

## Wellcome Genome Campus | 3-4 Anastasia Koch

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Hi, everyone. I'm Dr. Anastasia Koch, or Tash. I'm the co-founder of Eh!woza, that I'm going to tell you about now. I'm also trained as a biomedical researcher, and I did some work on genomics on *Mycobacterium tuberculosis*. So it looks like you've got a really fantastic course that you're attending. I won't be talking to you about science today, but I'll be giving you a very brief introduction to public engagement. And I'm sorry that this is so quick. I'm just going to touch on the key points, and I hope it's useful. I'm also just going to turn my video off while I'm going through the slides, but I thought I'd just turn it on to say hi to everyone.

So I'm going to give you a quick example of a public engagement programme which is called Eh!woza And that's the project that I started. So it was started because it was incubated within the Institute of Infectious Disease and Molecular Medicine at the University of Cape Town, where I did my PhD. And it really started because during my PhD I was very interested in using the knowledge that I was getting in my PhD to engage with people who were affected by the disease I was studying, which was TB.

And through that, I met an artist, and we started a very informal project in 2013. And so between 2013 and 2019, we implemented informal and distinct projects. And then in 2020, we got a discretionary award in public engagement from the Wellcome Trust, and this really allowed us to transition into an independent, not for profit organisation to implement high quality public engagement in the local setting. So this was just really to show that we started very organically and with a true interest and passion for public engagement, and the work has grown quite significantly over the years.

So what is Eh!woza? Eh!woza operates at the intersection of public engagement, youth advocacy, science communication, and skills development to bring together the biomedicine of disease with a social impact. We see our participants as active partners, and we aim to facilitate access to accurate information to encourage dialogue and debates and conversation around health and disease. And we focus on infectious disease-- mostly TB, HIV, and COVID-- but we're starting to do some work on NCDs.

We tell stories and make sure that representation of health and disease is contextually relevant and importantly to develop capacity in public engagement and the creative industries around health in our local setting, which is Cape Town, South Africa. Over the longer term, what do we hope to achieve? We hope to encourage positive health seeking behaviour, to engender trust in science, health research, and health care services, and to decrease stigma around disease.

So I've just put this slide up to show the team who works with Eh!woza. We're quite a small team. And what I put the slide up to show is that we're quite transdisciplinary. And so we've got people working with us that come from different places and different fields, and we work in a very collaborative way. And then also just to quickly acknowledge our funders partners and support networks who've really supported this work and without which it wouldn't be possible.

So very quickly, I'm going to try and tell you a little bit about what Eh!woza actually does in terms of its projects. And so the first project I'll tell you about is Eh!woza Learner Doccies. And this was our first project and also our oldest project, and was funded by an international engagement award from the Wellcome Trust in 2014.

And in this project, what we do is we engage high school learners from a township just outside of Cape Town called Khayelitsha. Khayelitsha has very high rates of HIV, TB, and COVID and also has high levels of poverty, inequality, unemployment. And so the two things collide and exacerbate each other.

And so learners are recruited and brought to the labs to be engaged with biomedical research in particular, rather than health information, in a very hands on way through talks and experiments. And after learners have got accurate information about TB-- we focus on TB but also touch on HIV and COVID-- we guide learners to make films about the personal and social impacts of these diseases in their neighbourhoods and communities. And what's really important to mention here is that learners maintain editorial control over the films. And so they make the films from start to finish, shooting to editing. And so they really tell their own stories.

And the other thing to mention is learners learn how to use industry-grade equipment, developing skills, but also ensuring very high production value of the films. And unfortunately, I don't have time to show you a film, but they are on our website. And hopefully you'll go and have a look.

The other programme that's more new that we've been running is Eh!woza Schools. And this is really to leverage the media that we've made in Learner Doccies to reach a broader group of high school going youth to engage with health research. And we started this project in 2018, and it's been growing slowly ever since. COVID was a bit of a roadblock.

And then we've got a science communication arm. And this was really, really encouraged by COVID because we saw the need for getting very, very accurate information out there and very quickly. And I thought I'd show you an example of one of our animations, but I don't think we're going to have time. So we made a lot of animations about COVID and COVID vaccines, and now we've just started working on TB. But these animations are available on our website and have been translated into some South African languages and are freely available for anyone to use. So please go and take a look, and feel free to use them if you'd like to.

And then finally, just to mention, we do a bit of engaged scholarship. And so we host two PhD candidates. We have an honours course in public engagement. And we publish in peer-reviewed journals. And this is really scholarship around public engagement, So, generating new knowledge around public engagement.

OK. So moving on very quickly to some of the principles of public engagement-- and as I said, this is really quick, and I'm sorry that I'm rushing through it. But I have put my email address at the end in case anyone has specific questions, together with a whole bunch of other guides and resources. And so first, I thought I'd define what public engagement is. So what is this thing that we talk about as public engagement? And I've put a couple of definitions up.

So public engagement is really when the activities and benefits of higher education and research is shared with the public. And what's important to mention here is that engagement is, by definition, a two-way process. So it involves mutual interaction and listening and mutual benefit. The Wellcome Trust defined why they see public engagement as important, and I've put an asterisk there because, as you probably all know, Wellcome's gone through a major update of its strategy, and they will probably update some of these ideas as well.

And so Wellcome sees public engagement as important because it empowers people so more people can participate and use and reflect on health research. It can improve research itself by making it more people-centred and allow researchers to understand people's experience. And then more broadly, it can help people value and think about science and health research. And this is really important. And I think it became very, very clear how important this was during the pandemic and around vaccine hesitancy and how important it is that we encourage trust in science. And public engagement is really useful here.

The next thing that I thought I'd just touch on is public engagement and ethics. So when implementing public engagement work, as with any other work, it's really important that we're ethical. And this follows the key principles of ethics. But importantly here, a lot of funders are starting to encourage this kind of work, and this can lead to tick-boxing. So it's really important to consider the motivations for doing this kind of work. And doing work that you think is going to work and you think is going to make a difference will make it more likely to do so and also makes it more enjoyable.

And then the other thing that's becoming really important in public engagement is impact assessment. So is the public engagement work that you're doing doing what you thought it would do? What does it actually do? And is it worth it to keep doing it? And how can it be improved? Did it have the impact you intended it to have? Or did it have unintended impacts?

And it's really important to try and think about this at the start of the project. So what kind of methods will you use to assess this? Will they be qualitative, quantitative, maybe both? What will you be measuring? Would it be a change in knowledge, change in behaviour? What kind of metrics will you use? And it becomes a lot more scientific here, but it's really, really important that we start generating evidence for the impacts of our work or for ways to improve the work.

And then finally, some general tips for developing and implementing public engagement work. Ensure the information that you're putting out there is very accurate. So this is a "first do no harm" principle. We know how much harm inaccurate information can do. The next point is to remain flexible and responsive. A lot can change very quickly, as you probably all know and are experienced in pandemics and outbreaks and disease. But also within hyperlocal communities, things can change in social conditions or in the sociopolitical context very quickly.

It's also important, before you start, to try and understand what people already know or are already doing. And this can be done through desktop research, short surveys, focus groups, even informal discussion. Lived experience is really important and really matters around infectious disease and especially in the context of public engagement. Consider the context to meet people where they are and think about how engagement could best be delivered. So for example, a social media campaign is probably not going to work in a place where there isn't good internet.

And then following on from that, find out if there are other people working on the same topics. They could provide collaboration. But also, it's not always people working in a formal way. So it could be community leaders who will provide you access in a particular community. And it's really important to establish these connections to, A, avoid offending people, to magnify the impacts of your work, and will lead to better public engagement.

And then consider working with people outside of your field. So it's been very rewarding working with an artist on this project, and I've learned a lot. And there's a new word, a buzzword, in public engagement, which is connectors. And I put a link there because there's actually some guidance on connectors. So these are people who are not necessarily researchers, or they're not necessarily academics or public health specialists, but form some really important role in public engagement-- community leaders, creatives, and things like that.

And then the other important point is to maintain a very keen awareness of power dynamics. So really carefully discuss expectations, especially in collaborative and interdisciplinary projects, expectations of the project with your team. And then something I learned early on is to start small and build as you learn. So really pilot work and see how it works and then develop it from there rather than aiming for too big because things can really get unmanageable from there.

And then the next point is to join a community of practise within public engagement. And when I started, I didn't think there were a lot of people doing this kind of work. And I think it's grown in the last 10 years. But there are people out there doing this work. And it can be incredibly valuable to link in with people. You get new ideas, ideas for collaboration, support when you get stuck.

And I've put all of these resources here. I really implore you to go and have a look. So Eh!woza's website is over here. Please have a look at the animations and email me if you'd like to use them. And also have a look at the forms. It would be great for you to see a hands-on example of what we do. And then the other platform that hosts a lot of information and resource about public engagement is MESH.

So thank you very much. I'm sorry I sped through that, but I hope it's useful, and I hope you enjoy the rest of your course. Thanks. I'll just turn on my video to say bye. Yeah, enjoy the rest of the course. I hope it goes really well.