Going Viral: Who Do We Trust in a Pandemic

MH [00:00:00] Hello and welcome to Going Viral, the podcast all about pandemics. I'm Mark Honigsbaum (MH), a medical historian and science writer. And today, I'm joined in the studio by three very special guests. The subject we're discussing: trust during the pandemic. The coronavirus pandemic raised significant questions about public trust, trust in science, trust in politicians and trust in the public health messaging. The pandemic drove the British government to make a series of complex, ethically sensitive judgements in a very short space of time. However, engaging with the public was largely one way. So today I'm exploring why trust matters in a pandemic, who we trust most to deliver complex scientific messages, and how can we improve trust in the future? On the panel today are Professor Sarah Cunningham Burley (SCB). Sarah is a professor of medical and family sociology and dean of Molecular Genetic and Population Health Sciences at the University of Edinburgh. Sarah was the lead on engaging the public as part of the UK Pandemic Ethics Accelerator, which completed its work in August 2022. She brought together members of the public to consider ethical issues arising during the COVID 19 pandemic, and she's joining us via Zoom. My second guest is Professor Christina Pagel (CP), who is a mathematician and professor of Operational Research at University College London, and she is based within UCL's Clinical Operational Research Unit, which applies operational research, data analysis and mathematical modelling to all sorts of topics in health care. My third guest is Anjana Ahuja (AA), who is a science columnist at the Financial Times. Last year she co-authored the bestselling ‘Spike: The Virus Versus the People -The Inside Story of the COVID 19 Pandemic’, which she wrote with Sir Jeremy Farrar, the director of the Wellcome Trust. Okay, so we've heard an awful lot about trust recently, but how important is it to have trust during a pandemic? And what difference might it make whether or not people trust scientists or politicians and their messaging? So can I ask you, Sarah?

SCB [00:02:12] Well yes, of course, trust is important, but it's also a kind of capacious concept, really. It holds lots of things. And I think we probably asked quite a lot of the concept, and we need to delve underneath that and think, what is it that we're really talking about when we're talking about trust in general and trust in relation to health care and in this case in the context of a pandemic. And I say that because one could have misplaced trust, you could trust in something that actually isn't trustworthy. And we need to focus more, I think, on the kinds of relationships and practices that warrant the use of the term trustworthiness or warrant of putting trust in those relationships or those systems or systems of governance or systems of health care.

MH [00:03:04] Oh, that's interesting. So you're already making a distinction between different types of trust. And some trust might be more positive or better to engender, and some types of trust might well actually be counterproductive or dangerous.

SCB [00:03:18] Well, in the context of the pandemic, one of the things we might want to think about is the range of information that is available both to decision makers but also to all of us as citizens, members of the public. And we have to make judgements about the trustworthiness of that information. And there might be many reasons why you might prefer or pay more attention to some kinds of information than others. So I think the important thing is of make visible, I suppose, some of those processes and practices in order that we can start to unpick ’Well, okay, if you're going to make some judgements based on evidence, then we need to encourage engagement with evidence and what makes some forms of evidence trustworthy’.

MH [00:04:06] Well, that very neatly brings me to our second panellist, Christina Pagel. Christina, you obviously very early on were very much always a public face. Lots of journalists went to you to unpick the evidence and you regularly appeared on the news, unpacking some of the science science and making it comprehensible. What is your take on trust and why might be important?

CP [00:04:29] The thing about trust is we trust different groups of people for different things. So I think for scientists it's people have to trust that they have it right and that they are fairly representing the evidence and what they know and what they don't know. I think for politicians, for me, it's do they have your best interests at heart and how are they acting? And then there's other types of trust, right? You have to trust journalists who often mediate the messages between politics and the scientists, because actually, it isn't me talking to the public. That's the only way I can do that really is something like Twitter. But even when I'm on a news program or in print that it's mediated through journalism, and then we have to trust each other and each has other people in the public to also do their bit. So I think there are different types of trust for different situations, and they all have to come together for an effective pandemic response.

MH [00:05:19] Anj, maybe I can bring you in because you were somebody we could turn to to unpack some of that, some of the science and communicate it and explain it maybe perhaps more in layman's terms, how do you interpret, you know, this value and how important it might be in your role in in disseminating trust?

AA [00:05:37] Well, it's really interesting, isn't it? Because I always remember one of the things that David Spiegelhalter said, you know, he's the Professor of Risk at Cambridge University and was very prominent in the pandemic. And, and one of his messages was that it's one of those things that you can't tell people to trust you. You have to demonstrate it by being trustworthy. And so it was really important to me to really research the articles that I wrote. I'm sure Christina was the same, to make sure that what I was conveying was what I thought was the closest to the truth. And it goes back to this idea that Christina talked about, you know, and Sarah as well, about trust, about what kind of trust are we talking about when it comes to politicians? You know, we're talking about intentional trust, aren't we? Do they have our best interests at heart? When we're talking about do we trust scientists, we're really asking, do we trust them to be competent and to know what they're talking about, to have gathered the evidence, to have looked at it and analysed it? And then, of course, I think in a pandemic, because we're talking about an infectious disease here, the behaviour of other people really matters. So do we trust other people to do the right thing? And as I'm sure we'll go on to talk about, there was this the great Lancet study on trust that and how this differed across countries. And if you know that you live in a country where people are following the rules, they're getting vaccinated, you are probably more likely to trust going out to public places, going out to nightclubs, restaurants, if you know that people are going to be masked. And so your societies are likely to have lower infections and and just things will run a little bit more smoothly. So I think there are lots of different ways in which trust is really important in a pandemic.

CP [00:07:23] Just equally, if you can trust that other people aren't cheating or breaking the rules, you're much less likely to do it yourself. I think there is this idea that as long as you think everyone else is following the rules, you will. But soon as you start seeing people going out, or I saw them breaking lockdown this or Oh, I saw them doing this, then you're like, I was fine if I do it. And then it kind of erodes trust in it and it can snowball very quickly into a situation where no one's really doing it anymore.

MH [00:07:48] Thank you for that. So I wanted to highlight some evidence to support our understanding of why trust was so important during the pandemic. And this is a quote from a study that was published in The Lancet in April 2022, which found a causal link between trust in authorities during COVID and infection rates. I'm just going to read the key extract from the report, I'm quoting here: 'Measures of trust in the government and interpersonal trust, as well as less government corruption, have larger, statistically significant associations with lower standardised infection rates, high levels of government, interpersonal trust, as well as less government corruption were also associated with higher COVID 19 vaccine coverage among middle income and high income countries, where vaccine availability was more widespread and lower corruption was associated with greater reductions in mobility.' In other words, those governments where trust was higher, were able to more easily restrict people's movements and command trust in the policies of social distancing. The study found that overall, an increase in trust of governments might have reduced global infections, almost 30% for government trust and as much as 40% for interpersonal trust. So I really wanted to ask what the panel's response to these findings are.

CP [00:09:06] I guess I'm not surprised and certainly I think the United States makes quite a good case study because you've seen - in fact, I think the Financial Times did an article about it recently, looking at the difference in vaccination rates and mortality rates among Republican voters and Democratic voters out there. And that's just this massive difference because there was so much less trust in the vaccines and in government measures among more Republican states. And they had much higher levels of infection and high levels of hospitalisation and higher death rates. And you can kind of see how trust just created these kind of quite different communities and different outcomes in the same country.

AA [00:09:44] What's interesting about that, I think is, is that if you don't trust the government and the government is telling you to get vaccinated, but you don't think the government's got your best interests at heart, so then you can sort of see how that dynamic surfaces. And I do think that that particular study was remarkable because it did adjust for things like income, age and so on. And it is really interesting when you look at the difference between a country like Denmark, which is - I think if everyone had been Denmark, we would have had something like 40% fewer infections, t that's the conclusion. And then you look at somewhere like Vietnam, which is very resource poor, not great on pandemic preparedness, but did really, really well. And and again, we were sort of going back to the example that our leaders set us, I guess. And I think one of the big things in this country is that we did have rule breaking right at the very top. And I think there is this sense that there was one set of rules for some and other rules for others. And I think that is really terribly damaging for trust.

CP [00:10:59] I think what's quite interesting about some low and middle income countries is that they already had in place pre-pandemic a network of health care workers who already trusted the people who go to villages and towns to deliver childhood vaccines or childhood nutrition or maternal care in a way that you tend not to have in high income countries, because in some ways we can sort of have public health solved if you see what I mean. So we didn't have that network and it's a trusted network, and they managed to leverage it really well in places like Vietnam, also in South Asia and parts of Africa to have behavioural change on a scale which perhaps here we were going 'oh that's just not possible', and it is possible.

AA [00:11:38] That was also important in Ebola as well, that those community workers, people who are having connections in communities and we saw that in the UK, around ethnic minority communities. I was really surprised because I think one of the early points about the vaccines being rolled out was one suggestion was they should perhaps go to people from minority ethnic communities first. And I thought, great, y this is this is because they're very at risk because of their jobs and their particular socio economic circumstances and that and for other reasons. And actually if you took somebody like Heidi Larson at the Vaccine Confidence Project, they did some work about why these communities were very, very reluctant to take this on board. And they felt that they were being used as guinea pigs. And so there was obvious lack of trust for being the first recipients of a brand new vaccine.

SCB [00:12:36] I agree. We had nonetheless quite high compliance in the UK, but I think the important point being raised is actually the need to not homogenise the whole country in the case of the UK because of local differences, differences amongst social groups and we kind of lacked the infrastructure to really work well at that local level, partly because of our public health infrastructure. It was no longer fit for purpose in that context. And so as we've already said, trust, first of all, operates at multiple levels and it's fundamentally about relationships. And those relationships are built up at local level and then onwards and upwards through a range of processes of engagement. And we have to take into account, as Anj has said, the kind of historical legacies of exclusions from research and exploitation through research that impact on how one feels today in terms of potential new interventions, as these vaccines were, and other kind of health- related interventions that may serve to stigmatise minoritized groups, while at the same time recognising that there were inequalities that needed to be attended to.

MH [00:13:54] Well, I think that neatly comes to the recording that our producer made with Charles Kwaku-Odoi (CKO), who's a community leader for Manchester. Charles works to bring equity and fairness across a range of health and wellbeing issues for people of Caribbean and African descent. What are the barriers that they have encountered?

CKO [00:14:09] One of the biggest barriers we've known since 2017, when we set out, was the lack of trust. There were five problems as to why we were set up, and lack of trust is riding the lack of investment in the community. And I suppose the lack of trust is both historic, and what's current then. So historic from a viewpoint about race, racism and the community, have we never prioritized; historic as well because of some of the medical research interventions that our community have been truthfully engaged on. When we had to work around the vaccination or COVID, many people were focused on ‘How come national government has been able, you know, around the world, how come they've discovered so quickly a vaccine for COVID when HIV was killing people two or three decades and there wasn't any free treatment?’ Lack of trust. And we keep talking about Global Village. So what was happening overseas did impact even to the very extent, the whole thing about clap for nurses or nursing professional or health professionals in the evening, people were talking about, ‘Oh, that is the time they're going to use 5G to collect data and intelligence from people. So don't take part in it’. So lack of trust historically, but then the community has never been engaged. So all the messaging that was coming up about public health messaging, about looking after ourselves, wasn’t trusted.

MH [00:15:39] With trust level so low in this community, we asked Charles how the Caribbean and African Health Network worked to build up more trust in the government's health messaging.

CKO [00:15:48] So, in April, when we started getting information back from our primary survey that we're doing across Greater Manchester, we decided to start what we call Health Hour sessions. So we thought, are there any black clinicians that we know that have been supporting our work that we could get on a webinar? Then we started running weekly webinars from the 2nd of May 2020 because what we wanted was black people to speak to other black people. We started a helpline as well, saying to our community, 'If you had any concerns…', and we were manning that from 7:00 in the morning till about 10 p.m. I remember in early May a lady ringing and saying, 'Oh, you know, a family member has been discharged from hospital and was coming home. Should we be wearing gloves, aprons and face mask in the house when this person comes?' And I said, 'If your family member doctors have cleared the person of COVID, then I don't think you should wear gloves, aprons, face mask. I'm more than happy to get one of our volunteer GP practising GP's here in the UK, to give you a call and offer you reassurance'. The lady said, 'No, that's okay. I wanted to hear from a black person'. Once again we've been running these webinars and we wanted to get black doctors who had the vaccine to come and talk about that. I worked on the 16th of January, ended up becoming a big national event with 1000 people on Zoom, 800 across YouTube and Facebook and the vaccines minister Nadhim Zahawi offered to come along. At any point in time between the 11 and a half 12, we would always have people wanting to join the Zoom, which was a thousand, but we had sold out. The moment we had Nadhim on there, we lost about 50 people. And so these underpin the lack of trust. So for us, whatever we've been able to do, it has been utilising the assets within the Caribbean, African people who look like us, who understand the culture, the religion, the foods, the challenges as well.

MF (producer) You mentioned misinformation, but I know it was a particular problem around the vaccine and vaccine hesitancy. To what extent were you encountering this as a problem?

CKO That was massive. We encountered that way before the first vaccine was signed off. And the first one, well, coincidentally, being Pfizer. And then it started coming to the fore, Pfizer's track record in Nigeria, where there was a clinical trial run, which meant some children that took part in it ended up being disabled without consent. They didn't know. And so there were people who said they weren't going to touch Pfizer and they would rather die because they don't trust Pfizer. And then it was other things being circulated via WhatsApp. There were some religious concerns, and that was mainly around the ingredients. So one was Luciferious race, and then you have biblical people, Lucifer referring to Satan. So then people start connecting that with six, six, six. And the fact that in the book of Revelations six is the mark of the beast, and then unfortunately, there was one time Boris Johnson, having gone through his own encounter with COVID, was saying, 'We're not out of the woods yet. we've got to keep our leg on the neck of the beast.' Hey, Mark of the beast, this virus. And we organise sessions, vaccine engagement sessions with church leaders, and some of them had picked up stuff. But once again, it goes back to the lack of engagement with our community and people not feeling prioritised and nobody speaking to them.

AA [00:19:29] I mean, it's about keeping dialogue open, isn't it? And it's often it's about health messaging coming from people who look like you, who know what your struggles are. You know how you live, you know how you worship, what your social structures are like and what your day-to-day life is like. And I think what was really shocking in the early stages of the pandemic was just how badly affected ethnic minority communities were in terms of infection rates, but also once they were infected, having higher death rates. And that was terrible and actually highlighted the point that Sarah was talking about, about

inequalities and about the fact that historically those communities have often had worse health outcomes. So if you think about black women and childbirth as it's notoriously bad experiences. So, I think it was really important. I remember in the pandemic talking to friends of Indian Heritage who were also suspicious of the vaccine, and actually probably about the most powerful thing I could say to them was, 'yes, I've had the vaccine',

MH [00:20:34] Christina, I wonder if you have any experience, did you find that your message wasn't getting through to some people because you were seen as a scientist kind of almost lecturing them from on high?

CP [00:20:44] Yes and no. I think I think it is really important people to hear it from people within their own community. But I did deliberately do things to try and reach out to different communities. So, for instance, I did a whole hour slot on vaccination and COVID for Islam radio and on Indie SAGE we would often have briefings where we try to get people on and we would answer questions and try and debunk myths. And certainly, especially luckily, we have a heap of scientists on it and they were like, you know, it has to be people have a right to ask questions. There is an understandable hesitancy among ethnic minorities. And I think a lot of people don't know the history of how badly in America, black people there and also in parts of Africa, how badly they have been treated by the medical community and how unethical some of the things that were done are. And those memories stay on. And I don't think people know enough about it. And so people tend to blame the communities and like you have no idea what was done.

MH [00:21:43] So we're talking about things like the Tuskegee experiment , where the US government deliberately gave syphilis to prisoners, to see, you how they do that and challenged them with vaccines.

CP [00:21:55] And there was a trial in Nigeria where they didn't properly get consent from parents and children died. And that was only in the 1990s. It wasn't that long ago.

MH [00:22:04] I just like to make a quick point that we've been talking a lot about low levels of trust among ethnic minorities and other marginalised communities who maybe don't have a very good experiences of accessing health care, never mind about historical memories. But I was struck talking to my son's friends. These are young men and women in their twenties. They were also extremely vaccine hesitant, and if they heard some celebrity who their respect or trusted say, I'm getting the vaccine, that would sway them more than perhaps me saying it or, a vaccinologist saying it. So is it simply we live in a different world now where people aren't simply going to obey or take on board messages that come vertically from on high, that we have a much flatter media landscape now. So it's kind of the WhatsApp effect people are going to adopt or more likely believe messages that come from their circle, from their WhatsApp group.

SCB [00:22:58] Well, yes. People always have have done that. We were trained traditionally in medical sociology to have the lay referral network that you you learn from and you deal with health issues in that kind of local context. I think social media kind of massively amplifies that because that local context is a different set of relationships. And you have many more of them and much more access to even more diverse information. So I think it's an amplification of the ways in which we think about and make decisions about our health.

AA [00:23:38] It's interesting that you, Mark, used the word vertical,- do we get that information from on high. I would say the information landscape today is much more

fragmented and much less filtered. And so that's why I think quite early on in the pandemic, the World Health Organization identified that there was not just a pandemic, but there was also an infodemic and it was very hard to work out who was purveying trusted information. But also the thing that exacerbated that was that often scientists disagreed in those early stages. So, for example, if we look at things like airborne transmission, there was quite a lot of disagreement in the early stages about how important that was. And that's coming through not just what we might call the legacy media. Newspapers, broadcasts and so on, but also scientists like Christina, you could see them conversing directly on Twitter with with other scientists. And so it does become sometimes quite hard to work out what's going on. And so I think faced with that plethora of sources of information, there's so many competing things that play into the decision about whether to get vaccinated.

MH [00:24:58] That neatly leads us into the topic of following the science that you've just very eloquently said there really wasn't any one science yet. Right from the beginning of the pandemic, this phrase was used that politicians, the government were going to 'follow the science', as if there was one science to follow. Do you think that was a mistake, Christina?

CP [00:25:18] Yeah, I think it was, not least because when they were saying it for the first two months, we had no idea what the science was that they were following because that didn't become public until, I think, May or June 2020. But as I said, the scientists did disagree. Part of it is uncertainty in the evidence. And part of it is that people interpret the same evidence differently. And science isn't science, right? Like, I know my bit, I know how to interpret data. I do mathematics. I can understand statistics, but I know absolutely nothing about virology or immunology. I stopped biology when I was 15. So when it comes to interpreting that evidence, I have to trust my colleagues. And how do I decide to do that? Right? I cannot evaluate it on the evidence because I just don't understand biology. So it has to be about, okay, well, I trust them because I know their institution, I work with them and actually I agree with them on other things. And I also then have to also trust peer review. So in some senses I know how peer review works, so I, kind of, I have a hierarchy in my head of 'well, these are the kinds of studies that I'm I think I will trust more'. So it is about who do I trust and where does where can I see a consensus line? Why is there a scientific consensus emerging? And I think that is really hard, especially for members of the public. And I think a lot of it comes down to, 'is this the kind of person who is normally on my side on other issues that I care about?' And is that always the best way of doing it? I'm not sure it is. And I can see sometimes people, on Twitter, agreeing with science that they can't possibly be evaluated solely based on who it is that saying it. And Twitter makes that much more available to people, as does Facebook and YouTube and so on.

MH [00:27:07] Can I ask you quickly Anj, did you have a kind of hierarchy of science - because you were trying to absorb this and make selections and try and pick the evidence or the scientists that you thought were possibly more trustworthy and that your readers should be paying attention. Did you have a hierarchy and did you make this (inaudible) ?

AA [00:27:23] Well, what's really interesting is, I think at the beginning, because if we go back to your original question, which was about following the science, I think at the beginning, because this was a crisis and it's really hard now to remember what it was like to be that fearful of something that you didn't know - you didn't know what was going to hit the U.K, and the only thing that gave you any guide, really, was what was going on in other countries, which was horrendous when you looked at places like Italy, Iran and so on. So, I

think in those kind of situations where you've got something brand new, you kind of have to look to the science first, because you have to establish the empirical facts. You know, how does it spread, What's the R number, who's susceptible, what's the fatality rate, etc. I think later on what became apparent is you had not just the science, but then how were we going to live with this evolving situation? And that's where your values came in. And at that point, I think you're right, Christina. What happens is often you see the science through the prism of your values. And I think for politicians, it meant that you could choose the science to follow. There was no longer one science. You know, when we came to sort of further down the road, among the few months into 2020, you could begin to see cherry picking in terms of the politicians were cherry picking the scientists and the data and the countries that they wanted to look at in terms of guiding the policy in this country. And then the 'following the science', that phrase, became so loaded that it could be whatever you wanted it to be.

MH [00:29:02] Can I just bring you in, Sarah? One of the things that I was describing going through was this something that the public also picked up on?

SCB [00:29:10] I think the idea of following the science, if that actually means what we want to do for good policy making, is bring in a diverse range of expertise, recognise uncertainty, look internationally, gather data across the world in order to then make the complicated, complex and difficult policy decisions that we have to we may have to make, then I think following the science is an appropriate thing. But actually it became a catchphrase that obfuscated those very processes so that we couldn't reveal, what science was being followed, who was making decisions about which evidence to use for what purposes, rather than actually looking in the round at the kind of range of evidence that was available or could have been made available in order to inform policy-making. So I think what we've already talked about, there is no one science. I think the values underpin everything science, the scientific process, the interpretation of science and the policymaking process. So I think anything that actually brings those value judgements to the fore and the importance of those in what we do is really relevant. And I think that that kind of call for transparency is what our publics in our dialogues were asking for. So it wasn't it wasn't a call for certainty, it was a call for let's discuss those kind of uncertainties in order to understand better the justifications for decisions. So I think it was that kind of lack of a clear warrant for why decisions were made and particular ways. And of course, some stark examples of the impact of those, for example, in relation to care home deaths.

MH [00:30:51] I'd like to actually pick up then on what some of these values were that were lying behind the science. So particularly if I can ask you, Christina, when we're in a situation where think back to the beginning where there was a lot of uncertainty both about how the coronavirus was being transmitted, what the impacts would be on hospitalisations, and also what the long term impacts would be of some of these policies on both on people's health but also on the economy. So I can certainly say that my sort of ideological prejudice at the beginning is that when we're uncertain, we should err on the side of caution and that protecting lives should be the highest value in a democratic, civilised society. Do you think that that principle was guiding other scientists' judgement or were there other scientists who were using other values or interpreting maybe the precautionary principle slightly more narrowly? I'm thinking kind of the whole debate around evidence-based medicine and real world situations here.

CP [00:31:47] I think in the first wave, in March 2020, I actually think people were broadly supportive of the precautionary principle. I mean, pretty much qua science. I do remember what it was like. I do remember being really scared. We didn't have a treatment. There

were no treatments. And I was working in the London Nightingale, I remember I thinking are we going to fill 4000 beds? It was it was it was genuinely, really frightening. And when you've got a disease that's doubling every three or four days and waiting two weeks to make a decision makes things eight times worse. And that just felt horrifying to wait. So, you had to do something. I think that summer, what happened was we could see who ended up in hospital, but we didn't have widespread testing at all in the first wave. So what was this big unknown was how many people had it but didn't have symptoms or didn't get that sick, and so how many people have some kind of immunity by that summer? And then there were vastly differing ideas. And then people saying, 'Oh, we've all had it, we're fine. It's over.' And all the people were saying, 'Well, we just don't know. We have to be more careful. It could come back.' And that first summer is the lowest rates of COVID we've had in the UK since the start of the pandemic, way lower than we have now. And there was this genuine thing of is it over? And then the people who were being more cautious like me, it did feel like you kind of got an uphill battle because everyone was like, 'Well, there's no one, no one's going got Covid'. And I was like, 'Oh, but we just don't know enough about it.' And even then, the science was only just coalescing around airborne spread, around asymptomatic spread. No one really knew about the impact of seasonality. We still didn't really have any treatments.

MH [00:33:32] Perhaps I can put it - I don't know if you want to comment on this….

AA [00:33:34] One of the things that I really wrestled with at the beginning of 2020 was when I was looking at the decisions being made and actually the speeches that that Boris Johnson was making. I was struggling to find evidence of the precautionary principle. So I can't remember the date of the speech. But at one point he got up and he said, 'many of us were going to lose loved ones before their time.' And I thought, 'What? Why why are you saying this? Does this mean that you you've given up the fight? And what about other countries? Look at what other countries are doing'. And I think at that point, I was beginning to struggle to see what the values were, what the guiding objective was of the government in trying to combat the coronavirus. And I do remember writing various columns where I was almost writing them to understand myself what the thinking was behind some of the policies that were coming out. And I think there's that there's that tension between whether scientists are just producing the facts for other people to decide on or whether they need to say, 'hang on, lots of people are going to die if you pursue these policies'. I think it's a very, very tough one. But yes, the guiding objectives and ethical objectives. Among them were ones that confused me a lot in the early stages.

CP [00:34:54] Just on values in science in public health. Public health is fundamentally - Martin McKee is a professor of public health – says that it is political, public health. The whole ethos is to improve the health of the public. And so in some sense, you have to advocate for the public. That's your job. Now, other scientists aren't necessarily trained in public health and felt very uncomfortable about the idea that their values or that they would have an opinion on the data. I guess my view is that everyone has their own values and that they inform the things that you do and the way that you present things. I think you can be transparent about what those values are and then explain that and say, 'okay, well, here's what the data are saying and if this is your value, then this is what you would do'. And then, if it's not your value, that's not what you prioritise, then you can take a different decision. But I do think to pretend that scientists don't have opinions is blatantly false. And I think sometimes scientists who say, 'well, I'm entirely objective and I don't let that inform me at all'. Well, that's bollocks. I mean, I can see the kind of things that you promote, I can see the evidence that you're presenting and it and you definitely have a point of view. You're just not being transparent about it.

SCB [00:36:08] Yes. And it doesn't mean that science is isn't rigorous just because it is also not value free, I think it just requires reflection, reflexivity and humility and openness about how data are being interpreted and the potential for utilisation. And so I think there's there's ways of engaging with science and evidence and the values that underpin those engagements, as well as underpin the science and the policymaking process, that can open up for discussion and the complex trade-offs that have to be made when you make decisions in this field.

MH [00:36:57] Welcome back to Going Viral. Sarah, tell us a little bit more about your work around the lack of transparency, around value judgements in your discussions with the public. Can you just outline the key findings of your public engagement exercise and then I'll ask our panellists to respond to it?

SCB [00:37:15] The dialogues were deliberative, so they took place over a period of time in two separate and two separate years. And we wanted to encourage participants to reflect on their experiences of what had happened, what was happening now and then, their ideas about what would happen in the future as we emerge. We still have COVID, of course, but as we as we move into a kind of living with COVID situation, and it was really clear that trust and transparency were absolutely key to what our participants were telling us about what they felt was lacking in terms of government responses in particular. So this was manifest in what they felt was a lack of an explanation of the policies from politicians and also policies including direct health ones such as moving people from hospitals to care homes, the procurement processes around PPE, so that poor transparency meant that people felt that there was a kind of a lack of accountability, a lack of proper governance of procedures, and therefore there wasn't a sense of trust in those models. And they were saying for any future pandemic, they would want those kind of reassurances and those processes of accountability, including community and public engagement. I think there's multiple dimensions to where that sort of trust and transparency was lacking. And we will all be familiar with the actions of political figures in terms of 'do as I say rather than not as I do', which in and of itself damages trust, but also, you know, the absolute lived experience of the impact of the pandemic and the inequalities in those impacts as well. So the need for transparent communication was seen as really key in our second dialogue, the one that took place this year, we made sure that we had participants across the home nations so that we could begin to explore some of the differences because there were some differences in in policy and in implementation and differences in leadership styles. And so it was very interesting to examine that. But it was clear that the opportunities for transparent communication that was particularly the case - at least according to our participants in Wales and in Scotland - can help generate a sense of what kind of role in this together can begin to close the gap between the vertical communications from politicians, first ministers and prime ministers, and the kinds of engagement and communication that has to go on on the ground, as Charles has spoken to us about. And that is possible through transparent communication to bridge that gap, I think. And there was some discussion of those of those kind of communicative actions in the dialogues.

MH [00:40:30] Let's hear now from Don Cameron (DC), from Fife in Scotland who took part in Sarah's dialogues.

DC [00:40:36] I'm Don. I am 65 years of age. It was good to exchange ideas and to hear the ideas of other people. One thing that had come out very, very strongly was that there was universal condemnation of Boris Johnson at the time. Now, obviously, I'm in Scotland

to have a different system , and many of the participants were down in England, and that came across very, very strongly to me. It was very damning condemnation as well, and deservedly so in my opinion. There was some idea from certain participants that some of the regulations were too strict, there should be more leeway and so on. But that sort of thing has to be decided by scientific experts, medical experts, virologists and so on. You have to go with the science and what the experts are telling you. One or two people, they weren't challenging it, but they just wanted a bit more leeway. Perhaps some of it arose from the confusion that Boris Johnson was putting across at the time.

MF (producer) What lessons do you think we can take, if you like, particularly around the trust and the way that we are given as members of the public about big decisions that we have to make?

DC Give us the facts. I think you have to be honest with the public. And I know that politicians and so on and then used to twisting information. You have to give the facts. You have to quote the science. Yeah, I would quite like some reference to some of the ongoing research work that's done. Perhaps politicians could quote some of that about. This is probably a forlorn hope, but encouraging politicians to be honest, I know they can't necessarily through every detail they are, otherwise it may cause mass panic, I realise that, but give forthright information diplomatically and tell the truth. I think what Nicola Sturgeon did, Mark Drakeford did, several other politicians did, and make sure the NHS is fully funded.

MH [00:42:47] So, Christina, I mean, what is your response to the research that came out of these discussions on the pandemic accelerator?

CP [00:42:55] I think the the transparency points are just so important and that there wasn't and there hasn't always been that much transparency, not least about actually what the mistakes are. I think honesty about mistakes is one of the best ways of building trust. And I think what you've seen in the U.K government is a reluctance to acknowledge mistakes or failure. And I think that has damaged trust. Say, for instance, when we did things like we stopped testing quite early on or there were issues with PPE, what the message was - we don't actually need tests, we don't need PPE instead to actually we do, but we can't provide it. And I think that kind of messaging damages things. And there is now this narrative, the NHS, which it didn't like, it hasn't emerged intact from this pandemic. It's been in crisis for well over 18 months. And many staff haven't got over the kind of what they call moral injury of having to give care to people way below the care levels that you would expect because of the pandemic. We did triage. We never discussed it. There were difficult decisions made, they never discussed. Some things have come out about Do Not Resuscitate orders on people with mental disabilities that haven't been discussed. That's not transparency. That's not how you build trust.

MH[00:44:07] Because we were told all through that we were protecting the NHS, stopping it being overwhelmed. But of course, what wasn't as transparent over these issues around triage that you've just mentioned, and I know that one of the principles that informed some of the discussions on this moral ethics group the government asked for advice on this issue was: was the principle that the actual priority is to save lives or are we going to use another principle? The likelihood that a patient in an ICU will benefit from this treatment? That's not a conversation I recall anyone ever having with a public, though. Should we have had that conversation?

CP [00:44:43] Absolutely. Actually, what was interesting is that I wrote a paper on exactly this in 2010 after swine flu with a colleague and a few ICU doctors as well about you have to have this conversation before pandemic. But what will our priority be? Because if you've got limited resources like we had. Do you prioritise overall lives saved? Do you prioritise people who will benefit most, which can be similar, but not necessarily? Or do you prioritise everyone gets an equal chance to get in? Because actually we showed that if you prioritise total lives saved, you would automatically have to exclude people who would take longer to get better because they're blocking other people coming in. And that is obviously people who have a pre-existing condition and other issues. And is that what we want to do as a society? And we haven't had that conversation. We still haven't had that conversation. And actually those decisions are made ad-hoc within different trusts at different times by different doctors, probably as best they could. But it did mean that the same person, if they went to say, one hospital bed, another hospital might have had different access to intensive care. And I don't think that is equitable and it's not transparent.

AA [00:45:52] This, for me, was a really fundamental ethical oversight because I remember at the time when the news was emerging from Italy, when they already were in the situation where they didn't have enough ventilators. I wrote a column for the FT saying this raises a very interesting and scary dilemma about it's not how many lives you save, it's who we save. It was, how do you make those decisions? And it was meant to sort of set the scene to almost prepare readers for the ethical discussion that was inevitably going to come. And it never came. It never came. And I thought that was shocking because you knew because if you talk to people, as you are in the NHS, that actually people were just abandoned to make these decisions in individual units on their own back and to bear the weight of those on their conscience. And I and I think that was that was a really terrible situation for us.

MH [00:46:52] It was a terrible situation to put doctors in frontline healthcare.

AA [00:46:55] Exactly. It's a terrible situation for those for those people. But it's also a fundamental dereliction, I think, of duty right from the top. The fundamental role of government is to protect citizens, I guess, and to keep countries running. And they have to take some responsibility and they have to be transparent and accountable and be clear about that.

MH [00:47:15] Could I just bring Sarah in here? In your discussions with the public, did they want more of an open conversation about end-of-life care?

SCB [00:47:23] They wanted more open conversation about all the dilemmas. So actually how you how you balance these trade-offs between individual needs and collective concerns. Yes, exactly. And the kind of here and now and the long term health consequences. And they absolutely felt that public dialogues have a contribution to make here in supporting the decisions that have to have to be made. So how do we balance the scarce resources in the case of ventilators? How do we balance individual and collective responsibility in relation to vaccines? All of that, all of those issues. And so I think when we talked a while back about following the science and we've talked about values, it's actually discussing the frameworks through which we can make those complex value-led and value-based decisions rather than them falling on the shoulders, as we've discussed, of individual health care professionals and individual family members. Do I go to the emergency room or don't I? Am I ill enough or not Am I taking someone else's place? And we can see the kind of consequences of that in terms of ongoing health needs. So I think that kind of openness of dialogue and having a very elastic notion of the range of

expertise that can be called upon to support this decision making is something that our dialogue participants and certainly supported. But it's what the Ethics Accelerator has also tried to, you know, try to create a sort of framework for the kind of kind of ethics ecosystem so that there are a range of experts, experts by experience and experts by scholarship that can help support through their theories as well as through empirical work. And this kind of decision-making.

MH [00:49:19] For the final part of our discussion, I want to circle back to the question of vaccines. Here's Charles Kwako-Odoi again on how he worked to build trust in the COVID vaccines amongst the African and Caribbean communities of Manchester, where vaccine take up was initially very low.

CKO [00:49:35] One of the phrases we carved out, which when we had an opportunity, a group of seven or eight of us to speak to the then Prime Minister said to him, 'The messenger is as good as the message. Who is conveying the message? Who is really talking about COVID and the impact?' I can tell you countless stories and that I'm also a church leader. There are things - and I keep saying - these are things church leaders could tell their congregation members that professionals wouldn't because of the lack of trust. So that's why we keep always saying, let's get that lived experience advocates from within the community to lead and fund those campaigns.

AA [00:50:15] I really like that phrase, the messenger is as good as the message. And even though we'd like to think that everyone hears the scientific message coming loud and through above everything else, we just have to accept that communities don't work like that. And we have to talk to - I suppose it's what some people call co-creation, isn't it, about making those health messages that communities will trust and actually even listen to. That's the first thing you have to do, find messages that people will actually listen to.

CKO [00:50:53] Many people were asking questions about and challenging the integrity of the MHRA. You know, how do we know they're not siding with government and all that? Because, well, Sage would say one thing, SAGE members in the media will say something, the government goes with a decision and all that was creating confusion. So I think we need to be consistent with our messaging, not making assumptions, breaking things down, and understanding the health and social care landscape. So with our wonderful, amazing NHS being the most diverse employer in Europe, let's begin to use the cultural assets we have. Lots of BME clinicians, you know, in junior ranks, but high up the they don't see people who look like them. So how do we begin a process where we really utilise and harness the assets that we have? So, understanding our communities, what really matters to them and starting from where they are and saying 'we will trust you, to lead and determine yes, we'll provide the framework, but we will trust you to lead and co-design stuff with us'. I think that will make a massive difference.

CP [00:52:07] At the at the top where decisions are made, you need not just a diversity of expertise, but a diversity of lived experience. Because if everyone up there is like you, then the messages you come up with are the ones that persuade you or your circle of contacts, and they're not going to be the same as other communities. And it doesn't even have to be, kind of, ill will. It can just be it's a blank spot that you don't see. So, for instance, you know, I'm not just religious at all. So it's not even like - it might occur to me eventually, but you need people in the room to think, 'okay, well, this is the kind of community that we need to get in touch with. These are the leaders that are important to talk to', and it has to be in there right from the beginning, when you design the messages, when you design your outreach, so it's not an afterthought.

MH [00:52:58] Covid-19 certainly isn't the last pandemic we're going to be facing. After it's said that with climate change and ecological collapse, we're living in a new era called the pandemiscene. So what are the key takeouts for you? Sarah, could I begin with you if you could pick out two or three final points that you would say should inform how we respond and deal with the next pandemic coming down the tracks?

SCB [00:53:23] It's really learning lessons from what has happened. Both the things that are that are positive we want to repeat and those that are negative and we would want to avoid. So I think that period of reflection, obviously the COVID inquiries will help that and that what we can learn from the ways in which collaborations worked well and how they could be extended, where engagement has worked well, how we could actually build that in as a systemic part of the way in which we do public health, do policy-making and the openness in terms of kind of actively listening to diverse experience across multiple levels of society. So I think is that and then secondly, make sure that we actually deal with the fundamental structural inequalities that are going to continue to pervade all the health threats that we'll be facing, and that includes climate change as well as future pandemic threats.

MH [00:54:20] I certainly echo that. We shouldn't ignore the politics.

SCB [00:54:22] As Charles has said, it's working with communities to enable that to happen. And I think that we can all do a lot to kind of demystify scientific expertise or in particular preventive health care messages. But it's the relational and human side of that that is really important. So whether that is working with community leaders and communities or in the case of public engagement dialogues like those that I've been involved with, they also involve bringing in scientists and others to talk to and with them and engage with diverse citizens. So I think that it all helps actually with transparency, but also with these are human endeavours, even if some of our results might be numbers. And I think it's bringing that element in. And we know from all the work on trust that that's absolutely key to building trust as well, because it is about relationships.

CP [00:55:22] Specifically around transparency. I think it has to be about about acknowledging mistakes, so you can learn from them. It doesn't have to be a blame thing. It has to be unless we can acknowledge that this was a mistake, we aren't going to be able to fix it in the future. And that also includes learning from things that went right. By the way, it's not just about learning from things that went wrong.

AA [00:55:40] My hope is that we learn from, for example, the COVID inquiry about what went wrong and what went right. My fear is that we have gone through an incredible trauma, whether that is personally, professionally, as a society, as a country. And my fear is that our national psyche wants to forget. And when I listen to ministers saying, almost talking about COVID in the past, the fact that we're not really collecting great figures anymore. My fear is that we want to move on without learning those lessons and that we regard this as a historical aberration in the way that the Spanish Flu was. And we don't recognise the reality that we are living in a world that is custom built for pandemics.

MH [00:56:27] And that's the key point, isn't it? Much as we'd like to believe that COVID is over and that it's safe to move on, the virus is still out there. Moreover, COVID almost certainly won't be the last pandemic. There will be others, which is why it's important to take stock now and reflect on our experience, before this moment is lost to history. Now that the UK's public inquiry into COVID is underway, we have a great opportunity to reflect

on the values that underpinned the scientific advice and the government's response in a way that wasn't possible in the heat of the moment. The inquiry will be taking evidence all next year, but it's already clear that if we want to improve trust in science in the future, we need to be more transparent about what those values are. And we also need to have an open and honest conversation with the public. In particular, we need to do a better job of reaching out to communities who may not share those values or who, for whatever reason, may harbour suspicions about science. And we should also acknowledge what we got right. The ways in which communities did come together and did learn to trust each other, and how we came to recognise that there is such a thing as society and a need for collective self-preservation.

Thank you for listening to Going Viral. If you've enjoyed this episode, please recommend it to your friends and we'd love for you to rate us too. You can find us on Twitter at goingviral_pod and on Instagram at goingviral_thepodcast. This episode has been produced in collaboration with the UK Pandemic Ethics Accelerator, which was funded by the UKRI COVID 19 Research and Innovation Fund. I'm Mark Honigsbaum, and the producers were Melissa Fitzgerald and Kate Jopling.