

Small Data and Big Data in the Waves of the Pandemic Building the Boat as we Sailed it

Mark Elliot: Hello, it is my great pleasure to introduce our closing keynote speaker for the festival, Trish Greenhalgh. Trish will need little introduction for many of you, but for the unacquainted she is a professor of Primary Care Health Sciences at the University of Oxford, having previously held posts at Queen Mary and UCL and also having trained as a GP. She has an OBE for Services to Medicine, and has Fellow of the UK Academy of Medical Sciences, and also Fellow of both the Royal College of Physicians and the Royal College of General Practitioners. Trisha is a prolific author with over 400 peer reviewed publications, with 35 being published in 2021 alone, which I make just shy of one a week. She has been particularly active during the COVID pandemic, bringing her interdisciplinary lens to bear on topics, including the remote assessment of patients, the science and anthropology of face coverings, and decision making in conditions of uncertainty. At Oxford, Trisha leads a programme of research at the interface between social sciences and medicine. And she is certainly one of the leading scholars in that interdisciplinary space. When I invited her to give a keynote, I was very much focused on that theme of the festival Health and Social Sciences. But as you will see, in a talk, Trish manages to touch on topics within each of the festivals themes. Her talk today describes how she and her colleagues went about her COVID research. But I think you will agree that what she has to say has much broader relevance and interest for all of us.

Trish Greenhalgh: Hello, I'm Trish Greenhalgh from the University of Oxford, it's a great pleasure to have been invited to give this talk on, at the National Centre for Social Research Methods e-festival. And the title of the talk, as you know from your programme is 'Small data and big data in the waves of the pandemic: building the boat as we sailed it'. And I got this metaphor of building the boats as we sailed it from the philosopher Otto Neurath, who of course, was part of the Vienna circle. And he said, 'We'd like sailors who have to rebuild their ship on the open sea without ever being able to dismantle it in dry dock and reconstruct it from the best components'. Well, that was in a completely different context of philosophical reasoning. But I still think the metaphor is relevant. And here we are building the boat as we sailed it, this is a sort of a timeline of what happened from the beginning of the pandemic, or at least from from about the beginning of February 2020. For one particular research project that I was involved in remote COVID assessment in primary care or recap. And you can see that for very good reasons, we were implementing remote COVID assessment in primary care from February 2020. We didn't get around to formulating our research question until after we'd started implementing this intervention. We were collecting data way before we started refining our question. We were analysing data before we wrote the grant application. And we were also writing papers before we'd formulated the question. In other words, everything was happening backwards.

The official funding period for the grants that we got, it's just coming to an end in a couple of months' time. The official funding period didn't start till July 2020, which was way too late because we needed to act immediately because of the pressures of the pandemic. Let's go back to February 2020. Do you

remember these slogans 'stay home, protect the NHS, save lives'. We've got them from the television, didn't we, every day. This was a new illness. It didn't have a name yet. And it was initially characterised as a violent pneumonia, sort of acute respiratory distress syndrome. And what we had as GPs were many, many patients, dozens, sometimes hundreds of patients phoning up the practice with respiratory symptom, with things like a cough, breathlessness, wheeze, fever, and the clinicians among, you will know, those are not particularly discriminating symptoms, you know, you get them and you got cold, for example.

There was also rapid switch to remote by default GP consultations, you had to really make the case if you wanted to be seen face-to-face. And there was a lot of pressure to keep people in the community to avoid overloading hospitals, which was what 'protect the NHS' sort of means and the social scientists, among you in particular, will sort of see that as a bit of an alarm slogan, what about if the NHS has to become patient in a way and sick people had to be kept away from the patient, so that the patient didn't get any more sick. So there's a big question around this time about how to assess people remotely.

Now, let's go back to 11th of March 2020. I remember it well, it's my birthday. And it's also the day that the pandemic was declared. And on that day, here's just one example headline, this was from the Daily Express, but all the, all the newspapers had it, the patients were told the doctor will see you now, but only by video. And in fact, what the data shows is, they didn't see people by video, they, they saw, they used the telephone. So the sort of whiz- bang idea that this was all going to happen through this futuristic video consultation. In fact, the vast majority said that 99% of these consultations were happening by telephone. Nevertheless, this was a massive organisational change. Arguably, it was the biggest and fastest change in the way services were delivered since the NHS was established in 1948.

Now, March 2020, was an extraordinary time because what I then did, I was commissioned by the British Medical Journal to write a paper for peer-reviewed paper for the BMJ in, within days, to say well, how do you assess people remotely? And I got together with two colleagues. And we did the best we could. We did some rapid reviews, there wasn't much, there was quite a bit of Chinese literature, but that was based on hospitalised patients, there wasn't much at all anywhere about how to assess people in the community. And we weren't too bothered, because we knew that a nice guideline was coming out. Rapid, nice guideline was due to come out, not long after that. But when the nice guideline appeared on the third of April, we found that they just referred back to our paper. So suddenly, having pulled this together, if that particular aspect of care, we were the nice guideline.

Now why didn't we wait until we've done some proper research? Well, you can see in the graph here, we had a quarter of a million accesses of the full-text paper on how to do remote assessment in primary care in March and the beginning of April, in other words, in the five weeks, so at the end of March, and the whole of April, in that five weeks, a quarter of a million people probably mostly GPs, were looking at that, and saying I will at least, I've got something to go on with assessing this new disease.

Now, let's just map that to a timeline here. And the histogram here shows death, deaths per day. And you can see right at the beginning of March 2020, people were starting to die, there were probably a lot of deaths that happened. But that didn't get included in, in the official statistics. But you can see that remote by default, there's the 11th of March again, there weren't many deaths, but very, very soon,

though, they rose very quickly. And our BMJ paper was published, as people were realising this was 'the real McCoy', this pandemic, this was gonna, this is going to kill a lot of people. And we really needed to do something. So at that time, the UK had very high written and rising death rates from COVID. Hospital mortality rate, as this newspaper clipping just shows was very variable. And that's an important point. Up to a third of patients being admitted to hospital died, and that was probably due to late referral from primary care, it's probably due to GPs wanting to, quote 'protect the NHS' unquote, by not sending in people that they didn't think were too ill.

So we've now got an issue here that, in a way the wrong people are getting to hospital and not enough people are getting to hospital, but we can't send everyone to hospital because we're supposed to be protecting the NHS. So thus was born the 'Remote by Default I' study. We got money from the UKRI COVID-19 emergency fund. And one of the work packages here was, how can we best assess and manage acute COVID in the community using mostly remote assessment and that meant mostly telephone assessment. So what we were trying to do was develop and validate some kind of severity score or list of questions you could ask the patients, maybe you could get them to take their pulse or something like that, to be used in the remote setting.

Now, right at the beginning, this will turn into a social sciences presentation in a minute, by the way. Don't worry, I'm not going to get too clinical. Right at the beginning, people were sort of using, trying to come up with with kind of semi-quantitative scores, the most controversial of which was the raw score, where you got the patient to take a breath, and then see how far they can count 123456789, etc. And the higher you got, the less breathless you were deemed to be. And so it was seen as because it had numbers in it. And you were measuring it in seconds that it would be more accurate than anything qualitative. In fact, people started dying when GPs use the raw score over the phone. So we quickly put out some rapid reviews saying, 'please don't use it'.

People also talking about getting a pulse, pulse oximeter. The problem with that was that there was a world shortage of pulse oximeters, nobody in the UK made them, they were being imported from places like Taiwan. And then we didn't know about the quality control of those instruments. So pulse oximeters now, you can just get one from Amazon, but you certainly couldn't then. And then there was this NEWS2 score, which was a score that that is used quite widely in the accident and emergency department. But basically, it sort of adds up things like your respiratory rate and your pulse and your temperature. And it's what I call the pre-mortuary score, because it really just picks up that you are very, very ill and, and the NEWS2 score remains normal till about 12 hours before you die, and then goes very abnormal. So it's not really much use for a telephone assessment of someone with COVID. The other thing is it needs kit, it needs a blood pressure machine and it needs someone who can take the pulse and the thermometer and all that kind of thing. So these weren't terribly useful.

Now, for some social sciences kind of stuff. I had a GP trainee who was based in one of the earliest places to get a kind of surge of COVID. She was based in Haringay, north London. And she said to me, on a Tuesday, she said 'it was a busy Monday, yesterday, I took over 100 phone calls as duty doctor, by the end of the day, I could diagnose it over the phone'. So this is new disease, we've never seen it before, we talk to 100 people who've got it. And by the end of the day, you're quite confident to diagnose you over the phone. So I was interested in this. It's all about clinical acumen. I said how and

she said all sorts of things. But mainly, I think, from the quality of the cough. She's sort of reflecting at that point. And I thought, oh, let's do some online interviews, online focus groups, get GPs and advanced nurse practitioners to talk about how they diagnose and assess people with possible COVID. And let's do the same for some patients and tap into that intuition and clinical wisdom.

So here's the design of the study. What we wanted to do was develop items for a score. For people with COVID, who needed what we call 'escalation to the next level of care', they need you to send them somewhere either hospital or hot hub, we didn't really mind. So we did some rapid systematic reviews, as I've said, we did some online focus groups, we did the narrative interviews with patients. And then we did an online Delphi panel. And I literally did all of this without leaving the room that I'm in now, which is my living room. And obviously working with a much wider team. But this, this was when everyone was in lockdown. So here's just a snippet of data from a patient interview. And this person is actually an allied health professional. I think she was a physio or an occupational therapist, something like that. And she said one day I have blue fingernails. I mean, I've real proper cyanosis on all my fingernails, and I've found the GP and the GP answers phone said if you've got any other signs of COVID ring 111. So I rang 111, I was put on hold and after over an hour, an hour and 20 minutes and nobody answered I put the phone down. So this was the level of stress. And under capacity that the NHS was experiencing at that point. What do you do when someone is this sick? She's got cyanosis.

Here's some free text comments, which people sent in, during the Delphi panel. Now the Delphi panel had patients and clinicians but these are quotes from clinicians. This is about how do you assess shortness of breath. And you can see, I'll just read the first one, over the phone I generally ask if they have stairs? And if so can they climb stairs as normal? Or do they have to stop at the top or stop halfway or after how many steps and if they don't have stairs? I asked how far can they walk without stopping? But this person says, 'stairs is a really good differentiator'. So here's someone who's getting a little story of people's functional performance and has found that stairs is a good one. And then in the second quote, this clinician is saying, 'in practice, we've noticed that patients are not articulating their breathlessness'. Well, now this was substantiated by other research by, and also by other data that we collected that you can have someone who was actually quite hypoxic, short of breath, but they didn't feel short of breath. And this, this turned out to be an interesting characteristic of COVID-19.

So again, this, this person in the second quote is talking about asking them about their activities of daily living, hoovering. It's all about changes to their usual activity, you might not feel breathless, but if the doctor asks you, can you still do the hoovering? Oh, you couldn't. So this is beginning to be interesting qualitative data. So what we did with this data is we generated some fictional vignettes, which have built up all those qualitative themes into little stories. And I won't read this, but you can, you can see, we've, we've made a lady of South-Asian ethnicity, she's had a cough and temperature, you've got the problem, that there's no common language, as she's going through her daughter-in-law to tell you these things. So you've got that, that language barrier to kind of struggle with. She claims to be not short of breath, but is that something you can hang your hat on, etcetera, etcetera. So we plant these various themes in the story, and we get the focus group to discuss them. And you can see the last sentence here, which is actually, you know, pretty typical for a lot of families at the time, they didn't have a thermometer they didn't have a blood pressure machine, they didn't have an oximeter. And nobody's got access to any kind of smartphone or video. So of course, you can change all these details in a

different case, and get people to discuss, well, what would you do? Would you send hospital, would you what other information would you want? And we ended up through a lot of qualitative analysis work, which I'm not going to go through in detail.

With this paper we published in BMJ open, where we actually produced a set of items, such as questions about breathlessness questions, about what people can do, questions about feeding shivery, aching, all that kind of thing, to put into a quantitative validation study. And this was the second part of recap, which is actually still going on, the big data, the scale validation to test the predictive value of those items, and the contribution of each item to three, not very nice outcomes, whether you're admitted to hospital, whether you're admitted to ITU, and whether you die. And the way we did this, was we got many thousands of patients to give verbal consent at point of care. We created templates in which we built in those different questions. And then we did data linkage with hospital episode statistics and also with the Office of National Statistics mortality data. And we then got stuck for 12 months in the quicksand of things, like data sharing agreements and other rules and regulations. But we do now have early data on the validation. And I can sneakily report that we've got some interesting data, which in general, affirms the qualitative impressions that I'm mainly going to be talking about today.

So we published a number of papers, and I'm putting the impact factors of these journals in not to brag about where we've published, but to just, just flag up that the way we were publishing was generally considered by the medical community, a bit, community to be sort of second rate journals of BMC health services research, we published in a trade journal for doctors, the Clinical Medicine Journal, it used to be the Journal of the Royal College of Physicians. So stuff that doctors read, but these were not high level academic journals. And then one paper in social sciences journal, actually, we published one around long COVID, because the people the patients we talked to at the beginning, actually, many of them were still unwell. And so we went back and heard their longer stories. So we did get a few sociological papers out of this. But there is now a major quantitative paper being written up, which will go to something like the BMJ or the Lancet with the sort of big impact factor because it's got more numbers in it.

Now, I want to now reflect on, on that whole pile of work, which is still going on and shift gear a bit, because actually, this conference is about methodologies. And I want to ask a question now about where our work was situated, ontologically, epistemologically, you know, we're no longer in the, in the wave of ,wave one or wave two of the pandemic. Did we know where we were going? Could we, could we have defended it? And I'm going to draw on these two papers, one by John Eakin called 'Educating critical qualitative health researchers in the land of the randomised controlled trial'.

And the second one, again, you may be familiar with this one from the Wilson Centre people in Canada, around 'Interdisciplinary promises versus practices in medicine: the decoupled experiences of social sciences and humanities scholars'. So this is about doing social science research, qualitative research, highly applied research, in faculties and departments were a kind of, a kind of main dish is usually the randomised trial. And in this social science medicine paper by Albert and colleagues, the argument is that social scientists, scientists in the medical faculty have to produce a dual stream of outputs. They have to produce outputs for their medical colleagues, who typically value objectivity over reflexivity, method over theory, quantitative over qualitative, larger with small sample sizes and

empirical studies over thought pieces. So I think many of you listening today have ever had to kind of shape your work to fit into that box. But then you've also got to produce outputs for your social scientists peers, who, who view researcher as inevitably perspectival, you've got to explain where you're coming from. They generally prefer depth over breadth. And they're rarely interested in a dump of data that isn't adequately theorised. So you've got to have that sort of schizophrenic approach. And certainly, I've lived and breathed this duality in my clinical career. And I say that as someone who trained initially as a social scientist, and then got a degree in medicine.

Joan Eakin's paper, I think is fantastic. And I encourage you all to take a look at it because what she does here is she analyses what she calls the 'transgressive space of critical social science within healthcare'. And she has problems. As she reflects on the career working in the land of the RCT, she says, clinical qualitative researchers often suffer from a deficit of concepts or theory to draw on, when analysing qualitative material. Such students also often have inadequate writing skills for the highly language-dependent research process of qualitative research. And suddenly, when we were doing recap one, there was an awful lot of really interesting stuff in the qualitative data, which many of our clinician colleagues just, just sort of didn't notice. And we kind of put that aside and our own paper on it later, but certainly that, that quote really resonated with me.

Joan Eakin lists a number of survival skills which we should be teaching our social scientists, including she says how to adapt their methodology to subvert, circumvent or appease the expectations of non-qualitative gatekeepers, such as supervisory committees, funders, journal reviewers, without violating a project's philosophical integrity, and interpretive potential. And I suspect many of you listening have got that T-shirt too. So do dig out that paper by Joan Eakin, it's just a fantastic read. Now, we had a number of ontological and epistemological and other philosophical challenges in the recap study, and I'm talking about the recap one study, the qualitative work. And the first was, there weren't any facts. The facts were really loose, no matter how hard we tried, how many hours work we put in. This was just inherently uncertain. I've put yet in inverted commas, the idea that we really believe that just around the corner, we'd be able to nail some of this stuff. And then we'd be able to say, 'right, we've got the facts'. I'm no longer so convinced about that. But certainly at the time that this was almost a factory zone and that was problematic.

Secondly, that patients' stories were not taken seriously by everybody that we were working with. Patients' stories were assumed to be distorted by what was known by 'recall bias'. And you can imagine the kind of arguments we had in amongst our multidisciplinary team, which included quite a lot of people who've never done qualitative research before. The situation was urgent, as I've said at the beginning with, with that kind of backwards slide of how we managed to implement stuff before we'd even got the money and done the research. The precautionary principle, what should we be advising doctors and nurse practitioners to do in that interim, that six months interim. Before we've done the definitive study, before we've got definitive findings? Was it okay for me to pitch in and basically produce a nice guideline, based on, not much more than intuition and chatting to people? Or should we just, you know, with 2000 people dying every day and the wrong people getting sent to hospital or the wrong people not getting sent to hospital? Should we just not have done that? I lost a lot of sleep over that. I can tell you.

Clinicians' hunches and anecdotes were for some people at the bottom of what they call the 'hierarchy of evidence', which calls as the randomised controlled trial at the top of the triangle the EBM people produce. And yet, as I've explained to you in this talk, the hunches and that story from my trainee that, having spoken to 100 people, she absolutely could nail that disease now. I felt that those anecdotes and hunches were a very rich source of, of very important data.

And the idea that prevailing quality standards said that a scale had to be, quote, 'validated' unquote, in large quantitative studies, including both internal and external validation. And as you can see from the timelines, we're now well over a year after we finished the qualitative work, and we're still struggling with quantitative data. And we still haven't got what is known as a validated scale, although others have produced scales that weren't validated. And they've just sort of published the intuitions of the doctors that they interviewed. And I don't think their findings are that different from what we're going to end up producing in our, in our final validated scale.

Well, let me move to a completely different topic now, but it's going to be related. I was greatly inspired to learn a few months ago about Jane Addams, she won the early pragmatist, she was a social reformer in America. She's a philosopher, she wrote a lot of academic papers, which are very applied, she actually set up a hostel for the poor of Chicago and did all sorts of interesting social science research with the people who lived in the hostel. And she published it in social science journals, quite good journals, and, you know, towards the end of life was awarded the Nobel Peace Prize. So she also drew on the work of all sorts of other pragmatists are listed down here, lots of others, but I'm particularly interested in Jane Addams and based on the work of the American pragmatists, some people have pulled out some key principles of pragmatist research, because I think that's what we've been doing is pragmatist research. And these principles really mapped so strongly onto my experience of the recap study. In fact, I nearly called this talk, pragmatist approaches. And then I liked that I liked the boat analogy, so I changed it.

So the first pragmatist principle is science is fallible, that proof and hard, definitive truth is always going to elude us. So the precautionary principle is not only okay, but it's the only way you're going to make progress in complex and uncertain and urgent situations, particularly pandemics, for example, the second pragmatist principle is that ideas and actions are very closely linked. That's what they call instrumentalism. In other words, if you've got ideas about how to make the world better, you've really got to be putting those ideas into action. And not telling people to, you know, sit at home and wait, while you are, while you're working on those ideas that a belief for example, say the pragmatist is something that you are prepared to act on. And so the fact that I had hunches at the beginning, having talked to a lot of GPs, nurse practitioners, paramedics, those hunches was something that I was prepared to act on practice. Marxism gives us a philosophical and theoretical justification for that approach.

The third pragmatist principle is that we need to look at problems in multiple ways we need to, we need epistemological pluralism, and we also need moral pluralism. You know that we look at a problem and say, well, the utilitarians would say this and the deontologist would say that and the virtue theorists would say that, but also, we did, and should indeed have done randomised control trials for some questions in the pandemic. For other questions, we needed to look at in depth case studies, we needed to do qualitative work, etc, etc, etc. So, pragmatism is absolutely up for that kind of pluralism.

Fourthly, something called symbolic interactionism, which some of you will be very familiar with. Humans create shared symbolic meanings, the interpretation of reality comes through the symbolic meaning of particular objects or practices, or words or, or phrases or something like that. The obvious one here is the mask, which became a symbol of oppression in the West, but a symbol of freedom, and social solidarity in the east. That's a bit of a sweeping statement, but you can see where I'm driving, vaccination is another very important and topical example of the symbolic meaning of something that for some people, this is just what we need. And it's, it's going to, you know, do all sorts of wonderful things to society and with other groups. Vaccination is a symbol of oppression and and, you know, government, overstepping its mark, and all that kind of thing. And unless we engage with those symbolic meanings, we're never going to make progress in public health or social reform, etc.

And finally, the fifth pragmatist principle, participatory democracy builds solutions with rather than four communities. And I'm currently working actually with the the long COVID community, there are many long COVID communities, but with groups of people who are still suffering from the long term effects of COVID. And doing what I hope is collaborative democratic research, in a sort of CO design framework. So those are five principles, which I think, come into their own naturally. In the example I've given the how do we do research, in the pandemic on the pandemic? I think this gives us a very interesting philosophical and methodological agenda. It underpins methodologies, for example, such as action research, community based participatory research, that that mishmash of stuff that's under the umbrella of mixed methods research, I got a toe in that water recently realised it needed sorting out. Pragmatism is used quite a lot actually in things like climate change research research that is complex and contested and looked at differently by different people in different groups.

In pandemic public health policymaking, I hope I've persuaded you of that in this lecture, and also a particular approach to evaluation called utilisation, focused evaluation, which you may have heard of it's really great approach. Actually, there's a website called better evaluation, which I'd encourage you to look at if you're if you're doing evaluation. So that is the end of this talk. I hope to be joining you to answer some questions shortly. So I'd like to thank a lot of funders, you can see them all listed down there. And also some co investigators, I've only had room to list three of them. But this is a very large team with a couple of dozen very hard working people from different backgrounds, from statisticians to anthropologists, to philosophers, and more. So thanks to my colleagues, my funders, and thank you to you for listening to this talk. I hope you've enjoyed it.