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Welcome to the seventh episode of the BBMRI-ERIC podcast. My name is Eleanor Shember, Head of Outreach, Education and Communications at BBMRI. This is part two of a two part podcast that shares different perspectives on why the patient pillar is so important. If you haven't already heard from Kathi Apostolidis and Stefanie Houwaart, I suggest you listen to that episode first.

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In this episode, you'll meet Eric Vermeulen, who's chair of the BBMRI Stakeholder Forum Patient Pillar. To explain the significance of the patient pillar and BBMRI's role in bringing patient organisations together, I'm going to hand over to Jana.

Jana - My name is Jana Pavlifç-Zupanc, and I'm the Head of Public Affairs at BBMRI-ERIC. It has been clear from the very beginning that the dialogue with the patient organisations is very intrinsic to biobanking itself, and that's why we've foreseen to establish a stakeholder forum.

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This is something that's been actually written in the statutes of BBMRI, with the goal of bringing patient organisations, primarily patient organisations, together with the biobanking community. And we are very proud that today we have organisations that we are working very closely together with, and they are coming from 13 different European countries and we also have a number of European level patient organisations with us. Now,

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We meet with the patient organisations several times per year, and this matters to us, but also to the patient organisations because we are discussing the topics that really matter to both sides, such as cancer research, new legislation, for example, European health data space and its consequences for both the patients and the biobanking. We are also looking to bring together patients with the policymakers and moreover, with the wide biobanking community, which we do quite regularly through our meetings and sessions and the European Biobank week.

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What has been more and more important is also to include the patient organisations in the scope of our work on different European projects, because there we really see that the patients are included in the most topical discussions on the EU level and their point of view is really taken care of and noted. So overall, BBMRI has a very structured, but I would say also strategic dialogue with the patient organisations and I would dare to say that this sets us apart from other organisations in the area and for our future we will work towards including even more patient organisations into our stakeholder forum and of course, ensuring that at least one patient organisation from every

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member state that we have is engaged and contributes and we can give back to that country also through engaging with patients.

Eleanor - Thank you Jana. Eric Vermeulen only recently took up the post of Chair of the Stakeholder Forum Patient Pillar. He's also a member of the Scientific and Ethical Advisory Board for BBMRI. He made time to talk to me on a rainy morning from the Netherlands.

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Eric, welcome and thank you for making time today. Congratulations to you on becoming the new chair of the Stakeholder forum. As you well know, the forum with its patient pillar has been a key element of BBMRI-ERIC since, well, since day dot. Now you have a background as a nurse with neonatal experience and as a sociologist, which I find fascinating.

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How do these different perspectives and the experiences that you have, how are they going to contribute to your role in patient advocacy, which you've done for years? And now as chair of the Stakeholder Forum?

Eric - Okay, well, I'll do my best to have them influence my work. Being a nurse always gives you a different perspective on patients, of course, because you're really in contact with patients not only around treatment, but also for the more social issues.

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So you do not treat the disease, but you help the patient. And specifically in paediatrics, you have to deal with the parents a lot of the time, which was my work in the neonatal unit. So studying sociology was something I always wanted to do, but it's really in line with being a nurse, in fact, because it's a social outlook on individuals.

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And as a sociologist, you never look at an individual, but you always see them as a yeah, influenced by, by their context, which is really what nurses also do. So it's it's really in line with that really. And, and with the hospital I was working in, in Amsterdam really had a progressive view on how to respond to patients because they were really the first ones to have sort of meetings in which they asked parents to evaluate the care they had.

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So after I think a half a year or something, they invited parents of children who were admitted to the hospital to give an open view on the care. They had to learn from them, and we always made sure that they were frank and clear, so they did not need to hold that back. And we were trained not to defend our work, but to really listen to what they thought it was because there was a doctor there who really was trying to improve care and it was very forward looking and that learned a lot about, you know, patient through presentation and patient perspectives.

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So that's really good. So that was in there from the first time I started working as a nurse, in fact, and as a sociologist, well you learn that especially in current society, representation is really important because all organisations have to legitimise their work and what they do. So involvement and engagement are really central. I think you are always in danger of having some upheaval about what you do in current society.

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And one means is good governance and involving engaging with patients and people who are involved. So as a sociologist, that fits also really neat with a patient engagement. Yeah.

Eleanor - That's fascinating. And I think you talking about as a nurse as well, having that contextual understanding for sociology, but as a nurse acting as a bridge between the patient and the doctor and seeing the whole patient, how how did you become involved then in patient advocacy and then the patient pillar?

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Eric - Yes. Okay. Well, at first I, after my Ph.D., I started to work in in the Dutch Cancer Hospital in the Netherlands. Your tissues and data can be used unless you opt out of this. But they found out that nobody of the patients knew that this was possible, so nobody opted out. You could opt out, but you didn't know about it.

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So they thought, well let's ask our patients what they think about this. And I was hired to do this research so that we did with questionnaires and with interviews. And that's really interesting because it made me realise that there is lots of tissues lying around in hospitals. They are stored in the context of treatment. If you are having surgery for cancer, for example, they save some of the tissue because that can be used for later diagnostics and it's really important to save it.

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And a lot of biobanking material or research is done with this tissue. So that's the normal tissue in hospitals. It's not specific biobanking because normally then you gather materials specifically for one goal or from one group of patients. But that research, it confronted me with patients and they said things like, "Oh, you still have a piece of me in the hospital," and because it was also cancer tissue, so they save some cancer tissue, but also healthy tissue, if it was attached.

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And they also said, "is it still growing then?" Or "what do you do with it?" "Get rid of it" or "I don't care because it's not me." But some of them said "it's really me that is being represented by this tissue" and that, for a sociologist, it's really interesting because that goes back to being an individual or being part of a collective.

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This tissue is really representing the patient and that's what I find very interesting about biobanking. You don't need to be there to be in research and the tissues are really important because they combine tissues and data from many, many persons. So that makes it even more valuable. So that's what got me hooked on biobanking, in fact. And later on I started to work for the Rare Disease Patient Association, you summarise their motto as ,Äòshare and protect,Äô.

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They have a big stake in sharing data because they are with very few patients. That means you can't do any research unless if you combine the data and the patient materials. But also they are really vulnerable because you can always identify them. If there are five patients in the Netherlands, you can anonymise the data, but you almost certainly find out who it is.

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So they are really, yeah, aware of privacy and identification. So for rare disease patients, share and protected is really important and biobanking and being in a registry also on a European base. So that's really comes natural to be a patient representative in this sense. And to come back to your question because the Netherlands always had the biobanking BMRI, the Dutch version and they also had a societal board and I became a member of that because of the tissue research and the patient views on that.

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So then we became aware of BMRI - the European version. So that's why I became a member of that too.

Eleanor - I think you've brought up some really important and differing views on how patients view and approach their samples and data being treated and the deep understanding around that. You have been involved in the stakeholder forum for a while, particularly on behalf of the Dutch Association and for Rare and Genetic Diseases.

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And what you've talked about in particular, that awareness, that understanding that being involved in research as a patient is critical and it's in your interest, but it's also real sensitivities around how your data is handled. Yeah. Now the patient pillar currently has three areas of focus that's biobanking with children or paediatrics, which you're very sensitive to, cancer, which you've already brought up and how patient data is treated.

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And they're all major areas currently at the moment as topics within biobanking and through your work, you've got an understanding of that through the Dutch Health-RI, and you have a particular understanding of GDPR in the European health data space, which is a huge project for those that don't know. Now what will be the contribution of the patient pillar to these areas over the next couple of years?

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Eric - Yeah, that's a difficult to answer question and maybe I should explain what I learned recently. The European health data space is trying to make data access better, possible, in Europe because currently countries have their own regulations and it's difficult to exchange or get access to more data. So patients, I think, would prefer that this is made possible. But the European data space also needs to protect patients privacy and possible misuse of of data, of course.

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So what the European health data space is, I think is going to do is to have data access organisations for every country with also patient involvement, engagement or citizen or other involvement engagement. And really, BBMRI-ERIC is a sort of model for this because they have the infrastructure already in Europe, they have the national nodes, the biobanking nodes with patients and citizens involved, and they also have the European branch, the stakeholder forum.

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So I think, yeah, for me this is an ideal example or maybe even infrastructure for the European health data space. Of course, BBMRI-ERIC stakeholder forum does not have the means yet to provide this for European health data space. But I think that as a model or an example, we can really use that and I think we should use that.

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And I think that's well, one of my goals. Indeed for the stakeholder forum is to increase the communication between our members and also their attachment to the nodes in the in the countries. For example, we now have many representatives from rare disease organisations, but not necessarily from the Biobank nodes. So I think it's our task to connect these better or make sure that they communicate with each other so that we learn what our developments or problems are, things that they want to be discussed in the national node and that we can also discuss that in the stakeholder forum on the international level.

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So I think BBMRI can be very important for the European health data space in that, in this sense.

Eleanor - It's really helpful that you've outlined it that way because there is quite a lot of fragmentation in terms of how health data is handled. And of course EHDS is about harmonising that and the way we operate is BBMRI with our national nodes,

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You've then got that sort of meta level of the stakeholder forum and BBMRI-ERIC. And then you've got the national nodes with that contextual understanding of countries positions on data and making sure that patient advocacy groups and members of the patient pillar are better connected through to those nodes. So that's really helpful. Thank you. You've set out some priorities before taking on the chairmanship.

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Can you explain to listeners what some of those priorities are and how the pillar, Ås going to achieve them?

Eric - Yeah, well, I think that in general, health data are becoming more and more important for health research and also for better diagnostic tools and then you think about the data that are stored in the context of care, but of course BBMRI is about biobanking.

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So they already have a lot of data and specifically gathered also, and they have the infrastructure to share among researchers. So I think that this, well like I said, that is also the model to proceed. What is really fascinating for me is that in the Netherlands we have with Health-RI, we are trying to set up a learning health system in which these data, in the context of care are used to improve treatments and diagnostics.

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So I think that the Biobank data should be connected to that too. I don't really know how that should be done, but I guess that should be possible in some sense. So yeah, that's what I think that the learning health system is really important and for this you really need the patient involvement and engagement. You want to be legitimate and you want also their cooperation because they can give you more data if they see the logic and the goals of gathering these data and using these data.

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So there's where I think BBMRI can be really important.

Eleanor - I think the focus on data is so important, you know, for those who might be listening and a less familiar with biobanking, it's not just about a liquid or a tissue sample being collected from that sample comes a lots of very detailed data about the sample, and that is also the sample.

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Eric - Yeah.

Eleanor - And so it's connecting those three together and making sure that anonymity, consent, re-use standards in data gathering harmonised. They're all major issues that need to be tackled to develop new treatments. And so the patient pillar is really important for helping to achieve that. Yeah. Something of additional importance is trust. And this comes, of course, with data, so trust with biobanking and medical research.

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And I know this is a priority for you too. How do you think the stakeholder forum and your link to the Scientific and Ethical Advisory Board, how can that help BBMRI really navigate greater transparency and

generate trust with the general public when it comes to working with biobanks and data?

Eric - Yeah, I think that we can only try to remain trustworthy is where I think that you need to show that in your governance you involve and engage with citizens and patients.

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So that is what I think basically is our task to show that we are involved, that we think with them, that we advise them also on on certain things. So that is where I think that I would want to increase the working of the stakeholder forum, for example, in the Netherlands, in the Health-RI Societal Board, we really take a topic and advise on this and we write this down and we send that to the Board of Health-RI.

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That is difficult because in BBMRI-ERIC, we are with far more people with different perspectives. So I don't really see how we can do this, but I think that is important to show on the outside world that we think and we advise from their perspective.

Eleanor - It is a very important perspective when there are major consultations out, having the patient pillar involved in commenting on them and shaping BBMRI,Ãs view on something that can't happen without the view of patient advocacy groups and thus the patient pillar.

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Eric - As a sociologist, I also see the limitations of this effort. It takes a lot of time. The topics are really difficult. Even if you read something, sometimes it's difficult to understand. Take, for example, the EHDS, I find that people have different perspectives on what it what the current proposal is. And we also do not really know what our representatives contribute, I mean, from the Belgian or the Dutch representatives or what they bring in in the proposal.

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So there are limits to engagement and involvement, I think, and we have to be aware of this. I think we cannot do more than be aware of this and try to manage it. I have also my time limits. I cannot read all and be involved in all activities, so I guess that is the same for the other representatives because they are always representatives of patient associations.

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So they,Ãre there for their perspective, even from their disease perspective possibly. So we have to be aware of this.

Eleanor - You make an important point, I think, that a lot of this work, particularly around the stakeholder forum, is done in kind. Yeah. What motivates you?

Eric - Oh, yeah. Well, the fascination for biobanking and for cooperation, in fact, and I see a lot of really enthusiastic researchers who really want to do good for patients.

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So I think that is the main motivation. Yeah.

Eleanor - Eric, thank you so much for your time. I really appreciate it. Over this two part episode, you've met members of the Stakeholder Forum Patient Pillar and got an insight into the diverse backgrounds and expertise its members bring to BBMRI-ERIC. The influence of the Pillar is key to ensuring that the organisation's direction has the patient, alongside the biobanks, at the heart of it.

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If you would like to know more about the Forum and Pillar, visit the BBMRI-ERIC website That's b-b-m-r-i dash eric Dot EU and browse the about section. We regularly share news from the patient pillar and projects involving patient input via the BBMRI-ERIC Newsletter. You can sign up for that too on our website. If you enjoyed this podcast, do share it with interested friends and colleagues and leave us a review on whichever platform you listen via, it helps us reach new listeners.

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