**Module 7 - GDPR and accessing information without consent (Scotland) - Transcript**

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

[00:00:03] GDPR and accessing information without consent for Scotland. We've devised this Scotland-specific module, not because GDPR is any different or interpreted any differently in Scotland compared to the rest of the UK, but rather because the common law of confidentiality is interpreted slightly differently north of the border. So just to reiterate, GDPR is GDPR, wherever you are in Europe, including wherever you are in the UK.

[00:00:31] Okay. Right back in Module 1 we examined the common law of confidentiality and we ascertained that the common law is all about delivering what is in the public interest. It is usually in the public interest to keep confidential information exactly that: confidential, because this helps to build and maintain trust.

[00:00:50] However, occasionally the pendulum swings the other way, and the public interest may be better served by disclosure rather than keeping information confidential. Now in Scotland what is considered to be in the public interest does vary from those sorts of decisions made down south. And in Scotland, research can be in the public interest. In other words, in Scotland confidential information can be disclosed in the public interest to support research.

[00:01:19] So just to kind of revisit what we're really talking about here. I want you to imagine a research team that has no relationship whatsoever with research participants, and this research team acquires confidential information about research participants. Research participants, they're not expecting that, they would rightly be surprised to hear that the research team now knows an awful lot of confidential things about them. This is what would constitute a breach in the common law. People don't reasonably expect the research team to have access to the information, they're surprised if they do. It's not an acceptable position and we have to manage that disclosure.

[00:01:58] One of the ways of managing disclosure is to manage people's expectations, to get consent, to ask participants: ‘Is it alright if we access your confidential information?’ If people say yes, go ahead, expectations managed. If they say no, fair enough.

[00:02:13] Now in some situations consent is just not possible, and one of the scenarios we've been looking at in the earlier modules illustrates this very well. It's the scenario where a research team, nothing to do with a care team, no duty of confidence with research participants, but they want to identify very specific types of patients to invite them to take part in a clinical trial. And in order to identify who to invite they need to go through medical notes to look at the details of patients’ disease. They have no legitimate right to access medical notes, they don't have a duty of confidence between themselves and those patients, they can't get consent from these people because they don't know who they are, consent is not possible. That's just one example where consent is really not possible in a research scenario. The other thing we do need to explore before we automatically start asking for disclosure to be in the public interest, is whether or not we can manage disclosure in another way. Is it possible to do this research using only anonymised information? In other words ensuring there is no access of confidential information outside of the duty of confidence. If you can't remember what anonymised or identifiable means, go back and visit Module 1B where we explored identifiability of information at length. Sometimes it is not possible, it just isn't possible to address the research question at hand using information that has been anonymised.

[00:03:43] And that includes having explored every technical avenue, including getting somebody else to do data linkage for you, someone who does have a duty of confidence, and then them then transferring entirely anonymised, but linked data sets, to the research team. Sometimes that works and that that's fine and the research team can get on and address the research question with linked anonymised data, sometimes it’s still not possible.

[00:04:09] And if really all other eventualities are not practical then you're going to have to ask for a public interest disclosure, and you have to ask for the duty of confidence to be set aside because you think it should be deemed to be in the public interest. Now the people who can give permission for the duty of confidence to be set aside are either the local Caldicott guardian, that is a senior person who is responsible for confidentiality within an NHS organisation, they can approve the release of confidential information from their own organisation. Or if you're wanting confidential information from more than one NHS organisation, you'd go to the Public Benefit and Privacy Panel, and that panel can make a decision on behalf of all the NHS Caldicott guardians. Whichever way you go, whoever it is who's this public interest judgment, if they do approve your access to confidential information despite the fact that no one would be expecting you to have access to it, you still must comply with GDPR if you end up holding and using personal data as a consequence of that disclosure. That means you still have to process this personal data lawfully, fairly and transparently. This is where it all starts to get really complicated to try and work out what that actually means.

[00:05:33] So let's try and explore it in a made up example. I want you to imagine that we're all sitting on the Public Benefit and Privacy Panel and we've been asked to look at this research study and to decide whether or not confidential information should be disclosed from the NHS to support this study, would that disclosure be in the public interest? And it's a study to investigate the effects of an acute exposure to aluminium sulfate which contaminated the water supply. This is an acute event which happened in 1988 in a discreet location. And the research question is, has this acute exposure increased the likelihood or the frequency of dementias in the contaminated population? So when I say contaminated population, I mean anyone who lived in the location at the time; anyone who attended school in that location, children attended school in that location; and anyone who worked there, and may have gone home may have lived somewhere else, but they worked in that location at the time. So the research team would like to access confidential information to allow them to look at whether or not this contamination has increased the incidence of dementia. We are being asked to make that decision. I would also encourage you to think what other conditions you may ask them to meet if you were to allow confidential information to be disclosed from the NHS to support this research study.

[00:06:59] So sometimes I know I keep banging on about this, but honestly I am doing it for a reason. Whenever I get asked a question about data and who should or shouldn't be holding or accessing, or whatever, data, I draw it out in a data flow diagram. It doesn't have to be posh, just a pencil, bit of paper, scribble it down, but it makes you really think where is data information coming from. Where is it going to, when is it identifiable, when can identifiers be stripped from it. Exactly how is data going to flow throughout the whole process of research, to get a really clear picture of exactly what's going on. I think it helps almost always. It definitely will help in this situation as well, just to quickly map it out. As I say just a paper and pencil exercise, it doesn't have to take hours.

[00:07:48] Once you've got an idea of where data is coming from and where's it going. I guess as members of the Public Benefit and Privacy Panel, we're going to have to ask ourselves a few common law questions. First of all, is this research team wanting to access confidential information, and if so, would it be reasonable to assume that the population would expect this or would they be surprised to find out that the research team has suddenly got access to their confidential information?

[00:08:17] Well I think it's true to say that yes, they do want to access confidential patient information. They want to know about dimentias, the development of dimentias within the population. They are also as an aside wanting confidential information from other agencies because they're interested in where people worked and who was attending what school. So it's not just patient information in this instance, this really is a kind of big data study with data coming from many different sources. So whenever you apply, or ask people to approve disclosure, you have to be aware of what information they have the authority to approve the disclosure of. The Public Benefit and Privacy Panel won't for example give approval for educational information to be released, or indeed information from a bank, I don't know, whatever else. But yes, the answer to these questions has to be the research team, yes they do want patient confidential information, no the population wouldn't expect it, and yes I think they would be quite surprised if they heard about it.

[00:09:18] Is it possible for research team to do this while getting consent? Is consent really not an option? That is certainly a question, as a member of the panel, I would want to ask: Have you explored all possibilities, is there other methodologies that you could apply which could involve consent and don't involve disclosure without consent?

[00:09:40] Equally, do you really need confidential information? Could the research team do this using only anonymised information? Is that possible, or isn't it? This is a question we're going to have to ask, as a member of the panel. And that includes, have they really explored all the technical solutions?

[00:09:58] Could you for example get different agencies to link the data together and then provide the research team with an anonymised data set. Is that possible? If it isn't, fair enough, we are still going to have to consider a public benefit disclosure.

[00:10:15] But I think these are the questions you have to ask before you automatically, don't automatically assume, the panel will not automatically assume, that public interest disclosure is the only avenue available. On a different slightly different tack, I think as a member of the Public Benefit and Privacy Panel I now also would like to be assured that if I were to allow the disclosure of confidential information to support this research, that I’m not encouraging the research team to then flaunt GDPR. So if I give you this data, does that mean you're going to end up holding personal data, is probably the first question.

[00:10:51] Will this research team end up holding personal data? Now this is just a quick reminder, we did talk about this in about module 2, so go back and re listen to the module if you're not sure. But personal data, just to remind you, is not the same thing as confidential information. Personal data is structured information. This will be structured information, it's going to be electronic probably. Does it relate to, or is it about living people? Well yes, this contamination happened in 1988. Some of the population may have died since, but the vast majority will still be alive. So yes most will still be alive. And will the data be identifiable? Either on its own or in combination with other bits of information that the research team is likely to have access to. And again we've already ascertained that it is confidential information, and confidential is by definition identifiable. So yes, it will be identifiable data that they'll end up holding. And if that is the case, then if we were to allow the release of this information to the research team, the research team would end up holding personal data and therefore they must be compliant with GDPR.

[00:11:59] And if they have to be compliant with GDPR, yeah, they've got to be lawful, fair and transparent.

[00:12:06] So again to revisit previous modules - Lawful is in some ways quite easy. Lawful just means they have a lawful basis, as outlined in GDPR, for their organisation to be holding and using personal data. And as we explored earlier, and if you if you don't remember this please revisit the module or revisit the animation that's available on our website that talks you through this, by lawful we mean they have a lawful basis defined in GDPR, which is likely to be legitimate interest if they do not work for a public body; or to support a task in the public interest if they do work for a public body. Because this data, that they will be accumulating, is likely to be special categories of data about health, so it will be special categories of data, they'll also need an additional condition as well as a lawful basis, and that additional condition is likely to be for research purposes. So in some ways lawful basis is quite easy. They should have it because they're working for a reputable organisation doing reputable things. However they also need to ensure that holding personal data transparently and fairly.

[00:13:11] What information has been made available to the local population that would tell the local population how their personal data is being used? I don't know, is the answer, but again I think we should probably ask that as part of the Public Benefit and Privacy Panel. What do the public in this discreet location, what do they believe or what information they have available to them telling them about how their data may or may not be used? Is research part of what they should expect, have they been told that, is that information being made available to them? I don't know, but we need to ask the question.

[00:13:44] On a similar tack but again differently, we've already explored this aspect of the importance of transparency. Research, we know is not an incompatible purpose. We know that if research is appropriately safeguarded, and again if you can't remember what the appropriate safeguards were and what I mean by appropriately safeguarding, revisit the module, you could have it explained again. But if research is appropriately safeguarded, it's not an incompatible purpose with the original reason this data was collected. This data was collected, so that is the NHS data, to look after these people to manage their care, that was the original purpose. But what we do need to ascertain is whether or not it is a new purpose, is research a new purpose? We have to be transparent, and as we've already said, having words like your data might be used to support research - full stop - isn't really transparent enough in this day and age. That the population involved in the, potentially involved, in this study they ought to have some idea the sorts of things their data is being used for. I don't know to support population-based research to look at the impacts of various environmental, blah blah blah, something along those lines. Certainly much more specific, I guess, much more detailed information should be made available to this population.

[00:15:02] So to cut a long story short, as far as this application coming to us, sitting on the Public Benefit and Privacy Panel, is concerned, I think we need to ask two important GDPR questions of the researchers sitting in front of us. The first one is: what is your lawful basis? They should have one, they should know what it is. And secondly, how are you going to make sure that you're being transparent with your population? Now they are not going to be able to go out and speak to each individual and ask each individual, show each individual a written piece of information they don't know where these people live. They can't find them. People move, they may not all still be in the same location, so they're gonna have to use best endeavours to try to provide information, to try and be as transparent as possible. And best endeavours in this type of situation may involve things like, I don’t know, sticking an advert in a newspaper or writing an article for the local newspaper, doing something on local radio. It’s best endeavours. Best endeavours is what we always try to achieve when it comes to transparency. We do our absolute best but it is, what that materially is, will change depending on the context, and in this context it's difficult, it may just be putting something up on your website. But importantly you're going to have to be transparent about the fact that the research organisation is now holding this data for research purposes. It's not just the fact it might be a new purpose, it's also a new data controller. Now if we disclose personal data to the research team, their organisation is now going to be held responsible for looking after it and ensuring compliance with GDPR. So if the data controller is changed from the original data controller, for participants we need to be transparent about that as well. It's a difficult job. Best endeavours - that's what we're aiming for.

[00:16:52] There are some other ethical questions which I think we may well want to ask in the Public Benefit and Privacy Panel. Even a really basic one like, is this actually an important question? If it really isn't an important question then why would we why would we think it's in the public interest to support a disclosure of confidential information to answer it, we wouldn't. Do they really need confidential information, we've covered that before. Is there another way of doing it, different methodologies, different tacks, do they really need confidential information? I think if we are going to approve the release of confidential information from the NHS, we'd want to be certain that what they're asking for is what they really need, so we limit the extent of the disclosure. We limit it in terms of the amount and we limit it in terms of the sensitivity of it. We also want to make sure that anything we do disclose is not disclosed further, so that this research team will look after the data as we would expect them to. And this means really we're going to have to do a little bit of question asking around who is the research team, what organisation do they work for, what kind of governance arrangements, what sort of oversight is in place to ensure that any data and information that we do give them, they look after appropriately, so we know we can limit disclosure. It's not like, I don't know, we approve the disclosure from the NHS for one research project and then suddenly it's broadcast and the whole world knows about it. And finally, this is a difficult one but it's a question I think you have to ask as part of Public Benefit and Privacy Panel, is whether or not the local population, how would they would feel about this research, if and when they find out about this? Would it cause substantial distress? Would it upset people to know that their confidential information had been accessed by this research group? And again I think it's a question you have to consider if you're thinking about public interest disclosure.

[00:18:39] OK, what do you think, you decide. I know it's difficult I haven't given you enough information and in some ways the point of working through that scenario is to think of what some of the questions might be. What is it that Public Benefit and Privacy Panel are likely to want to know before they agree to allow the disclosure of confidential information in the public interest? It’s a very useful exercise to go through because it really helps you to identify why you're being asked some of the questions you will be asked if you ever do apply to your Caldicott guardian or the Public Benefit and Privacy Panel. These are the kind of questions, the kind of conversations you are likely to have, and this is why. They will explore common law aspects of what you're asking for. They will make sure that you still can be compliant with GDPR. The other thing I should, I guess, throw into the mix here in terms of deciding, in the particular example that we've just given, NHS confidential information was only part of what this research team would need in order to get to the research answer that they were looking for. They're going to need information from, as I say, education and employment, can they do this research if they don't get that? Are there some conditions about access to other bits of information? Because again could we say it's a public interest disclosure to disclose confidential patient information to this group if they can't reach their research objectives because they can't access other information. So I think there's a lot of questions in there, as I say, I hope it's a useful exercise.

[00:20:11] Working through this scenario really does help put together the common law with GDPR so you really do start to explore the differences. For example the differences between consent and transparency, it really makes you look at them. In the next and the final module we're going to be exploring some common myths which, again will put all of this together, so again we'll be working through some common research scenarios which require us to look at both common law and GDPR.