**Module 5 - Sharing data - Transcript**

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

[00:00:03] In this module we're going to talk about the GDPR implications when sharing data.

[00:00:09] In earlier modules we asked you to look at some workshop examples, which we've provided, which looked at accessing data collected by someone else; accessing data that was being collected for an entirely different reason other than research; sharing data with collaborators; and also publication, including open access publication. We asked you to consider the common law implications, but now we need to look at the same scenarios and start thinking about GDPR implications.

[00:00:37] The sharing of data and the reusing of data is pretty central to the conduct of research. You could not conduct a multi-site trial without sharing a certain number of research records between sites and sponsors, for example. The whole point of collaborating is to maximise the use of research data collected, to get as broad an analysis, and broad interpretation of research data as possible. I don't need to emphasise the importance of making your research findings public. There’s a massive ethical imperative to do so, to place research findings in the public domain, so that anyone who is trying to make decisions, whether it's decisions about their own personal health and their own personal well-being, or whether it is policymakers making decisions about what national services should be offered - we all need access to as broad and as deep an evidence base as possible, and therefore we have to ensure that all research findings are placed in the public domain. On top of that we also now are asked to ensure that we can make our raw data, that is a personal level, person, sorry, level information available through open access. So that collaborators, peers, others can look at the data on which we have drawn the research conclusions that we have drawn, and also to make sure that that data can be made available for meta analysis, and so by producing stronger and stronger evidence to help inform decision making.

[00:02:10] We already know from the previous module that research is never considered an incompatible purpose. So although it might be a secondary use, GDPR does not prevent data, personal data, from being used again for research provided specific safeguards are in place. And again, if you want to revisit that as a concept and revisit what those safeguards are, you should go back and listen to the previous module. But we also explored that although research may not be an incompatible purpose, it may be a new purpose.

[00:02:45] And the importance of ensuring that we are open and transparent about the purposes that we are putting data to. So if we are putting data to a secondary use that we are transparent about that, we do inform people about what is going on.

[00:03:02] Remember we have to be lawful, fair and transparent, and it doesn't matter whether that is because we have to be lawful, transparent and fair when we first collect the data, we have to be lawful, transparent and fair every time we use that data. Every time it is used for a secondary purpose we must revisit, are we being lawful, fair and transparent?

[00:03:25] I would encourage you to look at the scenarios and start thinking about what the original reason probably was for collecting, holding and using the data. Who was the original data controller? How transparent would it be to start sharing the data or to access the data now? Would participants know what's going on? Would they know who the data controller is? Would they know what their data is being used for?

[00:03:51] And in terms of transparency, I'd encourage you to think about what best endeavours at being transparent would look like. The trouble with secondary uses is often this is some time after the data was collected, and if we had good foresight, or you had very good transparency information years ago, then fine, you probably don't need to address transparency again. But it is likely that because GDPR is new, the transparency information provided some years ago may not actually stand up to modern scrutiny. Trying to retro engineer transparency is very difficult, but for all the data that you hold, you have to be transparent about what you're doing with it, what you've got and what you're doing with it. So all personal data, no matter how long ago it was since you collected it. Obviously you cannot go out and actually ask each individual person whether or not they are happy with how things are, and the new uses you are putting their data to, and you're not asked to do that in GDPR either, you don't need to get consent to do that. But you do need to use best endeavours to ensure that the general public are aware of what you are doing. You are using best endeavours to be as open and transparent as possible about the data you hold and the uses you are putting it to. And I'm using the term ‘you’ here but actually it's your organization, or your data controller, probably more accurately. The data controller, who has to be absolutely, scrupulously open and transparent about all personal data they are holding now, even though it was collected historically, and about all secondary uses some of that data may be put to. It does not mean you need to get consent but it does mean you need to think what best endeavours might look like to inform. And that can vary from directly contacting, if you can; but it could be putting things out in a newsletter if you produce a newsletter, say for a cohort; it could be putting things up on a website; it could be using or engaging local press, local radio, I don't know, but best endeavours is what we're always trying to achieve, but best endeavours, the details of best endeavours, may look a little different depending on the circumstances that we're talking about.

[00:06:21] So as I say, have a look at the workshop examples. See if you can put some of the principles in place of GDPR that we've talked about; see if you can identify what the GDPR issues are likely to be; and really think about what best endeavours to be transparent might look like in each of these scenarios.

[00:06:39] Again, it can help to plot out data flows, so you can understand where data came from, who was the original data controller; what are you doing to it; what was the original purpose; who was originally processing it; is it being transferred, shared, who's analysing it; all the rest of it to map that out and then it's much clearer to get a picture to address your workshop examples.

[00:07:02] Anyway good luck with the workshop examples, see how you get on.