied consent an acceptable basis because there was nothing in the behaviour of patients and service users to imply that they consented. On this vote, a clear majority favoured one of the two options that mentioned reasonable expectations.

Scenario two

An NHS genomic medicine centre in the South of England receives a referral to provide care to a couple who have had two pregnancies terminated because antenatal scans have shown severe brain abnormalities.

Sequencing all the protein-coding parts of more than 20,000 genes in the parents' DNA samples identifies a rare gene variant carried by both of them. Further testing of a DNA sample which had been stored from one of the affected pregnancies showed that the foetus had inherited the variant from both parents. Testing of the couple's two healthy children shows that neither of them has inherited the variant.

Now the laboratory looks to assimilate other evidence to determine whether this variant was likely to be the cause of the brain abnormality in the two affected pregnancies.

They place information about the genetic variant and the relevant clinical history into a database. This database is used by a consortium of NHS genetic services to share data about genetic variants, opinion regarding whether they are thought to be disease causing, and high level clinical data. The data can be considered, in at least some cases, as identifiable. The consortium is arranged with appropriate data sharing agreements and with involvement of local Caldicott Guardians and other relevant approvals.

The team in the South of England identifies one other entry of this genetic variant which has been placed into the database by an NHS genetics clinic in London. On contacting the London clinic, the team receive confirmation that they had seen this variant in a patient who had the same rare clinical presentation.

On the basis of this evidence, a pre-natal test can be offered to the couple early in their next pregnancy to ascertain if the foetus had also inherited these two variants.

Other NHS teams who encounter this variant in the future will now have two entries on the database to help them assess the significance of this variant.

Voting on scenario two

Question: Thinking about the genomic data sharing scenario, which of the following best reflects your view?

- Conventional implied consent works best in this scenario (Option 0) 0 %
- Implied consent coupled with reasonable expectations works best in this scenario (Option A) 4 %
- Reasonable expectations as an alternative legal basis works best in this scenario (Option B) 18 %
- Any of the above 0 %
- Another legal basis would work best 79 %

Although participants' reasons for voting as they did were not recorded, it was clear from listening to debate that participants were overwhelmingly of the view that the parents' explicit consent should have been sought in the case described in scenario two, which would make it unnecessary to rely on other options.

Charting a way forward

In the final session of the seminar Prof Martin Severs asked participants to discuss in their table groups the reasons for and against adopting either Option A or Option B, or both, or something else. He encouraged participants to write reasons in favour of a particular option on green Post-it notes and reasons against on pink Post-it notes. People were free to express their personal view or reflect the view of their table. No limit was set on the number of notes that any individual could post, but the session lasted only 15 minutes and so participants had to restrict themselves to posting what they thought were the most compelling arguments. Little statistical value can be attached to the number of notes posted for and against a particular option, since the aim of the exercise was to get a flavour of the arguments that participants were finding persuasive. The results shown below are an unedited record of the comments posted. No attempt has been made to correct or interpret what may have been hastily written wording.

1. Progress reasonable expectations as an aspect of implied consent (Option A)

Pros (green Post-its)

- Already established in practice (Opt Out - Sharing)
- Reasonable expectations may be a lubricant to seamless care

- This is the status Quo
- Allows more sharing = better care and better prevention

Cons (pink Post-its)

- Risks too broad interpretation of implied consent - best avoided
- Implied consent is confusing as it is, it will be more confusing if it is banded reasonable expectations
- Implied consent is a paternal concept your health professional should not assume your consent and cannot always seek affirmative
- No, it is too hard to distinguish from implied consent
- It won't meet GDPR requirements
- Should not detract from obtaining explicit consent wherever possible - or even talking to patients
- Reasonable expectations are not properly defined
- Reasonable expectations will require a public awareness campaign
- Front line worrying if can share, not daring, scared of risk, fines etc.

2. Progress reasonable expectations as an alternative to consent (Option B)

Pros (green Post-its)

- If there is a sound logic for not getting consent then next best option should be reasonable consent
- Yes it provides a different possible legal justification for broken implied consent
- As we move away from reliance on implied consent in privacy legislation it would make sense to follow this route in CLDoC and this also follows EU legislation which raises the concept of reasonable expectation
- Patients often talk about "I thought you did this anyway"
- This option enables a clearly defined implied consent but enables reasonable expectation to be explored
- This must be about direct care but if the definition of this is clear reasonable expectation could become powerful
- Reasonable expectations goes with "no surprises"
- Makes possible useful activities on which consent cannot be implied
- Need for easily understood consensus in complex environment
- This keeps consent as a separate concept, which might be clearer for patients and professionals

- Data Sharing for direct care is a legal requirement therefore clinicians can be expected to do so and therefore it is key patients know when and how to object
- New models of care cannot be managed with implied consent. They will save many lives so we need to find some mechanism. This seems a reasonable way forward
- Reasonable expectations can be redefined as circumstances change

Cons (pink Post-its)

- Risk that could be interpreted as reducing need to get consent which would reduce / weaken Comms strategy to public override consent
- Concern that concept of reasonable expectation will over ride consent (cultural shift)
- Does not meet any of 3 methods for sharing under CLDoC
- Will the judges agree? We can't rely for decisions today on what courts will decide tomorrow
- Practitioners unclear what reasonable expectations are - subjective
- Additional confusion explicit consent, implied consent, reasonable expectations, consent under GDPR vs consent under CLDoC, keep it simple!

3. Progress both reasonable expectations options (A+B)

Pros (green Post-its)

- Don't make a choice until you have to
- More time to debate and assess both options together
- Robust and defensible approach before the courts
- Progress both options A & B reasonable expectation should stand the test of time (future proof)
- Flexible more dynamic than implied consent - what is reasonable can change over time
- Do both because not clear legally which is more sound - A or B
- Clarification for practitioners
- We need to find a route to unlock the information contained in NHS data in order to improve care

Cons (pink Post-its)

- A reasonable goal is to replace implied consent - a paternal concept at best
- This is contrary to the moves by the courts to respect individual patient autonomy
- Complexity in communicating the legal basis consistently to the public / patients
- Is due diligence sufficient PN/PIA/etc.
- This already exists in post-Montgomery
- No, too hard to distinguish reasonable expectation from implied consent

4. Address the challenges around implied consent in another way

Pros (green Post-its)

- Option to have an equivalent assurance body to decide if use of data qualifies as direct care
- You can't look at reasonable expectations in isolation to the rest of legal and ethical background
- Allows consideration of public interest > (expansion of it)⁷
- Opportunity to seek legal definition of direct care to support reasonable expectation
- All confusing ask the patient what they want!
- Are we in danger of adding complexity - we need to encourage / ensure that people are engaging with patients about how their data is used (i.e. tackle root challenges first)
- Stick to clear definition of implied consent, stand firm and address the pressure
- Why are people concentrating on not telling patients when that should be your starting point?

Cons (pink Post-its)

- There is an urgent need to do something, this is deferring the problem

⁷ On the same theme of developing the public interest test, one attendee later submitted a comment on the same theme using our voting technology: "I back option B, but think there's even more value in growing the public interest ground with examples including risk stratification, better NHS management, science, and testing and developing clinical techniques, medical devices and software."

- Defers the problem if a solution cannot be found now
- This is a leap into the unknown could easily mean do nothing

There was not time for thorough analysis of these comments during the seminar, but rapporteurs fed back some key points to a final plenary session and Prof Severs made a few concluding observations. It seemed from the volume of comments that participants were engaging more with Option B, which was to progress reasonable expectations as an alternative to consent. This option might become more valuable in a world of virtual transactions in which there might be fewer opportunities for patients to signal consent by their behaviour. However, there was clearly great interest in pursuing Options A and B in tandem. “Backing both horses” might increase the chances of success.

It was not the purpose of this seminar to reach a definitive conclusion. Prof Severs encouraged participants to think about the issues and provide the NDG’s Panel with further comment. He called for a final vote and the results were as follows:

Question: Thinking about the presentations and discussions today, which of the following would you suggest the NDG progresses with regards to reasonable expectations?

- Progress reasonable expectations as an aspect of implied consent (Option A) 13 %
- Progress reasonable expectations as an alternative to consent (Option B) 26%
- Both reasonable expectation options should be progressed (A+B) 45 %
- Do something else 16 %

Dame Fiona Caldicott closed the proceedings by thanking participants for their contribution to this complex, but important work. The two key aims of the seminar set out in the introduction by Prof Severs had been achieved. It seemed that health and care professionals did perceive challenges around the use of implied consent as a legal basis for sharing data to support care. Many of those present did believe that the legal concept of ‘reasonable expectations’ might help with challenges.

The outcome of this seminar will help to inform questions about reasonable expectations that will be put to a citizen's jury that is being run in January 2018. Having consulted legal experts, health and care professionals and members of the public, the NDG will then consider how to take this matter forward.

About the organisations

The National Data Guardian

The National Data Guardian (NDG) advises and challenges the health and care system to help ensure that citizens' confidential information is safeguarded securely and used properly. Dame Fiona Caldicott was appointed as the first National Data Guardian for health and care by the Secretary of State for Health, Jeremy Hunt, in November 2014. The NDG's role is to help make sure the public can trust their confidential information is securely safeguarded and make sure that it is used to support citizens' care and to achieve better outcomes from health and care services.

Sheffield Solutions

Sheffield Solutions is an initiative of the Faculty of Social Sciences at The University of Sheffield. It supports events, activities and outputs that connect social science perspectives to policy makers, practitioners and other external audiences in order to tackle pressing global issues. For further information, contact sheffieldsolutions@sheffield.ac.uk

Sheffield Solutions is in part supported by The University of Sheffield's ESRC Impact Accelerator Account.

Summary of terms

The terms and definitions used in this paper are based on those used in the Information Governance Review 2013⁸ and National Data Guardian Review of Data Security, Consent and Opt-Outs 2016⁹.

Anonymise: To rendering data into a form which does not identify individuals, or which makes the risk of re-identification sufficiently low in a particular context that it does not constitute personal data.

Consent: The informed agreement for something to happen after consideration by the individual. For consent to be legally valid, the individual must be informed, must have the capacity to make the decision in question and must give consent voluntarily. In the context of consent to share confidential information, this means individuals should be aware and understand how their information is to be used and shared (there should be ‘no surprises’), and they should understand the implications of their decision, particularly where their refusal to allow information to be shared is likely to affect the care they receive. This applies to both explicit and implied consent. See the Information Governance Review for definitions of explicit and implied consent.

Data Protection Act 1998 (DPA): The Act of Parliament which regulates the processing of information relating to living individuals, including the obtaining, holding, use or disclosure of such information.

Data sharing: The disclosure of data from one or more organisations to a third party organisation or organisations, or the sharing of data between different parts of an organisation. This can take the form of systematic, routine data sharing where the same data sets are shared between the same organisations for an established purpose or for exceptional, one-off decisions to share data for any of a range of purposes.

⁸ <https://www.gov.uk/government/publications/the-information-governance-review>

⁹ <https://www.gov.uk/government/publications/review-of-data-security-consent-and-opt-outs>

Direct care: Defined in the Information Governance Review as a clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals. It includes supporting individuals' ability to function and improve their participation in life and society. It includes the assurance of safe and high quality care and treatment through local audit, the management of untoward or adverse incidents, and person satisfaction including measurement of outcomes undertaken by one or more registered and regulated health or social care professionals and their team, with whom the individual has a legitimate relationship for their care.

General Data Protection Regulation (GDPR): The General Data Protection Regulation (GDPR) is the new EU Regulation 2016/679 adopted by the European Parliament and Council, which is intended to strengthen and unify data protection for individuals within the European Union.

Indirect care or secondary uses: Activities that contribute to the overall provision of services to a population as a whole or a group of patients with a particular condition, but which fall outside the scope of direct care. It covers health services management, preventative medicine, and medical research. Examples of activities are risk prediction and stratification, service evaluation, needs assessment, and financial audit.

Information Governance Review: Following a request from the Secretary of State for Health, Dame Fiona Caldicott carried out this independent review of information sharing to ensure that there is an appropriate balance between the protection of patient information and the use and sharing of information to improve patient care. It is available here: <https://www.gov.uk/government/publications/the-information-governance-review>. The Government's response, which was published in July 2017, is available here: <https://www.gov.uk/government/news/government-responds-on-cyber-security-and-data>.

Secondary uses: See 'indirect care'