

TRANSCRIPT: Module summary, ECR module

JULIA DOETSCH

Hello everyone, welcome back. So now we have a session on discussing the outputs and the learning points that we have learned so far.

So, the first question to everyone, what did we learn from the demonstration project?

HELEN COLLINS

Well, this was the first project that we carried out using the data nodes. So as well as the analysis, an important aim of the project was actually to get all of the infrastructure set up. It took us a lot of time for all of the cohorts to set up the data nodes as part of the platform. And there were a lot of technical and governance issues, which led to some unexpected delays. And we also found that because nobody had used the platform before, we had to spend quite a lot of time with the cohorts, making sure that they understood how to use the platform, how to upload their data, and how to carry out the harmonisation. And all of these steps actually took longer than we anticipated. But we've now got to a stage where a lot of the cohorts have got all of their data harmonised. And it's very exciting.

ANDREI MORGAN

I would agree, I think it is a very exciting project and it has been a whole big, long learning process. In fact, one of the other things on top of what Helen just said, was that we started trying to put this project together early in the lifecycle of RECAP Preterm, as the project was still being developed. And we had a lot of people providing input into the protocol. And so that was a nice learning process, because many people were contributing, but they didn't know each other so well at the beginning of the project and as we've continued to work together over the several years that have been involved, we've all got to know each other better and people have become more enthusiastic about participating.

And one of the really exciting things, as well, was the ability to also include the registers and to include some of the cohorts and the groups that we didn't anticipate including at the beginning of the project. And that has really, I think, come about by the fact that we all have such good working relationships together.

JOSEPHINE BILSTEEN

Yeah, I agree with, with the registers, we saw what the registers are capable of in an interplay with the cohorts. However, there are also some challenges, legally and with practically uploading the register data to the platform. So that's unfortunately not possible at the moment and will not be for all Nordic registers. However, I also think that this demonstration project, it shows that, that when you work interdisciplinary,

you can really get far, and so this is a project where we use a lot of different skills. So we have epidemiologists and people who have more technical skills, and it all had to come together in order for this demonstration project to work.

GONÇALO GONÇALVES

I agree. I think the fact that so many different people from so many different fields are involved... of course, it makes things more complicated. But it takes a lot of communication to get things done but in the end, I think it's worth it. And I guess to Helen's point about all the work that we did talking to people and making sure they knew how to do things on the platform (i.e. harmonisation) and basically just putting their data in the node. There was a lot of issues with that, and we had to solve them all. But in the end, I think, not only were we able to do what we set off to accomplish, I think it also helps in future endeavours, I would say, because the data is already there and so you can just come up with some other research question and just do it all over again, except the boring parts and the difficult parts, which were actually setting up the data. So I think it's a huge advantage that we did this, not only for this project, but for the future as well.

JULIA DOETSCH

Okay, thank you everyone, for your answers.

So next question, how can you start new collaborative research projects?

ANDREI MORGAN

Actually, I want to refer back to the point that Gonçalo just made, a minute ago. And I think one of the key things that has been evident, has been communication, and we've established very good communication. We've done that in the Early Career Researchers group and we've done it across RECAP Preterm. And we've had several different ways of communicating with each other using forums, using mailing lists, using in person meetings, we've exchanged telephone calls... it's been really fantastic and I think the relationships and the communication that we've developed to facilitate those relationships have really helped manage the collaborative working that we wanted to achieve.

HELEN COLLINS

I'd also refer back to something that Gonçalo said, which is that now the data is actually on the platform and there are quite a few harmonised variables that can be used for new collaborative research projects. So the starting point should be to look at the RECAP Preterm data platform, look at the data that's available and get in contact with the cohorts. Communication is obviously important, but also the data is there, so it's ready to be used.

GONÇALO GONÇALVES

Also, from a more practical point of view... this is something we haven't really explored but I think we will in the future. It is a feature of the platform of actually making data access requests and creating new research initiatives on the platform, referencing the data that you'd like to have access to and why and explain your project. So that's something I'm certain we'll look into in the future.

JOSEPHINE BILSTEEN

And in the data platform, you can also find metadata for the Nordic registers and I would encourage you to be in contact with people who are skilled in register research in the Nordic countries participating here, but also other countries if you want to work more closely.

JULIA DOETSCH

Okay. Thank you, everyone.