**Module1 – Confidentiality – Transcript**

[Spaces indicate when the slide changes, and some timings are included where these are captured by the software]

[00:00:05] In this first module we're going to look at something that has not changed as a consequence the introduction of GDPR. And that is the common law.

The common law of confidentiality. Information is subject to the common law and should be kept confidential…

… if it is identifiable; not already in the public domain; and given with the expectation that it will be kept confidential.

For example patients give doctors a great deal of information about them and they expect their doctor to keep that information confidential.

It doesn't mean to say they don't expect other members of their care team to also be party to that information. So it's not the same as a secret as limited sharing is expected by patients.

This care team, patients know can be multidisciplinary…

… and indeed some care teams will include researchers, and therefore sometimes researchers embedded as part of a care team will have the same relationship with patients as any other treating clinician.

When this relationship is as I've described, where there's clear expectation, we would say that doctors and in fact everyone else within the care team owe a duty of confidence towards patients. That is implied. It has never been made explicit and yet the common law would demand that the care team keep all information, that patients expect to be kept confidential, confidential.

Within a research context, quite often, more often than not I guess, we get research consent before we recruit participants and part of that consent process means describing the types of information we want to collect and how we're going to look after it and keep it confidential.

[00:01:59] In other words we are very explicit about what participants should expect and again in this case although it is an explicit act it's still the same duty of confidence that is established between the research team and research participants - participants have clear expectations of what they expect in terms of their confidential information.

However, there are some situations in a research context where researchers would like to obtain information about participants. They have no consent from participants and in some cases participants actually would have no idea that they are a participant.

Accruing confidential information in that scenario would be a breach in a common law - participants would be surprised. And that is the measure that the law applies. If people are surprised that someone has their confidential information there has probably been a breach in the common law. However that isn't to say that researchers cannot work without consent and accrue information about research participants without consent. But you must do it in line with common law requirements.

For example you must manage people's expectations or manage disclosure.

One way of doing this is to ensure the research team only collects non-identifiable and no longer confidential information. If information is not identifiable it is no longer subject to the common law - there is no disclosure.

This may be complicated and may require a technical solution, data linkage for example. But still if the end result is the researchers who do not have a duty of confidence only receive anonymous information, they do not receive anything that would be classed as confidential, there is no breach in the common law.

Alternatively is it possible for the research team if they need to get hold of confidential identifiable information about research participants, can they get consent?

[00:04:13] If you actually ask participants and again clearly explain what they should expect then you can explicitly establish a duty of confidence with this group of people. There is no disclosure provided you obviously keep that information confidential within the expectations that you have outlined to participants.

Sometimes consent is not possible and you do need as a researcher to acquire confidential information as in identifiable information about participants. Be assured that there are other legal avenues that may be available to you. We're not going to talk too much about them just now.

Suffice to say that really the common law is all about this balance. It's a balance between keeping things confidential and what is in the public interest. Usually, keeping, for example, patient information confidential builds trust in the NHS and therefore that is what the common law demands.

But occasionally the balance swings the other way and the public interest outweighs the need for keeping stuff confidential. In England and Wales we would say this public interest has to be overwhelming in order for the balance to swing the other way. Overwhelming, for example the prevention of a crime.

However, if you cannot meet such a large swing in public interest, be assured there are legal avenues available to or further legal avenues available to you in England and Wales. Section 251 approval given by CAG, the Confidentiality Advisory Group of the HRA. We're going to cover this in later modules.

Those of you in Scotland should be aware that although the same balance exists between keeping things confidential, but also disclosing if it's in the public interest, the balance point has been interpreted slightly differently in Scotland.

[00:06:14] So we say in Scotland that research could be in the public interest and as such and the public benefit and privacy panel or local Caldicott guardian can, in Scotland, decide that public interest is great enough for this research to take place, that disclosure can happen without there being a breach in the common law. And again we're going to talk much more about this balance in later models.

So in summary, information is subject to the common law if it's identifiable; if it's not already in the public domain; and if it's given with the expectation that we keep it confidential. And we've seen that that expectation doesn't have to necessarily be explicit, it can be implicit, implied in the relationship, for example between doctor and patient care team and patients. It's not the same thing as the secret. As I've said it can be shared in line with reasonable expectations. So although you tell a doctor or you tell a nurse information about you, you do expect them to share it with the rest of the care team. That would not come as a big surprise. You don't expect them to share it outside of the care team, that would be a surprise. And we've also touched on other legal avenues which do allow for disclosure in certain circumstances. One part of all of this which you may still be asking yourself - I don't really understand if this is identifiable. What makes information identifiable? Well we're going to cover that in the next module. I think that does deserve a module all of its own.

[00:07:48] If you want to explore the common law a little bit more, we have provided some real life examples that you can download from the website and see if you can identify the confidentiality issues in the scenarios and work out: How would you actually go about, either identifying potential participants in these scenario, or indeed sharing information with your collaborators in these scenarios.

To help you through those workshop examples sometimes it really helps to actually draw out where the data is coming from or the information's coming from. What are you linking it to? How are you going to keep it? And just mapping out all of the different flows of, in particular, confidential information, identifiable information. Once you've mapped it out, it becomes much clearer to be able to address those workshops and be able to address issues that you may actually have yourself in real life.

Good luck with the workshops.