

Transcript

00:00:04 Speaker 1

Welcome to After the End from the Ethoc Centre at the University of Oxford, funded by the Wellcome Discovery Award Scheme.

00:00:11 Speaker 1

I'm Patricia Kingori, Professor of Global Health Ethics at the University of Oxford.

00:00:16 Speaker 1

In this series, we explore endings and their aftermaths.

00:00:20 Speaker 1

Who decides when an end has been reached, whether the end for one person is the end for everybody, and what happens after these so-called endings.

00:00:29 Speaker 1

Today, I'm with Bobby Farsidis, former Professor of Clinical and Biomedical Ethics at Brighton and Sussex Medical School, and epidemiologist Lucas Engelmann from the University of Edinburgh.

00:00:42 Speaker 1

We explore ethics and endings in the context of public health, Bobby was involved in infected blood inquiry, and Lucas works in infectious disease modeling.

00:00:52 Speaker 2

I'm Bobby Farsidis, and I'm currently Professor of Clinical and Biomedical Ethics at the Brighton and Sussex Medical School.

00:01:01 Speaker 2

I say currently because I'm due to retire very soon.

00:01:05 Speaker 2

So the whole issue of endings has become very personal to me.

00:01:10 Speaker 2

And I want to thank and both bemoan Patricia for alerting me to how complex it is to think about something important in life.

00:01:22 Speaker 2

ending in formal and contractual terms, when of course the person you are and the things that you feel are important and the people that you have had the pleasure and privilege to work with for many years will be carrying on.

00:01:36 Speaker 2

So that's where I'll start today.

00:01:39 Speaker 2

But in terms of reflecting on the wonderful workshop we all attended at the beginning of Patricia's project, it really has remained with me in a very strong sense.

00:01:50 Speaker 2

So many of the interesting discussions, the presentations,

00:01:56 Speaker 2

but also this idea that we do have to think much more critically about how we define, interact with, analyze anything that's temporal.

00:02:07 Speaker 2

What do we mean by time?

00:02:08 Speaker 2

What do we mean by its passing?

00:02:11 Speaker 2

What do we mean by recollecting and utilizing things from our past?

00:02:18 Speaker 2

I just feel that this is such an exciting project.

00:02:21 Speaker 2

I'm going to grasp every opportunity I can to be part of it.

00:02:25 Speaker 2

When Patricia asked me to attend the workshop, I had to think, what am I going to talk about?

00:02:31 Speaker 2

Have I ever reflected on this idea of endings?

00:02:34 Speaker 2

And it was actually quite fortunate that I was very immersed in the work around the infected blood inquiry at the time, a full statutory inquiry that people had asked for over decades to investigate the reasons behind the contamination of blood supplies in the UK.

00:02:55 Speaker 2

which were then given to people with bleeding disorders, people who needed emergency transfusions, and very unfortunately resulted in thousands of people being infected with HIV and hepatitis B and C.

00:03:11 Speaker 2

Preparing for my talk gave me the opportunity to reflect on this idea of public inquiries, what they were set up to do, whether they achieved that or not, and to what extent having a public inquiry and taking it seriously and conducting it very carefully could provide any sort of valuable ending to people who had been involved in what we all have to acknowledge was

00:03:37 Speaker 2

a catastrophic failure of service delivery.

00:03:42 Speaker 2

I think what we all came to realize is that a public inquiry isn't the end of things.

00:03:49 Speaker 2

In fact, the evidence provided, and in the case of the infected blood inquiry, the very personal testimony provided by person after person after person who had been either infected or affected by the infected blood scandal.

00:04:05 Speaker 2

tells us that we've opened up discussions we need to continue to have.

00:04:11 Speaker 2

We have complex issues to resolve in terms of financial compensation.

00:04:17 Speaker 2

We have difficult lessons to learn about how we provide care for people within the NHS to ensure that some of the experiences that people have aren't repeated in future.

00:04:30 Speaker 2

At one level, I think we have to move beyond the shame that many people felt as a result of what was exposed by the public inquiry and own our mistakes, own the errors and

00:04:45 Speaker 2

respond compassionately, but also effectively to the recommendations that were made by Sir Brian Langstaff, the Chair of the Infected Blood Inquiry.

00:04:56 Speaker 2

And I know that he has said very explicitly that his final report, gargantuan as it was, and well received as it was, was not the end of the story.

00:05:05 Speaker 2

And he is personally taking responsibility to ensure that the recommendations that he made are followed through.

00:05:13 Speaker 1

Bobby, that was great.

00:05:14 Speaker 1

Thank you.

00:05:15 Speaker 1

It's a pleasure now to introduce Lucas Engelmann.

00:05:18 Speaker 3

Thank you.

00:05:18 Speaker 3

I'm a historian and sociologist of biomedicine in science, technology and innovation studies in Edinburgh.

00:05:25 Speaker 3

I run the EpidemiLab, which is funded by the ERC, the European Research Council, to study the history of how epidemiology became a scientific field in the 20th century.

00:05:39 Speaker 3

but also to understand how epidemiological reasoning, a form of thinking epidemiologically about the range of social and medical issues, has become equipped with a certain political authority in the 20th century and onwards into the digital world of the 21st century.

00:05:57 Speaker 3

My own project that I'm pursuing in this larger endeavor is to focus on the history of epidemic modeling to understand how a rather obscure set of mathematical formulas

that were developed almost like a hobby by some of the earlier epidemiologists slash medical officers from the British medical service in colonial British India

00:06:24 Speaker 3

how these formulas developed and advanced over the 20th century into establishing a field of infectious disease modeling or infectious disease epidemiology.

00:06:34 Speaker 3

that is by now almost exclusively carried out through the design, through the development, and through the application of mathematical models, such as the infamous SIR model, which many will be familiar with from the COVID-19 pandemic and the various modeling discourses and debates that brought up.

00:06:58 Speaker 3

Conventionally and through large parts of the 20th century, epidemics have been

00:07:03 Speaker 3

understood and approached as historical events, unfolding over time with a beginning, a kind of development, a form of arc that has a form of escalation, but also as events that then also come to an end.

00:07:17 Speaker 3

What's puzzling to me is that SIR models do not consider epidemics as such historically unfolding events, but rather consider them as an ever-present situation that is bound to patterns of looping

00:07:29 Speaker 3

because the temporality is always defined as being reduced to single time periods, which repeat as much as the model wants.

00:07:38 Speaker 3

SIR models create a compartmental view of society separated into susceptible individuals, infected individuals, and recovered individuals.

00:07:48 Speaker 3

And the model then begins to compute an epidemic dynamic by simply defining a shifting ratio of these compartments within society.

00:07:58 Speaker 3

SIR models was also the topic for my contribution to this fantastic workshop at Oxford that Patricia and her team organized.

00:08:08 Speaker 3

The question of temporality is a really odd one for my work, and it's a really strange one in the world of mechanistic modeling because it is a way of thinking about epidemic dynamics in which the temporality of epidemics is almost entirely suspended in terms of their historical development.

00:08:27 Speaker 3

Epidemics become dynamics that are internally governed by their own logics, by their own rules.

00:08:34 Speaker 3

There are certain temporal dimensions that then become reinserted out of the way models are designed.

00:08:40 Speaker 3

Models might have things like time periods, which then might represent a day, but they're often designed with a kind of total agnosticism towards the historical dimensions of epidemics or towards the empirical dimensions even of epidemics.

00:08:55 Speaker 3

And that is what makes these models attractive, and that is what makes these models useful for certain contexts, particularly when there's a poverty of data or lots of uncertainties about the empirical picture of a developing epidemic crisis.

00:09:09 Speaker 3

So my question for the workshop was, on the one hand, how can we make sense of that odd looping temporality that characterizes these models, their kind of indifference to the way that history and epidemics actually unfold over time in different contexts and very particular geographical, historical situations?

00:09:30 Speaker 3

But on the other hand,

00:09:31 Speaker 3

I was also provocatively perhaps asking, when do SRR models end?

00:09:36 Speaker 3

And what do we make of that ascent of modeling and epidemic modeling in the world of infectious disease?

00:09:42 Speaker 3

And what we've seen in COVID-19, particularly how dominant and how hegemonial really infectious disease modeling has become to navigate the public as well as the scientific as well as the policy discourse

00:09:55 Speaker 3

about how to engage with an ongoing pandemic, how to frame the crisis of an ongoing pandemic, and how to design and devise pathways out and beyond or to contain the pandemics and their ends.

00:10:09 Speaker 3

I thought it was a really fantastic setting at the workshop to test this question out, and I really enjoyed the feedback, and I really enjoyed also the many different responses I got, some of which were particularly pushing back against the idea that infectious disease modeling has become as authoritative as it seems to me.

00:10:28 Speaker 3

I also thought it worked to issue invitation to the wider field of researchers engaging with the world of epidemics, past, present, and future,

00:10:39 Speaker 3

to think through models and to engage seriously with the kind of thinking, with the way of seeing the world that models advance precisely because they are so impactful in our world these days.

00:10:50 Speaker 1

Thank you, Lucas.

00:10:51 Speaker 1

That's great.

00:10:52 Speaker 1

I don't have the answer to any of this, but what I wanted to do was engage with you and understand from your perspective what you actually see as the value of the beginning, middle, end narrative.

00:11:07 Speaker 1

I think it's really easy to approach these things in a very critical way to say it's much more complicated than that.

00:11:13 Speaker 1

But increasingly, I think that part of the reason why this narrative has had the duration it has and the reach it has is because it does provide some kind of value.

00:11:25 Speaker 1

And I would really love to think about that with you, Bobby, in relation to the infected blood inquiry and the scandal and the infected and affected people.

00:11:35 Speaker 1

And Lucas, in your case, to think about it in relation to modeling and how we think about epidemics.

00:11:42 Speaker 1

Bobby, do you want to go first?

00:11:45 Speaker 2

I think we, as human beings, we like order, we like coherence, we like to organize things.

00:11:54 Speaker 2

And there's a deceptive simplicity to this idea of things having a beginning, a middle, and an end, and we utilize it very readily.

00:12:03 Speaker 2

It's possibly only when people like you, Patricia, challenge us a bit, we start to think, well, who's defining this as the beginning of something?

00:12:12 Speaker 2

Who is permitting us to see this as the end of something?

00:12:16 Speaker 2

These are also categories that people can utilize, and they can misuse and abuse them if required.

00:12:24 Speaker 2

So if it's politically inconvenient for something to be seen as ongoing, because that would require us to address it in some way,

00:12:33 Speaker 2

then people might decide to announce that it has ended.

00:12:38 Speaker 2

But similarly, if people who are affected by something consider it to be ongoing, they will fight against that and say, There is no end here.

00:12:48 Speaker 2

This is my reality.

00:12:49 Speaker 2

I'm in the middle of something, and something maybe that people started and now don't want to help me to finish in some important way.

00:12:59 Speaker 2

It's very understandable that we like, particularly in our culture, this organized linear progression from a beginning to an end.

00:13:06 Speaker 2

And I hate to tread on Lucas's territory, but we sometimes like to pronounce things as historical because we can then choose whether to think they're relevant or not, or say that we have moved beyond them in some way.

00:13:21 Speaker 2

But where we have to acknowledge that important features of something are ongoing and may re-emerge in as problematic a way as they have in the past, it's very important not to think of something as ended, but to understand that we are in a new phase of understanding.

00:13:43 Speaker 2

And along with that comes new responsibilities

00:13:47 Speaker 2

and a need to continue to acknowledge people that need support from those with power and influence.

00:13:55 Speaker 1

I think that's so important.

00:13:57 Speaker 1

At the same time, really thinking specifically about the infected blood scandal and the community, or I know they describe themselves as a tribe of people who've been affected, infected and affected.

00:14:10 Speaker 1

I just think about how, in some ways, the notion of an end can provide so much hope, that this is an end to these types of things happening, that the inquiry represents an end to the silence or conspiracy, or at least in going through the different processes, the systemic processes that resulted in the infected blood scandal, that it would put an end to these kinds of practices happening.

00:14:39 Speaker 1

At the same time, I felt that there was a quite complex relationship with the end.

00:14:43 Speaker 1

On the one hand, wanting to bring an end, but at the same time, wanting to promote the idea that with an end comes an invisibility and a silencing of the community and that tribe.

00:14:55 Speaker 1

That kind of complexity was something I really thought about quite a bit after your presentation.

00:15:00 Speaker 2

Absolutely.

00:15:01 Speaker 2

And I think you've touched upon a number of important issues.

00:15:05 Speaker 2

One of the ways in which we sometimes deal with trauma is to bury it.

00:15:09 Speaker 2

And we know that that's personally very damaging and societally very damaging.

00:15:14 Speaker 2

And something that a well-run, thorough public inquiry does is it brings things out into the open.

00:15:21 Speaker 2

And that in itself can be a traumatic process.

00:15:24 Speaker 2

It's not an easy process for anybody.

00:15:27 Speaker 2

But that opening up, as you said, that removing of the invisibility and the silence,

00:15:33 Speaker 2

I think it is extremely valuable.

00:15:36 Speaker 2

But once you've done that, once you've exposed the terrible treatment that people experience, the stigma that was attached to being infected with HIV, particularly, the ways in which families have gone on to experience intergenerational trauma as a result of something that many people think of as happening long ago in a very different world.

00:16:02 Speaker 2

All this has been opened up.

00:16:03 Speaker 2

The inquiry made very specific recommendations of things that might be done in order to publicly recognize this in a real way, including financial compensation for those infected and affected, but going much beyond that.

00:16:20 Speaker 2

And I think until people feel confident that proper attention and effort is being paid to fulfilling those recommendations, which were accepted very quickly by the government of the day when the inquiry reported back in May 2024.

00:16:39 Speaker 2

A sort of wound has been opened up again, and people are waiting to see what happens.

00:16:45 Speaker 2

They don't have to wait like they waited decades for the inquiry.

00:16:49 Speaker 2

Imagine what that was like, how many people never got to be part of it, never got to hear what was said, never benefited from the recognition because they had died as a result of this scandal.

00:17:03 Speaker 2

But for those that are still alive and still affected, I think time becomes very important again.

00:17:09 Speaker 2

Things need to happen in a timely manner for people to feel that this really is a step in the community's recovery.

00:17:18 Speaker 1

I think there's a really important point, and I'd love to hear from you, Lucas, about what you think the role of this beginning, middle, and end narrative is in the work that you looked at in terms of epidemiology and epidemics, but in particular, the value of it and how we've come to rely on it.

00:17:35 Speaker 3

It's an incredibly interesting question to think through epidemiology and epidemics in the 20th century, because a number of different ways that we could unfold this, and I'm going to try one or two and see if that is something that gets close to what you're asking for.

00:17:51 Speaker 3

At the beginning of the 20th century, epidemics still were very much historical events that began, developed, and ended to some extent.

00:18:01 Speaker 3

And they were often perceived also as events that would return every now and then.

00:18:05 Speaker 3

There was a form of repetition, and sometimes there was a long debate about influenza, for example, thinking about the different trans-historical patterns that might emerge there.

00:18:15 Speaker 3

Why is it that influenza is really significant every nine or 10 years over the course of

00:18:21 Speaker 3

50 years, and what does that tell us about beginnings and ends, and should we begin to classify epidemics as those that have beginning and ends, while the larger epidemiological history might one that struggles with the idea of beginning and ends.

00:18:36 Speaker 3

Whereas other epidemics, and we have to, I think, recall there in the beginning of the 20th century, the wider context,

00:18:43 Speaker 3

Other epidemics were often just seen to be individual outbreaks that would overcome certain places for a short period of time, wreak havoc, and then disappear again.

00:18:54 Speaker 3

Plague would just arrive, would do something to a harbor, and then would simmer out and be over with until the next outbreak might or might not happen.

00:19:04 Speaker 3

similar with cholera.

00:19:05 Speaker 3

There were usually preceding circumstances, often famine or other sanitary issues that would escalate, would lead to a cholera outbreak, cause a significant amount of death, then disappear in the next few years.

00:19:18 Speaker 3

Usually the city, most of the debates at that time were about life.

00:19:22 Speaker 3

London would be safe against a repeated cholera outbreak.

00:19:26 Speaker 3

We have lots of those models, and I think they are connected to a number of very reassuring assumptions about epidemics.

00:19:34 Speaker 3

One of the most reassuring assumptions that is connected to that historical framing of an epidemic is that an epidemic has a clear cause.

00:19:41 Speaker 3

If an epidemic has a beginning, a development, and an end, then you usually also are within a framework in which you might not be able to say it for certainty,

00:19:50 Speaker 3

But you can, to some extent, also pinpoint what has caused the epidemic to begin.

00:19:55 Speaker 3

You might be able to speculate about what has caused it to escalate and to become really devastating.

00:20:01 Speaker 3

You might be able, if you're lucky, to also point out what has led to the ending of this epidemic.

00:20:06 Speaker 3

Also, discourse in the beginning of the 20th century that hounces all the way through to the 21st century is a debate about epidemics that are blamed on different races, on different sanitary circumstances, on immigration, on the global trade, that are blamed on causes that were fantasized or imagined to be clear-cut, obvious causes that we could all rely on, and therefore the epidemic isn't the kind of catastrophe and crisis that it might be.

00:20:35 Speaker 3

A really good example for this is, of course, the most recent pandemic, COVID-19, where discussions about the origin of the pandemic continued throughout the entire pandemic, often with an enormous amount of controversy and public interest and popular interest.

00:20:49 Speaker 3

There is, I think, a deep desire that is quite connected to how we make sense of epidemics to grasp and develop a sense of how we might make sense of the origin of a pandemic.

00:21:02 Speaker 3

Most epidemiologists would say, and I think we can say this for most of the infectious diseases that have characterized and shaped the history of human society over the last 3,000 years, we don't know their origins.

00:21:14 Speaker 3

We don't know how they came to be, where they had first been introduced in human societies or in human cultures.

00:21:21 Speaker 3

But with COVID, that kind of question, is it coming from a wet market?

00:21:25 Speaker 3

Is it coming from a laboratory?

00:21:27 Speaker 3

Is it coming from a specific place that we can pinpoint where exactly that moment happened where a mutation on that virus escalated that virus into the position where it was confronted with a critical density of human population that allowed it to be spilled

over into the global circulation of humans and goods and then became what then was eventually a pandemic.

00:21:50 Speaker 3

is a fantasy.

00:21:52 Speaker 3

And it remains a fantasy, because whenever we point at something in particular that might be blamed or that should be blamed for an outbreak of a pandemic, we are always confronted with an infinite regress of multiple causes that determine and contribute to this particular cause to have led to that perfect storm situation, which then results in what is the global pandemic.

00:22:14 Speaker 3

In the 1920s and onwards, we see then emerging this idea of much more complex understanding of epidemics, that most epidemics cannot be tied to a clear cause on why they begin, on why this outbreak of influenza is so much more devastating than the outbreaks of the years before.

00:22:34 Speaker 3

on why smallpox, even though it is somewhat under control through vaccination, still continues to develop so aggressively in some parts of the world, while other parts of the world seem to be fairly safe.

00:22:46 Speaker 3

And this is what Andrew Mendelson has written up in a paper back in 1998, as the period where epidemics became complex.

00:22:55 Speaker 3

when emerging thinking developed that a lot of the epidemics that we are surrounded by, diphtheria, measles, meningitis, are permanently there.

00:23:04 Speaker 3

They wax and wane a little bit, they develop towards endemic status, and then come back in a more epidemic phase, but they never really end, and also they never really begin.

00:23:13 Speaker 3

And that has thrown into question the whole cause and effect, the whole causal mechanism of how we might think about epidemics.

00:23:20 Speaker 3

From there, we can then, if we want to be, I don't know, shorthanded with the complex history of epidemiology, we can draw a line from that period then to the epidemics of chronic diseases and chronic conditions from the mid-20th century onwards, where that kind of model became the predominant model.

00:23:36 Speaker 3

These are all diseases of civilization, and all that epidemiology can do is keep an eye on the waxing and waning of these and speculate about the complex causes that are usually webs of causation rather than clear-cut causes.

00:23:50 Speaker 3

and then have a whole different set of temporal frameworks and temporal categories available to think through that rather than beginning development, escalation, and more or less sudden end.

00:24:00 Speaker 1

I think it'd be really great to hear Bobby's view on this because this idea of not having a cause or not knowing the people or not being able to necessarily always understand the context of the time in which something has emerged seems to me to be not the case in the infected blood scandal.

00:24:19 Speaker 1

And I think it actually really complicates what you're saying, Lucas, with a very real world example.

00:24:25 Speaker 1

Before I let Bobby speak, one of the things I'm really interested in about the scandal is the way that time can be seen to be used as a device of unknowing and not knowing.

00:24:37 Speaker 1

So the inquiry finalised May 2024, but it was really the culmination of nearly 30, 40 years of campaigning and work to get to that point.

00:24:48 Speaker 1

I think some people felt very strongly that even at the time, 30, 40 years ago, it was known that blood received in this way from these sources and given to people would cause considerable harm.

00:25:05 Speaker 1

But in the passage of time, you could almost dismiss some of that by saying, well, we just didn't know and it wasn't known.

00:25:12 Speaker 1

So I'm really interested in Bobby's view on how actually for people with power, time can be used as a mechanism of unknowing and not knowing.

00:25:22 Speaker 2

I'd just like to start by saying how fascinating and useful I felt Lucas's explanation was and how one can draw from it to think about the infected blood inquiry, because for some people there has been a very natural psychological impulse to find the people to

00:25:43 Speaker 2

And whilst there were clearly bad actors and bad institutions and organizations, I think one of the things that the final report does very well is to say that we also have to think about how we construct and organize institutions and how we deal with things going wrong.

00:26:08 Speaker 2

And in asking that, time is almost irrelevant.

00:26:11 Speaker 2

That's a question we have to ask ourselves now as much as we should have asked ourselves in the past.

00:26:17 Speaker 2

But to address your point, Patricia, about time almost being used as a way of maybe pushing something into the long grass, making it appear less urgent, relevant, because we're now looking back at something that happened so long ago in a different time, we simply can't apply the same standards people wouldn't

00:26:38 Speaker 2

have known the same things, et cetera, et cetera.

00:26:41 Speaker 2

This is something we really had to confront as the medical ethics group advising the inquiry.

00:26:48 Speaker 2

The approach we took was that it's true that 40 years ago, for example, doctors would not have had the extensive education, ongoing advice and support that they have around ethical issues, around professionalism,

00:27:07 Speaker 2

around how to deliver properly patient-centered care.

00:27:12 Speaker 2

However, putting that aside, we can still see behaviors that were wrong by any form of moral standard that doesn't necessarily need to be underpinned so explicitly by professional education, advice, et cetera.

00:27:30 Speaker 2

And we were able to say that things did happen to people that should not have happened

00:27:37 Speaker 2

irrespective of whether it was today, yesterday, or 40 years ago.

00:27:42 Speaker 2

Having said that, I think it's also important to acknowledge that the things that we looked at, sadly, haven't disappeared.

00:27:53 Speaker 2

I loved what Lucas was saying about this idea that you can almost have simmering epidemics.

00:27:59 Speaker 2

It doesn't have to be something that bursts onto the scene, causes catastrophe, and then subsides.

00:28:06 Speaker 2

There are things that just carry on below the surface, ever ready to emerge again.

00:28:12 Speaker 2

And that move to chronic epidemics, which become part of our everyday life, part of what a health service has to contend with.

00:28:21 Speaker 2

One of the things Sir Brian Langstaff tried to do when looking back at this very real, very explosive, catastrophic incident,

00:28:32 Speaker 2

was to think, what remains of that?

00:28:34 Speaker 2

What remains of the sorts of practices that allowed this to happen?

00:28:39 Speaker 2

Where have we not changed, for example, how as institutions, we deal with things going wrong?

00:28:47 Speaker 2

How have markets changed, if at all, in the way in which we trade on the things that are so important within our health service?

00:28:56 Speaker 2

And going back to your point, Patricia, about, well, surely people knew.

00:29:01 Speaker 2

I had a horrible moment of recognition in the early days of my involvement with the infected blood inquiry.

00:29:06 Speaker 2

I went back to my days as an undergraduate at the London School of Economics when I did introduction to sociology.

00:29:14 Speaker 2

And one of the books I was asked to read was Richard Titmus's *The Gift Relationship*, which set out so clearly the dangers of a commercial market in blood products and gave as its example practices in the United States of America.

00:29:31 Speaker 2

Now, this was a very long time ago.

00:29:34 Speaker 2

I remembered it as someone who'd dabbled in 101 sociology.

00:29:40 Speaker 2

How had this message not got out more broadly, or had it, and people simply had, for whatever reasons, put it to one side?

00:29:50 Speaker 1

This is really powerful.

00:29:52 Speaker 1

Thinking with the both of you and seeing how your experience and expertise overlap is really fascinating.

00:29:59 Speaker 1

It would be really great to stay with this idea of the complexities of epidemics and really draw on your experience, Lucas, as somebody that spent a long time looking at the history of HIV/AIDS.

00:30:15 Speaker 1

And I know that this is something that is also very pertinent to the infected blood scandals, because many of the people who survived were infected with HIV.

00:30:25 Speaker 1

So really looking at

00:30:27 Speaker 1

how in this period between the end of the 20th century, the beginning of the 21st century, how HIV AIDS has mapped onto that, but also how it's really almost shown how outdated some of the 20th century ideas of endings are.

00:30:43 Speaker 1

Because we would remember that beginning of when we started to know about HIV and in this epidemic stages was this idea of the war on AIDS and the cure for.

00:30:55 Speaker 1

We've now moved to the 21st century and there isn't so much talk of that anymore.

00:31:01 Speaker 1

So I'm interested in thinking about what does not trying to end something also do?

00:31:08 Speaker 1

Lucas, I don't know if you can talk to that.

00:31:10 Speaker 3

I can try.

00:31:11 Speaker 3

I think it's a really captivating question because it gets at the heart of what I tried with a lot less experience and insight to articulate in my PhD over a decade ago on the history of HIV AIDS, asking how it became first

00:31:25 Speaker 3

first of all, a subject for biomedical discourse and what we could learn from that.

00:31:31 Speaker 3

But then the really interesting question that didn't really leave me ever was what happens if an epidemic or a pandemic becomes normalized?

00:31:38 Speaker 3

If it becomes a situation that is neither urgent enough so that it rails everyone up to a big cause that needs to be overcome, where everybody needs to create the kind of conditions and frameworks to maintain a state of alert towards that crisis?

00:31:56 Speaker 3

when AIDS has stopped being a crisis for some, a moment where you wouldn't see an end of the epidemic or an end of the pandemic, but you would see a form of slow but steady disappearance into the background.

00:32:11 Speaker 3

And it became a fabric of certain aspects of our society.

00:32:14 Speaker 3

It became a normal day-to-day institution for sexual health in European countries and in the United States.

00:32:23 Speaker 3

But it also created extremely puzzling pictures where you had a kind of invisibility of HIV/AIDS that, especially from the late 90s onwards, once high active antiretroviral treatment had become available, a kind of disappearance and invisibility of HIV/AIDS in Europe and the United States

00:32:45 Speaker 3

while the pandemic was raging in sub-Saharan African countries, in Asian countries, and in Latin American countries at levels that were never before seen.

00:32:54 Speaker 3

And so this profound injustice of the global health framework also came suddenly embroiled in the proclamations of ENDS, or in the tacit experience of ENDS, because the epidemic just didn't matter anymore to some people.

00:33:10 Speaker 3

something that I found really interesting.

00:33:12 Speaker 3

And I always wondered to what extent this is more of a conditional framework than we would expect.

00:33:17 Speaker 3

It's not just falling out of synchronicity in the world.

00:33:21 Speaker 3

It is really this now that it is an epidemic over there, we don't have to consider it anymore as an epidemic here.

00:33:28 Speaker 3

And then you have this weird phenomena from the early 2000s onwards that infection rates come up again in many European cities.

00:33:36 Speaker 3

And from there, you can then draw a line to the beginnings of pre-exposure prophylaxis, PrEP, which introduced a new chapter.

00:33:44 Speaker 3

And it's one of the most effective instruments that we have available today to effectively prevent the transmission of HIV.

00:33:51 Speaker 3

But it also further escalates that picture of inequality because it becomes, once again, as it has been, with the highly active antiretroviral treatment,

00:34:01 Speaker 3

a question of availability and a question of access and a question of who has the means to proclaim and to create the conditions for an epidemic to end and who doesn't and how that then becomes like the story of HIV AIDS, I think is hugely important for that.

00:34:17 Speaker 1

Thank you, Lucas.

00:34:18 Speaker 1

That was really helpful.

00:34:20 Speaker 1

I could just talk to you and Bobby about this forever because your insights are so interesting.

00:34:25 Speaker 1

One of the things I'd be really interested in thinking about is what has been

00:34:31 Speaker 1

the most impactful feature of the workshop and what's it made you think about since we've had that time together?

00:34:39 Speaker 1

Bobby.

00:34:40 Speaker 2

I think the most impactful feature of the workshop is a really wonderful affirmation of my lifelong commitment to interdisciplinary research.

00:34:52 Speaker 2

But interdisciplinary research with knobs on, meeting people from disciplines that I've never had conversations with,

00:35:01 Speaker 2

before, meeting people with expertise, so beautifully specific and niche, who nonetheless had the ability to bring that to a wide-ranging discussion around time, around endings, and all the things that you, Patricia, wanted us to reflect upon.

00:35:20 Speaker 2

So I would say, all power to your elbow.

00:35:24 Speaker 2

A good meeting relies on the choice of good people, and you really did hit the spot in bringing

00:35:31 Speaker 2

together such a range of expertise.

00:35:34 Speaker 2

I think we all felt a little bit humble coming in, and we were ready to listen as well as speak, and it was just a wonderful experience.

00:35:44 Speaker 1

Thank you, Bobby, and I really hope that we can continue these kind of conversations and learnings as well throughout the course of the project.

00:35:51 Speaker 1

It'd be really great to hear from you, Lucas, about the impact of the workshop and how you think it's going to maybe shape some of the future work you do and do your thinking.

00:36:01 Speaker 3

I can't thank you enough for this workshop.

00:36:04 Speaker 3

What I think really impressed me hugely about what happened at that workshop was that it created an open space in which the question of temporality and time was discussed without, on the one hand, developing it into a kind of lofty philosophical abstraction, which is a risk always when you take abstract concepts and try to develop a discussion around it.

00:36:28 Speaker 3

But also, it didn't end up to be a lot of individual papers that were just talking past each other about different ideas and different concepts of endings that are incomparable and out of any relationship to each other.

00:36:42 Speaker 3

Instead, it really created that interesting moment of real reflection about different aspects of thinking about the end and different perspectives to theorize and conceptualize the end that I found extremely helpful for my own work to go back to first principles, to really get back to like, wait a second, when they're talking about a time period in this paper, what do they mean?

00:37:05 Speaker 3

Where does this come from?

00:37:07 Speaker 3

How does this echo with ideas and concepts of time and periods and

00:37:12 Speaker 3

minutes of time that exist.

00:37:14 Speaker 3

And I think it leaves me with that ongoing question of how to make sense of that shift between a more historical engagement with epidemics and a more ahistorical engagement of epidemics.

00:37:25 Speaker 3

And that open-ended question for which I don't have an answer yet is what the exact implications are of each of these.

00:37:32 Speaker 3

And I really hope we have further chance of conversation to figure that out.

00:37:36 Speaker 1

Thank you.

00:37:36 Speaker 1

For me, thinking about the implications of these kinds of questions is so important and it's really incredible to not have the answer, but to think with others on this.

00:37:49 Speaker 1

And I'm just really grateful for your camaraderie and being fellow travellers on this journey with us and the project to think these things through.

00:37:58 Speaker 1

So thank you so much for your time.

00:38:00 Speaker 1

It's always a pleasure to think with you.

00:38:03 Speaker 2

Thank you, Patricia.

00:38:04 Speaker 3

Thank you so much.

00:38:06 Speaker 1

That brings us to the end of this podcast and the end of the series.

00:38:09 Speaker 1

Thank you for listening.

00:38:11 Speaker 1

I'm Patricia Kinguri, and you've been listening to After the End, brought to you by the Ethoc Centre at the University of Oxford, funded by the Wellcome Discovery Award Scheme.

00:38:22 Speaker 1

Please share this episode on and subscribe to the series wherever you get your podcasts.

00:38:27 Speaker 1

You can find more information about the After the End project on our website at www.aftertheend.squarespace.com.