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Ian Winburn: Hello and welcome to Hemcast, a podcast series designed to help you keep up-to-date with advances in science, technology and clinical care in the rapidly evolving world of hemophilia.

Coming up in this episode we discuss the role of telehealth in hemophilia care and how the recent pandemic has accelerated our adoption of this digital engagement approach.

Roshni Kulkarni: If you do it once, you realize, wow, why didn't I do this before?

Cedric Hermans: I think the new technologies really help us to identify what's the best way to communicate individually with all of our patients.

Laurence Woollard: It's always been stressed by my clinical team that I can access them anytime, anyplace, anywhere, which funnily enough kind of sounds like a bank slogan. But it's actually, you know, really reassuring for me to know in times of crisis.

Kristian Juusola: When you build this kind of relationship where you have this trust, trust within each other and the patient will value your input, they will give back, they will contact you then, more easily and more often.

Ian Winburn: You might have heard the terms telemedicine or telehealth, but what does it mean in the context of hemophilia care?

Telehealth involves the use of telecommunications and virtual technology to deliver health care outside of traditional health care facilities. So it involves the use of information and communication technologies for the exchange of valid information to advance the health of individuals and their communities.

Now, during the recent pandemic, we've seen clinical practice change dramatically, which has been accompanied by a growing demand for telemedicine and digital health. In fact, a report from the US found that telemedicine visits grew by an astounding 400% across age groups and

by more than 950% in those patients over the age of 65, and that was just in just one week, as the states started to go into lockdown.

Now not surprisingly, we've seen a similar trend in Europe. For example, in France, the national insurance fund recorded 10-times more teleconsultations in a single week in March, right at the start of lockdown, than the entire month of February. As clinics and teams globally look to online tools and services to ensure continuity of care, the benefits, challenges, and future opportunities of this model have become a hot topic for discussion, for health care teams and patients alike.

In this episode of Hemcast, we will be exploring telehealth as it relates to hemophilia. We'll discuss how health care communities, and patients, are adapting to the "new normal" of virtual clinics and consider what this might mean for the future of hemophilia care. And we're going to start this journey by going back in time, to the world pre-pandemic, September 2019, to be precise, when we had the pleasure to speak with Roshni Kulkarni, a Professor Emerita of Pediatrics and Human Development at the Michigan State University in the US.

Professor Kulkarni participated in a Pfizer educational meeting, where she explored the role of digital, social and telemedicine in hemophilia, including how these technologies are helping expand hemophilia services and connect specialists from across the world to share experiences and support advances in care, even before the crisis forced clinical care teams to pivot to a more virtual model of health care.

So, I know that you, in your own practice, you really embraced telemedicine. Can you give us, sort of, an idea of what a day looks like when you're running a telemedicine clinic?

Roshni Kulkarni: So, essentially, I mean, we don't do it every day or anything like that. We sometimes do it, you know, once or twice a month. Or sometimes we do it if there is a patient who's gone to a distant area and what we do is, we schedule the telemedicine once a month or something like that, on a Tuesday, with a primary care physician, a pediatrician or a family practitioner and so we pretty, it's just like scheduling patients for your clinic.

You know which patients are coming. Some of them are new patients, some of them are return visits. So, we do what is called a pre-clinic, which means we, kind of, go over the patients and we decide if this is a new patient, it is just like getting an information from the physician saying this is what this patient is going to come for. So, we look at the list and then, when we then send the telemedicine site, which is called, actually, the originating site, because that's where the patient originates from, we send them a web link and it's a Zoom web link, but you can use other videoconferencing system, and, they join us and we usually have, like, four video-, four or sometimes six videoconferencing rooms.

So, a nurse can be in another office, and, our social worker can be in another office, and, if we can have two patients at a time even, so, our social worker can be seeing one patient and

getting pretty confidential information and things like that, while the physician can be sitting in a virtual office or sitting by their desk, basically, they just have a thing which shows that they're in an office. If you do it once, you realize, wow, why didn't I do this before? You know?

Ian Winburn: And, what do the patients make of it? What do they say, what's their feedback?

Roshni Kulkarni: Okay. So, the initials that we actually, when we got the green, we did a study and we said, what do you think about this and what was very interesting was, patients loved it. Remember, for many of them, they never see a specialist. It is so hard and he said, it beats, you know, traveling with the whole family. For almost eight-ten hours. And, but, then, some of them said that we wish you had or our team had introduced to them, saying you will be seeing a physician by telemedicine, this is the process.

So, what we did was, we wrote up a process where we now inform every patient, saying that this is a telemedicine visit. You'll be seeing the specialist by a videoconferencing system, this is what we're going to do and the specialist and your physician are going to discuss what labs to get and if you need a DDAVP trial, you can, the local physician will do it, with the guidance from the specialist. And, then, once the results are back, your local physician will tell you or, if you need to return for a visit, then you will be seen again via telemed. So, the process is very well explained to them, as to what happens to them. So, there is no surprises. The best surprise is no surprise.

Ian Winburn: Absolutely. Absolutely. Well, it, it sounds incredible and it's wonderful how you've embraced this, and I suppose my final question to you is, we've heard a lot about innovation at the Global Summit and about medicines that are in development coming through to change patients' lives. But, when you think about digital health and you think ten, 15, 20 years in the future, what really excites you when you're thinking about those innovations on the future?

Roshni Kulkarni: So, I think digital health is here, and, the applications are, kind of, exploding over the, I would say, in the next 20–40, people will say, what are you talking about? It's like a regular phone versus a cell phone or a smartphone. I mean, it, people have just embraced it. All over the world and just the same thing will happen.

But, you will see that things like artificial intelligence, things like, you know, social, digital applications, apps as we call it, are going to be a, a daily occurrence. Like, right now, I wear a watch which can measure my heart rate, my blood pressure. I can see how many steps I take and what I do. So, it's very exciting.

Ian Winburn: Unbelievably exciting times ahead.

So, as you heard, telehealth and telemedicine, already playing a vital role in bridging the gap between patients, health care professionals and health systems in hemophilia at Professor Kulkarni's center last year. Specifically, Roshni touched on the importance of supporting

initiatives that allow patients to access services and information wherever they are, regardless of where they live. Connecting health care services through telehealth can also make it easier for health care professionals to collaborate, allowing for the exchange of knowledge and experience within the clinical setting. So, a lot of potential for telehealth to support access to specialist services, and clear interest in advancing access to care through these mechanisms when we last discussed this topic in September.

Fast forward to 2020, and we find ourselves in a situation where, as we've already mentioned, the environment has almost demanded an acceleration in telehealth and telemedicine to support even basic access to care during the current pandemic. So with this in mind, we wanted to speak with members of the hemophilia community, to discuss with them how they are adapting to this new reality and what lessons they think this could teach us about the future of hemophilia care.

Ian Winburn: I'm delighted to be joined by Professor Cedric Hermans who is joining us today on *Hemcast*. Many of you may have heard Professor Hermans before but for those of you who haven't, Cedric, are you happy to just introduce yourself?

Cedric Hermans: Certainly Ian, thank you, thank you for the opportunity to join you today. So, my name is Cedric Hermans. I am based in Brussels, Belgium, where I'm heading the hemophilia treatment center of the clinic University of Saint-Luc which is a large hospital. I have a long interest in hemophilia, in hemophilia research, especially I'm quite interested in the impact of new technologies on hemophilia care today and tomorrow.

Ian Winburn: Yeah. Well, thank you, Cedric, and great to have you with us. So, look, these have been some very challenging times over the past six months or so. Tell me how have you been getting on? How has this impacted your clinical care and your practice in Belgium?

Cedric Hermans: Well, thank you, Ian. Well, this is true, it has been a very difficult and unprecedented experience for us. So, in March we realized that because of the pandemic it was not longer possible to manage our patients through clinical visits, face-to-face visits, and especially multidisciplinary clinics. So, that was not longer possible.

And we also were concerned by that, but we were also very concerned by the fact that our patients could be at risk. So, at that time there was no face-to-face visits, so what we decided to do really at the beginning was to inform all our patients that they had to follow very cautiously some very important measures, and we also realized that our patients needed some sort of information about this virus.

As you know, the hemophiliac community is quite used to, you know, these viral infections but this one is totally different. So, they absolutely need some sort of information. So, that was clearly a priority for us. And the only way to do that was to use, you know, new technologies. So, we had to use our phones, we had to use Skype, we had to use everything we had to get in touch with our patient.

What was very important too here is to have an updated database of all your patients and all their contact details. We should not forget this—if you want to contact your patients, you should make sure that you have a good database with a good list of all your patients you follow and with their contact details ideally, you know, their mobile phone number and their emails, I think this is important. And this is a lesson also for the future. Let's make sure that we have all details available to get in touch with our patients very rapidly.

Ian Winburn: So, as you say, you know, making sure you can get hold of people was absolutely paramount. But, what sort of, you know, if we go back to those early days in March, what were those first, sort of, conversations like, you know? Was there a lot of fear or a lot of concern? Can you remember what it was like?

Cedric Hermans: Well certainly, there was concern about being exposed to the virus and what the consequences could be. So, we had to provide our patients with some basic information about the virus, the disease it could cause and what they should do to protect themselves. We also had to make sure that our patients would quickly recognize the first symptoms, ok. So, if they had fever, if they had shortness of breath or things like that, you know, they should not wait. And we tried to explain to them how to manage this.

And then we also had to manage the management of their hemophilia and a major concern in the community was the access to treatment and also the delivery of concentrates. Because very quickly patients realized that, you know, everything would completely stop, including, you know, potentially the delivery and why not even possibly the manufacturing of their concentrates. So, our patients really wanted to be reassured and make sure that they would have access to treatment.

So, what we did with them, we, when we phoned them and when we were in contact with them, we made sure that there was enough concentrate at home for all of them. We tried to make sure that they would not overstock supplies of concentrate at all because we had to make sure that there was enough concentrate for all the patients. So, we had a lot of contact just to manage this, just to manage this.

Ian Winburn: And how did telehealth itself or, as you say, the digital technologies, how did that help to enable you to do that?

Cedric Hermans: Well, clearly, you know, that was an ideal way to interact with the patient, even, you know, it was virtually face-to-face, you know, using our screens. Also, you know, we used also a lot of emails. I think it's quite reassuring for all patients and my own team, we really mobilized ourselves to make sure that once we got emails from our patients, that we would provide them with a rapid answer.

But also, let's be realistic, not all our patients do have, you know, access to all these technologies, and we have some older patients with hemophilia. You know, they are not that

used, at least most of them have a mobile phone and so we could contact them by phone. But that was the only way to be in contact with them. So, let's not minimize, you know, the impact this pandemic had on this specific population and this is something we should think about in the future, is how to make sure that even older patients with less expertise in these new technologies, you know, get a proper education and can properly manage them. That was certainly something, yeah.

Ian Winburn: And it's a really important point, isn't it, you know, listening to how this is received by patients. Did you get any specific feedback from patients about how they found, sort of, engaging with health care during this time?

Cedric Hermans: Well, what was quite reassuring for the patients is to realize very quickly that their hemophilia team was there in backup, really, you know, keeping a constant eye on the situation, you know and trying to interact with them as closely as possible, and that was really, really reassuring, especially for patients because we had a few patients who developed the symptoms of COVID-19 and needed to be admitted.

So, we could also manage very properly their admission in hospital. So, I think it really helped to create, I think, a new relationship with our patients. Because sometimes, you know, the relationship is only based on this review clinic.

And here we could really enter, I think, a new world with a much closer communication and I think that's quite helpful. We also had to adapt ourselves because patients do prefer the phone, some prefer emails, some prefer face-to-face on Skype or Zoom or whatever. So, and I think the new technologies really help us to identify what's the best way to communicate individually with all of our patients.

And also, coming back to the messages, we really put a lot of our time and energy to make sure that all our patients would continue their treatment. That was important, you know, prophylaxis, continuation of prophylaxis was very important. And also, you know, even for patients without severe hemophilia, for patients with mild or moderate hemophilia, we tried to make sure that they were aware of what to do in the case of bleed or suspicion of bleed. Because here, and I think this is important, the strategy was really to minimize the need for hospital visits and hospital admission. So, everything was driven by that. Let's make sure that our patients will not jeopardize their health and, at the same time, will not need access or visiting the hospital. So, clearly, counselling here, distant counselling I would say, on hemophilia management was here critical.

And, honestly, honestly, we know that some of our patients are quite, you know, quite good at doing that. Some are, have less autonomy, I would say, and we really focused our energy on these patients because we knew that some patients might require much more attention than others. And that's why I also think that when you have this kind of crisis, you should have this, some sort of good profiling of all our patients and really understand in advance what the needs will be. This is important.

Ian Winburn: Yes, yes, I hear that very loud. And it was wonderful that you were able to provide reassurance that you were there but also, as you say, to be able to provide the counselling and the direct advice for clinical patient care while also recognizing that individual needs of patients were going to differ and it's a wonderful example you just described, where you were able to address that.

Now, Cedric, I know you have experience in the past of using telehealth. I know in your role with WFH [World Federation of Hemophilia] and parts of the twinning programs, that you probably used telehealth and telemedicine in different sort of spheres. Are you able to share any experience of how you've used telemedicine/telehealth in the past?

Cedric Hermans: Well, especially, you know, to interact with patients more frequently, I would say. You know, telemedicine, I think it's great, but it will never, in my view, completely substitute or replace, you know, the face-to-face medicine. But what really, what it really helps to do is to have much more frequent contacts, especially, you know, let's say you have a hemophilia clinic and during that clinic you will identify some priorities and also try to set goals, objectives and what telemedicine really helps to do is to make sure that the patient will be able to achieve these goals within the next three to six months.

Because if you passively wait for the next clinic and nothing is done, I think this is not a good strategy. But if you could interact with the patients frequently by telehealth, I think it really helps. It's quite stimulating for the patients and you can really see, you know, and evaluate the progress you are doing over time. So, I see this certainly as an adjunct, a way to keep in touch, in contact to reach objectives, and also to improve patients' education and patients' empowerment.

Ian Winburn: Yes. And do you think this is here for good? Is this going to be the future of how the patient–doctor relationship is going to evolve? Or do you think this is just, you know, a fad, something that is currently in fashion or do you think there's a future here?

Cedric Hermans: No, no, I think it's, well, you know, some people already anticipated that it would change how medicine is practiced but I think it would have taken years to become a reality. It's clear that this pandemic, and the pressure it put on us, completely changed the scenery. So, I think, you know, we will have to use these technologies. They are really useful. They have major benefits. They are quite complementary.

So, I think they are there and I think they will remain with us. But they need to be fine tuned, and I think they also need to find their place, in, specifically in the management of hemophilia. But I think they will create a new way of communicating between the centers and the patients, and we, it needs to be improved, it's clear, but it will never disappear, and we will never go back to what we were doing in the past, I'm sure.

But let's be realistic, you know, here in my hospital, we will have to make sure that the technology is there, that we have all the technology that is needed available at any time. So, that will require investment on our side and also investment of the whole team because doctors, we are open to this, but we will have to involve all other health professionals and I think this is a real challenge for the next few months and few years.

Ian Winburn: Yes, and thank you, Cedric, for that. And I think maybe just a final question. I'm conscious that there may be people listening to this podcast who haven't yet embraced, sort of, virtual health services and if you were to offer any recommendations to them, you know, starting out, you know, is there anything you would particularly recommend that they did to get comfortable with this technology?

Cedric Hermans: Well, if they have never done this, I would certainly stimulate them to start and try. Maybe try this with patients that you feel will be quite receptive to this technology and this new approach, do that with selected patients at the beginning and then try to broaden this technology to a much wider population and do this progressively step by step. It will not be a revolution within one day, you will have to implement this over time.

But please do it and don't do this alone. Involve the whole team. That would be my message. And also try to set up some objectives that you want to achieve with implementation of this new technology. But clearly, they are quite valuable, and they provide such a good adjunct to what has been our classical care up to now, I would say.

Ian Winburn: Yeah, well, thank you so much for your time today, Cedric, we really appreciate it. It's been wonderful to speak to you, wonderful to learn and listen to your experiences and I look forward to speaking to you soon. Thank you.

Cedric Hermans: Thank you, Ian, it was great and thank you, again, for the invitation and you for the opportunity to share this with us. Bye-bye.

Ian Winburn: Bye-bye.

Fascinating to hear from Cedric there about how his clinic has adapted and embraced telemedicine during the recent pandemic. I do hope some of his advice on how to adopt virtual health into the clinic has been useful to those of you wanting to embrace digital health. We now know that telehealth can enable the collaboration between physicians and patients within a virtual clinic, but how would this look for other specialties integral to the care of people with hemophilia, such as physiotherapy?

Physiotherapy has long been recognized as an important aspect of hemophilia care helping patients with functional improvements and recovery after musculoskeletal bleeds. Now most of us would recognize physiotherapy as a hands-on treatment, but the specialism is changing to adapt to different health care environments.

... And this is exactly what Sébastien Lobet, a physiotherapist and researcher at the Cliniques Universitaires of Saint-Luc in Belgium showed us in an interview earlier this year.

Sébastien Lobet: There were two interesting debates that can, that I maybe can explain to you. The first one was, do we still need a physiotherapist in the HTC, hemophilia treatment center, or do we need absolutely to collaborate with local teams, with local physiotherapists? At the end I think that the answer is that both kinds of physiotherapists are super important. We need a physiotherapist with a specialty in hemophilia that perfectly understands these patients and can follow them on a regular basis. To understand, really, treating patients we need to rely on the local team. And who is the best to explain to the local physiotherapists how to treat a patient with hemophilia? It's the physiotherapists from the hemophilia treatment center. So, both are very, very important and are totally complimentary. That was one of the first debates. The second debate was, do we need to use passive techniques such as manual therapy to improve for example, range of motion of your patient? Or is it better to take time to explain to your patient, how to do the exercise at home? That means self-rehabilitation. Because the fact is that probably 90, 95% of the world population will not have access to physio sessions, at least manual therapy sessions. Because it is costly. It necessitates a high skill of the physiotherapist. Of course, it is very efficient, but at the end what do we want to do? To improve the care in general or just for a minority.

And I think that all the agents was agreed that manual therapy is a very important concept of treatment as a physio, but we should also develop the concept of self-rehabilitation and community-based physiotherapy. That means that we have to teach the patient to take care of himself, or just to learn to the family how to do very simple and regular exercise with the child, with the children, to improve their range of motion. And we had recently, my team, a very good experience in the Ivory Coast, where we published the results of self-rehabilitation in patients that of course do not have access to physiotherapy. And the results were outstanding, with a very high adherence of the patients.

So, my conclusion was to say that now with the involvement, with the improvement of telemedicine, of new technology, we could combine this kind of new technologies with developing the self-rehabilitation. And really combining basic physiotherapy, but with very high technologies, just to follow the patients by distance. To correct them. To modify their program on a daily basis. Because when you do self-rehabilitation the problem is the motivation. If you go, if you decide to go to the gym on the 1st January, because you have good resolution, most of the time you abandon it after 2 weeks because you don't get the motivation. It is exactly the same for the patient. To have a self-rehabilitation program we need to continue to motivate them, by distance, in face-to-face, whatever, but we have to find a solution to continue to improve their motivation by doing their exercise.

Ian Winburn: Sébastien mentioned the challenge around access to care due to geographical barriers but also the challenge around motivation. Studies have showed that attendance to follow-up physiotherapy appointments and physio-prescribed programs are low. Ongoing

support and motivation to persevere with a physiotherapy-prescribed physical regime in the home may hold the key to improving long-term adherence and overall outcomes.

Applying a similar principle to the multidisciplinary care team at large, we wanted to explore how specialist hemophilia nursing teams are employing telehealth during virtual clinics, and what we, as a community, can learn from a center where telemedicine is much more established due to existing geographical challenges.

Ian Winburn: We are delighted to be joined by Kristian Juusola, a pediatric nurse from Oulu University Hospital in Finland, who specializes in hematology and oncology. Kristian, thank you so much for joining us. Would you like to introduce yourself?

Kristian Juusola: Yeah, thank you for having me. Yes, I work as a pediatric nurse here in northern Finland and we deal with the population of oncology and hematology. So the hemophilia patients is part of that service. And we actually take care of the half of Finland, basically because in geographically, population-wise, the northern part of Finland, there is obviously a little bit less people living here, than in the south. So we are the second largest pediatric oncology and hematology center here in Finland.

Ian Winburn: Well, it's great to have you with us, Kristian. And thank you very much, because I know these are very busy and also very unusual times. But I wondered if you could maybe, to start with, share with us how you have been adapting your current practice to the current times?

Have you had to make any immediate changes? How has life been up in Finland through these rather unprecedented times?

Kristian Juusola: Yes, it definitely has been something that no one anticipated. But I think we have been very lucky here in Finland in terms of how the COVID has changed our live. In a way of, we have had our fair share of situational changes, of course, but we really haven't been hit that hard.

And I think one of the reasons might be that, because we have got so much space here, where we live, that we practically don't see that many people in the same places at one time. And when it comes to the practice we definitely anticipated, and made some huge changes according to the global situation. And particularly for the hemophilia patients, we cancelled all the non-necessary appointments, and made them like via telephone or just postponed them. We did think about the medication changes and stuff like that, and all of them we put on hold just in case there are any problems with the infections, and stuff like that. So since we are not that big unit or service, we were quite easily, well maybe not easily, but we were able to sort of look through all the patient load, and we were quite lucky that we usually have a 6-month routines. And nearly all of our patients had already had their early year appointments. So basically the time period from April to August is quite slow when it comes to the hemophilia patients, so we didn't have that much of a strain to go through the patients. But of course there

are always odd patients that you have to deal with, but the regular ones, we have been able to accommodate quite well.

Ian Winburn: Sure, so you know you mentioned how, you know, you needed to either cancel appointments or move appointments to be done by telephone. You know, I suppose that was some experience of telehealth and telemedicine. Could you maybe share a few more examples of how telehealth, telemedicine has been embraced up in Finland? And what your experience has been of it really?

Kristian Juusola: Well, it's, obviously the situation is new, but the actual telemedicine is quite familiar for us already, because of, like I said, geographical challenges that we have because some of our patients live about 600 kilometers away from the clinic. So in a way we have been doing the telemedicine all along. And we've really made our kind of a practice different, we've been using them all the time. So this situation with the COVID, didn't really bring us anything new in a way. The only thing it was obviously is that it came so sudden, and stuff like that. But the telemedicine itself we have been using mobile phones and emails and different kinds of video conferencing when needed, but mostly the by phone, telephoning the patients. So it's basically nothing new.

Ian Winburn: Yeah, yeah yeah, well no, it's fantastic that you have been so familiar, but also so much on the front foot and adopting early, you know, ways that patient care can be modified, sort of, through the use of telemedicine. So as someone who has been practicing telemedicine for a while, what do you think are the key elements of making it a success?

What do you really need to focus on to have a really successful consultation, whether it be by phone or by email or by video app or just whatever the platform is? What are the real recipes for success?

Kristian Juusola: Well I would say that you have to begin with the proper kind of a communication and trust and laying the groundwork of the patient and doctor relationship, or owners, obviously. But first of all you need to know your patients and you need to have a face-to-face contact where you can build that relationship. And after that I think it's the kind of number of contacts that will then eventually become like a second nature.

So always the first contact you make through the telemedicine devices, is always a little bit awkward or you always end up thinking about the issues that could have gone better. But I think it's just making sure that the contacts are like regular, and the distance or the timeframe is not too long. So you have to keep in touch with them regularly. And that way, it will, like I say, it will become more or less like a second nature.

And it also builds the kind of, feeling for the families that it's okay for them to contact you as well. And the threshold for them to ask different questions, becomes less and less. And in that way, you will end up having a quite fluently flowing conversations and fluently flowing kind of intermediate appointments, should I say.

Ian Winburn: Yeah, yeah and that actually leads very nicely onto, sort of, the next thing I was going to ask about, and that was what the patients think, you know. What feedback do you get from, you know, your patients? Is it something that they have embraced as much as you have embraced, or your team has embraced? How do they find telemedicine?

Kristian Juusola: Well I think that they quite enjoy it, because obviously having a chronic illness, which takes a lot of, you have to have a lot of self-management with the disease. And once you have a person at the clinic who is also easily approachable, it makes it more like an individualized care where the patient really sees the value. And that way they want to let you know about things, and they want to ask you some questions, rather than just dealing them with themselves and seeing you maybe twice a year for 15 minutes.

So I think it's, like I said in the beginning, when you build this kind of relationship where you have this trust, trust within each other and the patients will value your input, they will give back, they will contact you then, more easily and more often.

And I think that they really enjoy it, because obviously life happens and it's not always that easy to deal with everyday life. So whatever you can make it easier for them to obtain any kind of documents, or whatever they need for their social welfare or their health welfare things, side of things. Like different kinds of documents, and stuff like that. So I think they really, kind of like it, I would say.

Ian Winburn: Yeah, well no it's great to hear. And it's great to hear how much Finland has embraced, sort of remote medicine and telemedicine, historically, which leads me onto really my final question. And with the fact that you have been leaders in this space, that you have been adopting early, what do you think the future holds for telemedicine and for remote consultation in the future?

What do you look for from it in the future? And if you could stare into your crystal ball, how do you think things may pan out?

Kristian Juusola: Well for definitely they are here to stay. I'm not sure if it's going to be the, kind of, first choice, but definitely on the side, it will continue to grow and develop. And with the health care providers and the patient a, kind of a contact of the side of things, it might take some time before it comes as a regular business. But then again between the health care providers, I think that more and more of the meetings and more and more of the kind of a collaboration between professionals, it will be through telemedicine, because the travel always takes so much time, and it's not easy.

But then again, I think also that we do have excellent options available, but the adaptation of these options is very difficult because people wherever they are working, wherever they are living, they don't have the same opportunities and they don't know maybe how to deal with these technical issues.

So that's a threshold that we really need to sort of lower and somehow get it easier and easier, so that we can adapt them more. So, I think it's just part of the, kind of a, keep practicing and keep doing it and then eventually we will find a solution that's like, let's say Facebook today, that everybody has it and everybody knows how to use it.

Ian Winburn: Yeah, yes. Well it's certainly a very optimistic view of the future and one actually that I very much subscribe to as well. Kristian, it has been wonderful having you with us today. Thank you very much for your time, and I look forward to speaking soon.

Kristian Juusola: Thank you for having me, it's been a joy.

Ian Winburn: Lessons for everyone, I think you'll agree, from Kristian's experience with telehealth before the COVID-19 pandemic, and how both his teams and patients in Northern Finland have embraced digital care into their practice.

Finally, the impact of adapting to a virtual health care community can surely be felt no more deeply than by those at the very heart of care – people living with hemophilia and their families.

Ian Winburn: So, we're delighted to be able to sit down, virtually of course, with Laurence Woollard, and we're going to discuss in more detail, telemedicine. So, I'm sure most of you will know Laurence, but for those of you don't, Laurence would you be kind enough to introduce yourself to our listeners?

Laurence Woollard: It will be a pleasure. Thank you, Ian, and obviously, thanks so much for the invite to the podcast. It's great to be here.

So, I'm based near Cambridge in the UK. I'm a patient strategist and through my consultancy On The Pulse, I collaborate, partner with and support global health care providers and third-sector organizations in the development and delivery of educational programming and engagement with people like me, living with rare chronic conditions such as hemophilia.

So, I live with severe hemophilia A, and have a known family history.

Ian Winburn: Thanks Laurence, for sharing that. It's great to have you with us, and particularly to discuss, sort of, telemedicine, virtual clinics and everything, sort of, digital around hemophilia.

Over the, sort of, past few months or so, we've really had an opportunity to speak with health professionals who have really adopted virtual clinics to support patients. And of course, it's been very relevant during this pandemic. Is this something you personally have experienced as well? How have you been maintaining contact with your medical team?

Laurence Woollard: So, yeah, it's a really great opening question. I think let me start by saying, you know, virtual clinics I think being one aspect of that broader telehealth or telemedicine approach, I think two terms often used interchangeably, like you say really emerged as a practical solution to mitigate ongoing clinical need during this type of global challenge, that is clearly unprecedented for both individuals and their families and their multidisciplinary care team.

Now in certain settings I would expect there has been some level of adoption of technologies pre-COVID, which have particular relevance for people like me living with chronic conditions that are designed to improve health management and outcomes throughout the life course. But I think it's interesting, you know, someone compared the way telemedicine is moving health care from hospital into the home to the way many consumers access online banking instead of in-branch visits. And it's always been stressed by my clinical team that I can access them anytime, anyplace, anywhere, which funnily enough sounds like a bank slogan. But it's actually, you know, really reassuring for me to know in times of crisis.

Ian Winburn: And just out of interest, is that something you've needed to do? You know it's one thing having it there, but just by the very nature of your hemophilia, have you needed to call on them anytime, anyplace, anywhere?

Laurence Woollard: Well, yes, it's been quite interesting because I think underlying, from my perspective, I think underlying that patient-physician relationship is one of interpersonal trust. And, you know, I feel really fortunate to have established a really good rapport, you know, with my consultant and clinical team to be able to communicate quite regularly on general, sort of, hemophilia topics via a popular messaging app.

But you know, albeit not as frequently in recent months, and I think like others I've been quite hesitant to engage where I have had no, you know, real emergencies considering many of the clinical team as I understand, were deployed to frontline practice to support here in the UK, the NHS [National Health Service] response to coronavirus.

So, it's been quite an, it's been quite an interesting dynamic really, but I think it's more especially in relation to, you know in terms of product supplies and also about postponements in certain, you know obviously appointments, but also personally speaking as well, surgical interventions.

Ian Winburn: Sure. So, it sounds like there's been advantages for you for using telemedicine over traditional contact with your health care professional team?

Laurence Woollard: Definitely. And I think there are without doubt, there's several possible advantages, I think, for a lot of individuals living with hemophilia, using telemedicine for their care.

I think broadly speaking, I think you know, in some cases that kind of improved time response to getting answers to questions, especially to facilitate early and appropriate management of an acute bleed. And ultimately, you know, reducing that, the time between the onset assessment and administration of treatment at home, which is really, obviously really important.

But also, that, you know, that ability to connect using different technology can further overcome that geographical access challenge. And there may have been more people especially living in underserved areas, to receive specialist care and take part in clinical trials. And I think that can reduce costs like travel considerably for some individuals.

And I think, you know, where that distance between home and a specialist center, you know it can be a notable barrier for continuity of care. So certainly, being able to have technology in place to support that engagement has been really, really important.

Ian Winburn: And I know you are particularly connected with the patient community, the hemophilia patient community in the UK, but also across Europe and globally. Has there been a lot of chat in the community around telemedicine?

Laurence Woollard: Well, I think it's, you know, it's I wouldn't say telemedicine *per se*. I think, you know, we've seen a lot of activity with the use of webinars to support educational programming and continued engagement with members, which I think has been really fantastic and mainly driven by the patient advocacy groups.

But actually, you know, specifically around the use of telemedicine, telehealth as a part of people's, you know, overall care. I think, you know, it's not necessarily a conversation I've personally had directly with peers and friends and colleagues.

But, but I think you know, like we've referred to, there's clearly definitely been a need during this, during this period. And I think, you know, we'll see, I'm sure we'll see some more dialogue and engagement going on around the use of virtual clinics and telemedicine more broadly.

Ian Winburn: Just moving on a little bit to other, sort of, platforms or other mechanisms. I'm thinking here about wearables, apps, other digital tools in the hemophilia space.

You know, do you think we've reached our full potential with respect to, sort of, engaging with your health and trying to maintain health and also, you know, I suppose, peak management of hemophilia? Do you think we've got there yet?

Laurence Woollard: Yeah, again, it's another really great question. I think when we think about mHealth specifically, without a doubt it's augmenting the health ecosystem, you know, and it can increase the effectiveness and effectivity of health care services through patient monitoring as we've discussed, health education, and tools for data collection. As well as to modify health-related behavior, again as we have recently witnessed through public information alerts, for

coronavirus. But, but in hemophilia specifically there's definitely been a shift towards developing apps to improve knowledge acquisition, self-management, treatment compliance, personalized care, and monitor treatment use and outcomes.

You know, we have, we have in the UK, we have an independent app called, Haemtrack, that was actually, it was reported in 2017 it was being used by something like 90% of treatment centers, being accessed by over two and a half thousand people living with bleeding disorders, and there was a compliance rate of 78%, which by all accounts is really good uptake. But to your point, I think, it's, you know, from my point of view a particular app like that is quite basic in its design. And we have seen other efforts to, to offer a better tailored experience using wearable devices to supplement treatment regime with sort of comprehensive, physical activity data.

Ian Winburn: Yeah, yeah, have there been any concerns amongst patients around engaging with, sort of, these wearable and apps?

Or is there generally, you know, this sense that these are positive and actually are there to help, help improve the quality of care?

Laurence Woollard: Yeah, I mean I think there's you know sort of natural concerns around you know sort of privacy and data collection for sure.

I think there's been, you know anecdotally, but also some kind of published studies. I know there was one in, done in Spain for a survey with around 181 people living with hemophilia on their expectations of mHealth use. And you know it was observed with that the privacy concern don't, you know, didn't significantly affect their intention of using mHealth. I think it was more about the lack of up-to-date and relevant information, the reliability and trustworthiness that can actually deter use.

But that's a really, I think that's a really interesting point though Ian, because I think, in the case of the context of hemophilia, you know I think it's really around transparency isn't it, from the clinical team in particular about the use of platforms to collect that type of data, how and where it's being used. And also to support education and dialog with community around the importance of those different types of apps and platforms and wearables.

And again, how that can support and empower you, not only in terms of your individual care, but actually collectively to drive up standards of care together.

Ian Winburn: Yeah, and you know it's quite noticeable, sort of, how much the community has embraced this shift towards digital and telemedicine as a whole.

But I suppose when you look back and reflect over the past 3, 4 months, and my word there is a lot to reflect back on past over the past 3, 4 months or so, but you know, what do you think

have been, sort of, the key learnings from this greater evolution towards telemedicine that, that we can apply to the future delivery of hemophilia care?

Laurence Woollard: So I think one of the biggest challenges with any sort of digital intervention, app, platform, website, whatever it might be specifically you know, is again whether users have had the opportunity, equal opportunity to become engaged and informed about their condition, to understand the app's utility, and derive value from the data they are inputting, again to enable them to actually improve their own care.

And I think there's always a risk of focusing on the tech itself, rather than addressing the underlying reasons and possible causes for poor self-management in the first instance. So, you know, I always, you know, from my perspective at least, I believe these should be more of an enhancement than a replacement to experiential and inclusive educational experiences, to increase community engagement and ensure users can actually maximize the potential of these technologies.

I would also say that I don't think again, telehealth can replace in-person patient care. I mean body language alone, is a strong determinant of how someone is coping with their health and well-being, and to sort of pick up on subliminal messages that you otherwise may overlook through a screen.

And I'm, as you might know, Ian, you know, I'm certainly a people's person, I really value my interaction in clinic. But as we've discussed, considering the circumstances that we're all going through, I think it's going to be fascinating to see how the telemedicine being used today and its effectiveness will determine its level of adoption by both HCPs and members of the community for the delivery of hemophilia care in the future.

Ian Winburn: Yeah, yeah no look, I couldn't agree more with what you have described there. I think it always comes down to having clear content, clear messages, clear, just say clear patient interaction as a health care professional.

And the platform itself, whether that be digital, whether it be face-to-face, it's sort of little bit, I wouldn't say irrelevant, but it's not the foundation of that, that clinical relationship. And these are methods to expand and to explore it in these trying times now, and probably well beyond. But I think your points are really well made.

So, Laurence it's been great having you with us today. Thank you so much for your time. Wonderful to speak to you and look forward to catching up soon.

Laurence Woollard: Thanks, Ian.

Ian Winburn: All right, all the best.

Laurence Woollard: You too. Thank you. Thanks for the opportunity. Cheers.

Ian Winburn: There you have it, Laurence highlighting the importance of the physician–patient relationship and face-to-face interaction in the care of people living with hemophilia. As Laurence described, telemedicine has already played a large role in improving care for people living with hemophilia and we are excited to see what new developments will come to hemophilia care.

So, a great opportunity to hear different perspectives on telemedicine and how physicians, nurses, physiotherapists and patients are all embracing this technology.

I look forward to seeing how hemophilia care will adapt and evolve in the coming months, and what the future may look like for people with hemophilia in an era of digital health. We hope you've enjoyed this edition of Hemcast.

All that remains is for me to extend my thanks to Roshni Kulkarni, Sébastien Lobet, Cedric Hermans, Kristian Juusola and Laurence Woollard and all our contributors for their incredible insights.

Until next time, goodbye.

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