Welcome to the Centre for Personalised Medicine podcast, where we explore the promises and pitfalls of personalised medicine and ask questions about the ethical and societal challenges it creates. I'm Rachel Horton and I'm here with Gabby Samuel, and in today's episode, we're talking about the environmental cost of personalised medicine. We're joined by Dr Susie Weller, Senior Research Fellow at the Clinical Ethics, Law and Society group at Oxford, who'll be helping me ask Gabby lots of questions about this issue.

Gabby, please could you start by telling us a bit about how you got interested in this area of the environmental cost of personalised medicine?

Sure. So most of my research to date has explored, I suppose, personalised medicine or the use of big data and artificial intelligence in the health sector. And while I was kind of conducting that research and doing interviews with a range of researchers, I've noticed that many of the guidelines that look at how to think about these issues in ethical ways, don't include questions about the sustainability of the use of the data.

So myself and a colleague at Oxford, Dr Federica Lucivero, decided that we would put in for a small British Academy grant to explore the area a little bit more and to see if ethicists could help at all in thinking through some of the issues that are related to sustainability. And we received that award, and I've subsequently received my Wellcome fellowship, that's now really focused on looking at the ethical, social, and regulatory issues associated with the environmental impacts of personalised medicine.

Thanks. It sounds like such a fascinating area. But to be honest, until I read some of your work, I just didn't really make a connection between personalised medicine and harms to the environment. Could you tell us a little bit more about that, and what the environmental costs of personalised medicine actually are?
Of course. I mean, it's not a connection that most people make at all. And I mean, there are a range of environmental impacts, but I suppose my research has focused more on the data side. So I'll just talk you through the environmental impacts associated with the data.

So personalised medicine, or some aspects of personalised medicine require the storage and collection and processing and subsequent analysis of large amounts of data. Now data is often... or the digital is often seen as something that's virtual. So if you think about the metaphors of data, data is stored in a cloud, which seems very immaterial, or you think about data streams, but actually data has physicality. And that physicality is associated with where the data is stored in data servers, which contains hardware, it contains cables, you know, large physical computers. And this has an environmental impact in terms of when you're running the data through this, this hardware, there are carbon emissions, but also in terms of like where the data centre has been set up?

So the hardware requires a lot of cooling. So there's a lot of water consumption that's related to data centres, data centres are often located in quite cold climates to try and decrease the need for cooling. But there are other biodiversity issues as well. But then there's more than just the carbon emissions that come from the use of the data. But also in terms of the mining, you need a lot of minerals to develop the data centres and the data servers and to manufacture them. So there's a mining impact as well.

And then there's a manufacturing impact. And there's a lot of carbon emissions from this, but also the development of toxic chemicals and hazardous waste from those processes, right through the lifecycle to what's called E waste, which is electronic waste. Only about 20% of E waste is regulated and the other 80% is not, so often it will be reused, perhaps in lower to middle income countries, but eventually will land in kind of like E waste dump sites. You'd see people coming in in an unregulated format, using acid baths to try and extract the minerals to try and go on and sell. And there's been a huge amount of research here that's explored the public health impacts for these individuals and the environmental impacts in terms of carcinogens being released into the environment, you know, 10 to 20 times the regulated allowed doses for these kinds of chemicals. So there's a whole range of environmental impacts that come from personalised medicine. And it's about kind of thinking about these issues, knowing that personalised medicine only uses a subset of the great digital infrastructure, and how we kind of think through those issues.

Susie Weller
4:23
Oh, that's really interesting. So I'm just wondering how much data the personalised medicine projects collect.

Gabby Samuel
4:28
We don't have enough data to look at personalised medicine projects because the environmental impact of personalised medicine hasn't been on the radar. In fact, you know, we know that sustainability has become much more of an issue in the last 10 years. So there are a few projects we can kind of look at to kind of gauge the idea.
So, UK Biobank, which stores health data on 500,000 participants in regards to their genomic data, other health data and sometimes neuroimaging data, says that in the next few years, it will require about 15 petabytes of storage. And that's just for collection and not for analysis. Because Genomics England says that the 100,000 Genomes Project in the UK, their project equals about 21 petabytes, which I think is equivalent to 40,000 years worth of listening to music. So it's quite a substantial amount of data!

And then there's been some really interesting work that's come out of Cambridge University recently, they've tried to calculate the carbon emissions associated with running genomics wide association studies. And they've said that with if you're just looking at one trait, it's the equivalent of driving a car 100 kilometres. So that's context-specific - it depends on the data centre you're using, the type of electricity that you're using and powering, whether it's renewable or not. But it kind of gives you an idea of the type of environmental impacts that come from these types of studies.

Rachel Horton
5:54
It sounds like there's an enormous amount of environmental cost behind something which doesn't obviously seem like it's going to have that environmental footprint. So it sounds like data use is a really big aspect of this. But are there other environmental costs to personalised medicine, too?

Gabby Samuel
6:10
There's a lot of other costs. And in fact, most of the research, if we're thinking about the environmental impacts of medicine more broadly, has focused on these other environmental impacts.

To give you an example, I've been doing some work with biobanks. So biobanks collect and process patient or participant samples, so blood or urine samples or saliva, and they then store those in very low temperatures for long periods of time. And they're stored in low temperatures to ensure that the quality of those samples is maintained, so that we can use them over a long period of time. But to store in their minus 80 degree freezers is incredibly energy hungry. And we need, you know, hundreds of freezers, hundreds of freezers to kind of store all of these samples. So think about UK Biobank, and it has 500,000 samples that it needs to store in this huge freezers, which again, needs to be in rooms that are cooled, which require more and more energy.

So there's a lot of work that's kind of exploring, can we increase the temperature of those freezers by 10 degrees from minus 80 to minus 70, because that has an offset on how much carbon we can save. There's a lot of tests at the moment, we're a bit worried about whether that will affect the quality. So we're just at that stage of thinking about these issues and trying to think about ways forward. Other environmental impacts have less to do with personalised medicine, but just generally in terms of research, so research labs have huge environmental impacts.
So the University of Oxford, just published a couple of weeks ago, this really interesting study that looks at the biodiversity impacts of Oxford University. And the impacts are greater for the research than it is for travel, whereas most people will think, “Oh, I'm a researcher, I'm going to try and reduce my travel”. But actually, the impacts that you know, single plastic waste, the toxic chemicals that are used in the labs, are all actually having a greater impact than travel. So there's a lot of work to be done, I think.

Susie Weller
8:06
So much to think about and comprehend really, that, as you say, Rachel, you don't necessarily associate with personalised medicine. But I wondered, how do we balance the benefits of work with healthcare data against these environmental costs?

Gabby Samuel
8:18
That's a really interesting question. And one I don't think I can answer? So I was at a workshop yesterday, which tried to bring together scholars and practitioners from digital health, so kind of personalised medicine, digital health and the health care and environmental sustainability scholars, and it's almost as if the two camps are just not really talking to each other, but we don't know how to bring them together, because how do you do those balancing acts?

And there was this call that we need to do a cost benefit analysis, but I think that's really reductionist, because you get into this polarised debate about... Well, when I did interviews, or my colleague did interviews with health researchers using UK Biobank data, they spoke about the worry about not having to worry about the environmental impacts, because their, their research was seen as intrinsically valuable. And there's a concern that if we say that something is intrinsically valuable, and requires so much benefit, that we could just maybe ignore the costs. So we need to be very careful about what that balancing means.

And I think it’s also really important because while personalised medicine has brought about benefits, real benefits, a lot of it is still promise. So if you're doing a cost benefit analysis, you're basically weighing up promises, against... or potential promises, against harms, so that complicates the matter. And then we need to think about other issues like health for whom, so who is going to benefit from personalised medicine? Very often those that are going to benefit from personalised medicine or can access personalised medicine are not the ones that are going to be most harmed by the environmental impacts of it.

And then finally, in terms of the costs, we can't measure the costs yet. So if you say “what are the environmental impacts of me running this personalised medicine project?” – we can't do that yet. There's too much contestation in the field about how to even assess carbon emissions, let alone environmental impacts, let alone water consumption, let alone everything else that's going on. And there are arguments in the field about which prediction models to use, what’s the most reliable, what’s not. So, in short, I can't answer your question, Susie. But that's what my research is trying to do at the moment, is to start to think about ethical frameworks that we can use to help guide how we conduct personalised medicine research as we move forward.
It sounds an incredibly complex and challenging area. And I guess there's also in some ways, wouldn't it have to be a societal priority rather than any one individual person being able to do much about this? I'd be really interested to hear what you think about that.

Gabby Samuel
10:52
I think you're like, totally right because from my interviews with health researchers, what I found is that some of them do want to think about environmental issues, but they feel like their hands are tied. And a lot of them would say, “Oh, well, you know, my institution is handling the data. So it's not really my issue”, or, “Well, if the funding body required me to do it, then I'd worry about it, but they don't. So I'm not really worrying about it, because I don't have to”, because we all know that we've all got different incentives, right, that we need to work towards. So I think, yeah, I think you're right, that it is... we need a more systematic approach to thinking about these issues. It's a collective responsibility.

Rachel Horton
11:32
Gabby, I think I've heard you talk before about this sort of paradox, where if you make something more efficient, people use it more. And that's got its own environmental issues. Could you tell us a bit more about that, please?

Gabby Samuel
11:44
A lot of my research is now kind of focusing on this issue, because it's the one that's most neglected in policy and also in research. And it's so complicated, because we don't know how to get around it. So it's called a rebound effect. And it basically means that, that the more efficient the digital system becomes that we have these, these rebounds, and one of the rebounds is that we can increase consumption.

So when I was talking to one of the health researcher interviewees, and we were talking about sustainability. And he said, “well, then the digital sector can make everything more efficient”. And I said, “Well, what would you do with that efficiency?” And he said, “I'll just run bigger algorithms”. So I think that really kind of highlights this rebound effect. I mean, we're doing some work in one of my other grants at the moment that's trying to figure out how best to get policymakers to take rebound effects seriously. And not just in the health sector, but more broadly, and we've come up with – they talk a lot about efficiency, it's the main thing that they talked about as a proxy for sustainability. And so we're thinking about ideas, such as saying efficiency with limits, where those limits are planetary limits, and where we become more efficient, but we don't fill that extra space with consumption. And how we move to that is, I don't know, anyone's guess. But I think we need to.
I think this is probably going to be a rather challenging question. But if you had to pick one message for people to take away from this podcast, what would it be?

**Gabby Samuel**

13:07

I think it would be that we need to move away from a techno-centric approach to thinking about sustainability. So a lot of my interviewees would say, “Well, we don’t have to worry about it, because the digital sector will worry about it.” But then when I conducted interviews with those in the digital sustainability sector, very often sustainability, well, efficiency is used as a proxy for sustainability. Right? It makes business sense as well, right? Because historically, that’s what they’ve always done, and it’s a cost issue. But by thinking in this techno-centric manner, you do ignore these rebound effects and the social dynamics that come with having increased efficiency. So it’s about… if we really want to be sustainable, we need to make some hard choices about consumption. So what do we want to do, and what do we not want to do? And I think personalised medicine, just as much as any other sector, needs to think about this very seriously.

**Rachel Horton**

14:04

Thank you so much, Gabby, that’s been incredibly thought-provoking. How can we find out more about your work?

**Gabby Samuel**

14:10

Have a look maybe on my website, either at King’s College London or University of Oxford, or follow me on Twitter, or just email me.

**Rachel Horton**

14:19

Thank you for listening to this episode of the Centre for Personalised Medicine podcast. If you’d like to find out more about personalised medicine and its promises and challenges, please visit the Centre for Personalised Medicine website at cpm.well.ox.ac.uk.