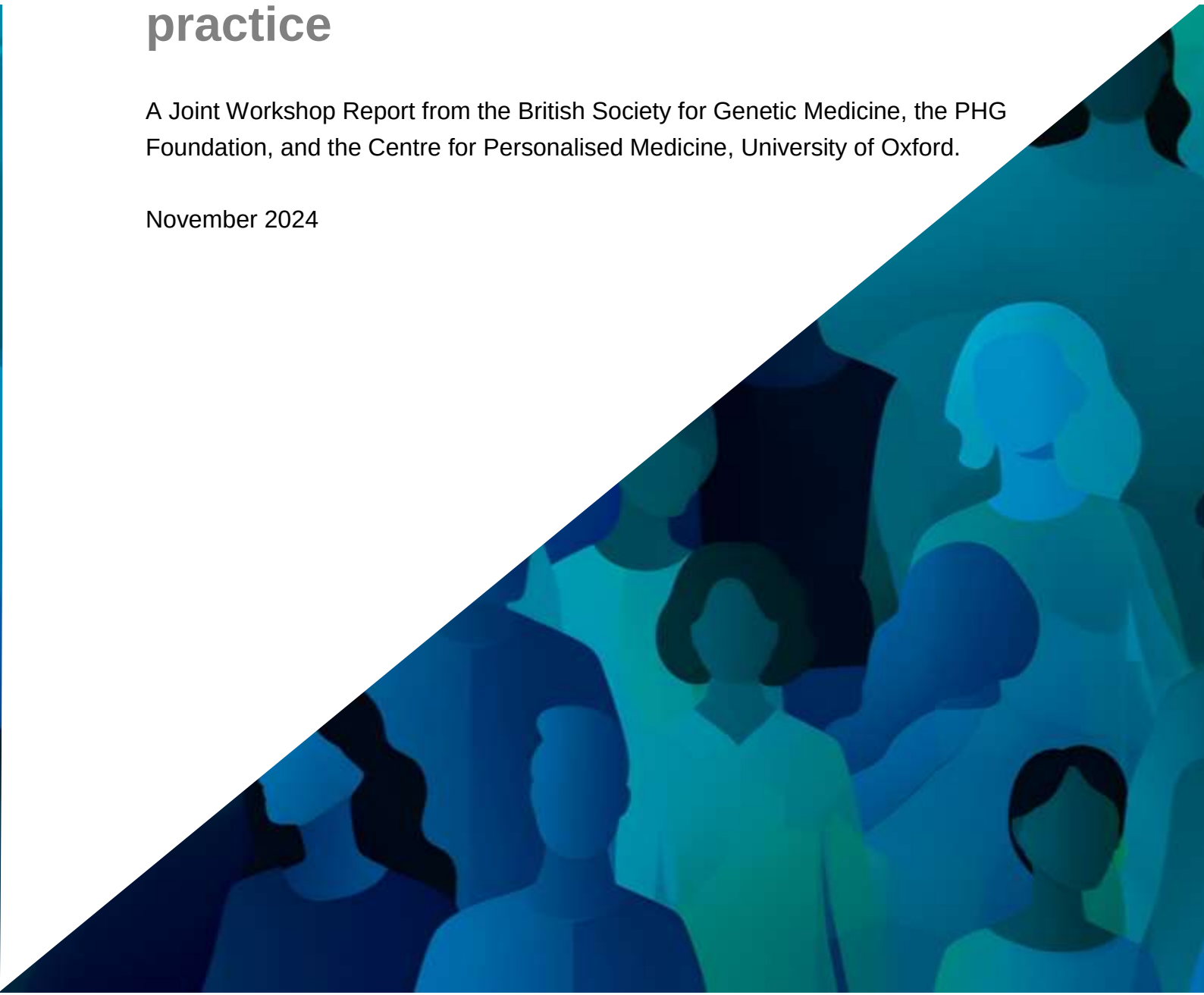
Familial genomic information:

Scope, context and implications for practice

A Joint Workshop Report from the British Society for Genetic Medicine, the PHG Foundation, and the Centre for Personalised Medicine, University of Oxford.

November 2024



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Contents

Introduction

The question of how genetic and genomic test results that are relevant to more than one family member should be managed in health care, has been debated for several decades. The difficulties of balancing duties of care in situations where a result reveals information that is both personal and at the same time (potentially) familial, continues to place healthcare professionals in uncertain situations. Such issues arise in at least half of all cases discussed at the UK Genethics Forum [1], which has held more than 70 meetings with healthcare professionals and other interested parties over the last two decades.

Professional guidelines such as those from the General Medical Council have long recommended healthcare professionals balance their duty of confidentiality to one patient with the prevention of harm to another. However, the legal framework in the UK offered ambiguous support for this until a judgement in the High Court in 2020 (*ABC vs St George's Healthcare NHS Trust*) established a legal duty to consider the disclosure of information in particular circumstances where a relative is at risk of serious harm.

Guidelines from the *Joint Committee on Genomics in Medicine* (JCGM) have also framed the duty of confidentiality as one that takes consideration of the familial aspects of genomic information. These consider whether it is sometimes possible to alert relatives of their risks without breaching the confidentiality of the person in whom the risk was first identified. This approach holds that – in some circumstances – sharing information about familial genomic variants will not identify a particular person or clinical information about them, and might therefore be done/happen without any breach of confidentiality.

The nuances of these guidelines and the implications of the *ABC* judgement are not necessarily clear to all working in health care. So, the Centre for Personalised Medicine CPM), The British Society for Genetic Medicine (BSGM) and the PHG Foundation (PHGF) convened a workshop to facilitate understanding and consensus building in this area, and to inform professional guidance.

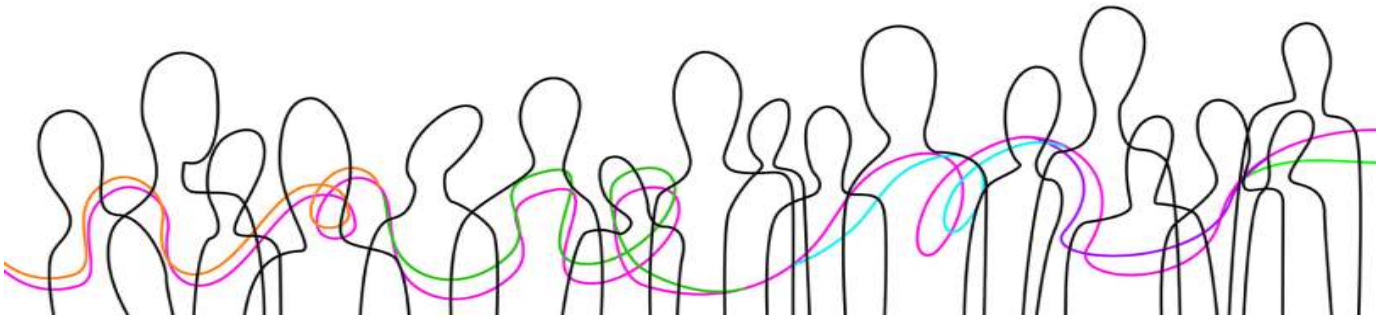
Workshop in Oxford

Fifty-three participants attended a workshop in Oxford in November 2023. They included representatives from patient organisations, and academics, lawyers, and healthcare professionals from several specialities. Workshop participants were provided with a background document setting out the clinical context and issues arising in this area, as well as key aspects of the legal framework governing the management and disclosure of familial genomic information.

The workshop was structured around four linked sessions and focussed on the following questions:

- What are the considerations and challenges encountered in clinical practice in relation to sharing genomic information with a patient's biological relatives?
- How do ethical and legal obligations impact on professionals and their practice?
- What are the implications of the *ABC* judgment? How might the judgment make a difference to practice or guidance?
- How might guidance such as that from the JCGM on consent and confidentiality be updated?

A brief overview of the day is available on the CPM website [2]. This report provides a more detailed account and was written from an analysis of the transcripts from the workshop. It starts with the clinical context and a summary of how issues arise in practice, and goes on to outline the key arguments made during four invited presentations. The presentations reflected a range of perspectives: an overview of the current clinical landscape; the ethical context of familial information sharing; the law and expectations of public ethics; and the implications of the *ABC* judgment. The facilitated discussion that followed has been summarised under the themes of patient and familial considerations; healthcare professional considerations; and supporting structures for communication and disclosure. A document that outlines the background information sent to participants before the workshop is available here: https://cpm.ox.ac.uk/wp-content/uploads/2024/12/Background-doc-for-familial-genomic-information-event.pdf



Clinical context and issues that arise in practice

As genomic testing has expanded to many different areas of clinical care, more situations arise in which there is a need to consider when, and how, potential tensions between the autonomy of individuals and the interests of family members with whom they may share health-relevant genetic features can be recognised and addressed in clinical services.

Genomic investigations often start with the taking of a detailed family history thus identifying family members who might ultimately benefit from knowing about the result of a genomic test. Healthcare professionals will often discuss with their patient which relatives might now benefit from the offer of similar testing and may also provide the patient with summary letters

to pass on to those relatives. However, the discussion highlighted how such communication may not always take place. For example, it may not be clear to patients what information needs to be shared, which relatives it is relevant to, if there is any urgency about sharing it, and how to do so. Consequently, at-risk relatives sometimes do not hear about their own health risk and healthcare professionals may, at times, feel competing tensions between preserving the confidentiality of their patient and alerting family members of their risk.

Respecting confidentiality of information is an important aspect of clinical practice and is vital in securing public trust and confidence in healthcare. Yet providing the patient with a veto over communicating and sharing information which could be equally important to their relatives is inappropriate. Such circumstances led to the seminal case, ABC v St George's Healthcare NHS Trust [see box 1 for summary].

Box 1: *ABC* v St George's Healthcare NHS Trust and Others

The case considered familial interests in genomic information. 'ABC' is the daughter of a man 'XX' who was diagnosed with Huntington's disease (HD) while detained under the Mental Health Act for killing ABC's mother. The doctors caring for XX knew that ABC was pregnant, and they wanted to inform her of her (increased) risk of HD. However, XX refused consent to the disclosure of his disease status and so the communication of the risk to his daughter did not take place at that time. ABC was subsequently told of her father's diagnosis accidentally and, following testing, discovered that she had inherited the HD gene variant from him.

ABC brought a claim for negligence against the NHS team who were caring for her father, for their failure to inform her of her risk. She alleged that they owed her a 'duty of care' to consider her interests, and that these should have outweighed her father's interest in maintaining his confidentiality. The judge concluded that healthcare professionals do owe a legal duty to balance the rights and interests of another person with those of their patient, where disclosure could reduce or prevent a significant risk of serious harm **and** where they have a close 'proximal' relationship with the at-risk person.

This decision established that healthcare professionals owe a legal duty, as well as a professional obligation, to balance the rights and interests of at-risk individuals with those of a patient who has refused consent to disclosure of confidential information.

Objective setting for the workshop

Dr Mills and Professor Lucassen outlined the objectives for the workshop, emphasising the aim of generating a discussion with input from all those present across the sessions. They explained the intention was that the discussions would help inform the revision of the JCG Consent and Confidentiality in Genomic Medicine Guidance (3rd edition 2019).

Professor Lucassen noted the difficulties some healthcare professionals have felt in understanding how to implement the 2019 JCGM Guidance and how to interpret the *ABC* case and hoped the discussion would consider:

- When can communication of familial *genomic* information take place in a way that avoids breaching individual *clinical* confidences?
- When should healthcare professionals make, and document, decisions about the competing interests of patients and their relatives if a person has not provided consent to disclose?

Overview of the current clinical landscape

Dr Helena Carley, Specialist Registrar in Clinical Genomics, South East Thames Regional Genomics Service, and Research Fellow, Centre for Human Genetics, University of Oxford

Dr Carley presented an overview of the challenges relating to information-sharing as they arise in the practice of Clinical Genomic medicine, using a case example [see Box 2] to highlight the conflicting obligations that healthcare professionals might experience.

Box 2: fictionalized case of M

M has genomic testing after developing breast cancer. Her test finds she had a strong chance of developing breast cancer. M's doctor says that her sister could be tested for this inherited tendency. If her sister has it, she could have extra screening or surgery to reduce her risks. Her sister has a 1 in 2 chance of having a strong genomic tendency to breast cancer. M has not told her sister about her breast cancer and does not want to tell her sister about her genomic result.

Dr Carley began by noting that Clinical Genomics has long involved the practice of 'family medicine' (for example, constructing joint pedigrees and holding family files), but noted that recent advances in the speed and cost of genomic technologies mean that genomic medicine is now available to more people through a range of specialities, and that these specialities may not be as familiar with the familial aspects of such testing as clinical genetic services have been. She explained how genomic information might be considered confidential at an individual or familial level. An *individual* approach takes the position that information is confidential to that person and any disclosure should be justified. A *familial* approach distinguishes between personal information (such as a cancer diagnosis, which should remain confidential to that individual), and genomic information, which is confidential to a family and as such should be shared with those to whom it is relevant.

Dr Carley gave examples of research papers [3] [4] [5] which suggested that patients and healthcare professionals may view this issue differently. For example, patients were generally supportive of a 'familial' approach to confidentiality whilst healthcare professionals tended to be more conservative, preferring to adopt an 'individual' approach. A qualitative study of the views of the wider public (with little or no prior experience of genomics) reported that the majority favoured the sharing of genomic information, but without a clear view on whose responsibility that might be [6]. Dr Carley advocated for a familial approach to information-sharing, but that this should always involve a careful weighing (and documenting) of the harms and benefits. She emphasised the importance of making this approach clear at the beginning of any clinical encounter and that such transparency was generally welcomed by patients. This approach has been recommended by professional guidance [7] but has likely not yet reached other specialities where such issues are encountered less frequently.

The ethical context of familial information sharing

Professor Michael Parker, Director of the Ethox Centre, University of Oxford

Professor Parker opened with the aim of stimulating discussion about why confidentiality matters and when it may be appropriate to breach confidentiality. He led the group through an exercise designed to encourage reflection on the underlying principles that matter most in situations where a patient does not want to share information with at-risk relatives. He first outlined some parameters:

- that everything possible has been done to facilitate information sharing by the patient (for example, the provision of resources, advice and support)
- that there are no routes to sharing information through other family members
- that sharing information would be feasible on a practical level
- that it might not be possible to share information without breaching clinical confidentiality

Professor Parker discussed three considerations which relate to confidentiality: (1) the harms and benefits of maintaining high standards of confidentiality, (2) patient expectations, and (3) autonomy and the ability to decide how information is managed. He highlighted how the ABC case established that a duty of care can exist to persons other than the patient, and that there may be grounds for reasonable disagreement between healthcare professionals on the morally and legally right course of action. This means that healthcare professionals may arrive at different decisions depending on the contextual features of a case.

The ABC case also highlighted the importance of the quality and reasonableness of the decision-making process, rather than providing a judgment on whether confidentiality should or should not be breached in individual cases.

He noted that virtually all the familial information sharing cases presented within the Genethics Forum involve reasonable disagreement about the most appropriate course of action, suggesting this is a common issue that is under-engaged with amongst many

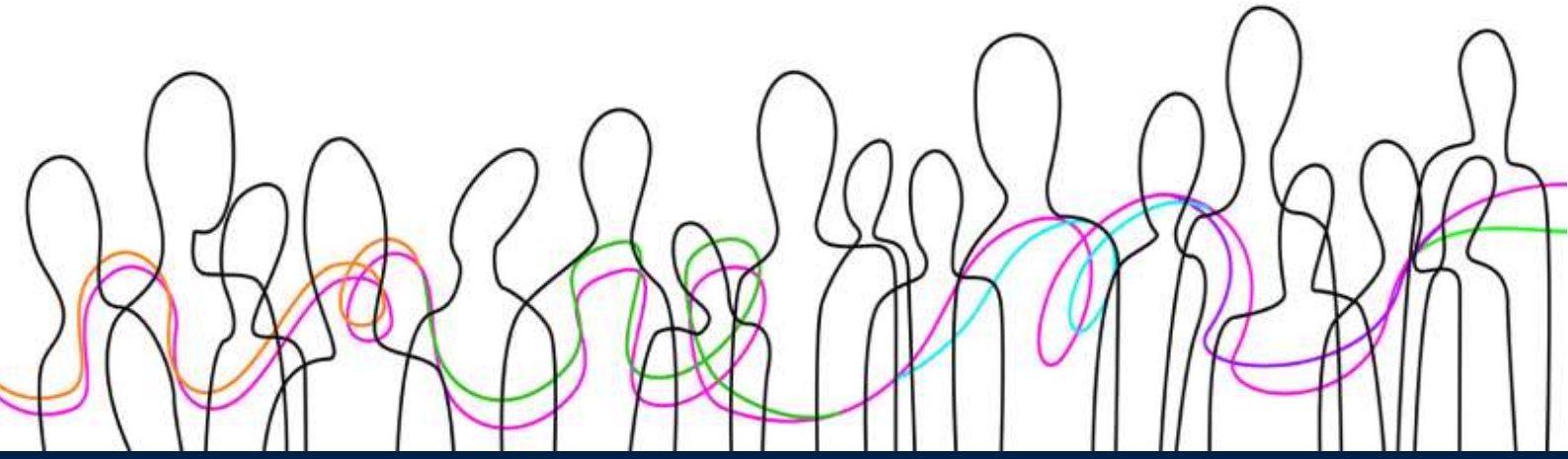
healthcare professionals. Rather than adopting a default ‘share’ or ‘not-share’ approach, Professor Parker suggested that healthcare professionals have an ethical and legal obligation to go through an explicit reasoning process before arriving at a decision.

The law and expectations of public ethics: ethical obligations of those taking decisions in public roles

Professor Sir Jonathan Montgomery, Professor of Healthcare Law, University College London.

Professor Montgomery’s presentation addressed the ways in which healthcare professionals might approach moral or legal uncertainty. Whilst the law tells us what we must do and what we must not do, in practice there is often a grey area between 'must' and 'must not' where a decision will depend on the circumstances. The law does not tell us what to do here, but it does address the appropriate processes to follow when healthcare professionals make decisions in this discretionary zone. Healthcare professionals need to exercise clinical judgement, which can then be scrutinised. The use of processes and mechanisms such as peer support, clinical ethics committees and the Genethics Forum can all be used to demonstrate that clinical judgement has been exercised conscientiously.

Professor Montgomery then turned to the question ‘whose decision it is to share or not share familial genomic information?’ He noted that the law upholds that healthcare professionals have the power to make decisions about medical care (e.g. the *Bolam / Bolitho* legal cases) and simultaneously upholds the more recent shared decision-making model (*Aintree* case / Mental Capacity Act 2005), leaving healthcare professionals uncertain about which approach should be adopted and what might be considered good practice. At the core of this issue are questions concerning the frameworks and standards for upholding accountability, the extent of formality involved and what the reasonable expectations of patients in such a scenario might be. He outlined how working with families and publics could lead to the development of shared ethical norms and standards about disclosure/sharing information. He concluded that the identification of a legal duty of care has strengthened what healthcare professionals were (often) already doing, and that the ABC judgment gives certainty and added weight to professional guidance.

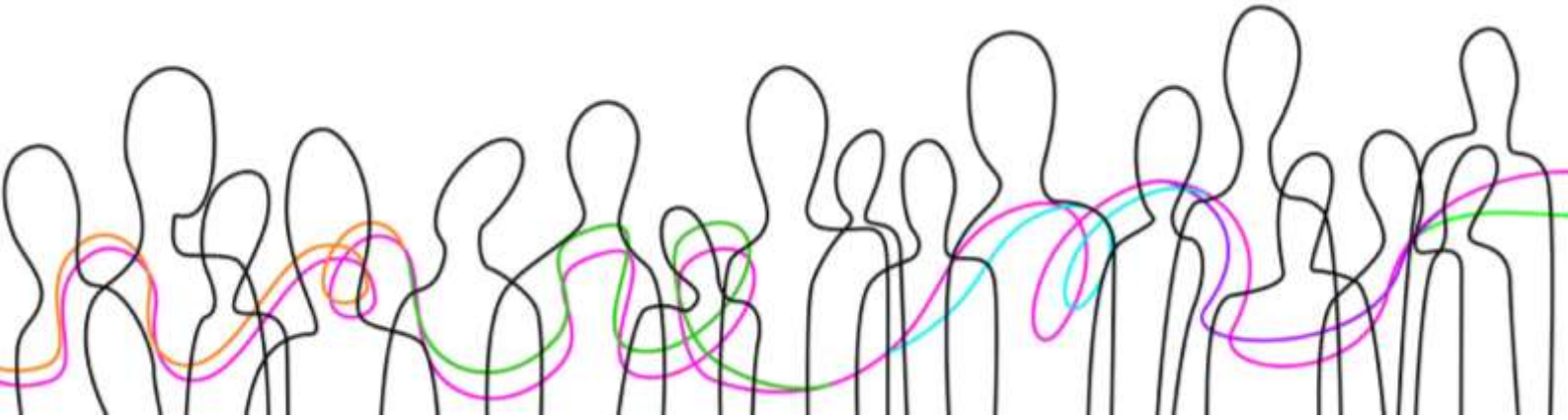


The implications of the ABC judgment

Jonathan Zimmern, Partner in the Medical Negligence team, Fieldfisher LLP

Mr Zimmern was part of the legal team acting for the claimant in the ABC case. He provided insights into the circumstances of the case, the approach adopted by both sides and by the Judge in her decision. He reiterated the importance of the decision and his view that the ruling affirms what healthcare professionals in this area already considered good practice. The case established a novel duty of care in law (owed to third parties with whom healthcare professionals have sufficient proximity) and reinforces the fact that undertaking reasoned and well-accounted-for decisions amounts to best practice.

Mr Zimmern clarified that the decision in the case was not whether disclosure should or should not happen, but rather that in such circumstances a balancing exercise should be undertaken, documented, and the decision made acted upon. There is a duty is to balance the interests of both parties, and to demonstrate this has been done thoughtfully, taking everything necessary into account to reach a logically defensible conclusion, whatever that conclusion is. As long as a decision is reasoned, rational and logically defensible, and a contemporaneous note has been made at the time of making the decision, there should be no great cause for concern about legal or professional ramifications. He emphasised that the ABC ruling leaves room for professional discretion and that it largely follows what is already considered best practice in this area: a requirement to balance the potential harms and benefits to the patient with the interest of the relative in knowing their genomic risk.



Discussion Themes

Discussion throughout the day reiterated how healthcare professionals have long been faced with questions about:

- What genomic information might need to be communicated to the family members of the patients they see,
- Who should be involved in its communication and
- When should this take place.

In the rich discussions that followed each of these presentations several common themes emerged:

1. Patient and familial perspectives and considerations

1.1 Implications of/for familial relationships

A key point raised was that non-disclosure of information is not necessarily an indication of problematic relationships within a family. There are many reasons why appropriate sharing does not happen, for example:

- a lack of understanding of why sharing is important;
- changing family circumstances, configurations and priorities;
- a concern about potentially negative effects of the information on a relative's mental health;
- a lack of clarity from the healthcare professional about who should be sharing what information and with whom;
- disagreement about who has responsibility for sharing and to whom that responsibility is owed (e.g. how far it extends beyond the immediate family).

The fundamental question of what is meant by 'family' in this context was raised by several participants. It was emphasised that family structures and ties are diverse. Unpacking the question of 'to whom information is relevant' is not always straightforward. For example, a spouse or partner who is not at risk themselves may have an important role to play in supporting decision-making and communication. Defining a family on biological lines is, therefore, problematic.

Participants expressed concerns that in some circumstances, sharing information may cause more harm than good. There was a recognition that communication and disclosure can affect different families and relationships within families in different ways. Participants spoke of the potential to 'drive a wedge' for example, between those who are and those who are not biologically related, or those who are aware of information and those who are not. It was felt important that the 'familial' approach to information sharing is used as a tool to identify those at risk, acknowledging that people feel differently about genomic and social relationships, and that genomic/social proximity are not synonymous.

1.2 Information needs and expectations

Participants highlighted the importance of recognising that patients and, in turn families, may not always interpret the information they receive regarding individual and familial risk in the way it was intended, and this can lead to misunderstandings. Workshop participants spoke of the importance of recognizing that the familial nature of genomic medicine might not be widely understood. Whether patients understand the implications for relatives and what they might be willing to share are likely to be shaped by their prior experiences and the wider context of their lives, and clinicians must be attentive to this.

Patient group representatives spoke of how families can find the prospect of sharing information an onerous responsibility and that it can come as a surprise to them. The importance of healthcare professionals discussing information sharing as a potential outcome of genomic testing during consent discussions and supporting patients to share information with their families was emphasised. A suggestion was made that it would be helpful to encourage patients to talk to their relatives about undergoing genomic testing early in the process, as discussions can be more challenging once information has already been discovered.

Several participants suggested that discussions with patients should include helping them to consider their moral responsibility to communicate relevant information with at-risk relatives and that clinicians can offer help with this process.

1.3 Disclosure as a process

The importance of thinking about disclosure as a process rather than a one-off moment was highlighted. Representatives from patient groups spoke of how undergoing testing, waiting for and receiving results is often an overwhelming experience; patients need time to adjust to the news themselves, and sharing information with family members may not be an immediate priority. Some may reveal information gradually over time or disclose to different relatives at different times (e.g. delaying sharing information with children until they are considered able to process the information). For healthcare professionals this can be challenging as long-term follow up to see which family members have been told is often not feasible. Clinical time and resource constraints may clash with suggestions that a 'case-by-case approach' was needed. One participant noted that whilst the focus is often on the moment of disclosure, the implications may be lifelong and / or inter-generational. What constitutes a reasonable amount of time within which to disclose information to relatives is not clear-cut.

1.4. Wider impacts of information sharing

Patient group representatives raised the concern that healthcare professionals sharing clinical information without the patient's agreement might stop some people from coming forward for genomic testing. Workshop participants felt that, wherever possible, discussing the prospect of communicating relevant information to relatives, without sharing the patient's personal or clinical information, should be discussed during the initial testing process.

2. Healthcare professional perspectives / considerations

2.1 Approaches to information sharing

It was noted that healthcare professionals are often cautious when it comes to sharing information and tend to worry more about the consequences of sharing, than those of not sharing. While worry about the consequences of sharing may, in part, follow from misinterpretations of the ABC ruling, other factors were proposed as potential drivers of this. These include a tendency for healthcare professionals to turn to lawyers acting for NHS Trusts first for advice, rather than exploring other routes such as clinical ethics committees. Advice received from Trust lawyers was characterised as risk-averse (generally advising against disclosure of confidential information without explicit consent) so it is important to consider how communicating test results could facilitate better care for family members. Similarly, some healthcare professionals may rely excessively on written consent to guide decision-making or treat the absence of written consent as equivalent to an objection to disclosure. Participants felt it was important to encourage healthcare professionals to move away from a cautious and/or written consent-based approach, and to discuss the benefits of familial communication routinely whilst also having enough time to work on complex cases. The participants also highlighted that healthcare professionals may not be aware that they are unlikely to be reprimanded for disclosing information without the patient's consent if they have undertaken, and documented a balancing exercise about the interests of both parties, and then acted upon the decision made.

2.2. Confidentiality

In their contributions, Dr Carley and Professor Lucassen reinforced an alternative approach to disclosure of relevant genomic information. This does not rest on the patient's consent or justification for disclosure without their consent. Instead, it distinguishes personal medical information from familial genomic information (i.e. those genomic variants that are shared by family members). On the basis that genomic information can be considered confidential to a family, information about genomic variants can be shared with those to whom it is potentially relevant without any breach of confidence and without the need for explicit consent. Some agreed that this distinction is helpful and would not represent a breach of confidence because it would limit the information disclosed to the shared risk (i.e. an individual's medical information would not be disclosed). Others worried that relatives might be able to infer who had been tested in the family and that this inference would constitute a breach of confidence.

2.3 Healthcare professional-patient relationships

Workshop participants worried that the consequences of breaching (or not breaching) confidence could be far-reaching and could negatively impact upon patients' and the public's relationship with healthcare professionals. Some were also concerned that breaching confidentiality would be seen as a breach of trust, and that in focussing too much on

'information that needs to be passed on', there was the potential to lose sight of the values and expectations of the patient-healthcare professional relationship.

3. The role of legal structures

3.1 Interpretation of the ABC case by patients, families and healthcare professionals

The discussion highlighted that the ABC case has been interpreted in different ways since the ruling in January 2020. For example, participants with patient group experience reported that some of these communities interpreted ABC as requiring information to be shared with relatives without consent. Conversely, participants with clinical experience reported that some colleagues are now more hesitant to disclose risk information without consent. This was also felt to be a consequence of the interpretation of the legal position by NHS Trust lawyers in their advice to healthcare professionals. Both Mr Zimmern and Professor Montgomery emphasised that there is professional discretion here and that it is the demonstration of reasoned decision-making that is key.

3.2 Clarifying and communicating legal requirements

Some participants felt that it would be useful to have example scenarios to illustrate the consequences of different courses of action and others wanted clearer definitions of terms such as 'proximity' and 'assumption of responsibility' as they are understood in law. There was a suggestion that it would be helpful for the review of the JCGM to provide further illustrative examples.

Mr Zimmern clarified that "…healthcare professionals should appreciate that the new legal duty is not a new obligation to disclose information to third parties in all circumstances. The judgment simply provides a legal obligation for healthcare professionals to do their professional duty properly. One of the most important consequences of this case, is that now a patient and their relative both have a right of recourse to the courts, whereas previously only the patient had that privilege."[8]

3.3 Consideration of at-risk individuals

Another issue raised was that for many healthcare professionals genomic testing is relatively new and may not realise that genomic information can reveal information about both an individual and their (close) biological relatives. It is important that they are helped to incorporate this issue (where appropriate) into their consent discussion. Research into the extent to which familial information sharing is incorporated into such discussions could be helpful.

Comparisons were made with other areas of clinical care which also require consideration of at-risk individuals:

- Sexual health: analogies were drawn with contact tracing in HIV medicine and how advances in pre-exposure prophylaxis and treatments for HIV allow for a more flexible interpretation of the context of 'seriousness' to include, for example, broader life impacts.
- Infectious diseases: the Covid19 contact tracing app which alerted individuals of possible exposures was discussed, and it was recognised that it was possible to infer an index case based on a person's contacts in much the same way that a relative might infer who in the family has been tested. But such inference is not the same as a breach of confidence.
- Safeguarding: a child safeguarding template stored in the electronic medical record requires healthcare professionals to think about every individual in a family or household in order to build a complete picture of potential risk. Might such an approach be possible in genomics in order to take everybody who is at risk into account? It was noted that in child safeguarding issues information is more likely to be shared than not shared.

Re-visiting guidance for healthcare professionals

The Record of discussions form (RoDF) to summarise clinical consent (Appendix 1.2 to the guidance from the JCGM) was discussed. This form aimed to be a prompt to clinicians of the issues to discuss when taking consent for genetic or genomic testing in the clinical setting, a copy of which patients could then take with them to remind them of their discussion in clinic. Its aim was also to distinguish it from a consent form to take part in a research study that needs to fulfil research ethics committee requirements. The intention was to make the importance of familial communication explicit and to prompt discussions about how this might be done without breaching patient confidentiality. However, the NHS genomic medicine service then adopted this form almost verbatim as a consent form for both research and clinical practice meaning that the starting point for discussion of familial communication may be different. More widespread adoption of the sentiment of the RoDF might avoid erring on the side of non-communication because of a lack of explicit consent.

The last edition of the JCGM guidance document was specifically designed to reach mainstream healthcare professionals, but engagement with it has not been tracked and anecdotal reports suggest that its reach could be wider. It was emphasised that the guidance is intended to support the process of thinking about communication, rather than being prescriptive about a particular course of action.

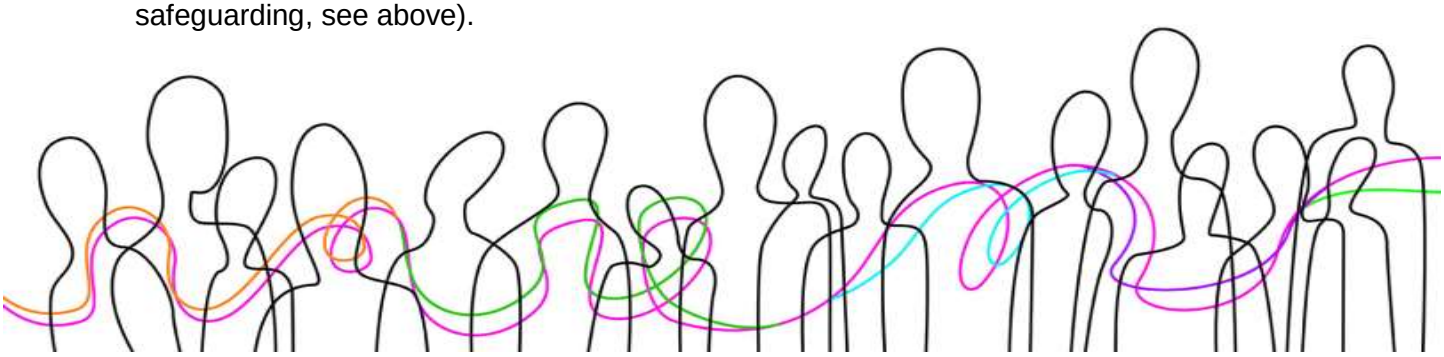
There was discussion about including a template / toolkit for healthcare professionals around the duty to demonstrate that both / all parties' interests have been considered fully and thoughtfully, and a template/toolkit for patients around why and how to share information in their family. There was also support for co-producing these with patient groups, and for including a plain English and EasyRead summary of the recommendations.

The role of support organisations and resources

The importance of ensuring clear communication about genomic information from the outset was discussed. The language used by healthcare professionals in clinic and in summary letters can obstruct communication with relatives. For example, complex medical terminology and an emphasis on technical details can make it difficult for patients to know what needs to be communicated. There was support for the suggestion that an emphasis on the relational (e.g. what might this information mean for my relative(s)) is likely to be helpful. Representatives from support organisations spoke of the support they provide to patients in terms of working out what information to pass on to relatives and how to do this, for example, by helping to draft tailored letters.

In line with regarding disclosure as a process, participants also argued that the availability of follow-up support for families must be taken into consideration. It is often not clear what happens after information has been shared with relatives or what the implications of the communication were. Representatives from patient groups felt they could play a role in promoting the JCGM guidance.

Initiatives to improve disseminating information within families are being researched, for example, the development of *My Kin Matters* [9] but these are not yet in widespread use. Furthermore, two different sets of problems were identified: (a) those who intend to share information but need help to do so, and (b) those who do not wish to share information. Practical guides to help healthcare professionals structure and document their thinking might be helpful, and could draw on existing examples in other areas of medicine (e.g. safeguarding, see above).



Conclusions and recommendations

There are a significant number of challenges and ambiguities surrounding the nature and scope of familial genomic information communication across health care. Although the decision in *ABC v St George's NHS Healthcare Trust* established that a legal duty may be owed to relatives in certain circumstances, nearly five years on there are still a number of different understandings of the implications of this ruling. Workshop participants agreed that sufficient resources are crucial to allow the time and space for sensitive conversations between healthcare professionals and patients**.** The need for further guidance and support for both healthcare professionals and for patients and families was highlighted, in particular the following:

Resources, further guidance and support

- Advice from experienced colleagues, clinical ethics committees and internal support structures should be available to healthcare professionals as a first port of call, rather than seeking legal advice
- The co-development of accessible resources to help patients
    - understand the familial implications of their diagnosis/genetic test result,
    - develop their confidence to share this with family members
    - recognise the importance of talking about potentially difficult issues with family members
- The co-development of resources to help healthcare professionals in all specialities
    - increase their awareness that genomic information can reveal information about an individual and their [close] biological relatives
    - further develop their skills in raising patients' awareness of the familial implications of genomic results
- The co-development of guidance and tools for healthcare professionals to support
    - the identification and weigh up relevant factors in their decisions about disclosing/not disclosing confidential information
    - recording these in order to meet relevant legal and ethical obligations For example- to revised guidance
- Further thought could be given to the co-development of guidance on
    - the role of non-biological family members (eg spouses/partners) in sharing information
    - when and how healthcare professionals should help patients consider their moral responsibility

Priorities for further work in this area

- Clarification of the extent to which shared familial information may be distinguished from personal information within existing legal frameworks
- Further work to better understand different cultural views and approaches to sharing of genomic risks among the family, to inform guidance and practice
- Exploration of parallels to managing and disclosing confidential information in other health or social care areas which could be adopted in practice relating to familial genomic information

Summary

Genetic and genomic test results are often relevant to more than one family member. Professional guidance has long held that healthcare professionals must balance their duty of confidentiality to their patient with the prevention of harm to others.

The ABC judgement is welcome because it supports this by establishing a legal duty to consider the disclosure of information in particular circumstances where a relative is at risk of serious harm.

The development of guidance, and the support outlined above, is critical both to maximise the possibility of genomic information being shared with all family members it is relevant for, and to demonstrate healthcare professionals' trustworthiness to patients and families.

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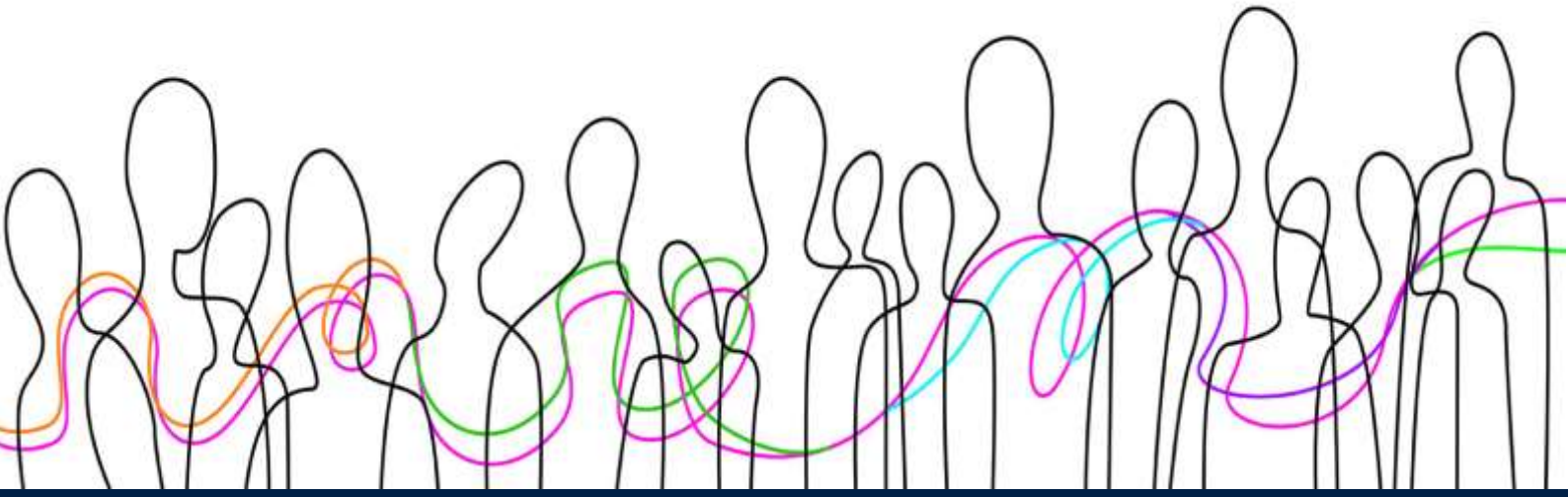

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