**Module 6 - GDPR: Know your rights - Transcript**

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

[00:00:03] GDPR: Know your rights. In this module we're going to cover subject rights and GDPR, and also what exemptions you have available to you if you're processing personal data for research.

[00:00:18] Here’s a list of the subject rights, which we all have made available to us through GDPR. Be aware that there are exemptions to all of these if you are processing personal data for research purposes. Now in this module I'm going to start going through quite a lot of detail and it is going to get complicated. My advice to you all is not try and memorise every detail of what I'm about to say. At the end I’m going to come up with, I hope, with a bit of a summary of what you as a researcher really need to do and to think about. But I am going to cover, as I say, the detail just so you get some kind of context, you understand where some of this is all coming from. And because I know that there are quite a lot of myths and strange rumours going around on the basis of misinterpreting what some of these rights may, or may not, mean in terms of research.

[00:01:07] So, in particular I think we need to start thinking seriously about how we're going to handle certain, certain situations. And these are situations that some of you may well have already come across, or others of you are just dreading that you might.

[00:01:24] Things like the research participants comes in and says ‘I've changed my mind. I don't want to be on the study anymore.’ They want to withdraw. You don't want to be in a position where you're second guessing what exactly is it they want, and what am I expected to deliver, what do I have to deliver because of GDPR.

[00:01:43] Withdrawal from a study can mean many different things. It could simply mean ‘I don't want to come in here again, I don’t want to visit this research clinic again.’ It could mean ‘I don't want you to collect any new or any more information about me.’ It might be that ‘I actually do want you to delete everything you already have about me,’ and it could be ‘I want you to delete every bit of data about me and I never want you to contact me again.’ You need to think what withdrawal really will mean in your study. What can you offer research participants, and really, to get a gold star, if you can be really clear upfront with research participants about what withdrawal will mean, then actually, that's job done. People know what to expect. Don't feel GDPR does force you to have to delete and erase all data if someone withdraws from the study, it probably doesn't. You do have exemptions available to you, you are likely to want to use them, but your best bet is to be open and honest upfront when people consider taking part in your study. You tell them what the deal is, you tell them what withdrawal will mean. Really you make promises that you can keep. You don't start making promises about withdrawal that in reality you can't keep, that really isn't fair. You have to be transparent and fair. So that's withdrawal.

[00:03:05] The next potential situation is someone walking in saying ‘I demand to see all the data you have about me, I know my rights’.

[00:03:13] Oh dear, what do you do if your study is blinded. Are you going to unblind a whole study in order to be able to give this person access to every bit of data that you hold about them? I think not. And again, there are exemptions, you can use the exemption. Again, it is worth thinking about what are you going to tell people upfront in the transparency information. Be open about it. If you're not going to let people have access to their data, you should tell them they're not going to have access to their data. They know what their deal is upfront before they take part in the study.

[00:03:46] And finally, someone demanding that data is corrected because it's out of date. ‘I haven't had a drink for five years. I want you to correct the data you hold about me so that you no longer have any information about my previous problems with alcohol.’ What happens if that is actually one of the major pieces of information that you're collecting to help address your research question? Again, you do not have to correct data because someone demands it, but you should start thinking now what are you going to do if someone were to ask, and you’re upfront and transparent about what you can offer people so they know what the deal is. Again, transparency in a sense it's just common sense, it's being open and honest about what you can deliver, not making promises you can't keep. But being really clear about what people are letting themselves in for if they take part in studies and if they allow your organisation to hold data about them.

[00:04:42] So, if we get back to the real nitty-gritty, having explored a couple of fairly common and thankfully not that common, situations and potential situations, some research situations. We do need to start thinking about: what does GDPR demand that we do and when can we access an exemption?

[00:05:01] There are exemptions to all of these rights. It is very likely that you will have access to most of them, most of the time. Whether you choose to use the exemption is another thing again. The fact you have an exemption available to you does not mean that you are duty bound to use that exemption, but you may choose to do so. And starting to think through, I think, some of these more common scenarios and what implications subject rights and exemptions may have is important. Suffice to say, you have to have certain safeguards in place in order to apply an exemption and the safeguards are not the same for each exemption.

[00:05:39] We've talked about safeguards before. In a previous module you know what the minimum safeguards are if you're holding and processing personal data for research under GDPR. And here they are again: you implement additional technical and organisational measures; your research, or your processing of data for research purposes, will cause no substantial damage or distress to the individuals concerned; and you are not intending to make any significant decisions about the individual participants on the basis of that research processing. If you are, or you believe you might be, then rather than saying you will not be making significant decisions you make sure that your research has been approved by a research ethics committee. On top of that you will also have a set of public interest tests which the Data Protection Officer largely, or Data Protection Officer, will need to ensure are in place. There isn't much you need to do to worry about those. Be assured that your DPO will be, from an organisational level, ensuring that those kind of checks are in place. All of this together really can be considered the kind of minimum set of safeguards, and I've denoted that with the little roundel, the little symbol there in the bottom right hand corner of the slide. I'm going to use that roundel to represent this minimum group of safeguards in the subsequent slides ‘cos I don't want to keep reiterating this great long list of things - so that's the minimum. Here we go, this is the scary bit.

[00:07:05] People do have a right to rectify the data that you hold about them but you do have an exemption if you have the minimum safeguards in place, and rectification is likely to render the research impossible, or seriously impair the achievement of the research objectives.

[00:07:25] Restriction of processing. This is a temporary restriction, stopping processing for a temporary, finite period of time in order to sort out a further GDPR problem. Again, you do have a right to ask for this, however in a research context, if you have the minimum research safeguards in place, and again, restriction of processing is likely to render the research impossible or seriously impair the achievement of research objectives, you can be exempt from the need to restrict processing on demand.

[00:07:58] Exemption from the right to be informed. Informed, not in a consent meaning of the word, this is about transparency. People do have a right to have been told in transparency information about what data is being held and what is being done with it. There is an exemption for this right available, again to researchers, if the minimum set of safeguards are in place and the data you obtain, the personal data you obtained from a third party, you did not get it directly, it came from a third party; and trying to inform somebody would likely to render your research impossible or seriously impair the achievement of the research outcomes again; or a disproportionate amount of cost, effort, resources would be involved in providing the information. Again in the previous module, just before this one, we started to explore what best endeavours of transparency, to be transparent, would look like. And actually if you always work trying to use best endeavours to be transparent, then you're fine. Being transparent does not mean necessarily having a conversation with every individual, but it is about using the best endeavours for that particular circumstance.

[00:09:17] Right to access: ‘I demand to see the data that you hold about me’. Again you have an exemption, you don't have to let them have access to their data if you have the minimum safeguards in place; and giving someone access to the data you are holding about them is likely to render the research impossible or seriously impair the achievement of research objectives; and the research results will not be published in an identifiable form, or if it is going to be published in an identifiable form a health professional has the opinion that access could cause harm. So again do not have to provide people with access.

[00:09:55] The right to erasure: ‘I demand you to delete all my data’. You do have an exemption from that if you conform to the minimum safeguards for research; and erasing the data is likely to render your research impossible or seriously impair achievement of research objectives; and consent is not your lawful basis. It is very unlikely that consent is ever going to be a lawful basis for research so that one really should never be a problem. And if you are conforming to technical and organisational measures and collecting a minimum amount of data I think we could argue that erasure may well start to impact seriously on the achievement of research, and therefore you may well be able to rely on that exemption fairly commonly.

[00:10:45] The right to object to processing: this is ‘I don't mind your organisation holding data, personal data, about me, but I don't want them using it for this specific purpose’. So for example ‘I don't want them using it for research’. Again there is an exemption if the minimum safeguards are met; and it is likely to render the research impossible or seriously impair the achievement of research objectives; and the lawful basis for research is public interest, which if you're a public body that is the most likely lawful basis; or your data controller can show that processing is necessary to support a task carried out in the public interest (but for example your data controller is a charity and therefore using legitimate interest, but actually the task is also in the public interest and I can show you it is). Then again, you have exemption for the right to object.

[00:11:34] Portability: someone demanding that you move or you give data. Your data controller passes their personal data onto another data controller directly. Again, can be exempt in the research context if minimum safeguards are in place; and you're not using consent or fulfillment of a contract as your lawful basis. And again it is unlikely that you'll be using either of those as a lawful basis.

[00:11:59] It's complicated, isn't it? I have gone through it, I know it's painful and I did tell you at the beginning try not to memorise all of it.

[00:12:06] Again I will reiterate, just because you have an exemption doesn't mean, necessarily, that you're going to use it. You just need to think, think clearly. What can you offer people in terms of withdrawal, in terms of informing them if things change, in terms of access to their data, in terms of correcting data, really think it through.

[00:12:29] There are a few questions I think you can ask yourself, in general. Will upholding the right render impossible or seriously impair your research, did keep cropping up over and over again. Will upholding the right cause distress to participants. And again this is not just the legal things, it’s also when you may, or may not, wish to use an exemption. If it's going to cause distress, even though legally you can, you may choose not to ‘cos you don't want to cause distress. Is upholding the right simply not possible, you just cannot do it, it's just not possible. Are you going to publish identifiable data; and is your study in the public interest, which you can demonstrate, the chances are that yes it is, and yes you can, you've got ethics approval, whatever.

[00:13:13] The big message is do not make any decisions about this on your own. As a researcher your Data Protection Officer will be working hard on exemptions. You should speak to your Data Protection Officer and with your research governance office and make sure that you're really clear, organisationally, what it is your data controller can offer, can't offer, what exemptions they are willing to extend, what they're not.

[00:13:38] I really would encourage you to start thinking about what withdrawal really looks like and to inform people of that, upfront in your transparency information. You've got to use best endeavours to inform people of what their rights are likely to be, and what access to the rights you really can offer them. And be fair, so don't promise things you can't deliver, only promise what you can, be really upfront and honest about it. If people don't like the deal, they can always say ‘no’ to taking part in the research.