Digital child health, with Professor Sam Shah and Richard Burley

Transcript of podcast – July 2023

RCPCH

This episode from RCPCH Podcasts features Professor Sam Shah, Digital Health Research lead at UCL Global Business School for Health, with Richard Burley, Executive Director of Digital here at the Royal College of Paediatrics and Child Health. Sam and Richard talk about the state of digital health today, especially in supporting infants, children and young people. We recorded over the phone, and you may hear a bit of outside noise – but it's a fascinating conversation and we hope you enjoy!

[music]

Sam

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[music ends]

Richard

Welcome to another podcast from the Royal College of Paediatrics and Child Health, where we examine the issues that matter to paediatricians and the communities they serve. My name is Richard Burley and I'm the Executive Director of Digital here and one of our strategic aims is to harness knowledge, data and intelligence to improve the quality of care for children and young people.

So today we're talking to Professor Sam Shah, Digital Health Research lead at UCL Global Business School for Health, and Senior Advisor for Health Care and Behaviour Change at Freuds.

We'll hand over the microphone to you Professor Shah in a moment and talk to talk about the state of digital health today, especially in supporting infant, child and young people's health. And maybe think about a little bit about what needs to change in the future.

But first I think it would be nice just in case anyone hasn't come across your work yet to potentially understand a little bit more about yourself and your experience. So I wonder if you could tell us a little bit about what you do today and maybe how you got there?

Sam
Richard, it's great to join you and great to join the College on this podcast. So I'm Sam Shah. I'm currently Chief Medical Strategy Officer at men's health company Newman, where we provide online healthcare for men. And I also work at UCL where in the Global Business School for Health, we teach on digital health and help people understand everything from how they evaluate digital health products to how they might create them and start them up. And that's working people from all over the world.

And of the some other things I'm really lucky to get involved with is supporting individuals with assessing how they might create new innovation and apply for support and funding for those.

And previously, I used to be at NHS England, so the NHS in England, which really supports the commissioning of services, and in that I was the Director of Digital Development, who I had a great time looking at different ways to digitise the health service in England and working with partners around the world, understanding what's worked elsewhere, what can we learn from what can we share, and how do people collaborate on digital health. So yeah, I'm super super lucky to join you and hopefully we can have discussion around those things that are working in both digital health in general, but especially those things are implemented in child health.

Richard
Fantastic. Thank you. That's wonderful. And I wonder very briefly if you can, what came first technology or children's health for you?

Sam
Ohh wow. For me personally it was probably getting involved in child health more than technology first. That all stems from my clinical career. I started off in originally in dentistry. Then I went into hospital and academia for a while and then public health and is probably really in public health where I really came across anything to do with child health and how we reduce inequalities in in child health. Technology is always part my life but bringing those things together didn't really happen until after I've been through that. And I'm very lucky that later on in my in my career I got to see how the world of treating patients, particularly the child patient in the keep setting and can really collide with technology to building a better outcome for those individuals.

So yeah, very much actively treating patients. Child patients came first, technology second. One thing I probably is my broken record which is really understand the person, the patient, the citizen, their problems, and technology second.

Richard
Fantastic. I love that. That's brilliant. I think we've definitely covered those bases. That's a really brilliant insight into yourself. So thank you for that. So let's jump straight to it. The reason why people might be coming to listen to this again is really getting your perspective a little bit on maybe where some of the most exciting recent developments

are in digital child health today. What's kind of the thing that's got your juices flowing right now?

Sam
I think if we were to look at the landscape of digital health particularly for children and young people, there's no shortage of technology, innovation, apps, wearables that are out there. I think that excites me most, though, is how we try and make the environment of child health, really the treatment end, more accessible to children, young people, their families, and also less imposing, less scary - especially that moment when families will be scared about accessing treatment, when children will be in unfamiliar environments. How do we use technology to break that part of the system is probably the most exciting.

There are lots of other things that we could do around prevention and public health, but those are probably more difficult and less in the immediate future, just because the nature of the long chain. And when I think about those things that I'm seeing out there and use of virtual reality and augmented reality has made a massive difference.

And many of the people listening would have known about some of these cases at places like Great Ormond Street in particular, some of the work that's been done at Liverpool - are trying to bring in the use of those things directly in the patient and the citizen environment, allowing children to really understand the moment they be going into when they'll be receiving acute care. That's kind of one end.

The other end of that that's equally I think interesting and, perhaps in some ways more so, is the use of technology in the world of prevention. Now you might think how on earth are children gonna use technology in prevention. The way I've seen it is actually in a space that sometimes is controversial, but using technology and games really and game theory to allow individuals young people to try and in some circumstances become more active when they might not be able to, or when it might be more difficult. And I'm thinking about those patients who might have difficult conditions where they're having to either stay isolated or in some cases they might be using other medical devices where they need a different type of game that might not be readily available. And that's been really interesting seeing that evolve and seeing technology that can that can really cater for those individuals with very specific needs. So I think those two areas are super exciting.

Of course there's no shortage of tech out there. We've got everything – something we won't cover today - but large language models and how they might be used for child health all the way through to apps and wearables.

Richard
Fantastic. Thank you. That's really really interesting. And if you don't mind, I'll just pick up on a couple of those very briefly. So when you talk about augmented reality and virtual reality, your it sounds to me like you're talking about it in the context of preparing children, preparing families for what they're going to experience. Do you also see it or how do you feel about its efficacy in treating and engaging with patients remotely?

Sam
I think this is you a new space to evolve, as you rightly mentioned. I was thinking about it originally from the perspective of preparing people for the environment they're about to enter into, reducing some of the fears and anxieties for those environments. What we've

seen it also works in other ways. So historically patients being treated under general anaesthesia, particularly children, is problematic both for the child, the risk and the health system.

One area very close to me is that at the moment, the biggest reason for children being admitted to hospital still as at today remains the management of dental decay and the removal of teeth under general anaesthesia in a hospital setting. And that involves so many clinicians, and of course has an impact on families. One area that I've seen is the use of virtual reality in sedation and providing goggles that will take people into an experience that allows the child patient but also the adult patient to experience a form of conscious sedation that is basically being generated through the use of virtual reality. And that then means that those individuals can be treated in out of hospital setting in a less traumatic way and an improvement that is often much more rapid with greater written much better recovery times.

That's another area and I see that increasing. But I also see other areas of its use. We're now beginning to see mainstream views of this type of technology for mental health conditions. That is a big topic area, in particular no different in children. What we're beginning to see that and I've certainly examined. I've certainly seen a few use cases in mainstream Europe where this has been the case.

Richard
Fantastic. That's really exciting. I think you know you you're talking about one of the things that that certainly opens up, particularly when we think about CYP is maybe the idea that the dentist chair or the surgery somewhere, medical office. It may not be somewhere where they necessarily feel at home more comfortable, but actually when you can take them into a space, a virtual space somewhere where they used to spending time, whether that's in a video game or some other kind of social technology context, then they can certainly help them perhaps feel in somewhere where they're more familiar to and engage with that experience. So I think that's really interesting insight, not something I'd come across all that much. So that's really interesting to hear about that.

You also touched early on, I guess gamification or sort of encouraging young people anyway to engage in a little bit. Little bit more exercise using games again. So there's a we're already seeing a little bit of a theme here in terms of the virtual world and using that as a tool for engagement with SYP. And I guess one of the things that I think people will recognise is this idea of competing for the attention of the child and indeed adult. But children in this case with some very tempting and some very rich media experiences that that they're being drawn to so.

Richard
I guess it makes total sense to think about bringing a physical activity and opportunity for better health into that context and in enticing them too, I guess, have that dialogue with their bodies in a way that they used to doing with just their fingers and their thumbs and their eyes around the gaming side of things. So yeah, I think that's really interesting. And I wonder whether we'll see more of that. Are we gonna get prescribed 3D gaming from the NHS at some stage?

Sam
Again, I mean, touched on it and the issue of trying to encourage people to do something and it doesn't come without its risks. There's the other risk that it's so successful, it becomes in itself a new form of addiction. And so how do we get that balance and how their healthcare professionals, paediatricians, those working in child health, anyone really get that balance right of how much they encourage and how much they really put up a barrier or discourage?

I don't think any of us have got the right answer and it will probably depend on the individual child assessing Of course here's no replacement for real interaction and real activity in the real world, but I think this is one of those areas where on a case by case basis, it can be used to try and precipitate, encourage a behaviour that might make a difference. And it certainly wouldn't surprise me if we see digital therapeutics that are prescribed for this very reason. Now we know in other parts of the world, we know in Germany, they have different therapeutics for quite some time. They're reimbursed and recommended through their government reimbursement scheme. In France, the same as about to start very, very soon. In England, we haven't quite got there. We had the NHS apps library that had applications confirmed accepted by the NHS. We haven't had replacement. So they're now very much local formularies. So I think until we see the model of commissioning of services change, the digital services become part of that Commission, we probably won't see prescribed different therapeutics in in the UK. I think we've got a little bit of time to go before we get there, but we'll see the art of the possible and so there will come a point where I think we will see these things happen.

And the message that I would have out there to people listening is before prescribing something or even recommending it, test how it's been evaluated. Ask questions and what the evidence is behind it, how it's been regulated, whether it meets the regulatory standard or not, what the position and view is of the evidence that's out there.

And those are the questions I certainly would recommend that clinicians, paediatricians, others in the round ask about any technology that that does anything. And for any parents that are listening, think about what the privacy standards are, what the security standards are of this technology, knowing that the data for children, young people using these products, that that data is safe. That we're clear about how it's going to be used and it won't be exploited. Those are important questions for people to ask.

Richard
That's brilliant. What a great what a great segue to the question I was going to ask next as well. But I think that's really interesting and I think you. You mentioned wearables, you've just talked about health data activity, data and things like that. What's your experience - I've been interested to hear about where the CYP that you're engaging with, where they're at in terms of the feeling they have about the controlling their own data owning their own data, giving access to it, other people using it. What's kind of the headspace at the moment with the young people? I guess there's a variety of opinions, but can you Categorise at all a sort of average position that that young people might have around that.

Sam
I think the first thing is that the position globally is quite different and there are some

really good studies out from the Financial Times and The Lancet Commission and others around this very issue. And if we look around the world, the experience of children and young people is quite variable. The degree of internet penetration, so the amount of internet availability, is very different in different parts of the world and even in the UK, it varies across the country. And the degree and the extent to which this literacy exists until young people is hugely variable.

We take a place like London, which is always highly digitised. Young, people have a very different digital experience in a place like London, so that they might have in some parts of the West Midlands. So that then results in children and their expectations of digital and what they might expect from digital health to be quite different as well, based on their own experiences. And that's only understandable. Also the experience of their parents.

The factors that sort of affect this is extended into that device availability. Those people living in deprivation, many of which will have the highest need, device availability will also be hugely different. So I use this anecdote where certain children we engage with including my own might talk to me about the devices that other people might have available to them, but have said no. That discussion in very different parts of the country where the availability of these devices will change. And why that matters is the type of tech that can be used, because of device majority, will change.

Internet access. We almost take it for granted. I certainly take it for granted. But actually for children, some children may not be given access. There may be restrictions in place. Rightly so. There might be parts of the country where it's just not, the internet is not accessible because the infrastructure doesn't exist. So this will also colour the experience of children and young people, and the degree of their own maturity will change. We're all familiar with the different standards of consent and the big reason freedoms to which people be able to access daytime services and regular services, let alone digital services. So again, this might change the extent to which digital services will be on the radar of children and young people.

Some of the things we know about from The Lancet Commission, and other work, demonstrates that young people and children will recognise everything from apps, websites, wearables as a digital health experience, you know, as much as they might do with regular services. They're often more likely to search online for answers to questions where they don't want to talk to healthcare professional or an adult about. That means that the burden on us in the way in which we regulate and make services available is much greater because we need to afford those young people protections.

It also means that we need to think about the way in which we might restrict a certain technology, for good reason, but actually we need to make them more available to help children. Young people answer questions where they may not be either familiar with talking now about may not feel comfortable in speaking out about, and there are certainly topic areas, including mental health, that seems to be quite mainstream right now. And we know that one of the big search areas online for children, young people are mental health conditions, and we see this cross-platform. We see this on social media outlets as well as regular web browsing.

So in terms of where children, young people are, I think it will vary based on conditions, mental health, those areas that might be the more social nature, might be topic areas of greater discussion, those relating to physical health and things like.... These might be of a of a lower nature in terms of priority, but they will change in different parts of the world. And a good example is a really powerful campaign in Brazil was around thrush for example in young people and trying to break the taboo around that and using digital public health communications to change that dimension - whereas that that probably wouldn't be such a mainstream topic in a place like the UK, where a bigger topic area happens to be mental health.

So sadly, no one answer to that question around what's important to children and young people, what they prioritise. But I think a recognition that we have to understand that in different communities that be different needs that be language needs, they'll be cultural needs and degree of digital maturity will in people will also affect what they can access.

Richard
Fascinating. Yeah, that's really interesting. Really good examples, though. I think, you know, it's really something that we try and be careful with is we have lots of ideas and as a sector and as people who particularly interested in child health technology, about how technology can support. But we must make sure we don't leave people behind in that effort. You know, we may see the value of it and we may be able to take up that value, but it's not always so easy for others.

I could talk for hours on this and I'm sure you could too, subject to availability. But I did wanna just jump into kind of the other side of the coin, I guess. So you've really described it a little bit about children's experiences. You've described some of the technologies that are already coming up or that are coming soon. And the way that they be, those can be a benefit.

How do people access it? How do we get this into the hands of paediatricians, how do paediatricians make the best use of these technologies, understand which ones are impactful, understand how to get the most value from them and really get those in front of children? How can we really encourage that to happen as a sector and for individuals?

Sam
The first thing I would say on this is that at the Conference, the warmth and the reception from those people to participating on this topic area was amazing. And it's since then I've connected to many paediatricians, some that I knew something I didn't know before, just to discuss this. How do they get involved both in either designing and developing technology or knowing what technology to pick and select for their patients and others they might come into contact with.

So it's been great to have that and I would welcome anyone to get in touch if they're interested in this topic area. But people have different interests. Some will simply just want to know what's in the formulary. Others will want to get right involved in tech and some will want to evaluate it. So for those thinking about what's available out there, first thing I would say is have a look at some publicly available resources. There are some publicly available libraries of apps, and they're often rate them and demonstrate what evidence they're based on. So, look at the evidence on them.

The other is working in an NHS organisation, many of them have a local apps library and that'll explain what's available, but also how they've been evaluated. For anyone that is familiar with an organisation called ORCA, I've and I've done some work for ORCA, they also will publish their apps library online and you can examine what's available in the in those libraries and they will show how they been evaluated, the efficacy of those products. If they provided that and also who they're intended for. And that helps select the right thing.

Then there's paediatricians and those working child health across the spectrum who might want to get involved with either technology or learning about technology. A few ways you can do that. There are lots of courses out there. They're great. They're also interesting. And they're university courses. There's also freely available courses online that come from some organisations. Some will come from pharma and drug companies. Some will come from some of the royal colleges. So will come from the faculty of clinical... So worth looking out for those courses, webinars, programmes.

There's events. There are so many events in the UK. I could name a few, but they include, for example, that takes place in September, Rewired in March, health plus care later on in the year, plus lots of other events throughout the year in digital health and technology that you can participate in, learn about what the discussion is and learn about some of the issues that are taking place, whether it's around data or the evaluation of products that are that are available there.

And then finally, how to evaluate them. There's the framework and government, the digital health evaluation and framework that exists that anyone can access freely online. NICE has its guidance on this, and also there are some advice points there that will see from certain universities, digital health units, my own included UCL, that provides information on how to evaluate. But the fundamentally the same principles you'd used when you thinking about evaluating anything. Ask about the level of research, it doesn't necessarily have to be a trial, it might be something else. Just ask the question and understand what are that means, whether it's applicable to your audience and the people that you're treating and have a think about whether or not this is something you be comfortable using yourself.

Most importantly, think about where you record it. So use a record the data and where the data flows around this. But I'd encourage you all paediatricians, all those clinicians involved in in paediatric and child health and then anyone who's involved in the management support of young people to get involved in the topic area. Speak to Informaticians, speak to the CCIO or the chief collaboration officer, the chief Nursing Information officer of your organisation. Speak to people in national organisations who are involved in this topic area and any special interest groups. And you can get involved and get involved in the development design of these things.

Richard

Brilliant. Thank you so much. That's really useful. And in terms of giving people a place to start and to look into kind of where they can increase their knowledge around technology in healthcare. I think it would be really interesting if we could to get your view just a couple, maybe a couple of key topics if someone was interested in getting more into it

and they wanted to really look at some of these topics that could be an impactful and you've mentioned some of them, there may be a couple more.

Sam
First thing I would say, the most important one is just identify how you understand the technology, just get the skills of working out what is it that's in front of you? Is it an app? Is it wearable? Is it a website? Is it data? Is it infrastructure. Just those key things of what it is.

The second one I would say is just get an understanding how you evaluate these things. What's the evidence base behind it, numbers of users, the experience, those things.

The deeper you get into this, you also want to know how to do some user research and what questions to ask. You don't need to become a user researcher, but you might even do some soft research by asking the patients that you treat or their families about what they're looking for, their experiences and what it might be that helps them and the outcome you that you want them to achieve and try and relay that to any technologist. Then there's kind of the next layer below that, if you really get into development. You might want to develop some coding skills that you may not want to become an engineer, but some basic coding skills - So coding for clinicians, so coding for anyone working in the sector – is and ca be important. You don't have become an expert. But there's many free courses online and then some short courses.

If you wanna go a level beyond that, you might then get into the space of how do you actually start an R&D project that's working with maybe university partners, industry partners, taking your idea and going through it becoming an idea to it becoming maybe a pilot or a research project and going from there to becoming something you might launch. A great examples of paediatricians that I know who have actually launched their own digital health products that have been highly successful in the space of autism, in the space of hearing loss, in the space of artificial limbs, there are many, many more. So there are good examples of paediatricians of operators in this space.

Richard
Fantastic. Thank you. And what's your kind of position or your advice to people who might be thinking? Well, that sounds well and good, but I'm quite happy, you know, doing my bits and bobs, just meeting people face to face, talking to children, talking to families and you know. Maybe you aren't necessarily fully convinced that technology is something that's gonna be important to them over the next few years, next five to 10, 15 years in their career. What would you say to them?

Sam
Firstly I would take nothing away from the importance or the power of the conversations they have face to face with people, with children, with young people, with families and parents. They probably learn more from those things than many of us do in other settings. So I think that's the most important thing they're going to be learning about things that they can translate.

But they're also quite powerful those conversations. One they'll be able to influence the future of technology. Two for those who are less convinced, we have to think about the everyday world and our everyday lives. Digital health technology is around us. It's not

going away. The likelihood is it will form part of many of our interactions as time goes on. It will contribute to efficiency in our health services. It will contribute to outcomes for the population and the likelihood is it will be part of the lives of those people we treat, our friends, our families.

So I'd certainly say embrace it if you can. But do so with healthy scepticism. Ask questions about whether it works. Be curious about how something works and find out how something is evaluated and how it's monitored and researched on an ongoing basis. So there's every reason to think carefully and cautiously. But there's also every reason to embrace it when it's done right.

Richard
Brilliant. I think, you know, we've heard a couple of times from you there, this idea that we all need to become our own quality control. We all need to become our own, you know, knowledgeable reviewer of possible technologies and combine our own, I guess, our own rigour in looking at the sorts of technologies we might be thinking about and what those options are. Combining that with - not reinventing the wheel - looking at some of these places where there are catalogues, there are kind of lists of technologies that might be appropriate that people can begin to take up and start looking at and doing that in a way that works with children in the worlds and in the platforms that they inhabit, in places where they feel comfortable and recognising the power of the fact that the younger generation are, you know - technology is the default. It's not something that's additive. But still being very mindful of the digital divide and health inequality in regard to access to these sorts of things.

So there's quite a lot to unpack there. There's quite a lot to consider. There's quite a lot to think about. But I think you've given certainly from my perspective, you've given some really interesting avenues for people to pursue. You've given some really, really good starting points there, which people will be able to start from, begin their journey or continue their journey or augment their journey.

And I think one of the things I really enjoy about digital healthcare technology for young people is there's always something new to look at. There's always something new to examine. There's always something new to consider. And in that sense it's exciting. But it's also, there's an onus on, I guess, all of us to really think about making sure that we're targeting impactful, efficacious technologies. And in that sense, you've, as I said earlier, you've said it very well – really skilling ourselves up to understand what efficacious technology looks like. What are the solutions that are impactful in the real world rather than just necessarily taking something's someone's recommended or the first thing we find on Google, which I'm sure people wouldn't do anyway. But really thinking about how do we get to the root of: is this impactful? Is this safe? Is this valuable?

So I think that's a really good call to action. Be critical in your thinking, be open minded, be inclusive about the digital divide with young people. Talk to young people in a way that they recognise, that they understand and do so in spaces and places and with technologies that they're comfortable with. And I think you know, it's a really, really exciting future and I certainly hope from my perspective that will have the opportunity to perhaps continue or explore in more depth some of the branches, some of the doors

you've opened there because it's such I think a vital space and something that's only going to grow in importance.

Sam
Well, Richard, thank you so much for inviting me and you some summed it up incredibly. One of the things I would leave everyone with is asked three questions

Always ask what's the clinical need we're solving? What's the emotional need we're solving? And what's the practical need that we want to solve for the people to whom technology might be important?

And always ask those curious questions. Does that help direct us and take us to a place where the digital health technology that we adopt is there for the benefit of people and patients were trying to treat?

Richard
Fantastic. Thank you so much for your time. I really hope we can have another discussion. As I said, in the future. And thank you so much for joining our podcast series.

Sam
Thank you, Richard. It's been an absolute pleasure.