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Transcript

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

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

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In this series, we explore endings and their aftermaths.

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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.

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In this podcast, we hear from Bobby Farsidis, former professor of clinical and biomedical ethics at Brighton and Sussex Medical School, on ethics and endings in the context of the infected blood inquiry.

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I've worked in the field of biomedical ethics for many years now.

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My origins are in philosophy and political theory, but I moved into medical ethics really in the very early days and have had a fascinating career trying to help medical practitioners and scientists find their way through all the challenging issues that they face, particularly when they're working in new and innovative fields.

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I was absolutely delighted to be invited to the inaugural workshop for the After the End project, led by the wonderful Patricia Kingori at Oxford University.

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Patricia asked me to speak very specifically about the infected blood inquiry upon which I'd been working recently.

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We explored the possibility of inquiries helping people to bring to an end the trauma that they had suffered as a result of what we now think of as one of the UK's biggest medical scandals.

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For those who are not familiar with the infected blood inquiry, the issues it addressed go back decades.

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Many, many people have been infected with HIV, hepatitis C,

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have died and sadly continue to die as a result of being given infected blood products when being treated by the NHS.

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A particular group that has suffered are those with haemophilia, bleeding disorders, who regularly required transfusions and the use of plasma products.

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The inquiry was a very long time coming, and therefore, many people didn't have the opportunity to hear the facts being laid out bare, hear people being challenged and their role in what happened, and very, very importantly, realise that they were not alone and many people had suffered in the way that they had.

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My role in the infected blood inquiry was to co-chair the expert group on medical ethics.

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So we provided evidence, we presented in person and were questioned by counsel to the inquiry.

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It was really interesting for me to be part of this process because I first really learnt about public inquiries when Sir Ian Kennedy was leading the Bristol inquiry, which followed the very unfortunate discovery of high rates of mortality associated with paediatric heart surgery in Bristol hospitals.

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Now, the interesting thing is that the chair of the infected blood inquiry, Sir Brian Langstaff, was actually counsel to the Bristol inquiry.

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And I would argue that you can really see the resonances of his experience there, because one of the things that Sir Ian Kennedy wanted to ensure was that whatever the outcome of his inquiry,

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Being part of the process would be a positive experience for the bereaved families.

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You can imagine the trauma that they had gone through and actually facing that head on again could have been a further trauma.

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Sir Ian really wanted to avoid this and paid a lot of attention to how to treat those families, how to create a safe space within which to conduct the inquiry, and how to ensure that it was, in a sense,

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gentle inquiry into the facts of the matter rather than a harsh legalistic process that he might have been more used to.

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So Brian really followed on from these principles and at the heart of the infected blood inquiry was his concern for the people who he often described as the infected and affected.

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and the fact that they should be at the centre of everything, and that systems and processes should be set up with due regard to their needs and their sensitivities.

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So we were, in a sense, their servants as members of the inquiry.

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And it was evident throughout that after many, many long years, the inquiry sought to bring people some sort of personal relief and resolution.

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As the medical ethics group, we were asked to really focus on the medical interventions involved.

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We didn't get into the actions of governments and other organisations.

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And it was very important to us to be careful not to judge through hindsight.

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We were looking at actions people had taken decades before, and we had to, in a sense, consider those actions in the context of the time, rather than judging them on the basis of what we now know about medical education, medical regulation, the advice available to doctors, the whole culture around medicine.

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Having said that,

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It was also clear to us that if we saw standards falling below something that we would think of as ethically reasonable in any context at any time, we needed to call that out.

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We needed to be clear when there had been wrongdoing.

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And there were issues where we felt that, irrespective of when, where, and how it happened, things could have been done better.

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As an expert group, we were very mindful of the fact that the questions set to us were not set by experts in the field or indeed Sir Brian or his team.

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They were questions set by the core participants in the inquiry.

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These were the things that mattered to them, the things that they needed and wanted to know more about and to hopefully understand better.

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As soon as we were appointed to the expert group, we were also invited to attend sessions and thereby see with our own eyes the testimony and evidence being given by the core participants, the people whose lives had been affected either directly or indirectly by the scandal.

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This was an incredibly powerful experience.

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Not only were you mindful of what was being said in the room, but looking around the room, you could see people who turned up day after day because this matter was so important to them.

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Some people who by this time were in poor health, but still felt they needed to be there.

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They needed to witness what was being said and how much it resonated with their own experience.

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If anyone's interested to know more about the infected blood inquiry, one of the things that Sir Brian was very clear about at the end of the process was that he wanted this almost to stand as a historical document.

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And there's a fantastic website where you can access more or less everything about the inquiry.

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YouTube videos of sessions, documents, commentary, et cetera.

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And there you would find the sorts of questions that we as a medical ethics group were asked to look at.

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They fell into various categories, but I suppose the things we focused on most were the issue of consent, had consent been gained for the sorts of treatments that people then sadly became infected through.

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What could we find out and think about and reflect upon in terms of the information people had been given subsequent to being infected?

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And sadly, we had to look very carefully at the ethical issues governing medical research because some of the most upsetting incidents occurred within the context of medical research rather than purely clinical treatment.

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The way in which an inquiry is set up means that the recommendations that come out of it are very much the responsibility of the chair as advised by their team.

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But of course, some of the things that we covered were pertinent to the issue of compensation.

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We often think of compensation as something that addresses a wrong or makes up for a harm.

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And we spent a lot of time thinking about the sorts of wrongs and the sorts of harms and the degree of wrong and harm that had been done to the infected and affected.

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And I think Sir Brian will have been cognizant of how that bore on his ultimate recommendations.

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I think one of the things I've learnt very clearly through being part of this inquiry, and only a very small part of this inquiry, I should say,

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is that things don't end on the day that the final report is announced.

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And I don't think I was reading too much between the lines to hear Sir Brian saying at the end of his final report that he was going to be watching very, very carefully to see how the recommendations he made would be carried out.

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So reflecting on the inquiry in relation to this issue of endings is actually quite a complex matter.

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I think there's a mistaken public belief that an inquiry is a quick and easy fix for something that's gone disastrously wrong.

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I am very confident that they make a difference.

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I think being heard, having the chance to tell your story, having the chance to hear others defend or explain their actions, all of this is valuable and at some level curative.

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But going back to Sir Ian Kennedy, he was very well aware when he set up the Bristol Inquiry that he could not do what most parents wanted, which was explain and make right what had happened to their particular child.

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We have to think of the inquiry almost like a public health measure, where we try very hard to move things on to make things better, but realise that for individuals, the pain, the loss, and I would say the intergenerational trauma will still to some degree exist.

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That brings us to the end of this podcast.

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Thank you for listening.

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Do join us next time when we hear from epidemiologist Lucas Engelmann from the University of Edinburgh on infectious disease modeling.

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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 Welcome Discovery Award Scheme.

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