



Podcast

Creating a level playing field for collaboration

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12 Tineke Abma: Redefining research - the power of sitting next to, not in front of people

Published 19 March, 2025

Keywords

Experiential knowledge, not-knowing, artists, older-person care, participatory research, trust, creative methods, research agendas, research impact

Episode description

In this episode, we welcome Tineke Abma, a professor of arts and health at Erasmus University and Leiden University Medical Center and executive director of Leiden Academy on Vitality and Aging. Tineke shares her fascinating experiences and insights on participatory research, particularly with older adults and people with disabilities. She emphasizes the importance of experiential knowledge and collaboration in making research relevant and impactful. This implies seeing people as a whole and creating a level playing field by sitting next to them rather than sitting in front of them and asking questions. For example, taking nursing home residents seriously and involving them as co-researchers, sharing uncertainties, and collaboratively seeking solutions are crucial for building trustful relationships. Listen to this inspiring episode to learn more about how creative methods, working with artists, and collaboration with stakeholders can positively change healthcare and research agendas.

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Introduction to Tineke Abma and her work

In this episode, we welcome Tineke Abma. Tineke, welcome. Hi, Tonnie. Good to meet you. **And of course, we are very anxious to know why you are here and maybe you can introduce yourself a little bit more.** Yeah, my name is Tineke Abma. I am a professor in arts and health at the Erasmus University and also a professor at the Leiden Medical Center focused on the participation of older people. And I am the executive director of Leiden Academy on Vitality and Aging. So, these are my current positions. I've always had an interest in creating a space for all kinds of people to join. And I think that's the connection with your podcast series.

And I know you from your participatory studies, particularly with older adults, because I find them fascinating, and I learn a lot from them. So, I hope you will share some of your experiences, some stories on how to create a level playing field for collaboration.

Yeah, thank you. When I started my research, I was part of a movement called user involvement. So, there were many people in the healthcare field who were thinking about how can we engage and involve patients into research? Because until that moment, funding agencies and researchers were the ones who were determining what the research questions were. And many people were concerned that those questions formulated by those parties did not well reflect the issues of the end users of patients themselves. So, I got engaged in that field and I started to work with people with spinal cord injuries.

Stepping into the field engaging patients and other stakeholders in research

That was one of my first projects and that has been, a key experience for me because I started to talk with people with spinal cord injury, what their concerns and issues were. And these were all over the place. These had to do with entering a medical field, communication with doctors, but it was also about having dreams, a planned career that got stuck. It was about not being taken seriously in society, sitting in a wheelchair, talking about you or treating you like a child. These patients had all kinds of issues which they considered to be important. And after many interviews and focus groups, I also started to talk to the professionals and the medical doctors, but also to civil servants at municipalities. And it was very fascinating to discover that their focus was very small and one-sided. Their scope was very specific. For example, most of the researchers in that field were focused on mobility. So all the research money was going into what someone with a wheelchair said, making the wheelchair more effective. But you know, that wasn't their issue in life. The incongruence between what patients found important, all those issues related to their lives versus what professionals found important was so obvious and for me that was so convincing that we really need the knowledge and the ideas and the issues of people themselves. We need experiential knowledge in order to make research relevant for their lives. That is where my fascination started and also my persuasion that we really need to create what you call level playing fields to have the various types of knowledge on board in order to address issues that are relevant to people's lives.

Okay. And what happened? Some of the established researchers were not amused by the research agenda that was formulated by the patients, because that was not addressing what they were studying. On the other hand, there were also researchers like psychologists or sociologists who said I want to enter that field of spinal cord injury, but I was never given a chance to do a project because the funding agency also focused on those medical issues. And



now, because I also engaged funding agencies, the funding agencies also said, we really need to broaden our research focus and have other researchers on board to have an impact as a funding agency because we really want to do something that has also relevance for people and that the audience and public also understands that we are there for people with spinal cord injuries. So they broadened their agenda, new participants entered the field. And also, what many of the patients said was, we really need more applied research. Because most of the researchers did fundamental research, which takes, of course, lots of years before someone will experience an improvement. So more applied research and also more research on coping, on disability in society, making society more inclusive. The funding agency really listened to the results of this project.

Participatory research with spinal cord injury patients

Okay, so the funding agencies play an important role. Maybe you have an example of a project you were involved in. How do you involve different disciplines and also the clients, the patients, or is it still interviews or one-on-one? Well, when I started, this was, I think, 15, 20 years ago. One of the first things I did was I don't know anything about spinal cord injuries. So I found out the patient association for about 18,000 people with spinal cord injuries were related somehow with this patient organization. And I asked them, are there people who are willing to work with me? Because I don't know this diagnosis. This is really new for me. And they really liked the idea to work with me. So the board said, yes, we want to work with you. And they also said we have someone who we think could work with you as a sort of patient researcher. And that was really new in the field. I got into contact with Elise Adriaanse, she used a wheelchair, and I had this fascination: what is spinal cord injury? Can you tell me more about it? How does it affect your life? And can we work together to do research? I remember I went to her house, and I saw how her house was adjusted to her sitting in a wheelchair and how she got along with her kids. So I really got to know her life-world. And she sort of became a friend of mine and I really needed her. I mean, it was not because I wanted to please her or no, I just, you know, I needed her knowledge, and I needed her network. And she really felt, I think, that we were going to be partners in that.

It was more mutuality, more reciprocity than usual. Yeah, yeah. I was really curious and fascinated. And I think it also helped that we both had, this interest in, what are the issues of patients? She knew, of course, as a person herself, some of the issues that bothered her. But she also got an interest in, let's go to the people who are members of the association and let's talk to them and see, what are their issues? And we soon discovered that they really liked to talk with each other. Interviews weren't the most important things. I mean, that was okay, but we saw that the need to meet each other and to exchange how everybody was dealing with this illness and how their families were dealing with it. From the start, this was really participatory as, coming together and researching their own lives and discovering among us what is our agenda, what is important for us? And often it also was an eye-opener for people that they, because they often very isolated, didn't know or meet other members. And then they had these meetings and then they discovered, such an illness, you don't have it on your own. It's also your partner and your family and you coped in different manners and how do you do that?

It was a real positive energy. The interactions were also not as, I am the researcher, I am asking you the questions. No, we were all researching. What does it mean to have such an illness? We were all researchers. And that was the atmosphere. We were asking questions, we were listening



to each other. We were thinking, who should know this? That was the kind of deliberation and dialogue that was going on. And it was very, very valuable for people themselves also.

Empowerment through collaboration, broadening research agendas

And the results of that project, of that process? Of course, what you said, the recognition, meeting each other is also already a result. The recognition, the relational empowerment, I think that is indeed also a very important outcome: that people recognized that the concerns I have with a society who is belittling me is not just something I experience. This is a broader societal issue, and we can collaborate to put this on the agenda also of policymakers and funding agencies. I don't have to struggle with it myself. There are more people who experience this, if we bring our strengths together, we will have a greater hearing. I really find that important that research is not only for knowledge for outsiders, but that it helps the personal and mutual understanding of those whose work and life is at stake. So if they learn more and if they get more grip on their lives and if their critical consciousness is growing, I am happy. And of course, it's really nice that this was also picked up by the funding agency and that they really redesigned their whole research program in the sense that they made it broader, opening up for other scholars, also introducing the idea of perhaps we need patients on a scientific board. Why do we only have medical doctors on board? If it comes to the relevance, we also need people themselves. So then you got the discussion with the scientific board and discussion about relevance criteria. It really had an impact on the whole system, you could say.

Not only for this project, but also for the whole agenda. Yeah, because I started with this project, then people got interested. So other charity, health charity organizations, 'Gezondheidsfondsen' (Health Funding agencies), also got interested in this methodology because I did not only do this project, but I also described the methodology I was developing along the way. And so other charity organizations also asked me, the Parkinson's Association or people with kidney disease. They also asked me, we also like to develop such an integrative patient led agenda. Can you do that with us?

Improving a nursing home with the older residents as co-researchers

Okay. And nowadays you also work with older adults, even people with dementia. And how do you involve them? Because sitting and talking may not be the only way. So how do you invite them or involve them? How does it work? Well, one of the first projects with people I did in a nursing home, and I just went to their environment. So I didn't ask them to come to the university and join my project, but I just went to one of the nursing homes in the location where I was headed at that time at Maastricht University. And I just got curious, what does it mean to live in a nursing home? What are your issues? And one of the things was the food. They were really concerned about the food, the quality, the ambience, but they didn't know that of each other. And as we moved along, we decided to work with each other to see whether we could improve the meals. So again, I formed a sort of action group with older people. I think they were about six to eight older ladies, different ages, various disabilities. And one of the challenges in that project was that they were kind of, they felt fear, they felt reluctant to share their critique on the nursing homes. They thought that is not something that is really chic and perhaps, this will have repercussions for my care. So they were anxious about that. Sometimes they shared stories and then they said, no, it's not so bad at all. And we do understand, shortage of



personnel, there's no budget. So it was really difficult to let them talk about things that bother them.

But eventually there was, there's one critical incident I remember, there was one lady and she sat in that big room where they were eating together and she said, '*I'm not going to pay for this meal.*' And the whole room got silent, because she stood up. She was a large woman. I'm not going to pay for this food. She thought it was terrible. And she didn't want to do it anymore. And that was sort of 'burgerlijke ongehoorzaamheid' (civil disobedience). She did something that other people said, we do not have to accept this. We can bring this issue to the managers and to the board of the nursing home. That was an important dynamic in that project. But then I encountered another difficult moment where people got into a kind of negative complaining mode of all the things that were bad in the nursing home. And they felt no room at all to think about possible solutions. And I didn't know how to proceed. So I honestly said, well, perhaps this doesn't work at all, perhaps I have to quit. But then they said, no, no, no, no, we want to continue. And then I thought we need another more creative approach. And that was a key experience again. I asked them to imagine and dream what would be the best future they could think of. I had all kinds of papers and colours, and I asked them, just make a sort of bricolage of what you think would be the most beautiful nursing home, the best meal, whatever you like. And then the energy came back and quite soon some of the ladies said, well, we have a kitchen here in the nursing home, but they closed it. How great would it be if we could reopen that kitchen and if we could hire the chef? So here the question to dream, to use your imagination and to have the creative method really helped the process forward.

Beautiful. But it starts with taking them seriously, seeing them as co-researchers. They know so much. I mean, it's their lives. **And how were the professionals in the nursing home? How did they respond?** Well, it was interesting that especially the lower position people in the kitchen, got very interested because, they had ideas how to make this ambience more attractive with candles. And they had ideas about more beautiful desserts. And so they got on board. And it was also nice to see that the location manager also thought, well, these ladies are not only complaining, they are coming up with interesting ideas. Perhaps I need to do something like that. So he opened a captain's dinner each Friday. People could enter his room and have a captain's dinner and talk with him about what they thought would be wonderful to organize or something they were concerned about. So he embraced the idea. And the care personnel also got a new idea of what all the people were. In their eyes, older people were individuals who you have to take care of. They are dependent.

But now they encountered these, they called themselves the Taste Buddies, these older ladies. Now they encountered the Taste Buddies, and those Taste Buddies had all kinds of, notions and ideas how you cook things, and it helped to see their own pre assumptions and stereotypical ideas they had of the residents. By naming themselves the Taste Buddies they had created a collective identity, and I think such a collective identity is needed to foster change. They were really, like I said in the other example, there was a relational empowerment among these women who were initially kind of afraid and anxious and now they were proud, they were supporting and encouraging each other, that had an enormous impact on the whole atmosphere in that nursing home.

Sitting next to people, using creative methods



One of the keys I take from your story is the change was the creative method you introduced, like dreaming and envisioning your ideal future. Maybe that goes for other creative methods too. What's your experience? How do you use creative methods?

I've used it in all kinds of ways. My first study was in psychiatry and that was part of my PhD, and I had to do an evaluation of rehabilitation program. And my first struggle was that the professionals said, no, no, no, no, you don't need to talk to the patients. We have already talked to them. We have those surveys. We know what they want. We know how satisfied they are. I said, well, if I want to evaluate the program, I need to talk, of course, to the professionals, but I also want to talk to the patients. And they really made me anxious because they said, but if you're to talk to them, they might become psychotic. These people have a psychiatric disease.

But in the end, I succeeded. So I thought, now, I'm there, I can talk to them. And I started to do interviews and that didn't work at all. Big failure. I only got very cryptic answers. I could tell they were afraid of me. I got socially, desirable answers. This was not at all the way to go. I sat in front of them, they were just super afraid of, again, a professional who is sort of taking an exam, asking you all those questions and you either do it good or you do it bad and you don't know what comes from that. So I had to think of something different and then I decided to do a sort of participant observation. I just went with them. A couple of patients worked in the garden. I went with them to the garden. I worked with them in the garden, sat next to them, talked to them, and got a relationship. And then there was trust. And from trust, they were willing to tell me stories.

Not sitting in front of people, but sitting next to people because, of course, the gaze, people who are staring at you, who have all these ideas about what you cannot do, about your pathology. So sitting next to them, that really worked. And then from there, I also started to work with images, with photos to really deepen their story. I gathered a whole set of photographs that also had, emotions, different colours, black and white, and then ask them to choose a picture. What is the picture that resonates with your feeling? And then they started to talk about themselves, also in the group. So through the photo elicitation I was getting much richer material, really valid, authentic material.

I could tell that was also is changing something in their lives. It helped them to transform, to get more grip on their story. Because if you don't have the possibility to share your own life story, it will be very scattered and chaotic. And if you can talk to people, then you will slowly develop your story with a beginning, a middle, and an end. So you will (re)gain narrative autonomy. It will give you not only witnessing justice, but also hermeneutic justice, because people will ask you questions, and it will help to reconsider what has happened to me. The creative methods are very well suited for individual transformation, but also in a group and within an organization, because it touches on many things that are unsayable, but really meaningful for people.

In my experience many research projects are still about talking and about the rational part of being human. What I take from your examples is that you far more see people as a whole and what I really like is how is it not sitting in front of people but next to them. I think that's very important on creating a level playing field and building trust and developing relationships.

Yeah, and also acknowledging as an expert that sometimes you do not know what to do. So the not knowing and really experiencing, I do not have the answer. I do not know how to solve this situation and share that with the group. And from their search for other ways to enter into a



renewing contact. That is, I think, very important that you are really responsive to what does the situation need. I don't know. What I do doesn't work. How can we, you know, together find a way to move on and to share?

In my practice, I often see that it's very difficult for experts to say 'I don't know' because we are born and raised as experts to know things. That is difficult and sobering. And again, also, one of the most beautiful things, if you then feel, if we do it together, we come much further. And it's much more a shared and co-owned project, and also the resonance, the emotional connection that grows from that, it gives me also a lot. It's mutual.

Researching with artists to mirror and honour emotions

Thank you very much for sharing your wisdom. I loved your stories. As a check-out, is there something reflecting on your stories that you would like to share?

Well, perhaps one last, we talked a bit about how I work also with artists or people who have an artist background and are also a medical or health professional. And one of the beautiful things is that artists are looking differently at situations are much more focused on energy levels, on tensions, joy and they can give that back to a group, mirror the group. They may have a very different perception of what they are doing. So I can work with creative methods, but working with an artist in my experience is also really helpful and fruitful if you work with groups.

Maybe you can give an example, maybe what you told me about the, I think it was a dancer?

Yeah, Tamar is a dancer, and she was there when I worked with a group and she just sat there and she observed the group, she listened to the group and after a while I asked her, can you dance for us what you heard and saw? And then she chose a song, and she improvised a choreography for us. And people in the room got really emotional because they said, this is exactly, this is the struggle in my work. And I have all those words, but this is how I feel. And seeing you dancing feels like an honouring of my emotions that you have seen and heard me, and I can now embrace it myself more because I've seen it, how difficult the situation is I am in.

Thank you. I think we could talk for hours. Maybe to be continued. So thank you very much for sharing. Yeah, thank you Tonnie for the nice conversation.

More information

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