SWDTP Webinar Using co-produced data in the doctorate-20260519_120122UTC-Meeting Recording

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1h 2m 13s

Jonathan Chow 0:03

Hello.

Apologies for the slightly late start. Hopefully we'll catch up. Last of our sessions in this series today feels like a big moment. So thank you in advance for all of you who have joined us. Today we're looking at co-produced data.

specifically in the doctorate. So 2 really great presentations coming up. If you've been to one of these before, you know how it works. We don't use the chat function, but we use the Q&A function. So feel free to leave your questions in the Q&A.

Kate Matzopoulos 0:26

Okay.

Jonathan Chow 0:43

section throughout the session. If you'd like to ask your question by using your mic, then please feel free to use your virtual hand. We will have 20 minutes for each presentation and there'll be 5 minutes after each presentation for questions.

The there will be there will be captions available. Just be mindful that they are automatically generated. Without further ado, I think I will now introduce our first speaker, who is Kate Matzopoulos from Bath, are you?

I'm not prepared yet. So, Kate, over to you from University Park.

Kate Matzopoulos 1:28

Thank you so much, Jonathan. And thank you, Angeline, for sharing my slides for me. I'm having some internet issues and both Jonathan and Angeline have offered to assist.

In that regard, so, as soon as...

Thank you so much.

So.

Thank you for joining me today. And as you might have seen earlier, I am going to be talking about the value of doing a pilot study prior to doing the main research. So

this presentation looks at the value of that.
And when I was thinking about this and thinking about my own work, I was thinking about how, as I've moved deeper into indigenous methodologies and decolonial thinking, I've become more attentive to the ongoing
ramifications of colonial histories that are embedded within research language itself. And therefore, I have started moving away from using the word pilot study and speaking more about relational grounding instead. So as I move through this presentation,
when you hear me saying relational grounding, I'm speaking about a pilot study really. I skipped past all introductions. I should have said that my research is situated in Namibia, in Norma. It's a small village that is
and northeast of Namibia. I work with an indigenous group of people called the Junwasi people who have become very dear to me. I've been working with them for five years now. Angeline, we can go to the next slide, please.
So, you know, when looking at relational grounding, at one point I was calling it a pre-grounding and now I'm calling it relational grounding. You know, I became to, I quickly realised that the methodological tools that I have inherited from
Western educational research couldn't be applied to the community as ready-made instruments. So as touched on earlier, indigenous and decolonial methodologies remain underrepresented within educational research. And this is what initially prompted
a period of pre-grounding or relational grounding prior to the research itself. So however, over time, this grounding came to be understood not as something separate from the research, but essential to it. So, you know, sometimes if you're doing a pilot study or a relational grounding, you could think of it in a linear
way where you first do this and then you do the actual research. But I found that the pilot study or the relational grounding itself was an essential part to the research. And in many ways, the lack of prior research done
with this community in terms of educational research became a gift rather than a limitation to my research because it pushed me away from relying solely on external and imposed methodological frameworks and helped me move towards learning from within the community itself.
from the relationships that are formed through daily life and from knowledge systems themselves. And just figuring out together with the community how research could be carried out ethically and within an indigenous and decolonial framing.

Alongside this, I also drew from broader indigenous scholarship beyond the immediate context in which I work. And rather than treating this uncertainty as a failure or feeling insecure, the grounding revealed that this uncertainty can be really productive.
because it became an opening for listening and for forming relations with the people I am working with, and also made me more responsive to life as a methodology itself.
Thanks, Angeline. So, what pilot studies are usually framed as, or what they are used for, is to test methods so that we can cheque the feasibility of the methods, and then we find the tools that we use when doing those, when doing the research, and therefore reducing risks when
you doing a larger research project so that you know that, oh, well, this failed earlier, so I'm not going to use that again, or this worked really well, or maybe I can just tweak this a little bit and then it's going to be better when I do the actual thing. But within decolonial and indigenous research, relational grounding does something more than this. It becomes a way in which, as I said earlier, relationships can be formed and in which
responsibilities towards each other, yourself, towards the people that you work with and them towards you, because you very much become part of, or I did, very much become part of the community that I was working in. So figuring out the relationships and the ethics around that within the research,
setting is something that began to emerge. And this only was able to take place because of the grounding that had happened. And I might add that my project has been an ongoing project for five years now.
So it's very, very grounded in daily lives and within relationships that I have formed with the people in Norma.
So the pilot as a relational groundwork, over here we can say that, you know, relationality is not just an add-on. It's not just a nice thing to add or to have.
it becomes a methodological necessity. You know, the or the sand people in general have are one of the most researched people in the world documented anthropologically, but not, as I said earlier, through education.
know, research. So forming a relationship with people and not, you know, again, objectifying them and extracting from their actual lives to discuss in places such as this, I feel is very important for to be an ethical researcher and just
to be, you know, human with other people. So the work that I did is grounded in and

emerges through relationships. Within indigenous and decolonial approaches, knowledge does not sit outside of relationships, waiting to be collective. The relationship itself becomes a condition through which knowledge can emerge ethically and meaningfully.
So, you know, life is really short and there's so many ways in which we can choose to live it or research it. So for me, there's very little point to doing this kind of work, which is difficult work if there are no relations within that, if you're not doing it together with friends.
And it makes complete sense to be friends with the people that you are working with. And in my case, these are in the picture, you can see it, some of the people I work with here. So with relationships, all of the unnecessary formalities
start to fall away and people can move together more openly and more honestly and more responsive, like be more responsive to things that are happening around us. So rather than sitting outside the research process as a distant observer, we're able to sit together within the heart of the work itself.
And it's through this grounding that research questions shifted, that methods changed, and that work became increasingly shaped through the relation rather than prior methodological design. And I feel that this is very, very important to do.
in a setting that is, you know, where so many different things happen constantly. And there are very many difficult things to navigate. So it is very important to be able to be responsive to these situations and to be and to be able to respond to them together with the people.
all that you're working with. So with the research emerging through relationships, it allowed research to shift daily. It released the need to fit into methodological categories. It helped the methodology to be open.
and it helps me as a researcher to move away from extraction.
And to be able to do this, you need to have a lot of trust between yourself and the people you work with. And this is exactly why grounding is so important.
So...
Relational grounding revealed that methodological certainty itself can become a colonial impulse. The desire to know in advance what research will look like, how knowledge will appear, and how people will participate. It makes evidence how models employed by Western research logics, even those
that are anti-colonial in nature or those reaching towards developmental aspirations. If they still encourage outside of framing, they still rely on categorization or pre-

designed methods or are drawn from deficit assumptions made about
people outside of so-called developed nations. So grounding in relationality enables working without these framings and a move away from extraction for academic consumption. Because when you hold someone dear to you and they become
like your mother or like your sister, like your brother, then it becomes a bit more difficult for you to speak of them in a sort of abstract and objectified way and you treat them as another human being. And that is the whole purpose of decolonial work.
I think.
And this is really what working from the inside out is about for me. You know, the inside being, I guess, I mean, you could term it like, oh, insider, outsider if you wanted to, but I think it goes beyond that because
It's just about really working with...
with tools and with knowledge that is endemic to the community that you are working with and creating a pilot study or not a pilot study or relational grounding from that itself. And to be able to do that,
you need to be able to form the relations with people to get to that level of trust and to be able to now work to emerge from Indigenous worlds themselves. So working from the inside out means
As you can see these bullet points here, it's about relational accountability. So being accountable not only to the institution in terms of ethics, paperwork that we need to fill in, but being accountable to the people that
you are doing the work with and for. And it allows, grounding also allows knowledge to emerge from the community's ways of being. And it permits one to refuse research that is
shaped from.
external forces and allows you to work from within the community itself. And grounding also means that you are able to make the project community led and refuse outside of framings that would
frame communities like Norma in deficit terms or see their ways of being and knowing as less than or not knowledge at all.
So this is what I found was possible or was made possible through the grounding, pre-grounding, relational grounding that I carried out prior to the main Phd study. And when I say prior, I mean
It's constantly ongoing all the time. It's an ongoing relation as you would have with

anyone else in your life, I suppose, who you value.
So just to close, I might have skipped through that really quickly, but relational grounding, it did not really only simply prepare me for later research. It enabled me to transform the research itself.
It shifted my understanding of methodology from something designed in advance to something that is lived relationally. In a sense, the grounding was not outside the research process. It was the beginning of learning how to research differently. And it's only through my relation with
with this community that I was able to learn that. I was able to learn what it means to share. I was able to learn.
how knowledge is done differently, I was able to learn how to research differently as they research in their daily lives. And I would not have come to that understanding or that knowing at all had I not built a relation with them.
And this is what a grounding, a relational grounding or.
In Western terms, a pilot study helped me achieve.
Thank you so much.

Jonathan Chow 17:17
Fantastic. Thank you so much, Kate. We've already got a question come in, so I'm going to jump straight into it as you receive your virtual applauses and hearts. This question comes from Wem, who's interested to know how you framed the project when explaining to the community before you started, especially since
Your relational grounding approach meant that your research questions and methods would be flexible and liable to change, and Wem is thinking that they might be in a similar situation, but with children in a forest school community for their research.

Kate Matzopoulos 17:54
Yeah, so initially when I went five years ago, I was interested in developing a learning framework in which a decolonial curriculum is inside, because at the time I was thinking there's no point in
in creating a decolonized curriculum if the framework is still Western. So when I went to the community, I followed, I guess you could call it protocols, although they don't call it protocols, but I suppose in Western talk, you can call it protocols or in North American,

Indigenous literature call it following protocols. So I followed the protocols of the community and I explained what I was hoping to achieve. And in turn, they talked to me about what they were hoping to achieve in terms of education for themselves within their community.
And like this, we were able to bring our thinking together. So it wasn't so much where I had to explain so much, like, this is how I'm framing the project. It was, this is what I'm looking at. And then they would say, well, this is what we're looking at. And then together,
we framed what has happened up until this point, which is now we have a framework and we're working towards a curriculum and we have a tool now where school is happening every day.
in an indigenous style. So yeah, that's how we framed it together.

JC **Jonathan Chow** 19:35
I see. So even the kind of scoping exercise in itself is kind of co-produced, isn't it?

KM **Kate Matzopoulos** 19:42
Yeah, everything is together.

JC **Jonathan Chow** 19:42
Cool. We've got, yeah, we've got a hand up from Kristen. I'm just going to allow you to unmute now, Kristen. There you go.

KB **Kristen Hope Burchill** 19:54
Hello, can you hear me?

KM **Kate Matzopoulos** 19:55
Yeah.

JC **Jonathan Chow** 19:56
Yes.

KM **Kate Matzopoulos** 19:56
Yes.

Kristen Hope Burchill 19:57

Hi. Hi. Well done, Kate. Thank you for this presentation. It's really compelling. My question is about, I mean, overall, like where would, in what context might you say that there's also limits to relationality? So the reason I'm asking this, my research is I'm in Cairo at the moment doing research with adolescents from Gaza who have fled since the start of the genocide. And we know in the context of, for example, international development, that a lot of saviourist behaviours can come from this idea, well,

you know, like for example, like adopting children, like who are like, you know, who have been displaced or, you know, by war, that this sort of saviourism can come about because we're like, oh, they could be like my child. You know, so, because this came to mind when I was listening to you speak about what we have to think about, you know, maybe people that we're researching with, there's like family members and friends, but like,

I guess I'm kind of trying to probe a bit more around, like, in some ways, can that be problematic and lead to problematic, you know, like, say, saviourist approaches? And also then when might there be limits? Like, you know, for example, I'm working with, you know, actually girls who are the same age as my own daughter, who is

actually back in the UK while I'm doing this research. And, you know, so, you know, I guess, yeah, again, what, where might there be limits to these kind of, you know, framing our relationships with people we're researching with in terms of these kind of, you know,

in more in interpersonal and intimate kind of family relationships, given that, yeah, I mean, these, the young people I'm working with, even though they're, you know, incredible, they will never be my child and I would never want to be their parent. You know, I, some of them have been orphans, some of their parents are dead in Gaza. and they speak to me about how they want to go back and see their graves. I can never, as a researcher, ever dare to step into that, assuming that I could be that for them. And so, yeah, this is all very raw for me, so I'm getting quite emotional because this is what I'm hearing. But I wondered if you had any kind of thoughts about those things.

Thank you.

Kate Matzopoulos 22:14

Thank you so much, Kristen. Yeah, I can really appreciate what you're saying and I can appreciate
the sense that you would never want to step into such a role because it's a really big responsibility to take on and it's not something that you would want to film anyway, maybe. I think with forming relation with people, it's not something that, well, when you say
saviourist, you know, approach. That I feel is something that is imposed on people. Forming a relation with people is something that comes from two sides. It's not someone that steps in and says, I am here to save you. That is very different from when you are in together with someone for a long time and and together you establish a relationship with each other through many events that have taken place. So I think I think for me that that is the difference where, you know, when you're coming in saying,
I'm here to save you, and that's not that's not what I believe relationality is.
I hope that answers your question.

JC **Jonathan Chow** 23:40
Thanks, Kate. I have a question while we wait for any other further questions. So, my undergraduate was actually in anthropology. So, the names Joanna and the Sun are familiar names to me as subjects in

KM **Kate Matzopoulos** 23:45
Yeah.
Yeah.
Oh.

JC **Jonathan Chow** 23:59
Western anthropological research. I wonder if, partly because they are such historically like extensively researched people, I wonder if they have any kind of preconceptions of what being approached by Western researchers is like.

KM **Kate Matzopoulos** 24:02
Mhm.

JC **Jonathan Chow** 24:19

whether that has been a challenge for you and perhaps also whether by adopting a more kind of co-produced approach, whether that's something that's new to them and whether there's been any kind of adjustments, interesting kind of relationships there that are new to you, to them.

Kate Matzopoulos 24:38

Yeah, that has definitely come up. The community that I work with, many San people work in tourism. I mean, and that's just outside of research. And many of them see research as a viable way in which to generate income for their families.
So it is something that they are familiar with and something that they negotiate often in their lives. I mean, even in Namibia, there are things called a living museum where some people are
while they paid essentially to dress up in their traditional clothes and pretend that they are like living a life that they might have done many, many years ago. And people come and, you know, view them doing that. So
Yeah, they're very used to.
to navigating the space. It is something that I had to work through, you know, with their understanding of who I am as a person and who I am as a researcher, which I think is why relationality, again, is so important because
When getting to know me outside of a preconceived idea of what a researcher is and what a researcher does, they were able to, or I believe they were able to approach the work differently.
because we were doing it together. And because we were, we found ourselves in situations where our collective work required me to open my home in the same way that they have opened their home to me. And yeah,
So that just created opportunities for them to have an insider view in my into my world as in the same way that I have into theirs. And I feel that that has made the process more ethical. And I feel that it's made it
is more manageable and also more honest and realistic in terms of their expectations as well as my own.
I hope that answers your question too, Jonathan.

Jonathan Chow 27:09

Beautiful. Thank you, Kate. I'll just, we'll take one more question. Quite a long question. Let's see. This is Britain E. I don't know if Britain is your first or last name,

but I'm a music therapist and did a project in Ethiopia. Music therapy is all based on relationality within relationships, and I use this approach when in Ethiopia.

Kate Matzopoulos 27:09
Beck.

Jonathan Chow 27:33
I was working with a different client group, including those in hospice care and mental health institutions. This caused difficult scenarios in terms of that relational aspect. And I wondered, although I appreciate the differences in client group, whether you had to manage any conflicting ethical issues and how you manage these either in the ethics process or in undertaking the research.

Kate Matzopoulos 27:51
Yeah.

Jonathan Chow 27:53
Yeah.

Kate Matzopoulos 27:56
Like the ethics process, you mean with the university itself?

Jonathan Chow 28:01
Yeah, kind of, yeah, in the within kind of, yeah, getting, yeah, the research past ethics.

Kate Matzopoulos 28:04
Yeah.
Yeah, so, yeah, yeah, to get past the ethics. I mean, thankfully, there are many indigenous scholars that have done work in this regard prior to me. So I have been able to reference their work in my application, in my ethics
application to the university. And I've been able, because of the grounding work that I've done prior to doing my Phd, for example, I have a lot to draw on to explain the dynamics within the community and also the
the dynamics of the research itself. And with that, I don't want to call it evidence, but with that knowledge and together with literature from other academics that work in

this way, I have been able to
Um...
I don't know, put at ease the ethical requirements of the university where I'm able to meet their standards and their demands, but then at the same time work in a way that is authentic and true to the community too. Hasn't been easy, but it was done.

JC **Jonathan Chow** 29:28
Cool. I'll just allow Emma to unmute. I assume it's a follow-up question. Emma, you're able to unmute now.

BE **BRITTON E. (2375224)** 29:40
Firstly, Kate and Jonathan, I come across in writing very bad. And what I meant more so, Kate, was around the ethical dilemmas of having that friendship type approach. Did that cause any problems in terms of things like safeguarding or

KM **Kate Matzopoulos** 29:53
Mm.

BE **BRITTON E. (2375224)** 29:59
any issues in terms of interacting and being that.
that companion almost to the people that you were working with, rather than working, I don't want to say on, but working, rather than being the researcher and a client, you are, you've got that lovely relationship of

KM **Kate Matzopoulos** 30:11
Yeah.
Yeah.

BE **BRITTON E. (2375224)** 30:24
Friendship.
I love that idea, I love that concept. I think I'd struggle to understand how to manage those conflicting parts. That was kind of what I was going for more, so I'm so sorry.

KM **Kate Matzopoulos** 30:35
Yeah.

No, no, that's fine. So, you know, I mean, there have been times in my research where I, where I wish I had stayed, you know, more distant and where I could just say, well, you know, this has got nothing to do with me. I'm just here to collect this information and then I'm going to leave.
it would be so much easier and cleaner to work that way. There's been so many moments, but then my work wouldn't be half as rewarding or rich as it has become. And also, I think that for me, when I am working with people,
regardless of the setting that I work with them in, I really do value friendship. And I really do value, you know, human to human connection. So even though it does get get tricky sometimes because things happen. You know, people are hungry, people die, children die.
you know, lots of bad things can happen. And when you are a friend to someone, you are together with them in those moments. Those are not moments that you step away and say, well, I'm just a researcher and I'm just like getting the information and it's nice knowing you. So you struggle through those moments together.
Because, you know, when working with people, especially marginalised people, people who are as marginalised as the community that I work with are.
They really are sharing their lives with you. And it's not something that you can just go in and like get a survey off of or, you know, interview someone. They're sharing their actual life with you. And then for you to, for me as a person, then to feel comfortable with someone sharing their
their life with me, you know, opening their home to me. If you can imagine that, you know, someone coming into your house, your actual house, and like living there and, you know, watching your every moment of your, you know, and like working together with you in everything and sharing so openly with them and then
the moment something goes wrong for you, that person who you've shared absolutely everything with then turns around and says, well, no, I'm just here to get this information and so sorry about that. And then you close the door. It just doesn't sit very well with me as a person. And
That is why I choose to work how I do. It's for me, it's just a more ethical and it's a better way for me. And that's not to say that I discredit other ways of working or that I think that working in a more distant way or separate way is not good.
It's just not good for what I am trying to achieve, which is a co-creation of a decolonized and indigenous curriculum. And that entails, you know, incorporating their worldview and their

their way of being, their ontology and their epistemology within the curriculum itself. And that would require me to place myself within that too, rather than observe it from from afar.
because then I would lose half the information when some of the indigenous ontologies don't fit neatly within the framework of an outsider, if that makes sense. So it's essential. It's not easy. It is tricky. You know, lots of times I wish I didn't, but I did and I'm glad I have.

Jonathan Chow 34:31
Hey.
Thanks, Kate. Yeah, great. I acknowledge Helen's question, but I think I'll save that for later. And if anything, it might also be a question that Louise might want to respond to in the context of her presentation. But yeah, what I'll do is I'll now pass over to Louise.
Louise, would you like to try and share your screen again or would you like us to just share it for you?

Louise Toller 35:06
I'll have a go.


Angeline Mbogo Barrett 35:06
Process of sharing it.

Louise Toller 35:09
Hopefully.
Can you see that?

Jonathan Chow 35:15
Yes, yes we can.

Louise Toller 35:17
Brilliant. Okay.
No.
All right, so my title today is quite narrow. It's about a specific method I used in a very specific topic area, but my aims today are broader than just telling you about

what I specifically did. So
So I want to encourage you to think outside the box when it comes to the methods you use when you're designing your study. And I also want to highlight that it's okay to not know exactly what you're doing when you start. Excuse me. I learned from doing a pilot study, I definitely didn't know what I was doing before that.
but then I also continued to learn throughout the process of doing my research. So I want to offer you some insight into my experience of this. So I'm going to start off with a very brief overview of my Phd project and then move straight into talking about methods. So I'll talk about why I decided to use visual methods.
and then move on to the main focus, which is my pilot study. So I'll cover why I did a pilot, what I wanted to achieve, what I actually did for this pilot, how it went in relation to my objectives, and then the changes that I made to my methods as a result of this. My Phd research investigated the lived experiences of young adults with the chronic illness ME, also known as chronic
fatigue syndrome. So this is a serious, complex but contested illness of currently unknown cause, characterised by severe fatigue and a wide range of other symptoms, including things like pain and brain fog, which fluctuate unpredictably and increase following activity. It's also not readily visibly apparent
And when sufferers are at their worst, they may be housebound or even bedbound, so tend to disappear from society. So these aspects of their experience aren't seen by many people. My study had three phases. First, I carried out episodic interviews. If you're not familiar with these, they're similar to semi-structured in that you followed follow a guide, but their key feature is that you explicitly ask for specific experiences to illustrate each answer. So you're keeping your data really grounded in your participants' actual experiences rather than abstract things. Then participants took photos about their lives and wrote accompanying captions.
And then we discussed these photos and the process of taking them in a second interview.
So why did I decide to use visual methods? Well, I came into my Phd having only carried out sort of standard verbal interviews and really the main reason was that I actually wanted to try something new so that this research wasn't wholly based around words. In my early reading, I came across this paper on the experiences of young women with serious and chronic illnesses that also happened to use participant
generated photos. And I thought it looked like it might be something interesting to

try. So I did a bit more reading about it. And this reading suggested that actually this could also really suit my participants and what I was trying to research with them. So literature suggested that photos can capture otherwise inaccessible aspects of experience.
things that the researcher might overlook and not think to ask about, things that are hard to articulate verbally or that happen in private times and spaces. If voters are taken over a period of time, they can show change over this time, such as over a course of treatment or during recovery. They can capture a moment in real time, rather than relying entirely on retrospective recall like interviews tend to do, and can encapsulate really detailed stories about what's pictured and the context that the image was taken in. They can ground data in participants' everyday lives and worlds, making it visible to you. And finally, they can give
participants greater control over the direction and content of the research and how they're represented, although this isn't a given, which I will address a little later.
There are also limitations in using visual methods in the literature. So some things can be hard to represent visually, such as how symptoms feel. Photos can be hard to interpret, the meaning may not be obvious, or you might not interpret a photo how the photographer intended it.
to be interpreted. Participants may not be able to take all the photos they want, or there might be photos they don't want to take, so things are missing. And these points all suggest that the words relating to photos are also important, so it's not just about the images. A point made in several studies using photos specifically about illness
is that these photos can be boring or mundane, but the conversation surrounding these photos can again reveal deeper meaning and offer insight into aspects of illness experience that are boring but still significant. So one paper gave the example of a photo of the view from a sofa.
which looks uninteresting and doesn't really seem to reveal anything about illness, but it can reveal the significance of having to rest a lot while ill. So in the case of my particular research with participants who have very limited energy, this could actually be a really big benefit.
So I decided that yes, I did want to get my participants to take photos, but I really had no idea what I was doing. Published papers often lack practical details about this, and my supervisors also had no experience using visual methods. So I decided to pilot just the photo-based parts of the study, so the

photo diary and then the interview afterwards. I had two main aims here. The first was to trial my drafted instructions for participants and get feedback on these and what the process was like. And secondly, to see what sort of data the photos generated and how it differed from what I'd expect.
to get in a standard verbal interview.
So as I suggested earlier, the instructions given to participants impact the photos that they take, just like the questions you ask influence what they talk about in interviews. So in the literature, there seem to be 3 main options for how to approach this. The first group of papers gave very broad instructions and little direction.
which reduces researcher influence and gives participants the most control, which is really good if you're trying to get at things that you perhaps wouldn't think to ask about or if it's a piece of exploratory research. But instead of being empowering, previous studies have actually found that this can lead to participants being unsure what to photograph.
The second group takes the other extreme and gives a list of very specific prompts to address or questions to answer, which means that you're likely to get really relevant data and it makes it easy to compare between different participants, but loses the participant control. And the third group
falls somewhere in between, so gives a suggested list of topics, but encourages participants to include anything. This means that you retain some control and gives participants ideas to reduce uncertainty, but it also leaves them with plenty of freedom to decide how closely to follow the suggestions and scope to include things that you haven't included.
So I went for the third option. It seemed generally the best one to me, but also specifically suited to my participants. I wanted to make it easy for people with limited energy and brain fog to participate, but I also knew there would be things that I didn't think to ask about specifically. So I wanted to spark ideas without being constraining.
Apologies for the huge amount of text on this slide, but this is the first draught of the instructions that I was going to give to participants. I generated this list of suggested topics from the literature, just like I would generate questions for an interview guide. So these are things that had come up as important in previous research on ME.
and on chronic illness or disability more generally.
So moving on to the pilot itself, my pilot participant, Emma, is someone who I knew through personal contacts who fitted my recruitment criteria. Before we started, we

chatted over e-mail about the process and what it would include. I wanted to see what she thought about my suggested time frame of two weeks.
which was to try and capture some of the fluctuations of illness without being too long or burdensome. And if a suggested number of photos would be useful. We settled on 20 to 30, as this would allow two per day and also approximated pre-digital studies using disposable cameras. I also checked that my instructions were clear.
She said they gave her enough to think about without being too overwhelming. So off she went. Now Emma took her photos and wrote captions for them and sent them to me once she was all finished and then we discussed them via Skype. So I started by asking her how she found doing the task, if I should change the instructions at all,
if the time frame and number of photos were suitable, and if she thought people would find it interesting to do. So evaluating the pilot of the photo based phase. And then I moved on to the questions that I intended to ask all my participants. So piloting the photo elicitation interview. We discussed each of her photos in turn.
I gave her the choice of doing this either chronologically or in another order, as these were both options that had been mentioned in my reading. She chose to discuss them chronologically as this refused decision making, but it also made it really easy for me to match the photos and the transcripts later. So I took this forward into the main study as well.
I had made notes about each of her photos and anything specific I wanted to ask her about them, but mostly this process was just her telling me a bit more about them. And then I finished by asking a set of more evaluative questions about the set as a whole, which was mainly aimed at mediating some of the limitations of using photos. so what it was like representing her illness experience visually, how she decided what photos to take, and if there were any missing photos.
So how did it go? Well, Emma said she found it hard to start with because her life with Emmy was just her life. She'd been ill for long enough that it was hard for her to pick out things that were specifically about living with illness because she didn't usually think like that. But she said the instructions were helpful in giving her ideas when she got stuck.
and also that it got easier as she got used to it, which suggests that both the timeframe and the list of topics were helpful. She also took at least one photo every day and actually ended up with more than she needed, so she could choose a

selection to send to me. She said that there were some missing photos, so in one of her captions she mentioned a photo she had forgotten to take.
So she had taken this one instead. And this meant that the absent photo and the experience it would have captured was still accessible to me.
So in my initial instructions, I said that I wanted to see the good, the bad and the ugly of having ME. And this worked to some extent in my pilot. Emma noted that she tried to show the fallout of activities, so the payback in terms of symptom exacerbation. But she also noted that when she was feeling worse, she often forgot to take a photo.
So the bad and the ugly aspects weren't necessarily always there. And when I asked her how well the set represented her experiences, she said it was a bit embellished and that she'd been glad it was a fortnight when she'd been doing more things than normal, so it looked less boring. She also said the set didn't show how much time she spent doing nothing.
This was present but it didn't accurately represent the significance of rest in her life and there was actually too much activity or too much good there.
So I made a few changes for my full study after this. In my instructions, I asked participants to show me the boring as well as the bad and the ugly to try and get at things they might worry were too boring to share, sort of giving them permission that this was something I was interested in, because having a chronic illness can be really quite boring, especially if you have to spend lots of time resting.
but this is also a significant part of your experience, so it's important to capture.
Related to this, I also added a question asking how well the set as a whole represented how participants actually spend their time.
So while the main focus of the pilot was checking how the method worked in practice, I was also interested to see if the data generated was different to what I would expect to get from an ordinary verbal interview. And it did seem to be different to me. So some of Emma's photos captured very specific experiences and they really did act
act as memory prompts. One showed a train ride and while she spoke generally about the importance of public transport in getting her around and giving her greater freedom because she didn't drive, she also recalled that specific day. So where she was going, what she was wearing, who she was meeting and how she felt in great detail. I'm not sure I would have got that in a regular interview.
There were also things that I wouldn't have thought to ask about, so she took a

photo of her hair freshly dyed in bright colours and spoke about how dyeing her hair made her feel more herself and like she was making more of an effort with her appearance, which added little details to the picture that I got of her life.
And yes, many of her photos were apparently boring, even if she'd been worried about not wanting it to be boring. So there were photos of her, what she called her typical setup in bed with her laptop where she spent most of her time. But just because these things are mundane, it doesn't make them any less significant than the photos of times that she left the house.
which she didn't actually do very often. And I actually argue that these were made more meaningful, not less because of this.
So what do I want to take you to take away from this? One, be comfortable stepping outside your comfort zone when it comes to your methods. Don't just automatically use a method that you're familiar with or that is most commonly used in your discipline or your topic area. I'm not encouraging you to use different methods just for the sake of it.
but think about your research, your aims and your participants. What is it that you are trying to get at and how might you be able to do that? Two, there are things you can only learn from doing, not from preparing. I did an awful lot of reading before my pilot and I still went in not really knowing how it was going to go or what was going to happen or if it was even going to work and give me what I was hoping. And that was quite a scary place to be. But I would suggest that building a pilot in dual design can really help with that. The tweaks I made after my pilot changed my research for the better, but it also just made me feel a lot more comfortable with what I was doing. And actually receiving participants photos and then talking about them turned out to be my favourite part of the research process.

Angeline Mbogo Barrett 50:28
Ohh.

LT

Louise Toller 50:46
And finally, be open to data that isn't quite what you expected. Obviously, this is something that can happen with any method, but for me, it especially came from the photos. There were plenty that were the sort of things that I was expecting. And yes, many of these were very mundane. There were lots of photos of beds and pets and medications.

But there are also surprises. And I think methods that don't rely so heavily on your questions or prompts offer more scope for this, for getting at things that you wouldn't ask about, but that however mundane they might be are significant parts of participants' experiences. Carrying out a pilot was a really key part of the process of me gathering this mundane data.
I wouldn't have known what might have been missing had I not had that discussion with Emma and the mundane in life with chronic illness turned out to be something significant and that especially came up in my photo related data. I want to leave you with a photo from one of my participants in my full study.
that I think illustrates some of this. So most of my participants captions were a sentence or two elaborating on what was in their photos and giving me an idea of why they'd taken them. But Jessica's were all just one or two word labels. And some were quite obvious like tests or wheelchair, but others were much less so like this one.
And all I had here was the photo and the word fork. I guessed it must be related to food, but that was as far as I managed to get. But for Jessica, when we came to talk about this photo, it was an illustration of how severe ME can be and how people often don't realise this, because at one point in her illness, she wasn't physically able to lift a fork.
It was too heavy and she couldn't grip it. So she had to be fed by someone. And even then she needed to be held up and she said that chewing was like a workout. It also showed the progress that she'd made because most of the time now, while she couldn't prepare meals herself, she could eat them. And all of this was encapsulated in a photo of a fork, which I
certainly could never have anticipated and I'm not sure how I would have phrased a question to ask about that.
And there's some references for you, so thank you very much.

Jonathan Chow 53:06
Thank you very much, Louise. That was great. I remember I was on a participant active research training course once, and I remember one of the exercises we were asked to do was to do that kind of photo exercise. It was only to take one picture or whatever of three pictures. But yeah, it made me think A lot.

Louise Toller 53:21
Mm.

Jonathan Chow 53:25
I think it gave me a lot of a lot more agency to think quite consciously about what I how I wanted to represent my experience. But anyway, we have a question from Lindsay, who is interested in using photo voice with autistic children to help them share
their experience of stress during interviews. I was wondering how you could integrate the photos with the transcripts into the data analysis. I plan to use thematic analysis. Was it purely through what participants said about the photo or did you refer to the image in other ways?

Louise Toller 54:06
So a lot of it was about what had been said, but I did also try to treat the photos as data in their own right, because I didn't want it. Yeah, one of the reasons that I wanted to use the photos was to get away from it all just being about words. So I didn't want to ignore the photos in the analysis.
So I suppose I would say that I did analyse the photos. I looked at them on their own and sort of treated them like I would the words for a thematic analysis. So looking at what common themes were in the photos. But I also, when I was
carrying out my analysis on the transcripts, I looked at the photos that the words related back to. So
I think it's hard to get away from analysis of transcripts being about the words even when, you know, they're sparked by photos, but I definitely did try to include the photos there as well in their own right.

Jonathan Chow 55:09
Cool, thanks. Question from Christina. Did you find that adopting A photo voice methodology changed the direction of your research because of this being a more collaborative approach to generating data?

Louise Toller 55:23
Man.

I think so. I mean...
Tse.
I wasn't, if I take the example that I spoke about where things being sort of the mundane in life with chronic illness, that was not something that I was asking questions about. It wasn't something that I was expecting to get at. And it really mostly came up in the photo. So these were things that I wasn't
asking participants about, but that were clearly significant enough in their experiences. So I think it did in some ways change the direction because it's far more directed by what was important to the participants and what they were experiencing than what I thought might be important. So
Yes, I think it did, even though I wasn't specifically trying to be more collaborative, it was sort of built into the method.

JC **Jonathan Chow** 56:25
Thanks. Kristen was just asking for the reference slide. I've already copied and pasted the references into the comment section, but obviously we'll also be sharing slides after the session as well.

LT **Louise Toller** 56:38
I do also have many, many more references on this. So if anyone is particularly interested or would like other other references, then feel free to get in touch because I've got a lot more than are on that slide.

JC **Jonathan Chow** 56:53
Yeah, I would imagine so. Thank you, Louise. And yeah, happy to share that on afterwards. Kristen, please, you've got your hand up.
Oh, no, that's a thumbs up. Right, just while we're waiting for another question to pop up, I'm just going to post for one last time a link to our survey. And the reason why I post this every single time is it really is helpful in
making sure that the training we put on is relevant and that it is actually beneficial to you. So I really appreciate it if you could just fill that out and let me know what other training you'd like. And hopefully, whether you're SWDTP funded or not, we'd be able to offer something that interests you. But I'll take one more question now from Emma.
Yeah, Emma, you can, you can, you can unmute yourself now.

BRITTON E. (2375224) 57:52
Louise, thank you first and foremost for your research. I'm an NE diagnosed patient myself and the fork picture resonated something amazingly. I wanted to know, we can be very bad at representing the mundane aspects.

Louise Toller 58:04
Yeah.

BRITTON E. (2375224) 58:10
because there are so many. Did you manage to find out any correlation in your study around why we struggle to use the photographic aspects when we are unable to show the exciting?
parts of life, so more mundane. Was there any...
Conversations that happened that made you think.
that we, that there's a reason why we don't like to show that side more so.

Louise Toller 58:49
It wasn't really something that I was specifically talking with my participants about because I don't think I real, it wasn't something I was expecting to come across and I don't think I realised quite how prevalent it was until I was getting into my analysis. So after I'd done quite a lot of my interviews,
But there definitely seems to be this idea of...
the boring being a bad thing, we want things to, our lives to look exciting and we don't want to be thought of as being boring. That's not something that specifically came from my participants, but thinking about what Emma said, she was reluctant to show me that
her life was actually primarily quite boring, which is why she took so many photos of exciting things. So I think perhaps there is this sense that we just don't want to be thought of as boring, even though for everybody the mundane is most of our lives. And perhaps when it comes to having an illness, particularly one that is so sort of socially contested,
Um...
We don't have very much to show people and the idea of, you know,
being thought of as lazy or just not bothering because, you know, to the people on

the outside, it looks like you're not really doing anything, when in fact it's because you can't. I think there's something caught up around there in how we all want to be thought of, or society wants us to be, you know, hardworking and always active. And there's something perhaps almost embarrassing or that causes shame when you can't live up to that.
So, yes, so there is definitely a reluctance surrounding it.

Jonathan Chow 1:00:44
That's great. Thank you, Louise. Well, it's time. So thank you once again to Kate and Louise for your wonderful presentations. Lots to take away from them. And thank you so much to everyone who's joined us today or indeed in previous sessions.
So we will get the slides and we'll get the recording for the session ready and we will send you a link when that's available.
That's it for me. This is where I usually say there's more sessions coming up, but there isn't. But you can review recordings on our website. They're all available there. So once again, thank you very much, everyone. Have a good rest of your day. Bye.

Angeline Mbogo Barrett 1:01:31
Can I just come in and say a big thank you also to Jonathan for organising what's been an amazing, convening what's been an amazing webinar series. I don't think we've ever had so many webinars in a series. And they've been, some of them have been, well, they've all been quite brilliant.
So yes, thank you to all the contributors and a big thank you to Jonathan as the convener.

Jonathan Chow 1:01:57
Thank you, Angeline. No, it's been an absolute pleasure. Some really great conversations that we've had.
Thank you.
Right, thank you everyone.

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