Episode 6 – Pervasive sensing, privacy and patient care: a glimpse into the future

Guest: Fokko Wieringa, PhD

Peter Kotanko
Welcome to the Renal Research Institute's Frontiers in Kidney Medicine and Biology, where we share knowledge and advances in kidney research with the world. In this episode, we discuss pervasive sensing, privacy, and patient care. A glimpse into the future.

Our guest is Dr. Fokko Wieringa, who is the principal scientist with the connected Health Solutions department of IMEC in the Netherlands, and Associate Professor of medical technology in Utrecht.

Dr. Wieringa has over 30 years of experience in the med tech field. He has published extensively on technical topics in medicine. He co-authored several international safety standards and the European Union directive on Optical Radiation Safety. He is also a core driver of the Dutch Kidney Foundation's new kidney initiative to develop a portable, artificial kidney.

It's my great pleasure to talk today to doctor Fokko Wieringa, who is actually an expert in wearable devices and pervasive sensing. He has researched this area for decades, is an associate professor at the University in Utrecht, and principal scientist with the connected Health Solutions department of IMEC in the Netherlands.

Now, we will talk about pervasive sensing, privacy, and patient care, and a glimpse into the future. So Fokko, really, it's a great pleasure to welcome you, and we will chat a little bit about pervasive sensing. Now, an obvious question is, what is pervasive sensing? Is there actually a sort of a definition that you can offer to our audience?

Fokko Wieringa
Well, it's a relatively new concept, and, in fact, in 2000, David Nagel from George Washington University in DC, wrote the first technical paper on it. And while he defined it as, well, a quite wide definition: *"the widespread and possibly dense deployment, and continuous either latent or real time employment of diverse sensors, networked to systems, or people, for the gathering of information of practical use of their interest"*.

Now, that's easy to repeat, of course, you will know this by heart when I said it once. It's a broad definition, but we're coming back to that. Now, if we look upon history, six years later, the RAND Corporation, and that was their national *security* Research Division, which is important in this context.

They published a report with some technological predictions, up to say 2020. And they defined pervasive sensing, in the security context, as: *"the presence of sensors in the most public areas, and the ability to network sensor data to accomplish real time surveillance"*. So, one could sense

some similarity with the prediction of George Orwell's 1984, although Big Brother was not mentioned. But this is what's under security context.

Then, if we go to 2015, Viana Johnson from the automation firm Emerson, defined pervasive sensing as: *"the use of sensors to capture data on anything in a plant as an industrial, industrial and installation, that could affect its operation"*.

Okay, so now what is **pervasive sensing** in our context, **in healthcare**? Well, replace plant by person, and operation by health. So, you would end up with: ***"the use of sensors to capture data on anything on or around a person that could affect its health"***. And that is probably doing the trick for us today.

Peter Kotanko
Okay. Now, this is very interesting. So, thank you for providing this historical perspective. Now, let me think about a few examples. I mean, we have Apple watches, we have built in sensors like with defibrillators. Would all this fall under pervasive sensing?

Fokko Wieringa
Actually, I think it does. You know, this is... sensing itself, of course, but *pervasive* would mean that it's couplable, it can be networked. Basically, pervasive sensing could also be said, the Internet of Things that can sense. Used in our case of pervasive sensing for healthcare, it would be used then for healthcare, but the Internet of Things, of course, is used for many, many other things, like my parcel that I'm sending to you with some courier, I want to track that parcel. That also is pervasive sensing, but not used for healthcare, unless there's medicine in there, maybe.

So, the Internet of Things, contains a lot of sensors. Most of those sensors are not medical at all. But on the other hand, you'd be surprised on the air quality in your neighborhood, which might be a medical sensor after all, because it might affect a whole group of the population there.

So, never before in the known history of mankind, are we having so many sensors that are collecting so much data, usually wireless or networked, so they can be collected centrally. The trouble is not the lack of information, the trouble now becomes *making sense of sensing*.

Some relevant use cases well, coming back to the nephrology part: In 2017, we published an open access, systematic review, on whether wearable sensors can benefit patients with chronic kidney disease at all. And, well, we didn't name it pervasive sensing at that moment. But we foresaw that wearable sensors indeed could benefit CKD patients in connection with cardiovascular disease, chronic heart failure, COPD related parameters, of course diabetes - clearly, huge - and fitness and frailty related parameters sensed by wearable devices. We think those all could indeed benefit chronic kidney disease patients.

Peter Kotanko
I just have to think back when you and I met for the first time in a restaurant over lunch, and I believe you had three watches or devices on your arm. That would sense all sorts of different

things like oxygen saturation, heart rate, mobility, and so on. So, is there a sort of priority you would give to certain signals? I mean, now that people have Apple watches, and Fitbits, and many other devices?

Fokko Wieringa
Yeah, so in fact, that review that we published then already looked upon which parameters would make sense to measure, and which ones would be also doable with. Of course, that's already a few years ago, but I think it still pretty much holds. So, blood pressure: Preferably cuffless blood pressure measurement, which is, of course, difficult, but now is coming into reach. That is an enabler. Then ECG, of course, ECG by itself is not new, it's very, very old, but making it very, very wearable, energy efficient, and inside something that you carry along all the time anyhow, then it becomes interesting because you can have longitudinal data, either continuous ECG, which is a little bit difficult because then you would need a device like a patch or so.

But sometimes, intermittent ECGs are also already giving a lot of things away. One of the examples is a person I know that uses it's Apple Watch to have this uncanny feeling with *"oh my heart, it's not good"*. And recording some episodes where the cardiologist can say… or can at least grossly determine what kind of problems there are. In this case it were PVCs (premature ventricular contractions). So, it helps to collect data.

I think a very big one will be fluid overload and body composition. That will be a new one, although, we know that there's bedside equipment now for bioimpedance spectroscopy, that can monitor things like this on the bedside, but that's a spot check, and the good news is that nowadays chips can be made very, very small, and very energy efficient, that can be incorporated in wearables that can have, you know, bioimpedance spectroscopy longitudinal, which really can help to measure both fluid overload and body composition.

We are also publishing, recently, we have a great PhD working on this [Melanie Schoutteten] and she has published already that wearable bioimpedance spectroscopy is doable in dialysis patients. Of course, then blood glucose, well, there's a lot of work going on in blood glucose measurements, and we see that also, not only sensing, but continuously sensing, but also closed loop control is now really becoming into reach.

We are seeing, not only insulin, but also even insulin and glucagon injection possibilities, so that you can have both of these drugs being injected. And closed loop control is getting better and better on this. So, that is really an area that's booming. Where, of course, people that want to avoid kidney disease can have a lot of profit from. And patients on dialysis, or patients with kidney disease, may have relatively often diabetes, and that [i.e. better glucose control] helps to at least slow down the progression of your kidney disease as far as I know.

I'm not a medical doctor by the way. We have to be sure about that. I'm just a technologist. Then, of course, physical activity. That is also both in the monitoring way, to measure physical activity like the step counters and calorie burning measurements, but also the stimulation of

nudging people to, you know, wouldn't you just get up and walk a bit? Or would you take a break? That kind of stuff… that is also coming now with wearables.

Then the last one that was identified in that review of 2017, a very systematic review by the way, was anemia. We thought it was interesting, but only if it will be very cheap and simple as, for instance, a byproduct of SpO_2 sensing. Or, as hematocrit measurements during hemodialysis anyway.

And I forgot to mention, sorry, PPG, so photoplethysmography and SpO_2, the measurement of oxygen in blood optically by using light, those are already inside many wearables and mobile phones, and they have their applications. For instance, the detection of atrial fibrillation is nowadays doable from basically any mobile phone by using a web subscription. It's called FibriCheck, and it's been validated by the FDA. So that is new, these kinds of probing measurements that are not so obtrusive, and can be kept in your mobile phone, or a simple wearable, that can help to detect early these kinds of problems.

Peter Kotanko
So, this is actually really interesting. I mean, when you think about it, the opportunities to gather data. And I recently came across a paper that would describe sensors that are built into walls. So, for example, that can be used for movement and others. I mean, how do you discuss with someone who might say *"oh, gosh, I actually don't want to give all my data away. I have real privacy concerns here. I am concerned that things may get hacked. I have concerns…"*.

Speaking of closed loop insulin pump, say the pump gets hacked and the wrong dose of insulin gets injected. I mean, there are papers out there on this. How do you have a conversation with these people, like, who have concerns? And, so, I guess at the end of the day, it's the balance between what can you get out of it and what you have to give for it right? Or how do you see that?

Fokko Wieringa
No, that's totally true, and those concerns are certainly real. I mean, people *should* be worried about their privacy. Apart from medical sensing, apart from nephrology, just the cameras that we are using and the microphones that we are using on our laptops and phones and whatever.

We know that even presidents of countries can be just tapped via their mobile phones by other countries. We've read it in the newspapers, it's happening. So, privacy is probably one of the very, very most scarce things in the world in the end. That is totally true.

Nevertheless, there are also a lot of opportunities. So, let me start with the threats: Security breaches in data access and security breaches in control of the device. Those are the real nightmares. You don't want those to happen. That means that you have to make extremely good keys on this. And one thing that you don't want: keys to have as a property is that they're easily being reproduced. So, software cloneable keys are the nightmare because those, at once cracked, can be spread everywhere. And, you can believe me, there is a lot of malware which exists that you can use.

You drive your car by to any home, and you run that software for two minutes, and you know exactly how to get in the network of that place. Even if it's a reasonably good network. So, security breaches in data access and device control, those are the biggest hurdles.

And there are hardware solutions on that. Like, for instance, physically unclonable features. The best way to explain that is -- any chip has a certain hardware signature, which is determined by the hardware, and if you send in a certain ping, certain code, or certain command, you will get a unique signature back. It's like in the movies, the typewriter that was used to type the threatening letter, the blackmail letter. Every typewriter, no matter if they're made in the same factory and they have they have serial numbers that are following each other. Still, every typewriter has a little bit of minimal mechanical differences with the other one. And that is the signature, and the police used to use that to identify *"now this letter indeed has been written on this typewriter"* or *"this bullet has been fired by this gun"*. We know that. So, in chips, you have the same kind of *hardware signature*, and *you cannot clone it by software*. And that is one, I think, very promising area.

Of course, we also have blockchain, all these technologies, and if you combine them, it's even getting better. But you have to make sure that this is well regulated. That this is not getting into the wrong hands. That is going to be not only for medical, but for the whole world, also for the financial world, is going to be the cornerstone of security. The last… during the COVID crisis, I haven't paid anything cash. For one and a half year, I only use my electronic chip. So, I'd like to have that security also not breached. So those problems are the same.

Peter Kotanko
Yeah. So, I mean, the good thing is that there are so many other areas or domains of our life where cybersecurity is getting more and more relevant, be it the finance sector, as you just said, but also just the Internet of Things, personally, the electronic assistance, etc., etc. So, I think it's something where healthcare, in my mind, has to be at the forefront, because what data are more intimate than information about your body, your health? So, I think it will take quite some in-depth conversations on a societal level. What kind of data should people be mandated to share? If they have a certain illness, for example. Or what is their opt-in opt-out version? So, I think that this is an area where currently, of course, a lot of discussion is going on, but I think though in my mind at least, there are still many, many open questions.

Fokko Wieringa
Oh yes. And it's also a race. It's like counterfeit money. There's always a race between the characteristics of realness, the technologies to make that, and the counterfeiters that are trying to imitate that. There's always a race between those two, and that race still also will be between the people that try to keep security intact, and the ones that try to breach it.

Peter Kotanko
So, Fokko actually, where do you see the future directions of pervasive sensing, in healthcare, in general, but also specifically in kidney medicine in nephrology?

Fokko Wieringa
I think the good news for, well any healthcare, but also for nephrology, is longitudinal data throughout daily life. Although, even for patients that are, for instance, doing dialysis in center, most of the time they're not in the center, fortunately for them. So, even if you have people coming in three times a week in the center, still, most of the time, they're not in, and the things that are interesting sometimes happen or, likely also happen, outside of the clinic.
If you have longitudinal data throughout your daily life, you see... you are recognizing patterns.

Also, for instance, the typical white coat effect that we all know from blood pressure measurements, and a simple spot check blood pressure measurement by the physician. There are a lot of people that have the white coat effect. Some somehow, they have a false high blood pressure or a false normal or false low blood pressure when they see a white coat. I don't know why, but it is really there. And, if you measure a parameter like blood pressure in daily life, you can avoid that. And you can find the real cases, and also, whether your treatment is working or not. And whether you have to fine tune it. It's also for stimulating self-management. While you keep an eye on the outcomes, that would be good. I think that there are a lot of patients that could have more self-management that could handle that. Especially the younger ones.

Now, we see people of 80 years who are using the internet and installing new software and apps and whatever. My mother-in-law is 82, and she taught me how to install an app last week. Okay. So, we are seeing that people, may become more self-management like, but it's good if you also can keep an eye as the doctor on that.

Now, for COVID, home dialysis, typically would be stimulated, if you know that your parameters, and the meaningful events, are being measured and being seen by your physician, but you can do your treatments at home. That is a real benefit. Not just for your agenda and you know, the way that you live, the way you plan your life that we knew. But COVID taught us a forgotten benefit, namely, self-isolation. If you want to… if you want to isolate yourself from the possibility to get contaminated, staying at home is great. But not if you're on in-center dialysis, how would you stay home? You're going to die, so you have to go, and this is probably a factor that none of us, two years ago, was calculating in that much. But it appears now to be an interesting one and a very solid one.

And, as you just mentioned, also the data. So, the data ownership is going to be interesting, who owns my data as a patient? Do I own that data? Does my doctor own the data? But then I have maybe a cardiologist and a nephrologist. I have a GP. Who owns it? So, that's going to be an interesting question, and probably the responsibility chain on that data has to be looked at very well. But I can imagine that patients will have a lot to say about their data ownership.

Also, telling about one of the threats. You may have seen the movie Apollo 13 where the crew, Jim Lovell, just ripped off his electrodes. He was monitored all the time, and he got a remark on that, and he said, *"I don't want those remarks, I have to have my head on what I'm doing, and I don't want people looking over my shoulders and breathing down my neck."* It's a bit counterintuitive, because, from a professional point of view, and I think that we all agree that astronauts are being heavily professional people. But still, they're *people*. So, that's an

interesting sign about the uncanny feeling that, on being observed, this can be sometimes too much. And, if astronauts as highly professional people can have that, then we *all* can have that.

Going to the advantages. I think that recently, and it's a very good principle, the FAIR principles, for data ownership and data hosting have been formulated quite well. I've included a link [https://www.health-ri.nl/fair-principles]. if you can include it in the PDF, would be great. Namely, FAIR stands for Findable, Accessible (and I think personally also that "A" should also be *anonymously* accessible), Interoperable, and Reusable. And it's a very interesting concept, where the data doesn't move, it stays secure where it was, and doesn't go to another disk or another storage facility. The query that is used to search that data is accepted, it has to fulfill a number of prerequisites, and if it fulfills the prerequisites, it's allowed to go into the database, do the query, collect the outcome, but do not take any IDs, not any identity characteristics, and then go back with the answers. So, that's an interesting one, because the outcome of the query goes back but *anonymously*. Still valid, but anonymously, and the data stays where it is in a safe place. Interesting concept.

Then, of course, what we want to avoid is the possible misuse, not only a security breach of people that are getting to data that are not allowed to get the data, but also the other one. People that are allowed to go to the data, but they might misuse their monopoly position.

Suppose that you're a big firm, you have a huge network, and you are getting all the data from your equipment, and you put it in your database. And then you say, that's mine. And if somebody, if a patient goes to another provider or just move to another country with another organization, which can be done, and then the provider said: No, no, no, you cannot take your data with you! It's mine, could be happening... And that, of course, is not good. And because, yes, you have all the rights to use that data because you're treating the patient, but if the patient, for instance, moved to another country, it would be good in the interest of the patient that other historical data would be accessible. Things like that should also be somehow regulated.

And then, we come to one of the most... So, apart from the security, the nightmare of any doctor is the 3 Ds, namely, Doctors Drowning in Data. That is a nightmare. You don't want to have that. What the doctors want, as far as they told me, and I've been talking to quite a lot of them, is that there's a *distillation of meaningful events*. Preferably, it probably will be done with artificial intelligence, to not get a huge amount of data, but only the events that make sense. To say, wait a minute… *"Something's fishy here. Something's changing."* I just give you an example. My mother was saved. Her life, literally, was saved by the neighbor that drove by in the car and said *"Hey, Mrs. Wieringa still has the curtains closed. Normally, she's up at this time."* And when she got back from the village with the groceries... *"Hey, curtains are still closed. That's not normal. Normally, she's really up at this time. I'm going to take a look."* And so this was not artificial intelligence, that was real intelligence here, but hey, the pattern is deviating from its normal thing, this is weird. Let me take a look. And that is the moment that, as a physician, you want to be pulled on your sleeve and say, wait a minute, something's wrong. This is not the normal pattern, this patient is normally stable, something's happening with the pedestrian. And that is the moment that you want to be giving attention. But you don't... you don't want to see kilometers of ECG. Remember, the first holders that those poor cardiologists had to go through

literally kilometers of ECG registration to look for abnormal entities. That is, of course, crazy. So, it pretty soon became that their software was recognizing weird events. Or hey, this is a weird beat, take a look at it. And that's much better. Sorry, that I'm taking so much time.

Peter Kotanko
No, no, no. I mean, this is really interesting. And, I have to say, it certainly widens my perspective on the topic. Now, some of our audience may ask themselves, what pervasive sensing technologies have already made a real difference to patient's health, or to general populations' health? Can you point us, maybe, to one or two examples where you think that pervasive sensing different technologies have really improved the life of patients?

Fokko Wieringa
For me, personally, it is the physical activity stuff. That is helping me to keep... be reminded about, you know, take more exercise. I do think of that, but it depends, but blood pressure... simply just taking blood pressure in the morning, and in the evening, already helps a lot. And the availability of the simple devices that we all know now, even with the cuffs, already brought a big difference. There was a time when these devices were simply not available, and you simply had to go to a doctor for your blood pressure to be measured. Those days are gone and keeping track of your blood pressure literally might, well, save you, but at least prolong your life quite a bit. It is… blood pressure is something that is really silent. So, I do think that it may be an old one, but it's an oldie but a goldie one. But that's my opinion… I'm not a medical doctor, and I think you'll have better ideas on that.

Peter Kotanko
No, no, I was just thinking like blood glucose measurements. Especially, in type one diabetics. This is, I mean, although this is not pervasive sensing, I would think it's more point of care testing, but it might fall under a wider definition of sensing that's brought to the patient's home. And I think that this might be another one. Yeah, I mean, just to wrap this up… a final question... what, in your mind, is the next big thing in this area? Is it something like the confluence (congruence?) of say, pervasive sensing with AI? Is it certain pervasive sensing technologies? Is it in the area of connecting pervasive sensing data elements say with other data sources, be it weather data, be it mobility data, etc., etc.? Just in maybe in two or three sentences? I know it's a difficult question worth a whole lecture, but just to the point, what do you think is the next big thing here?

Fokko Wieringa
Well, definitely the pattern recognition in many parameters. That definitely will become interesting. And, if we quickly try to focus on nephrology then there, because that's the purpose of this interview. I think that, for instance, peritoneal dialysis might relatively strongly profit from this stuff, because, so far, that was considered more of a low-tech dialysis technology.

But recently, we've seen sensors now that are easy, applicable, and that can monitor, and very precisely judge the dialysate that you're entering into the belly and the effluent, which comes after the treatment out. That alone, or for instance, with a mobile phone, have a picture of the entrance site of your catheter, and the redness judged by machine learning. So, those things

alone can have a huge impact on being early with detection of infection. And that makes a hell of a lot of difference. I think that that is really is making a difference. Of course, in hemodialysis also, but I wanted to point out also the more low tech considered treatments can profit hugely from this. Miniaturization overall, definitely, that's going to be a big thing.

But we should not forget, miniaturization is one thing, but power efficiency. That is crucial. You hate to charge your phone halfway in the day. You hate to charge your watch halfway in the day, that doesn't work. Yeah, you're okay with it, putting it on the night table, but energy efficiency to at least cover a whole 24 hours? That really is a very crucial point because, otherwise, people get annoyed, and stuff ends in the sock drawer.

Still, I think data security and privacy are the biggest things. Getting good keys on that is really crucial. I also think tiny artificial intelligence. Remember that the chess program that won from the world champion in chess, was on a big mainframe. It was the edge of what was possible at the moment, and it won from a human.

But nowadays, we can put tiny artificial intelligence on a quarter of my pinky nail, and we... I think we need that, because for really meaningful medical devices, you don't want to be dependent on your quality of your internet connection. You want to have a *local* intelligence that can do the most important decisions right away.

Peter Kotanko
This is actually so interesting to see your perspective. I mean, as I said, you are an engineer with decades of experience in the field, you publish in it, you conduct active research, you have intellectual property in this area. So, you certainly have more insight, certainly than I do. And I guess, some of our audience, too. So, Fokko, thank you so much. It was a real pleasure having you on this series. I'm sure it won't be our last conversation. Maybe we revisit this topic again in a few years from now. But really, thank you. It was a terrific pleasure having you.

Fokko Wieringa
The pleasure was fully mutual, Peter. Thank you very much for having me.

Peter Kotanko
Thank you for joining the Renal Research Institute for this episode of Frontiers in Kidney Medicine and Biology. We invite you to engage with us on our social media channels and look forward to seeing you again soon for the next episode of Frontiers in Kidney Medicine

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