

# ABC v St George's Healthcare:

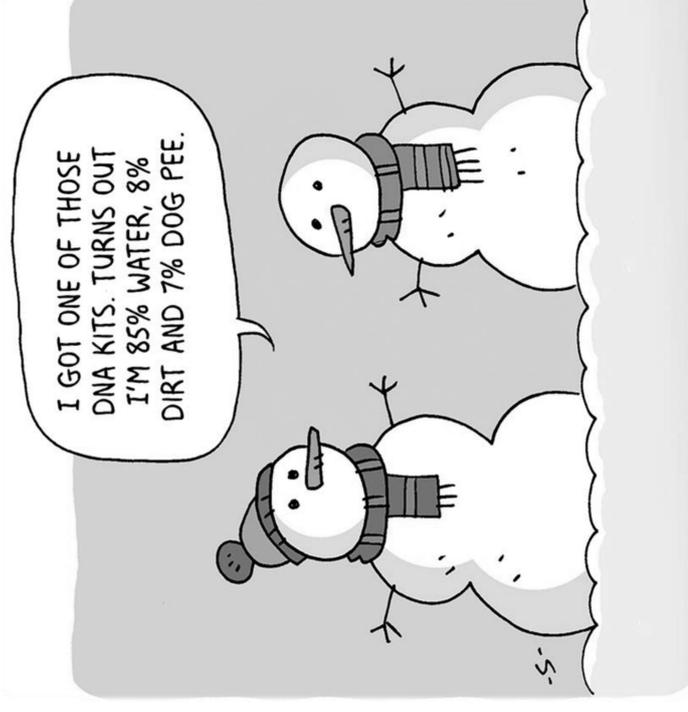
## where might we go next?

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# Overview

- ▶ The Crux of the Problem
- ▶ ABC in the Courts
- ▶ Where do we go next?
- ▶ Possible Outcomes



# Brit DNA breakthrough will save thousands of kids from killer diseases

EXCLUSIVE: A new screening for babies is poised to achieve a world first and allow early treatment for life-threatening conditions

## DNA breakthrough: Revolutionary healthcare could save thousands of newborn babies

NEWBORNS will have their DNA tested at birth by the NHS for free, starting next year.

# The Crux of the Problem

- ▶ Joint Committee on Medical Genetics:
  - ▶ “Whilst **genetic information is relevant to an individual**, as noted, **it may also be relevant to that person’s family** because much genetic information will be common to both. Indeed, genetic testing may only be requested because of wider knowledge about a condition within a family.”
- ▶ Traditionally, law about keeping information private/confidential

# ABC v St George's Healthcare:

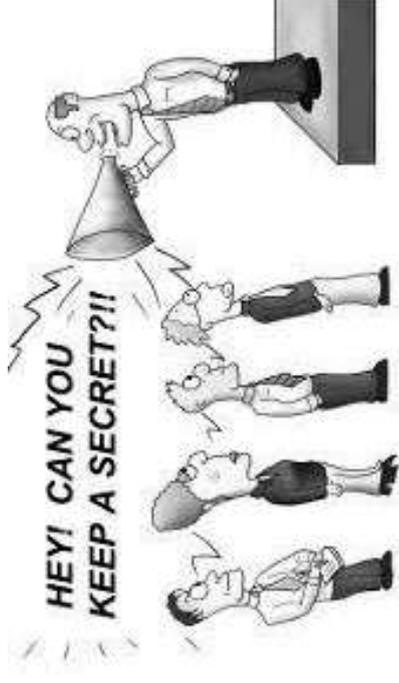
- ▶ 2007 – Claimant's father (F) shot and killed Claimant's mother. Convicted of manslaughter on grounds of diminished responsibility – sentenced to a Hospital Order under MHA 1983.
- ▶ 2009 – suspected he was suffering from Huntington's Disease and he was referred to St George's Hospital; November 2009 – confirmed that F did indeed have Huntington's Disease.
- ▶ Because of genetic origin of HD, various health professionals sought F's consent to disclose the diagnosis to his daughter. F refused to allow the medical staff to tell his daughter about this diagnosis. Claimant was pregnant at this time.

# ABC v St George's Healthcare:

- ▶ Claimant's daughter was born in April 2010. In August 2010, Claimant accidentally told by one of her father's doctors that he had Huntington's Disease. In January 2013, Claimant diagnosed with HD.
- ▶ Claimant alleged failure to tell her of her father's condition was actionable negligence on the part of the Defendants.
  - ▶ Pleading: had she been informed of father's condition, she would have undergone testing. Once that showed positive, she would have terminated her pregnancy.
- ▶ She argued suffered psychiatric damage because of the Defendant's failure to inform her, and, if her daughter does have the disease, the Claimant says she will also incur additional expense which would otherwise have been avoided.

# The Relevant Law: Confidentiality

- ▶ '[a] doctor is under a duty not to disclose, without the consent of the patient, information which he, the doctor, has gained in his professional capacity.'
  - ▶ *Hunter v Mann* [1974] QB 767, per Boreham J at 772
- ▶ Unless:
  - ▶ Patient consents
  - ▶ Authorised by Law (e.g. Terrorism Act 2000)
  - ▶ It is in public interest
  - ▶ Confidentiality can be 'outweighed by some other countervailing [public] interest which favours disclosure'

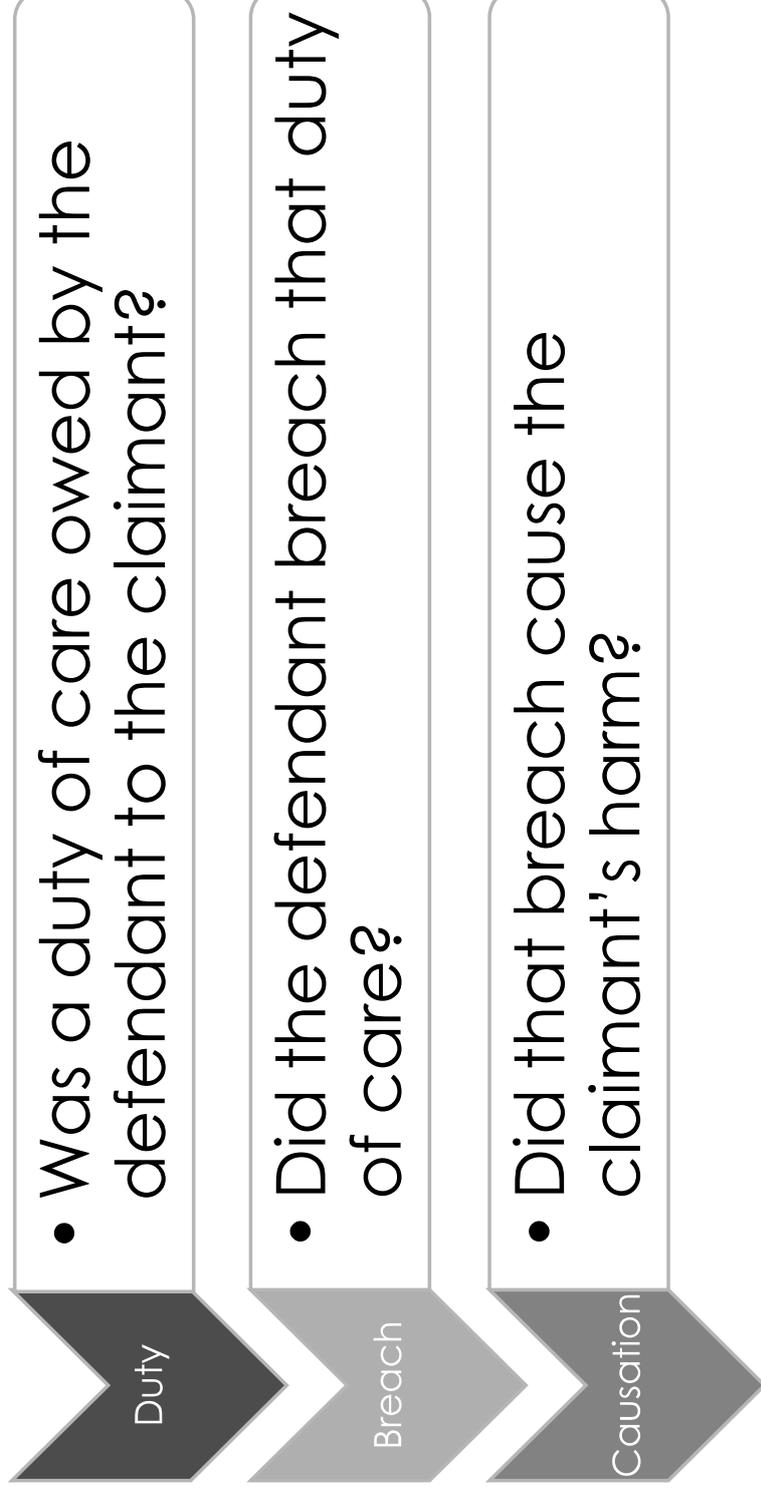


# Acting Within the Law

- ▶ GMC: Confidentiality – Good Practice in Handling Patient Information
  - ▶ Doctors, like everyone else, must comply with the law when using, accessing or disclosing personal information. The law governing the use and disclosure of personal information is complex, however, and varies across the four countries of the UK.
  - ▶ In the legal annex to this guidance, we summarise some key elements of the relevant law, including the requirements of the **common law, data protection law and human rights law**. In the main body of the guidance, we give advice on how to apply ethical and legal principles in practice, but we do not refer to specific pieces of law unless it is necessary to do so.

# The Relevant Law: Negligence

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# A Duty of Care

- ▶ A Duty is established if:
  - ▶ A defendant actually or reasonably foresees that failure to exercise reasonable care might cause some type of harm to the claimant, or class of persons of whom claimant is one.
    - ▶ Risk is reasonably foreseeable if more than mere possibility
  - ▶ Defendant and Claimant are proximate or “neighbours”, meaning claimant in defendant’s reasonable contemplation when acting
  - ▶ It is fair just and reasonable to impose a duty (public and legal policy)

# ABC: The High Court Judgment

1. Not a public interest in disclosure.
2. A doctor can disclose confidential information in certain circumstances.
3. Doctors would be subject to conflicting duties.
4. Will undermine the trust and confidence with patients.
5. If doctors owe a duty to third parties, it may result in doctors putting pressure on their patients to agree to disclosure.
6. Some third parties may not wish to receive information.
7. A third party may suffer psychiatric harm if they are told the information in question.
8. The duty would be burdensome.
9. Contrary to the incremental way the law of negligence ought to progress.

# ABC: Court of Appeal Judgment

- ▶ (1) Public or Private Interest?
  - ▶ Public interest in doctor/patient relationship must inhere confidence in way doctors approach their obligations to patients
  - ▶ Difficult to see how public confidence is necessarily improved if private law action is available to enforce only some professional obligations laid down in relevant professional guidance.
  - ▶ Where professional guidance allows a clinician to consider breaching patient confidentiality if the circumstances demand it, but public confidence not necessarily increased because patients could sue but person who needs the information could not.

## (1) Public or Private Interest (cont.)?

- ▶ It might logically be said that current law incentivises clinicians to play safe rather than take the difficult step of overriding patient confidentiality.
- ▶ Strong trend in clinical negligence, to emphasise autonomy of the patient. Arguable it is irrational to emphasise this whilst depriving a remedy to identified individuals about whom a doctor has specific information.

## (2) Confidence & (3) Conflicting Duties

- ▶ Self-evident that there is public interest in avoiding excessive litigation and in keeping to a minimum defensive medicine.
- ▶ Not necessarily correct, in a situation where patient confidentiality should be waived or, if necessary breached, that the common law should so clearly incentivise obligations in one direction.
- ▶ At least arguable that may encourage rather than diminish defensive medicine.

## (4) Undermining Trust and Confidence

- ▶ Possible that confidence in the doctor/patient relationship may be reduced if patient is aware confidentiality may be breached.
- ▶ Question the degree such loss of confidence may be affected by the existence of a common law duty to a “third party”, as opposed to any professional duty to disclose, which already exists
- ▶ Implicit message in Defendants’ reasoning: existence of a duty to “third party” may cause confidentiality to be overridden more often. Not self-evident. Any claimed liability would be tested by reference Bolam test qualified by the consideration that a professional decision must be a reasonable one.

## (5) Lead to pressure on patients to disclose

- ▶ It may be that the objection would be made out in some cases.
- ▶ However, premise of objection is clinicians will act self-protectively or “defensively” .
- ▶ It is not obvious that public interest or rigour of the common law is served by an incentive to act self-protectively only in one direction.

## (6) Not wanting to now & (7) Psychiatric Injury

- ▶ Evident the difficulties outlined in reason (6) and (7) already faced by clinicians.
- ▶ These problems arise in respect of such decisions whether or not legal liability exists towards the “third party”
- ▶ It is difficult to see how the extension of a legal duty of care affects this problem.

## (8) Burden

- ▶ It seems plain [from professional guidance] that this duty already lies on clinical geneticists. There is no basis on the material before us for considering that they are, or will be, distracted from treating their patients by this problem.



## (9) Incremental Development

- ▶ The question here is whether the difficulty of the geneticist already faced with such conflicting considerations identified in the relevant professional guidance requires to be protected from such a common law duty of care.
- ▶ Also: the ambit and content of the duty of care in such cases has long been a matter of common law, developed by judicial decision. If that were to cease to be so, the law would ossify in this area.

# Where do we go next?

- ▶ The High Court Part II
  - ▶ Full Trial
    - ▶ Claimant must prove all elements of negligence to make a claim
      - ▶ Duty (only whether it was fair, just and reasonable argued)
      - ▶ Breach (not argued at strike out)
      - ▶ Causation (not argued at strike out)

# The Importance of Legal Change

- ▶ No clear legal basis for disclosure
- ▶ If no clear legal basis on which to set confidentiality – and HCPs are acutely aware of their duty of confidence to their patients – professionals may feel anxious about acting on a discretion to disclose.
- ▶ Even if they believe discretionary judgement to be professionally correct, may still be concerned about whether it will be found legally correct.
- ▶ Coexistence of duties of confidentiality to patients and care to patients' relatives reflects the discretion that is afforded by professional guidance
- ▶ Professional guidance alone may not offer sufficient protection to give HCPs confidence to act against patients' wishes
- ▶ legal duty to protect interests of all parties involved, and ensure HCPs are protected from legal actions where they acted in accordance with ethical and professional good practice.

# The importance of legal change

- ▶ Public interest ground does not seem to provide adequate legal basis for modifying obligation of confidence in context of disclosure of genetic information to patient's relatives
- ▶ This is despite GMC guidance making clear protection of private interests is also a matter of public interest.
- ▶ In the High Court in *ABC*, Nicol J seemed to rule out the ability to rely on public interest as a legal basis for setting aside the obligation of confidence:
  - ▶ 'What was put against the public interest in preserving confidence in the present context was not a public interest in disclosure, but the private interest of the Claimant'

# Possible outcomes?

- ▶ High Court could:
  - ▶ Reject duty and, effectively, restate importance of confidentiality
  - ▶ Align with clinical guidance / duty to conduct a robust balancing exercise
  - ▶ Impose a weak form of duty to disclose
  - ▶ Impose a strong form of duty to disclose

# Restating Confidentiality

- ▶ Essentially keeping status quo:
- ▶ Only confidentiality legally protected
- ▶ Maintaining confidence incentivised regardless of professional guidance
- ▶ Would follow some European examples
- ▶ Could this encourage defensive practice?
- ▶ Unsatisfactory
  - ▶ Leaves doctors in uncertain position, caught between what the law says and what professional guidance allows.

# Align with Clinical Guidance?

- ▶ Court could align law with clinical guidance; i.e. *Montgomery* (2015)
  - ▶ Duty to comply with clinical duties?
    - ▶ Essentially, following clinical guidance would become minimum standard of care.
- ▶ Is there enough certainty in guidance?
  - ▶ might be read as suggesting that resolution of the disclosure dilemma is a merely discretionary matter, rather than a core part of a professional's obligations

# Align with clinical guidance

- ▶ Should guidance become minimum legal expectation?
  - ▶ Too strict?
  - ▶ Does it place limit on clinical discretion?
- ▶ Adv. Professional guidance recognises tensions between interests of patients and relatives and provides that it may be justified to breach confidence where the aversion of harm substantially outweighs confidentiality.

## “Consent and Confidentiality in Genetic Practice, Guidance on Genetic Testing and Sharing Genetic Information” (2006) RC.Path, BS Hum Gen

- ▶ 2.5.3 Where consent to release information has been refused:
  - ▶ The Human Genetics Commission, the Nuffield Council on Bioethics and the GMC have all expressed the view that the rule of **confidentiality is not absolute**. In special circumstances it may be justified to break confidence where the aversion of harm by the disclosure substantially outweighs the patient’s claim to confidentiality. Examples may include a person declining to inform relatives of a genetic risk of which they may be unaware, or to allow the release of information to allow specific genetic testing to be undertaken.
  - ▶ Before disclosure is made in such circumstances an attempt should have been made to **persuade the patient in question to consent to disclosure**; the benefit to those at risk should be so considerable as to outweigh any distress which disclosure would cause the patient; and the information should be anonymised and restricted as far as necessary for the communication of the risk.

# GMC: Confidentiality (2009)

- ▶ Confidentiality is central to the trust between doctors and patients. Without confidentiality, patients may be reluctant to seek medical attention or to give doctors the information they need in order to provide good care.
- ▶ Appropriate information sharing is essential to the efficient provision of safe, effective care, both for the individual patient and for the wider community of patients.
- ▶ Disclosure without consent may be justified in public interest if failure to disclose may expose others to a risk of death or serious harm. Still seek patient's consent if practicable and consider reasons given for refusal.
- ▶ If patient's refusal to consent to disclosure leaves others exposed to risk so serious it outweighs patient's and the public interest in maintaining confidentiality, or if it is not practicable or safe to seek the patient's consent, you should disclose information promptly to an appropriate person or authority.
- ▶ You should inform the patient before disclosing the information, if practicable and safe, even if you intend to disclose without their consent.

## GMC: Confidentiality – Good Practice in Handling Patient Information (2017, updated 2018)

- ▶ When deciding whether the public interest in disclosing information outweighs the patient's and the public interest in keeping the information confidential, you must consider:
  - ▶ potential harm or distress to the patient arising from the disclosure
  - ▶ potential harm to trust in doctors generally
  - ▶ potential harm to others (specific person or people, or to the public) if the information is not disclosed
  - ▶ potential benefits to an individual or to society arising from the release of the information
  - ▶ nature of the information to be disclosed, and any views expressed by the patient
  - ▶ can harms be avoided or benefits gained without breaching the patient's privacy; if not, what is the minimum intrusion?
- ▶ If failure to disclose would leave individuals or society exposed to a risk so serious that it outweighs the patient's and the public interest in maintaining confidentiality, you should disclose relevant information promptly to an appropriate person or authority.

# GMC: Confidentiality – Good Practice in Handling Patient Information (2017, updated 2018)

- ▶ **Disclosing genetic and other shared information**
- ▶ Genetic and some other information ... might also be information about others with whom the patient shares genetic or other links.
- ▶ Most patients will readily share information about their own health with their children and other relatives, particularly if they are told it might help those relatives to:
  - ▶ get prophylaxis or other preventative treatments or interventions
  - ▶ make use of increased surveillance or other investigations
  - ▶ prepare for potential health problems.
- ▶ If a patient refuses to consent ... disclosure might still be justified in the public interest if failure to disclose the information leaves others at risk of death or serious harm. You will need to balance your duty to make the care of your patient your first concern against your duty to help protect the other person from serious harm.
- ▶ If practicable, you should not disclose the patient's identity in contacting and advising others about the risks they face.

# Joint Committee on Medical Genetics

- ▶ **Fundamentals of clinical genetic practice**
- ▶ Whilst genetic information is relevant to an individual, as noted, it may also be relevant to that person's family because much genetic information will be common to both.
- ▶ Genetic testing may only be requested because of wider knowledge about a condition within a family.
- ▶ The traditional medical approach which focuses on the individual patient to the exclusion of others may be difficult to apply to the use of genetic information.
  - ▶ For example, testing one person can reveal information about the chances of a condition occurring in their close relatives and providing the tested person with a right of veto over such risk information in all situations may be legally and ethically unsound.
  - ▶ At the same time, respecting confidential information is an important aspect of clinical practice and is vital in securing public trust and confidence in healthcare.

# A Duty to Conduct a Robust Balancing Exercise

- ▶ Obligation to consider both risks and benefits of disclosing genetic risk information and to weigh these risks and benefits against the well-established duty of confidentiality owed to the patient to keep medical (including genetic) information secret.
- ▶ When HCP receives genetic information and it may have relevance to members of the patient's family, and patient does not consent to disclosing information, HCP must undertake balancing exercise and make justifiable decision.
- ▶ Whether disclosure is justified will depend on facts of individual case, including:
  - ▶ the condition in question; its severity; whether treatment or prevention exists; the likely age of onset; the likelihood of harm to the family members in question; and the likely personal significance of the information to these family members

- 
- ▶ Could be discharged by:
    - ▶ non-disclosure (accommodating possible interest in *not* knowing); or
    - ▶ various forms of disclosure:
      - ▶ full disclosure
      - ▶ general indication that information is available (which may not breach confidence),
      - ▶ initiating discussions with other relatives who have relevant genetic information and willing to share it.
      - ▶ draw attention to known symptoms (i.e. in ABC, tell daughter her father's symptomatology (that she knew about) may indicate inherited tendency she might want to look into).

# A Weak Duty to Disclose

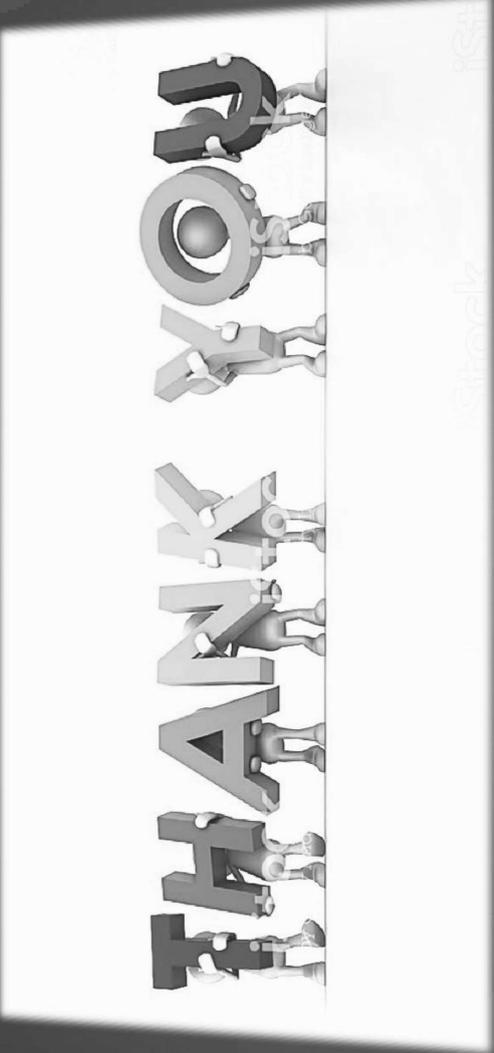
- ▶ The Court could find a "weak" duty of care exists to third party
- ▶ Discharged by telling the patient
- ▶ I.e. Pate v Threlke from USA
- ▶ Unsatisfactory
  - ▶ Does not answer question: what happens if you disclose directly to third party?
  - ▶ Does confidence then apply?
  - ▶ Does not tally with clinical guidance

# A Strong Duty to Disclose

- ▶ The Court could find a “strong” duty to third party
- ▶ Discharged by disclosing to third party
- ▶ I.e. Safer v Pack in USA
  - ▶ Owing duty not same as being in breach
- ▶ Question:
  - ▶ What would be standard of care?
    - ▶ Clinical guidance?
  - ▶ More rigid list of conditions / risks?
  - ▶ What would be test for breach? *Bolam* or *Montgomery*?
  - ▶ Inappropriate to mandate certain threshold of disclosure?

# Conclusions

- ▶ Legal change is necessary
- ▶ Law must not stifle clinical guidance by incentivising confidentiality when disclosure appropriate
- ▶ High Court has difficult task ahead
- ▶ My view:
  - ▶ Likely to go up to Supreme Court
  - ▶ Duty to conduct balancing exercise / strong duty best options, but no perfect solution



THANK YOU

Questions?