



Dorota:

Hi, my name is Dorota and I'm a research fellow at The Hub and I work alongside the team of co-researchers. We co-analysed the data together.

Lizzie:

Hi, my name is Lizzie. I am a co-researcher. And when we asked so many people what they thought about questions that we had to ask them, we got so much feedback and so many people answered our questions. We'd just like to say thank you to all the people that answered them.

Mick:

Hi, I am Professor Mick Grierson, and I am research leader at the UAL Creative Computing Institute. And I am a core team member at the Heart n Soul at The Hub project as part of the Wellcome Hub. And I worked with Dorota a lot to try and put together a process that would allow us to do this work.

Dorota:

I'm so proud of the team when we watch this together now, how we began the project and where we are at now. Mick, isn't it like your dream that all co-researchers will be talking about machine learning approaches on their own terms?

Mick:

It's extraordinarily satisfying. It's extraordinarily satisfying. I couldn't believe it. I still can't believe it. It's amazing. So many incredible things were said in the video, much more than I could ever have hoped for,

because obviously my role has been to help kind of create an environment and a space and to kind of almost to try to help set things up, and then to step back and to see how it developed. And to see that the process worked and that people enjoyed the process and that stuff came out the other end, also that everybody really understands. It was clear from watching the video, everybody really understands what they were doing and was really into it. It can't have been easy, right?

So Lizzie what do you think were the biggest problems? Or what were some of the problems?

Lizzie:

Getting my head around the graphs, like the different numbers. And then getting my head around how I wanted to explain it. And I didn't know how I wanted to explain it. And then Mark came up with a bright idea. Mark said, "Why don't you do it in a song?" And then me, Pino and Mark S got together and we did it in a song.

Mick:

It's not very often in research that people use creative ideas to explore and to understand and analyse things. How does being creative with the process help you? Is it possible to say how it helps?

Lizzie:

Freedom.

Mick:

It's the freedom?

Lizzie:

It gives us another type of freedom. It gives us another type of voice, doing it with art or doing it with music or doing it being creative. Yeah, it's much more effective with me. Though I'm very good at speaking and explaining myself, but doing it through music, I don't have to because the music just speaks for itself. We done plasticine models as well, making different scenarios with the plasticine is really cool.

Mick:

So it was kind of a way to visualise. It's interesting that because we do that all the time in research. I do it all the time, but we don't use plasticine.

Lizzie:

Showing the people the sheets (paper) that we done and bringing them to the conference, that was a big thing to do. Really important.

Mick:

I think, to be honest, that there aren't many conferences where they're listening to people in your position, Lizzie, and in the whole co-research group. There aren't many conferences where they're listening to the things that people in your position say. So it was a privilege to be able to help that happen and make that happen.

Lizzie:

Yeah.

Mick:

And to hear your voice in those environments. What you were saying earlier about the way that you use creative tools.

Lizzie:

Uh-huh (affirmative).

Mick:

I think that's really cool because the truth is, in all forms of science, my experience is that it's those creative tools that really help everyone understand what the data is. In analysis, it's when you see graphs that you get a chance to really understand what's happening. But sometimes those graphs aren't very good. So some of the graphs that you made in the co-research group, they look amazing because they show a different perspective on the data. And it's not just me. I think a lot of academics think it's really valuable.

Lizzie:

I know it matters because we get our voice heard.

Mick:

Yep.

Lizzie:

It's an amazing gift that we've got, that we can be someone else's tool. It's an amazing gift.

Mick:

Do you think understanding how people live their lives is important?

Lizzie:

Oh yeah. Yeah. It's important that we know how people live their lives, and we know how easy or how difficult it is for people.

Mick:

Dorota, I want to ask you, in terms of the perspectives that Lizzie's talking about, how did they become findings? Because you're a researcher, you've done loads of work. Everyone's working together, analysing the data. How did you end up at findings? This word findings is the stuff that you uncover.

Dorota:

I think it all started with this idea of me kind of showing to co-researchers data science and data outputs that we received based on our survey responses. So we started pretty much with a high bar, where we would be looking at bar charts, graphs that any researcher would be looking at.

Mick:

Yeah.

Dorota:

I think that that was the starting point. And then we needed to make sure that everybody can be involved in this conversation of what makes sense, what doesn't make sense, why do we even have to talk about this? The question wasn't really about how to make sure that we can translate a specific graph to something that the public can like or understand better, but I think it was this internal question for us where

we got to the point that co-researchers and, for example, I remember Ifeoma said, "What do I do with this?" And I said to Ife, "Do whatever you want with this." And she's like, "Oh, but I didn't understand the details of it and the numbers and the height." And to be honest, once we started from that position, do whatever you want with this. Just redesign it, recreate out of that. That was very the key moment for me as the researcher. I think for you guys, as co-researchers, when you had freedom to do whatever you want with this scientific data information.

I think that, of course, we needed to use data science approaches in order to somewhat make sense out of this data. And that was our goal from the beginning of the project. I think that we realised that we are receiving many, many responses. Not tens, not hundreds, but around 2000, lets say, for survey number one. And, of course, this is the time when we have to think about the methods of how to analyse it. And we also have to consider accessibility and inclusion behind it.

So in fact, when you think about how to consolidate this information to something simpler, machine learning approaches helped us to do so. Even a simple thing, such as looking at the word cloud, which Robyn nicely explains in this video, helped us to start looking at these responses in this kind of nutshell of a word cloud. And in fact, it helped us also to hypothesize, okay, so this is the word cloud. These are the keywords that people talk about. What do we think it can mean? What does it mean to us? And from this kind of very basic data science principle of a word cloud, we could move on then to co-analyse and interpret the most representative responses and getting to more complex issues around that.

Lizzie:

Once I knew how the word cloud worked, it was pretty easy with the words that we had to put them into sentences. It became into like a game with us type of thing. What we would think that word actually meant.

Mick:

David said this thing in the film about taking control of data, taking control of their own data, and also doing the data analysis. I felt really moved by that.

Lizzie:

The person that's got the disability or, yeah, they take control. And it's about them basically. It's about them,

Mick:

And it should be that way.

Lizzie:

And we'll get there one day. Now, just wonder what they would think.

Mick:

I think everyone would want to hear what they think.

Lizzie:

Yeah. Yeah. They have a voice too.

Mick:

That would be the best thing.

Lizzie:



That will be an achievement if we did that.