



Mason Institute  
symposium on  
healthcare  
professionals' duty of  
care: should it extend  
from patients to genetic  
relatives?

Symposium report  
July 2018

# Symposium report

## *Symposium on healthcare professionals' duty of care: should it extend from patients to genetic relatives?*

### **About the Mason Institute**

The J Kenyon Mason Institute for Medicine, Life Sciences and the Law (MI), based at the University of Edinburgh and located within the School of Law, serves as an interdisciplinary research network aimed at investigating the interface between medicine, life sciences, and the law in relation to medical and bioethical developments on a national and global scale. MI is dedicated to conducting innovative world-class research, and raising the quality, quantity, and awareness of the research being undertaken, individually and in cooperation with other domestic, European, and international partners at the University of Edinburgh. As an institution, we provide evidence-based research and policy advice and are a nexus for international collaboration and exchange, drawing on and pulling together a diverse collection of existing networks and forging new ones.

### **About the Duty of Care symposium**

Genetic information gained in the course of a clinical encounter between a healthcare professional (HCP) and a patient might lead the HCP to know that certain genetic relatives of the patient are also at risk of a particular health problem. This has been a challenging ethico-legal issue for many years and is much discussed in the literature, particularly in the context of potential responsibility of clinicians to close relatives of their patients. It is also a question of growing, contemporary importance given the increased incorporation of genetics and genomics into routine healthcare.

On 12<sup>th</sup> June 2018, a symposium was convened at Edinburgh Law School to explore the central question at issue: when HCPs receive a patient's genetic information and that information may have relevance to the health of members of the patient's family, in what circumstances, if any, should they owe a *legal* duty to communicate this information to relevant parties? Framed another way, should there be a 'right' to be informed about a known familial risk?

Some academic commentators have supported the notion that such a duty could be found in law in the UK,<sup>1</sup> and recent English authority (e.g. *ABC v St George's Healthcare NHS Trust and others*<sup>2</sup>) has opened the door to such a finding as well. This is the first case of its kind in any UK jurisdiction. Other commentators, however, have argued against a legal duty of care extending to genetic relatives.<sup>3</sup>

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<sup>1</sup> See e.g. Victoria Chico, 'Non-disclosure of genetic risks: The case for developing legal wrongs' (2016) 16 *Medical Law International* 3-26.

<sup>2</sup> *ABC v St. George's Healthcare NHS Trust and others* [2017] EWCA Civ 336.

<sup>3</sup> See e.g. Edward Dove, 'ABC v St George's Healthcare NHS Trust and Others: Should there be a right to be informed about a family member's genetic disorder?' (2016) 44 *Law and the Human Genome Review* 91-

While much has been written on this topic, UK law remained unsettled at the time of the symposium. The symposium was, therefore, very opportune. Its aims were two-fold:

- 1) to articulate more clearly and fully the normative basis for positions on either side; and
- 2) to explore the likely legal, ethical, and policy implications of any changes in the law beyond the context of recent legal decisions. Five speakers from across the UK contributed their expert views on the HCP's potential duty of care to genetic relatives. All participants were encouraged to share their views on the topic.

This report, co-authored by the symposium participants (see Appendix 1), summarises the papers presented and the ensuing discussions. It also lays out next steps for the group.

## Speakers

### Session 1

**Prof Rachael Mulheron**, Professor of Tort Law and Civil Justice at the Department of Law, Queen Mary University of London, provided an overview of recent and earlier case law on the topic. Specifically, her analysis focused on situations where a HCP treats a patient for a hereditary illness or disease, and the claimant is a genetic relative of the patient, so that he/she might have a genetic predisposition to contract that illness or disease.

Prof Mulheron observed that there was no UK jurisprudence on this topic until the recent leading cases of *ABC v St George's Healthcare NHS Trust and others*<sup>4</sup> and *Smith v University of Leicester NHS Trust*.<sup>5</sup> There are also two prominent US cases: *Pate v Threlkel*<sup>6</sup> and *Safer v Estate of Pack*,<sup>7</sup> and a Quebec case (thus concerning a civil law jurisdiction): *Watters c White*.<sup>8</sup>

In *Pate v Threlkel*, the Supreme Court of Florida found that a physician has a duty to inform patients (framed as a 'duty to warn') of the heritable nature of the condition for which they are being treated, and that this duty extends to third parties when the prevailing standard of care creates a duty that is obviously for the benefit of certain identified third parties and the physician knows the existence of those third parties. The Court held, however, that the duty is discharged by informing the patient him- or herself of the familial implications of the condition: 'Our holding should not be read to require the physician to warn the patient's children of the disease. [...] To require the physician

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112. See also Shaun Raviv, 'When you have a serious hereditary disease, who has a right to know?' *Mosaic* (10 July 2018), available at <https://mosaicscience.com/story/right-to-know-doctor-patient-confidentiality-law-ethics-genetic-testing/>.

<sup>4</sup> *ABC v St George's Healthcare NHS Trust and others* [2015] EWHC 1394 (QB); on appeal: [2017] EWCA Civ 336.

<sup>5</sup> *Smith & Another v University of Leicester NHS Trust* [2016] EWHC 817 (QB).

<sup>6</sup> *Pate v Threlkel*, 661 So2d 278 (Fla 1995).

<sup>7</sup> *Safer v Estate of Pack*, 677 A2d 1188 (NJ Super Ct App Div 1996).

<sup>8</sup> *Watters c White*, 2012 QCCA 257 (QC CA).

to seek out and warn various members of the patient's family would often be difficult or impractical and would place too heavy a burden upon the physician. Thus, we emphasize that in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient.' The Court did not discuss the nature of the physician's duty if the patient refuses to disclose the information to relatives. Prof Mulheron characterised this form of the duty as a **'weak' form**.

In *Safer v Pack*, the Superior Court (Appellate Division) of New Jersey held that a physician had a duty to inform (again, framed as a 'duty to warn') individuals known to be at risk of avoidable harm from a heritable condition (in the facts of this case: colon cancer), and that the duty extended to a patient's family members. According to the Court: 'We see no impediment, legal or otherwise, to recognizing a physician's duty to warn those known to be at risk of avoidable harm from a genetically transmissible condition. In terms of foreseeability especially, there is no essential difference between the type of genetic threat at issue here and the menace of infection, contagion or a threat of physical harm.' The Court further found that 'the duty to warn of avertable risk from genetic causes, by definition a matter of familial concern, is sufficiently narrow to serve the interests of justice.' Interestingly, the New Jersey Superior Court referred to the earlier Florida decision in less-than-positive terms: '[w] decline to hold as the Florida Supreme Court did in *Pate v Threlkel* that, in all circumstances, the duty to warn will be satisfied by informing the patient. It may be necessary, at some stage, to resolve a conflict between the physician's duty to warn and his fidelity to an expressed preference of the patient that nothing be said to family members about details of the disease.' Prof Mulheron characterised this form of the duty as a **'strong' form**, and noted that, ironically, the very conundrum identified in the previous sentence then arose in the leading English case of *ABC v St George's Healthcare NHS Trust*.<sup>9</sup>

In *ABC*, the patient (father) was very clear that he did not want his daughters told about his Huntington's disease diagnosis, expressing a particular concern that one of his daughters, who was pregnant at the time of his diagnosis, might seek an abortion. The uninformed daughter went on to give birth; sometime after she had given birth, she discovered her father's diagnosis. She brought an action claiming, *inter alia*, that if she had known of her father's diagnosis, she would have elected to terminate her pregnancy. This was framed as a duty to inform the daughter directly (see discussion of *Safer v Pack*, above); the case was struck out at first instance at the High Court of Justice by Nicol J, but remitted on appeal (i.e. it was sent back to the High Court to be considered on the facts). In doing so, the Court of Appeal suggested that a 'strong' form of the duty may be possible under UK law. Indeed, Prof Mulheron suggested that the Court of Appeal was only speaking of a strong form of the duty, given the facts (i.e. that the father refused to consent to the disclosure of his diagnosis), and the policy reasons articulated by Irwin LJ (writing for the court) in upholding an arguable duty of care. This is important, as we know that although the father did disclose his presumed

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<sup>9</sup> It bears noting that *Safer v Pack* was legislatively overruled when New Jersey enacted a genetic privacy law (NJSA 10:5-47 (2001)). The law prohibits disclosure of genetic information without the consent of the individual, unless one of 10 exceptions is met (e.g. court order, identification of a dead body).

diagnosis to his brother, he was adamant that he did not wish the claimant (his daughter) to be told (and likewise requested his HCPs to not inform her). In the Court of Appeal, Irwin LJ suggests clearly there is a public interest in disclosure (e.g. because public confidence in the healthcare system would be enhanced), and agreed with the claimant that should she become ill with Huntingdon's disease, her child may require significant state support. The Court of Appeal dealt with nine separate policy arguments posed by the defendant Trust. Among other points Irwin LJ made:

- the respective duties of care to patients and relatives can be aligned, but where there was a conflict of duties, a breach may be hard to prove.
- the duty of confidentiality is not absolute, with both legislative and case law exceptions.
- the putative right 'not to know' does not preclude a duty; concerns of psychological harm from knowing arise already, in relation to the transmission of such information with the consent of the diagnosed patient to his or her relative.
- there was a distinction to be drawn between closed classes and non-closed classes of diseases (distinction between genetic diseases vs. contagious diseases – the latter has not been litigated as a ratio point in UK as yet, but elsewhere there is a division of judicial opinion around the duty to warn in both the weak and strong forms)
- there may be cases in which nothing would be gained from informing the relative of the risk of transmission (e.g. if the claimant was past child-bearing age, there was no cure, and the claimant would be frightened), in which case no duty of care may be cast; it will require a case-by-case determination
- although there were no closely-aligned cases in UK law to date, a duty of care to a third party was recognised in other jurisdictions in this area; and furthermore, the development of a duty of care at common law is properly the remit of the judiciary instead of Parliament, as otherwise, the law would 'ossify'.

In *Smith*, the High Court struck out a claim brought by a patient's second cousins regarding the patient's doctors' failure to provide the patient with an accurate diagnosis, which would have resulted in the claimants being diagnosed with a serious hereditary disease earlier than in fact they were. The claimants argued that the doctors' failure to conduct the test caused harm and that a duty of care was owed in respect of the patient's relatives. The defendant conceded the issue of foreseeable harm but argued a duty was not fair, just, and reasonable when treating the patient and no other, or, alternately, if the duty was to inform then the cousins were insufficiently proximate to the HCP. Ultimately, the judge had to strike out the case because *Smith* came at a time when the High Court in *ABC* had ruled against a duty and so the court in *Smith* followed suit. Prof Mulheron said there are indications both ways in the language of the judgment that the duty of care which may be upheld could be a strong or weak form, but it was not resolved as to which might hold sway.

In her presentation, Prof Mulheron emphasised that under the weak form of the duty, it is easier to find for a defendant because all that is required of the HCP is to inform the patient. There may be causation issues, however (e.g. failure of the patient to then disclose to the family). Under the strong form of the duty, however, the HCP is required

to actively take steps to warn or disclose to the patient directly. In Prof Mulheron's view, it is **time for English law to recognise a weak form of the duty**. (Some participants commented, and Prof Mulheron acknowledged, however, that this would not necessarily provide a solution for the HCPs in a difficult *ABC*-like position.) All ramifications should be communicated to the patient; it is then up to the patient whether he or she wishes to pass on the information. The obligation should not be more onerous than this, and it is analogous to other professions, where a weak duty exists (e.g. in the legal profession for certain third parties of the lawyer-client dyad). If *ABC* returns to the High Court, it will be interesting to see whether a legal duty is recognised, and if so, whether it is the 'strong' or 'weak' form.

Questions from the symposium participants considered, among other issues:

- Where/whether there should be a duty of care owed by the proband/patient (rather than the HCP)? (Some participants noted, though, that the law does not usually concern itself with domestic disagreements in families.)
- At what 'level' of kinship does a duty of care stop, if at all?
- What kind of duty is at issue here: a duty to warn or a duty to inform the patient to pass the information to the genetic relatives?
- What are wider implications of imposing a duty of care on HCPs, including:
  1. Healthcare system capacity
  2. Funding and costs
  3. Cost effectiveness
  4. Wider networks
- Genetic risks are mostly about possibilities and probabilities, not a diagnosis per se – as such, the knowledge on which the duty is founded is far from certain.
- Blurring of boundaries: enhancing this duty in law has wider social implications, such as patients vs non-patients; risk vs disease; diagnostics vs therapeutics; prevention vs preparedness.

**Prof Graeme Laurie**, Professor of Medical Jurisprudence at the University of Edinburgh, next presented on professional guidelines and the limits of law in this area. He argued that it is problematic to extend a legal duty in this area. A particular area of concern he identified in the wider medical law case law is the shift away from medical paternalism and discretion (e.g. *Sidaway*,<sup>10</sup> *Bolam*<sup>11</sup>) towards the pernicious rise of a **'thin view' of autonomy** (seen in the UK Supreme Court case of *Montgomery*<sup>12</sup> and elsewhere). This legal view of autonomy is 'thin' because it tends to focus on individual choice alone. Ethical accounts of autonomy offer far richer conceptualisations. Prof Laurie argued that we are living in an 'era of autonomy', most prominently since *Chester v Afshar*<sup>13</sup> in 2004. But this is a caricature of what autonomy is and what it means to be a patient or citizen. The wish to know familial genetic information – turned into a 'right' by duty of care cases such as *ABC*, is an acute form of this fetishisation of autonomy in law. Moreover, Prof Laurie argued that the Court of Appeal in *ABC* collapses obligations

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<sup>10</sup> *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871.

<sup>11</sup> *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

<sup>12</sup> *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

<sup>13</sup> *Chester v Afshar* [2004] UKHL 41.

of confidence and obligations of negligence. Robust professional behaviour already exists in law and policy that could accommodate an ethical and lawful decision to disclose in facts such as those in *ABC*; why add a new legal duty in negligence?<sup>14</sup>

Prof Laurie discussed the recent UK Supreme Court case of *Robinson v CC W Yorkshire Police*,<sup>15</sup> which he wondered might '**stop the runaway train**' of creating new duties of care. The third arm of the *Caparo*<sup>16</sup> test (the fair, just and reasonable arm of the test) raises concern that it is being used as a catch-all to extend the duty of care. As the Supreme Court judged in *Robinson*, this is not a correct view of the law: one needs precedent or sound analogy to bring the law forward. In *ABC*, what analogies might hold? In the Court of Appeal decision, Irwin LJ cited *Bolitho*<sup>17</sup> and *Bolam*, which Prof Laurie argued are not analogous: these were precisely about the thin view of autonomy; *ABC* is more about professional discretion in the face of competing interests. As to accurate analogies, Prof Laurie suggested that perhaps these could be found in child abuse cases where parents are wrongly accused. The courts have said that the first duty of care owed by social workers is to the child, not the parents who might be indirectly affected by the decisions. Thus, it remains unclear what analogies would work in the genetics context.

Prof Laurie raised several questions to consider if a duty of care were to hold. These included: what would count as genetic information? What kind of duty is at stake: to protect, warn/disclose, or even to hunt for information? What does this precedent look like if actually accepted? Is it just about the genetic context, or is it about various forms of knowledge about known levels of risk to identified third parties? Where do human rights fit within this? Human rights should *not* have been so easily glossed over as they were by both courts in *ABC*. The High Court and Court of Appeal in *ABC* did not engage in the distinction between the common law duty of confidentiality and the European Convention of Human Rights (ECHR) Article 8 right to respect for private life, including the conceptual basis for the right not to know. Prof Laurie argued that any such 'right' – better seen as an interest in not knowing – is a matter of respect for private life and not simply an autonomy issue. Also, what is the harm? *ABC* is not necessarily a wrongful birth case,<sup>18</sup> as the child has not been tested for Huntington's disease, so why did *ABC* move right into the third part of the *Caparo* test?

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<sup>14</sup> On this point, some participants queried whether this is a reflection of the fact that confidentiality was not breached in the case; a claim by the father *if* his genetic information had been disclosed would have been brought as an action for breach of confidence, not as an action in negligence. Prof Laurie agreed the current action of breach of confidence is not absolute and allows for lawful disclosures either with consent or in the public interest. Indeed, in the human rights era, a disclosure could be justified as necessary and proportionate to protection the rights and interests of others (ECHR Art. 8(2)). Where he disagreed with some of the participants is that they seemed to interpret his statement about 'robust professional behaviour' as only applying because confidentiality was *not* breached. Prof Laurie stated that an action for breach of confidence allows disclosure in the above circumstances, so long as it can be fully and robustly justified, and it would serve as a defence. For him, then, there is no need to take the further step of introducing a new duty to disclose.

<sup>15</sup> *Robinson v Chief Constable of West Yorkshire Police* [2018] UKSC 4.

<sup>16</sup> *Caparo Industries plc v Dickman* [1990] UKHL 2, [1990] 2 AC 605.

<sup>17</sup> *Bolitho v City and Hackney HA* [1996] 4 All ER 771.

<sup>18</sup> On this point, some participants were of the opinion that *ABC* is sufficiently analogous to the wrongful birth case of *Rees v Darlington Memorial Hospital NHS Trust* [2003] UKHL 52.

Ultimately, Prof Laurie argued that improved professional training and education are needed in the genetics area about the nature and limits of legal duties and professional discretion, but it is **inappropriate to extend a HCP's duty of care to genetic relatives**. Extending a duty of care in this area is a 'runaway train', setting up a conflict in law (confidentiality versus duty of care) that should remain in professional practice and ethics alone. We are talking about a discretion, rather than a duty, when the balance is being made by medical professionals. There are hanging, arguable points in *ABC* following the Court of Appeal decision, so there is a strong need for this to go to the High Court and avoid legal limbo.

Questions from the symposium participants considered, among other issues:

- Does the current legal uncertainty leave space for professional guidance to be developed?
- Where is the place of 'pure omission' in professional guidelines? Pure omission liability seems to be at play here, and would be a retrospective imposition of liability on the HCP.
- Some participants wondered whether the reference in the *ABC* Court of Appeal decision to 'future patients' could serve as both a demarcation of the class of potential plaintiffs (floodgates) and a way to satisfy the fair, just, and reasonable requirement under *Caparo*.
- *ABC* is set up as a conflict of autonomies, but there are other values at stake (human rights, family interests, etc.). This could have the effect of setting up conflicting duties for HCPs in law as well as in practice. Even though autonomy appears to be underlying *ABC*, it is not actually raised in argument (likely because the sum of recovery would only be nominal, whereas a breach of duty of care in negligence attracts much more compensation).
- Professional guidance already recognises a public interest exception in confidentiality and this is allowed in the case of serious risk of harm. Clearly there is a public interest in disclosing (serious) risk information to genetic relatives, but this can be accommodated within existing professional guidance frameworks. There is a risk in collapsing professional and legal obligations (confidence and negligence).
- Conversely, it was suggested by some participants that some professionals might welcome a legal duty to disclose as 'lawful permission' to breach confidentiality.
- It would be important for *ABC* to come back to the High Court and not be settled out of court, so that it can be fully tested whether a duty should be owed, or whether this can be achieved in the realms of professional judgement.
- Some HCPs lost confidence in their ability to exercise judgement after the High Court decision in *ABC*, out of fear of breaching confidentiality. That is, the strike out judgment of the High Court was seen as causing *professional uncertainty* – HCPs interpreted the decision as evidence that they did not have to apply professional judgement. This raised some discussion around whether 1) there is a lack of understanding of how confidentiality works – rather than about the need to create a new duty; and 2) whether law can be flexible enough to provide a proper solution or may exacerbate problems (e.g. duty of candour, which raises

an issue between professional and legal duties). Some participants thought that a ruling of non-disclosure feels 'heavier'; in some scenarios, having a legal duty would be helpful in providing clarity (provided the duty is contained).

- This is some concern that HCPs are 'fetishising' consent and relying on it in the context of confidentiality.

## Session 2

In the second session, **Prof Anneke Lucassen**, Professor of Clinical Genetics at the University of Southampton, observed in her presentation that new technologies are changing genetic practice, introducing it into many more areas of medicine, but that the situations where a single gene test will predict ill health with a high degree of certainty remain rare. For many common diseases, genetic factors known to be important in the aetiology of the disease, for example, offer at best only weak predictions of future ill health. Using a particular phenotype (be they signs, symptoms, or a family history of disease) can often be confirmed by analysing particular sections of the genetic code. However, the other way around, using a genotype to predict a future phenotype, works much less well, not least because it turns out we all have approximately half a million rare genetic variants, and 70-80 *de novo* variants.

As approximately 99.9% of the human genome is identical in all humans, Prof Lucassen queried if this could really be considered sensitive, personally identifying information. Surely this can only apply to the 0.1% differences between us? Within families, a greater proportion is shared: e.g. father and daughter share approximately 99.95% of their genome. So is the shared code confidential to the individual simply because it was first detected in them? Once a potentially shared predisposition to disease has been identified, who needs to know about it? This raises a broader question in law: is the traditional view of confidentiality applicable in genetics? Referencing her long-standing work with Prof Michael Parker at Oxford, Prof Lucassen advocates a '**joint information or joint account model**',<sup>19</sup> whereby we should assume that genetic information should be available to the joint account holders unless there are good reasons to do otherwise. The model would consider that the diagnosed person acts as a genetic 'beacon': we only know about the potential familial information because of them, but does it follow that information is then confidential to them? A joint account model turns the question of harm on its head. Instead of asking what is the harm from non-disclosure, it asks what is the harm of disclosure?

Prof Lucassen noted that the GMC guidelines on confidentiality in 2009 (which were applicable in the *ABC* case) stated that doctors may override a patient's consent to disclose health risks to other persons if the failure to do so leaves others at risk of serious harm, and that for the first time they specifically mentioned genetic findings as a potential reason to breach confidentiality without consent. Illustrating the confusion between confidentiality and negligence alluded to above, Prof Lucassen highlighted that a press release from the GMC themselves that framed this as a duty to disclose. These

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<sup>19</sup> See e.g. Michael Parker and Anneke Lucassen, 'Genetic information: a joint account?' (2004) 329 *BMJ* 165; Anneke Lucassen and Michael Parker, 'Confidentiality and sharing genetic information with relatives' (2010) 375 *The Lancet* 1507-1509.

guidelines recommend that in certain circumstances, HCPs should disclose relevant information to relatives even if consent is not possible, if it is seen as being in the public interest (e.g. not disclosing the information would expose others to risk of death or serious harm). The guidelines add that attempts should be made to communicate the information only, and not the identity of the 'genetic beacon'.

Prof Lucassen queried whether it is possible to separate confidential clinical information from shared familial information to facilitate certain data usages. She stated that HCPs do not have to disclose a clinical diagnosis or details, but instead can suggest to relatives the existence of a heritable condition so that they can be tested should they wish. In the *ABC* case, the doctors could have kept her father's clinical diagnosis confidential, yet told the daughter that the information she already knew (her father's deteriorating physical and mental health and a family history of dementia) could be due to a heritable condition, and the route to find out more. The Joint Committee on Medical Genetics' guidance on consent and confidentiality from 2011<sup>20</sup> includes a model consent form outlining a presumption that clinical genetic services will sometimes need to use genetic information in the care of family members. This has been used in the South of England since 2004 with very few reported issues; unfortunately, other services have amended the national form, so that practices are now varied across the UK.

Prof Lucassen noted that empirical research suggests there is a discrepancy between patient and professional views about this. Patients distinguish the impact of a (genetic) condition on their daily life (seen as personal, private information) and familial knowledge of the mutation and presence of condition, which they view as familial information (and knowledge). HCPs, though, see the two as overlapping and align strongly with the idea of consent: they are generally hesitant to disclose genetic information to relatives absent explicit consent from the patient.

Prof Lucassen argued that patients often agree to allow information to be shared with relatives if they understand what is at stake. In fact, it is more often the difficulty in communicating that is the issue than a refusal to do so. She added that sometimes patients have no objections to the HCP communicating with family members directly. Even where patients refuse, she argued that it is **good practice for HCPs to alert relatives (where sufficient details are known to do so) where such sharing would enable treatment and much better prognosis**. This might be done for example, by contacting the relative's GP to help with such communication. Even with new technologies, the number of cases where the information is sufficiently predictive, and where there are no other means for relatives to discover their risk, will remain very small.

Questions from the symposium participants considered, among other issues:

- Professional guidance is framed as a defence around disclosure, rather than a duty. Should we not be promoting this rather than creating a new duty in law?

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<sup>20</sup> Joint Committee on Medical Genetics, *Consent and confidentiality in clinical genetic practice: Guidance on genetic testing and sharing genetic information* (2011), available at [http://www.bsgm.org.uk/media/678746/consent\\_and\\_confidentiality\\_2011.pdf](http://www.bsgm.org.uk/media/678746/consent_and_confidentiality_2011.pdf).

- Why should we not just encourage better training of HCPs?
- Consent seems to be used as a catch-all to prevent disclosure; clinicians often forget they *can* breach confidentiality in appropriate cases and so long as this can be justified in the public interest. Some participants responded to this point that Nicol J accepted in the High Court that this was not a case of public interest, but rather the private interest of the claimant (paragraph 13).
- There is a (legal) distinction to be made between a 'right not to know' versus an interest in not knowing.
- There remains a lack of empirical work in court decisions (the law is always reaching always for fictitious persons). Why do the courts rarely, if ever, acknowledge this growing body of empirical work? How does empirical data link in with the law?
- Given a soft duty of care already exists in practice, would it make a huge difference if law formally recognises this?
- Where does one stop with the disclosure to relatives? There is a cascade approach, whereby the HCP starts with immediate family, then works out to their immediate family (depending on several factors, including the ability to trace relatives and the disease in question).
- How much of this discussion surrounding duty of care is rooted in a risk-centred paradigm? Is this likely to change if another quality or parameter is at the centre of discussion such as human rights or privacy?
- Precision medicine seems to be encouraging notions of individual consent and confidentiality, but genomics seems to pull in the opposite direction, towards group consent and shared information.
- What if *ABC*'s father was deemed to *not* have capacity at the time he refused to share his diagnosis with his daughters?
- The claim in *ABC* is not a wrongful birth claim on the grounds of the daughter's pregnancy possibly being affected, but rather that because had *ABC* known she had inherited HD, she would not have continued with her pregnancy in the knowledge she would not be able to parent the resultant child till adulthood (she is likely to develop symptoms of HD over the next few years).
- There is a potentially significant difference between disclosing clinical data about a patient and disclosing just the genetic information that is inherently shared with and, arguably, 'belonging to' the relative, too. Relatedly, language in this area is significant: 'access' and 'sharing' have very different connotations.
- What do we mean by genetic information or genetic diagnosis? Sometimes this is the result of analysis of genetic material, but sometimes it is inferable from a patient's symptoms or phenotype.

### Session 3

Leading off the third and final session, **Dr Vicky Chico**, Lecturer in Law at the University of Sheffield, considered **reasonable expectations of privacy in the non-disclosure of familial genetic risk**, asking what is reasonable to expect in such scenarios. Is there a role for the 'reasonable expectation of privacy' test? What would this entail?

Stemming from her recent work with Prof Mark Taylor,<sup>21</sup> Dr Chico noted that the importance of *informed* consent in protecting patients from a breach of confidence is not well defined, given the relative paucity of case law dealing with breach of patient confidence. However, it is clear that consent is only one of the grounds for negating an action in breach of confidence (along with statutory authority and overriding public interest concerns). It is not clear, though, whether a consent which negates an action in breach of confidence needs to be underpinned by the level of information that would traditionally be required for an informed consent to medical treatment or research. In any event, there is a turn away from traditional notions of informed consent to notions of privacy, which have been fueled by the implementation of (European) human rights law.

The relative paucity of legal discussion of the informational requirements of a valid consent might be because many of the leading cases on breach of confidence focus on justifications *other than* consent. Furthermore, there may be an assumption that the law here simply mimics the requirements of a valid consent in other areas. Can we obtain a valid consent to the disclosure of confidential patient data, such that this disclosure would not amount to a breach of the common law duty of confidentiality, having provided less information than would typically be associated with an 'informed consent'?

The HCP is able to rely on implied consent when sharing confidential patient information for direct care, as long as the patient does not object (see 'Caldicott 2' – the [Information Governance Review](#)<sup>22</sup>). Although most people are unlikely to object to sharing patient information for direct care, they are unlikely to have been given detailed information about the flows of this confidential patient information.

The National Data Guardian (NDG)<sup>23</sup> advises and challenges the health and care system to help ensure that citizens' confidential information is safeguarded securely and used properly. Implied consent is often invoked, but as it is now harder to prevent information collected for one reason to be used for another, so it is more difficult to rely on a notion of implied consent for direct care (people simply may not be aware). Indeed, the concept of implied consent might not be a suitable legal basis to support new

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<sup>21</sup> Victoria Chico and Mark J Taylor, 'Using and disclosing confidential patient information and the English common law: What are the information requirements of a valid consent?' (2018) 26 *Medical Law Review* 51-72.

<sup>22</sup> Caldicott review, *Information: To share or not to share? The Information Governance Review* (2013), available at: <https://www.gov.uk/government/publications/the-information-governance-review>.

<sup>23</sup> National Data Guardian, available at: <https://www.gov.uk/government/organisations/national-data-guardian>.

models of care. Legally, non-disclosure weighs more heavily; absence of consent acts as a veto and stops consideration of any reasons or potential benefits for disclosure.

Dr Chico suggested that **we can justify in law genetic information disclosure to genetic relatives without the need for consent**. Indeed, the EU's General Data Protection Regulation (GDPR) is moving us away from consent as a lawful basis for sharing personal information. The UK's National Data Guardian has considered whether 'reasonable expectations of privacy' could replace implied consent. The decision in *R (on the application of W, X, Y, and Z) v Secretary of State for Health*<sup>24</sup> confirms that **there are some circumstances where the patient cannot reasonably expect his or her privacy to be maintained under an obligation of confidence, even though the information was imparted in the context of the clinician-patient relationship**. Even though there was no explicit refusal in *W, X, Y and Z*, this case indicates that a patient's refusal to consent to disclosure might not automatically require a clinician to maintain confidence, but rather that a patient's refusal might only require protection where it reflects a 'reasonable expectation of privacy'.

Nevertheless, evidence suggests that geneticists and genetic counsellors may find it difficult to disclose when the patient objects. It is also difficult for practitioners to make the decision to disclose when the legal duties are weighted against that, as is the case currently with the prioritisation of the legal obligation to maintain confidence. There is value then in looking at the professional balancing exercise between the interests of the patients and of the family. How would this be determined? Dr Chico said that empirical evidence suggests patients do not see the genetic information as private and believe a more familial approach should be taken. The 'common view' is that this is shared information and that patients are obligated to share it.

But what happens when someone refuses to share? If evidence suggests that patients of ordinary sensibilities would share and the test is based on whether an individual can be said to have a reasonable expectation of privacy, a refusal to share may be deemed to reflect an 'unreasonable' expectation of privacy. As the NDG continues its consultation work on reasonable expectations in relation to uses of confidential patient information, it might consider how to interpret a refusal to allow uses of information which appear to be in opposition to the objective position on what can be reasonably expected. Empirical evidence around the norm would make a refusal *prima facie* unreasonable, but it would be rebuttable. This might require the law to enquire into the reasons for an ostensibly unreasonable choice. Dr Chico recognised that this was not the usual approach in English law, which typically does not enquire into reasons behind consent to treatment. Where a legal test is based on reasonableness, the basis for this test is in objective interpretation of the relevant standard of conduct. Where an objective position is determined that there cannot be a reasonable expectation of privacy (as in *W, X, Y and Z*), a refusal to share therefore presumably reflects an unreasonable expectation of privacy. It may follow that this does not require legal protection where the test is whether the expectation of privacy is reasonable.

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<sup>24</sup> *R (on the application of W, X, Y and Z) v Secretary of State for Health* [2015] EWCA Civ 1034 (CA).

However, if where a person refuses to share in circumstances where the objective position is that most patients would support sharing and forgo their confidentiality, they should be able to rebut the position that their expectation of privacy is unreasonable, for example by demonstrating the reasonableness of the expectation in the circumstances. The circumstances of the particular non-disclosure will be an aspect of determining the reasonableness of a particular non-disclosure. However, the patient's reasons for choosing not to disclose will also be a factor in determining the reasonableness of that choice.

As stated, English medical law does not traditionally examine the reasons behind decisions – choices are respected whether they are rational, irrational, or non-existent. However, this position relates to choices to run risks that do not affect third parties. The legal protection of decisions whether or not to undergo medical treatment is not based on their reasonableness, making the reasons for the decision irrelevant. However, where the reasonableness of the decision is relevant for its legal protection, the reasons for the decision become relevant – but this is new territory for English medical law.

Dr Chico offered an example from Clark et al.'s study in 2005 that in 40,000 consultations with genetic information disclosed to families, there were only 65 non-disclosures, and privacy was cited only in 6 of those 65 as the reason for non-disclosure.<sup>25</sup>

Evidence suggests that in many cases where a patient refuses to share genetic information with at-risk relatives, their reasons for doing this are not to protect their privacy, but one of a multitude of other reasons. There could be several reasons provided for non-disclosure, including: practical reasons (e.g. loss of contact, distance, relationship issues), protecting relatives (i.e. concern that the information would cause relatives anxiety), and preventing choice (as in the *ABC* case, the choice here whether to abort the foetus).

Dr Chico argued that where protection of privacy is the reason for the non-disclosure, the transmission of the genetic information should be considered an infringement of a patient's right to privacy only if: (i) he or she has a reasonable expectation of privacy in the information and (ii) the balancing exercise comes down against disclosure. A breach of the fundamental privacy right will not be established unless both (i) and (ii) are satisfied.

Dr Chico concluded by stating that she is not downplaying the importance of privacy, but rather wanted to highlight the reliance on privacy to protect other interests which might be better protected than they currently are in law. With adequate resources and support, patients might change their position on non-disclosure. The removal of the legal incentive to protect privacy as a matter of personal choice by incentivising the obligation of confidence over that of disclosure (even where the clinician favours disclosure) may help clinicians to explain their rights to patients and help them in persuading a consensual disclosure. This shift to equally recognise the interest in

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<sup>25</sup> Angus Clarke et al., 'Genetic professionals' reports of nondisclosure of genetic risk information within families' (2005) 13 *European Journal of Human Genetics* 556–562.

disclosure could mark a **culture shift in favour of disclosure** which in itself may diminish choices not to disclose.

**Dr Michael Fay**, Lecturer in Law at Keele University, immediately followed Dr Chico's presentation (group discussion was saved until the end of the third session) and ended the session by discussing how a court might craft a duty of care owed to genetic relatives, based on a *Caparo* test, i.e. 1) reasonable foreseeability of harm; 2) proximity, and 3) it would be fair, just, and reasonable to impose a duty.

First considering the arm of 'reasonably foreseeable harm', Dr Fay noted that the threshold a claimant must meet is not generally demanding: *Page v Smith*.<sup>26</sup> That said, reasonable foreseeability was not fleshed out in *ABC*; the query is generally broad but the defendant must foresee the general type of damage. Various harms were alleged in *ABC* – wrongful birth, psychiatric injury (but would need recognised illness), economic loss (not always recoverable). In *Montgomery*, Lady Hale suggested that autonomy was part of physical/psychiatric integrity, but does this have to be shown to have been breached to claim? The only harms recognisable in law are clinical and material (including economic), so there is as yet no duty to disclose non-clinically actionable information.

Looking at case law on the duty of care in tort/delict more generally, Dr Fay argued that *ABC* does not fit the above test. There was no evidence the child is disabled, so the case does not fit in a classic wrongful birth scenario (genetic predisposition may not be a 'disability'). The closest analogy is that the harm was undisclosed risk, but this was not invoked. At issue with Huntington's disease is that we are talking about impacts on reproductive choices or limitation of its freedom rather than personal 'harm' within the negligence paradigm. Dr Fay posited that there is a 'spectrum' of reasonably foreseeable injuries, ranging from the outcome of undisclosed risk (*Montgomery v Lanarkshire*<sup>27</sup>), the manifestation of preventable medical condition (*Gregg v Scott*<sup>28</sup>), the birth of a child with a hereditary disease (*Farrar v King's Healthcare NHS Trust*<sup>29</sup>), to the birth of disabled child (*Parkinson v Seacroft University Hospital NHS Trust*<sup>30</sup>).

Regarding the proximity arm of the *Caparo* test, Dr Fay stressed that it is difficult to pin down the limits of proximity. An 'identifiable victim' is found in US case law (e.g. *Tarasoff v Regents of Uni. of California*<sup>31</sup>) – and this could reasonably be first-degree genetic relatives. In the UK, proximity has been used as a way to prevent extensive liability (*Alcock v CC South Yorkshire*<sup>32</sup>). UK case law suggest there is some need for the 'victims' to be identifiable individually and not merely a class of persons. Dr Fay wondered if there might be tripartite liability: the tortfeasor, a primary victim, and secondary victim, where the secondary victim has a close blood tie with the primary victim (such as parent-child). He posited that genetic links are less likely to engage

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<sup>26</sup> *Page v Smith* [1996] 1 AC 155.

<sup>27</sup> *Supra* n 12.

<sup>28</sup> *Gregg v Scott* [2005] UKHL 2.

<sup>29</sup> *Farrar v King's Healthcare NHS Trust* [2009] EWCA Civ 1203 (CA).

<sup>30</sup> *Parkinson v Seacroft University Hospital NHS Trust* [2001] EWCA Civ 530 (CA).

<sup>31</sup> *Tarasoff v Regents of Uni. of California*, 551 P2d 334 (Cal 1976).

<sup>32</sup> *Alcock v Chief Constable of South Yorkshire Police* [1991] UKHL 5, [1992] 1 AC 310.

floodgates arguments than in the case of psychiatric injury, where the courts require the secondary victim to have a close tie of love and affection, and witness the shocking event or its immediate aftermath and with unaided senses.

Dr Fay queried if public interest favours disclosure in genetic disclosure cases. Which public interest(s) is/are in play: the utility of genetic information, the prevention of harm, the prevention of the spread of disease? Dr Fay queried also if Art. 2 ECHR (the right to life) means that known risks lead the NHS to have a duty to warn and advise. In *X v United Kingdom*,<sup>33</sup> the European Court of Human Rights considered the duty to the State under Art. 2 ECHR to include the provision of adequate and appropriate healthcare (this was not defined in the case). And in *LCB v UK*,<sup>34</sup> the European Court of Human Rights suggested that the State could be required to take steps to warn and advise of risks to as yet un-conceived children.

Ultimately, the crafting of a new duty of care owed to genetic relatives would have to fulfil the *Caparo* test, or in light of the decision in *Robinson*,<sup>35</sup> would need strong precedent or sound analogy to bring the law forward. Dr Fay expressed some hesitancy as to whether a duty of care, at least in the 'strong' form as charted by Prof Mulheron, would achieve all three arms of the *Caparo* test or find sound analogy in other relevant areas of the law.

Questions from the symposium participants considered, among other issues, raised by both Dr Chico and Dr Fay's presentations:

- What if the father in *ABC* had not been told the information about his diagnosis and implications for genetic relatives? The father is then the primary victim. Could his daughter claim secondary victim status as suffering from nervous shock if she and the father found out about the diagnosis, and, thus, be a successful third party genetic relative claimant, where the *Alcock* criteria are able to limit the number of claimants? This hypothetical, however, does not articulate the legal harm that is being suffered. Usually the language of primary and secondary victim arises in economic loss cases. What are the harms in this scenario?
- How much do doctors pay attention to matters of autonomy, privacy, confidentiality as legal concepts when they make clinical decisions?
- Might *ABC* be seen as another example of a 'loss of autonomy' case, akin to the conventional award given by Lord Bingham in *Rees*? It is not a classic wrongful birth case; at best, the mother can argue that she is disabled because of Huntington's disease (akin to *Rees*), and the actual harm is one of being deprived of the ability to choose a different future if she had known.
- What kind of precedent is this going to be? Otherwise, what actions would be required to discharge the duty?

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<sup>33</sup> *X v the United Kingdom*, Application No 8416/78, (1980) 9 DR 244.

<sup>34</sup> *LCB v United Kingdom* [1998] ECHR 108, (1998) 27 EHRR 212.

<sup>35</sup> *Supra* n 15.

- When would the duty be triggered: just by having knowledge, and if more, what more would be required?

## Conclusion

The symposium then concluded with a discussion of ‘where next for law, policy and practice?’ Discussion revolved around the following issues:

- There are multiple factors regarding the question of the scope of ‘what should be included?’ in a disclosure, including:
  - Which kind of professionals would be included under a duty of care (i.e. not just geneticists, but GPs, and perhaps also clinician-researchers and maybe even pure researchers)
  - What kinds of information / potential impacts? Only genetic information? Only monogenic highly predictive information, or also less predictive susceptibility information?
  - Which relatives (how remote? In practice, it is step-by-step, i.e. close relatives only, and further contact would be on the basis of *those* relatives’ test results, etc.)
  - Which harms? Physical harms? (that are not strictly caused by non-disclosure), loss of a chance of a better outcome?, loss of autonomy? Psychiatric injury? Economic harms (e.g. a new class of wrongful birth).
- There seemed to be a mood amongst some of the participants to deflate the ‘floodgates’ fears, i.e. it would be possible to make meaningful distinctions and resource anxieties are belied by clinicians’ reluctant responses to what they would do even if given more resources. At the same time, there was also recognition that with (a) increasing power of genomic analysis, (b) the blurring between treatment and research, and (c) biobanking, the implications are potentially vast.
- A question arises as to how to ‘alert relatives appropriately’. This means not only whether to tell, but *how* to tell. Some participants emphasised that feared harms could be averted by sensitive communication and that perhaps attempts to persuade patients of the value of telling cannot always be a one-off event, but may need to be a process.
- This issue is very unlikely just to arise in clinical care or in patient/doctor relationships or even to be just about the duty to tell relatives – it has implications for all contexts of genetic information disclosure, including in biobanking.
- Many participants thought that a clearly stated policy of non-disclosure might not be sufficient on ethical or legal grounds. Some also thought that it is difficult for clinicians to rely on professional guidance if the law seems to be strongly weighted towards liability for failure to respect patient confidentiality, thus incentivising non-disclosure. Thus, some argued that we need a legal ‘duty to protect’ to give clinicians the confidence to do legitimate and necessary weighing of confidentiality versus disclosure. Others, however, questioned the need to turn to new law when we have perfectly good public interest exceptions in the

common law duty of confidentiality. A question arose as to how public interest would be construed or constituted in this context. Must it be the protection of public health, preventing material harm or saving lives, or could it be understood more expansively (e.g. to facilitate better informed reproductive choices)?

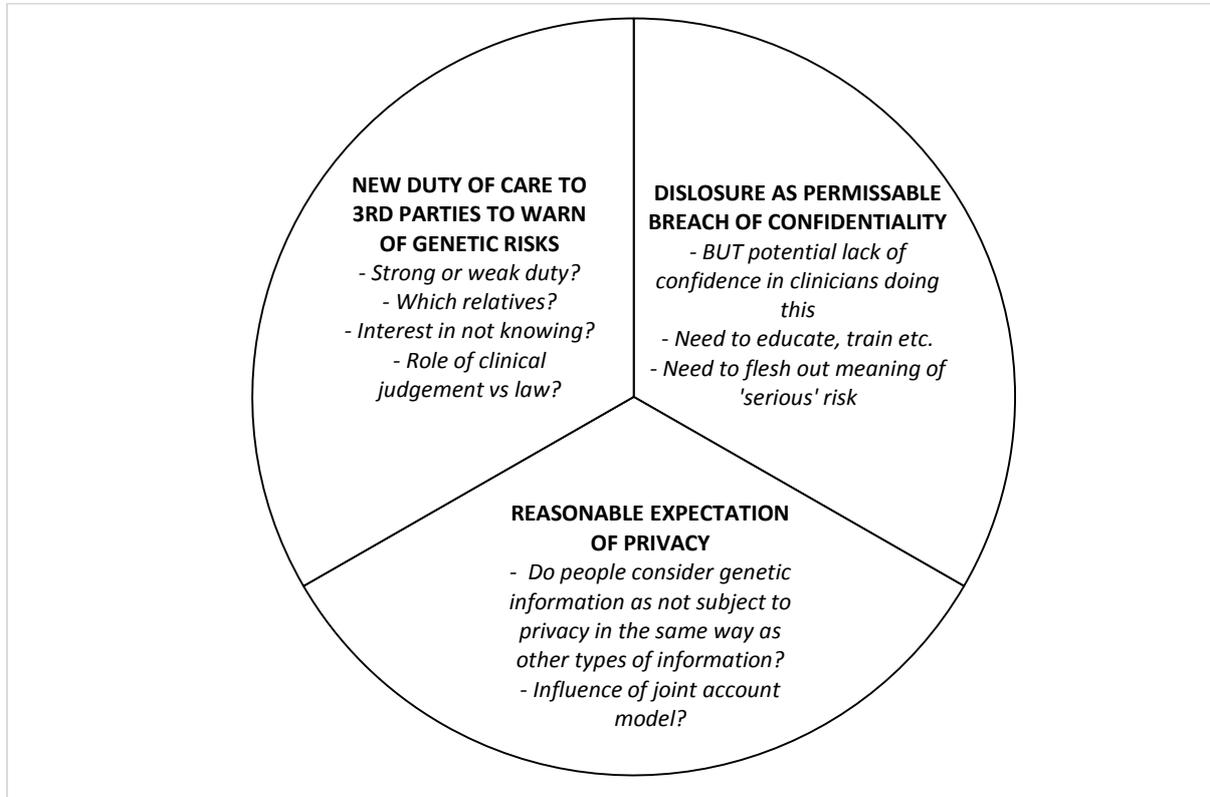
- Protection of autonomy is increasingly prevalent in the jurisprudence as a possible harm to be avoided by disclosure, but...
  - Why? Some argued it is attributable as a trend in law and in medical ethics (e.g. *Chester, Rees, Montgomery*). Moreover, it is a thin and impoverished conception of autonomy, often not articulated further by judges and even if it is, it is often connected only to making choices and usually clinical choices (as contrasted with autonomy as the wider capacity to determine the course of one's life in light of one's values).
- Some participants thought that the 'right not to know' is over-emphasised: there are possible harms from knowing, but we need to take the harms from not knowing just as seriously. Also, the language of a 'right' not to know may not be helpful; if one speaks instead of an interest in not knowing, this becomes more of a balancing interests of all considerations and less an exercise in finding a trump right-type claim.
- Participants were keen to dispel the myth that by suggesting genetic testing to someone, one inevitably effects *de facto* disclosure. This is misplaced – it may sometimes be possible to open the discussion without disclosing genetic information about a patient.
- Genetic information presents challenges to concepts of harm because unlike infectious disease, it is already 'transmitted' to relatives. In other words, physical harms from genetic disease are not a matter of negligence per se.
- Some participants argued that there could be information that relatives really want to know about and have non-trivial reasons for doing so, without it being clinically actionable, or even actionable at all. This is not necessarily reducible to psychological preparedness for disease either, e.g.
  - A thicker conception of autonomy
  - Reproductive autonomy
  - Planning parenting (or avoiding parenting)
  - Self-conception

Indeed, patients may have their own conception of what counts as actionable that may not accord with clinicians' views.

- Overall, the symposium discussion moved quite a long way from a specific duty of care in negligence law to a more general discussion of the contours of a legal duty – potentially under a public interest exception to maintaining confidentiality, and possibly grounded in human rights.

The participants concluded the day-long discussion by conceiving three potential ways forward in this area, as pictured below (courtesy of Ruby Reed-Berendt).

**Figure 1. Ways forward in crafting a HCP's duty to disclose genetic information to genetic relatives.**



The symposium participants agreed to work on several academic and policy outputs in the coming months to flesh out these possibilities.

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**Appendix 1: Symposium participants**

Edward Dove <i>(symposium organiser)</i>	Lecturer in Law, University of Edinburgh
Graeme Laurie	Professor of Medical Jurisprudence, University of Edinburgh
Rachael Mulheron	Professor of Tort Law and Civil Justice, Queen Mary University of London
Anneke Lucassen	Professor of Clinical Genetics, University of Southampton
Vicky Chico	Lecturer in Law, University of Sheffield
Michael Fay	Lecturer in Law, Keele University
Agomoni Ganguli-Mitra	Chancellor's Fellow, University of Edinburgh
Sarah Chan	Chancellor's Fellow, University of Edinburgh
Nayha Sethi	Chancellor's Fellow, University of Edinburgh
Emily Postan	Early Career Fellow in Bioethics, University of Edinburgh
Annie Sorbie	Lecturer in Law, University of Edinburgh
Gerard Porter	Lecturer in Law, University of Edinburgh
Catriona McMillan	Online Content Developer/Support Tutor in Law, University of Edinburgh
Murray Earle	Online Content Developer/Support Tutor in Law, University of Edinburgh
Nasser Al-Azri	LLM Medical Law and Ethics candidate, University of Edinburgh
Ruby Reed-Berendt	LLM Medical Law and Ethics candidate, University of Edinburgh
Gabriel Muñoz-Cordal	LLM Medical Law and Ethics candidate, University of Edinburgh
Lydia Shotton	LLM Medical Law and Ethics candidate, University of Edinburgh
Hen Dyson	LLM Medical Law and Ethics candidate, University of Edinburgh
Hannah Nicholls-Harrison	LLM Medical Law and Ethics candidate, University of Edinburgh