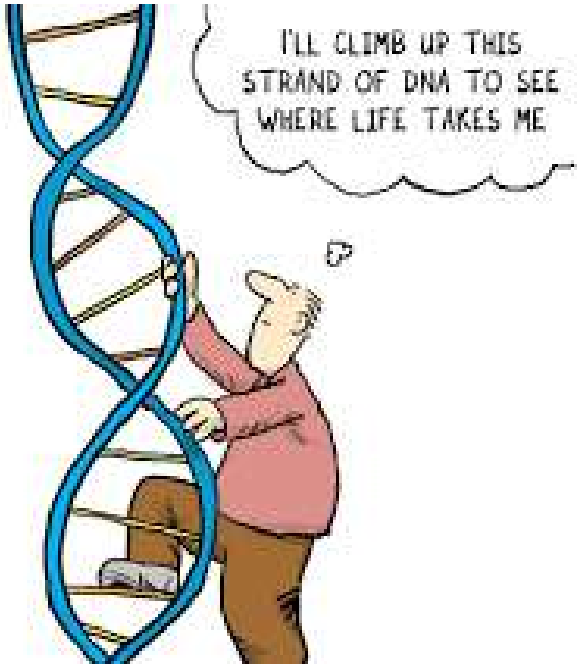

After ABC v St George's Healthcare

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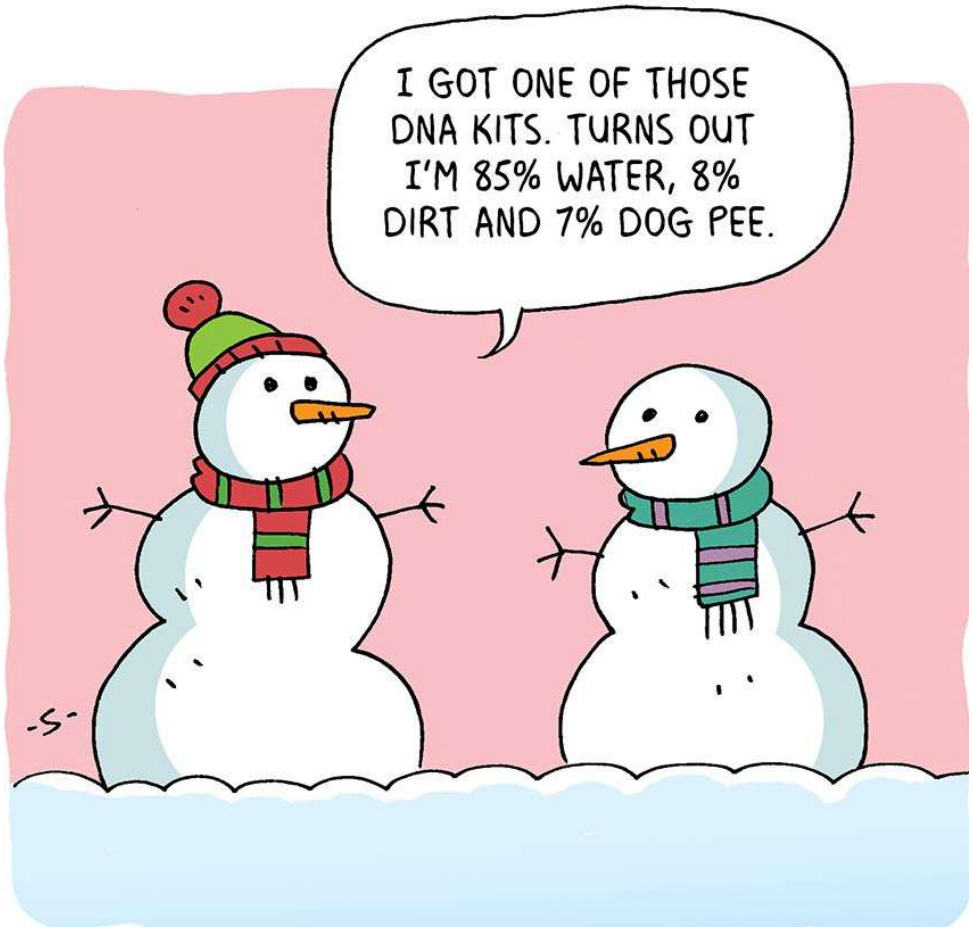
Overview

The Crux of the Problem

ABC in the High Court (round 2)

The outcome

Where are we now?



News ▸ UK News ▸ DNA

Brit DNA breakthrough will save thousands of kids from killer

Health

EXCLUSIVE ... threatening conditions

Health of nation study calls on millions to sign up

7 days ago

DNA b... Revolu... save thousands ... babies

... s largest genetic study of ME

12 September

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. Sues three trusts (1. St George's; 2. SW London & St George's; 3. Sussex NHS FT)

Pleaded: 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' – Att. Gen. v Guardian Newspapers (1990)

Negligence and 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)

Questions for the Court

i) Did the defendants (or any of them) owe a relevant duty of care to the claimant?

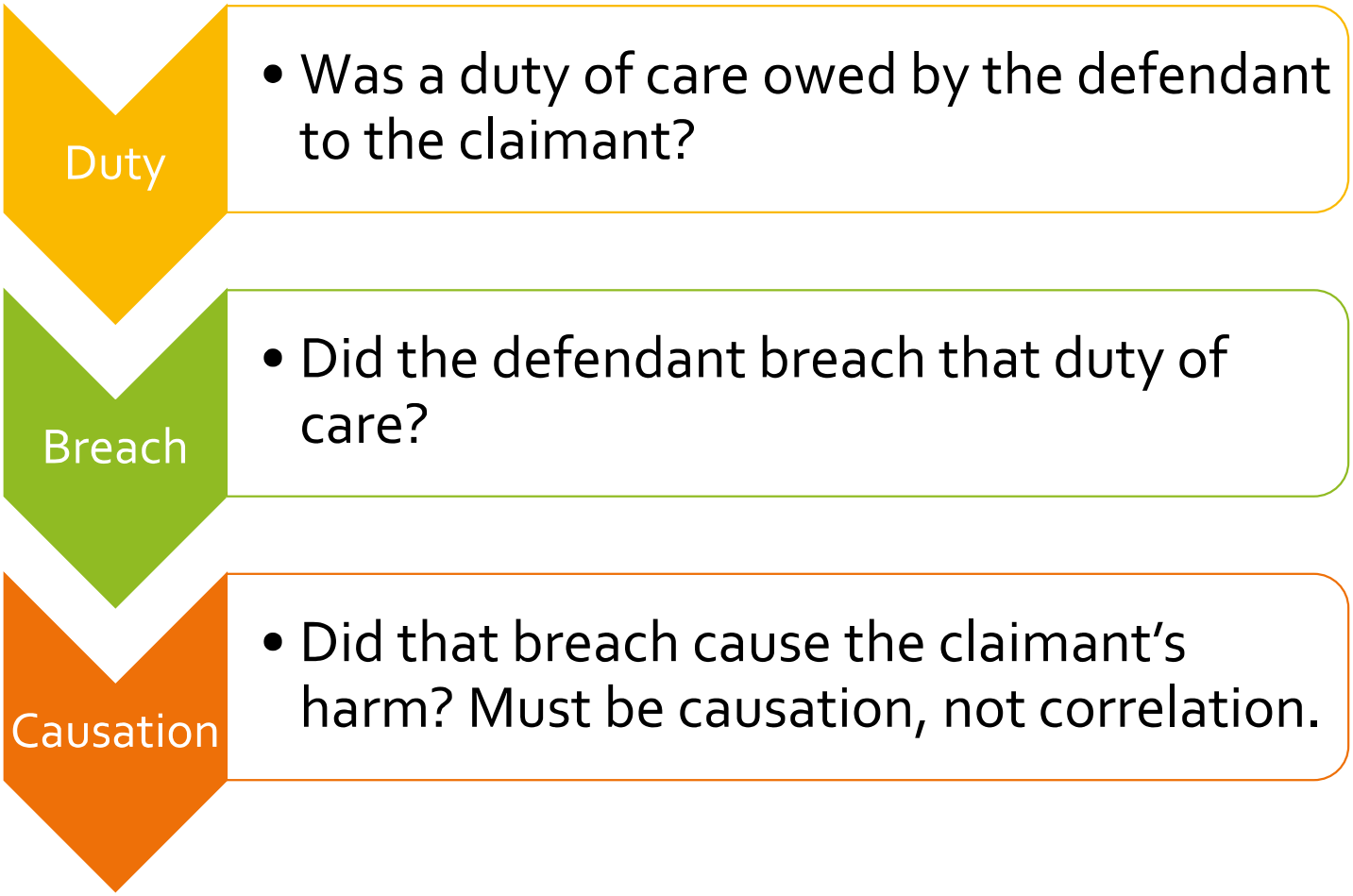
ii) If so, what was the nature and scope of that duty?

iii) Did any duty that existed, require that the claimant be given sufficient information for her to be aware of the genetic risk at a stage that would have allowed for her to undergo genetic testing and termination of her pregnancy?

iv) If a duty of care was owed, did the defendants (or any of them) breach that duty by failing to give her information about the risk that she might have a genetic condition while it was open to her to opt to terminate her pregnancy?

v) If there was a breach of duty, did it cause the continuation of the claimant's pregnancy when it would otherwise have been terminated? (would ABC have had opportunity to undergo genetic testing and a termination?).

The Structure of a Negligence Claim



Acting Within the Law: Confidentilaity

- *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.

A thought on the law *before* ABC.

- Court of Appeal:
- It might logically be said that current law incentivises clinicians to play safe rather 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.

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'

Claimant's three duty arguments

i) The claimant was a patient of the defendants (or at least the second defendant) so that the case falls within the scope of the established duty of care arising out of the doctor-patient relationship.

ii) The forensic psychiatry unit of the second defendant assumed responsibility for the welfare of the claimant, both in the context of providing family therapy and through her long-standing relationship with the team caring for XX and her involvement in his rehabilitation programme.

iii) If neither of the above routes are found to apply, by the application of established principles to the facts of this case by incremental extension (as explained by *Caparo v Dickman* and *Robinson v Chief Constable of West Yorkshire*)."

Justice Yip's Judgment

- No evidence "that it is probable that the claimant could have been alerted to the genetic risk without a direct breach of XX's confidentiality".
- Claimant was patient of family therapy team, but claim was not "properly characterised as badly performed family therapy".

Justice Yip's Judgment

The Claimant's three potential routes to Duty:

i) No doctor-patient relationship: "even as a patient of the second defendant, the claimant remained a third party to the relationship between each of the defendants and XX".

ii) No assumption of responsibility: "no question of the claimant having relied on the defendants to undertake the balancing exercise as to whether she should be told of her father's diagnosis".

iii) Possible duty under *Caparo/Robinson*: "the courts have been willing to recognise that a doctor or health authority may owe a duty of care to persons other than their primary patient but that such a duty is only capable of arising where there is a close proximal relationship between the claimant and defendant".

Justice Yip's Judgment

- Duty
  - Foreseeability of the claimant suffering harm as a result of non-disclosure was not just foreseeable, but in fact foreseen by the second defendant.
  - Proximity between claimant and family therapy team.
  - Fair, just and reasonable to impose on the second defendant a legal duty "to balance her interest in being informed of her genetic risk against her father's interest in preserving confidentiality … and the public interest in maintaining medical confidentiality generally".

Justice Yip's Judgment

- Lack of consensus of opinion amongst the medical experts
- Claimant had not demonstrated that the defendants' experts' views were illogical.
- Decision not to disclose was not in breach of duty. The balancing exercise required had been carried out.
- No causation: "the claimant has not proved that she would have undergone a termination if notified of the risk during pregnancy".

A matter of clinical discretion?

- At the time, they felt there was no therapeutic benefit to the daughters because there was no known treatment or cure for the disease. [Dr McEntagart] contrasted that to other conditions such as the BRCA1 gene linked to breast cancer, where knowledge could make a difference.
- Dr McEntagart recalled discussing the potential for the claimant to terminate her pregnancy but had not thought that would be termed a "therapeutic intervention" such as might justify breaching confidentiality.
- Dr McEntagart acknowledged that being deprived of the choice to have a termination could be harmful but said that she had not considered at the time that a mother with the gene might want to have a termination as a result of her own status, regardless of whether the foetus was affected.
- She had not viewed the case as one in which "serious harm", within the meaning of the professional guidelines, might result from the non-disclosure of the information. (ABC, paragraph 82)

General Position

- Yip J careful to make clear she was not attempting to define the limits of any duty of care owed by doctors to those who are not their patients.
- Was only required to determine whether, on the facts of this case, a relevant duty was owed to the claimant.
- Yip J found recognition of a duty would be a modest incremental step as foreseen by *Montgomery* in circumstances where there is professional guidance on the point.
- General position post-*ABC* is professional guidance, with claimants to make out duty on case-by-case basis.
- No explicit duty to warn, but starker case could find balancing exercise weighted in favour of disclose.
- This would (likely) be where illogical not to disclose – i.e., a serious but mitigable risk – or where accepted practice is/becomes to disclose.

"Consent and Confidentiality in Genetic Practice, Guidance on Genetic Testing and Sharing Genetic Information" (2006) RC.Phys, 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 Handing 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 Handing 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.

GMC: Confidentiality: patients' fitness to drive and reporting concerns to the DVLA or DVA (2017)

- If you become aware that a patient is continuing to drive when they may not be fit to do so, you should make every reasonable effort to persuade them to stop. If you do not manage to persuade the patient to stop driving, or you discover that they are continuing to drive against your advice, you should consider whether the patient's refusal to stop driving leaves others exposed to a risk of death or serious harm. If you believe that it does, you should contact the DVLA or DVA promptly and disclose any relevant medical information, in confidence, to the medical adviser.