



# Diabetes Podcast: Do It Yourself/Open Source Artificial Pancreas Systems: Part 2

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**VG:** Hello my name is Victoria Glasson and I am the Managing Editor for Diabetes Therapy. Welcome to our Technology in Diabetes podcast. Today we will be continuing with part 2 of our podcast with Dr Sufyan Hussain and Dana Lewis, discussing the artificial pancreas system.

**SH:** So how do you see things developing with the diabetes technology now?

**DL:** Ideally, I would love to see more of the ideas developed from the patient community that are solving really concrete and discrete problems with regards to quality of life be involved and brought into the traditional and

academic and industry development processes and see those development processes and timelines sped up because a lot of the technology development we're talking about now is software and algorithm development. I think we need to encourage other companies to separate their development timelines of software from the hardware timeline and hardware testing processes that tend to be a little slower and tend to slow down a lot of other things. I would like to see more technology developed more quickly and meet the standards that are being set out by the diabetes communities themselves.

**SH:** Another slight controversial question if that's okay? There have been some controversies around using what's called DIY/CGM or something that has widely been used in Europe called Libre [1, 2]. In the states (USA) it's probably a more recent thing whereas Libre has been out in Europe for quite some time. This is an area where I see some disparity in views about how we apply artificial pancreas systems and, related to that, also the reporting of issues. What are your thoughts on those two aspects? DIY/CGM and reporting?

**DL:** I think your use of the word 'disparity' is really key. I think there are disparities in diabetes care and access around the world. Even in what are considered to be very forward developed countries people are struggling with access and affording insulin. Same thing goes for CGM

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or things like the flash glucose monitoring you mentioned. The cost question drives people to make different choices than they might otherwise if their pump and CGM sensors and insulin were fully covered. So I think the question around DIY components like the flash glucose monitoring system being converted into a continuous glucose monitor and things like that are a symptom of these choices. I think it would be great to see the world address the cost question. There are too many people going without insulin around the world and too many people being forced to make choices which we maybe don't agree with but we may not be in their situation to understand their choice in terms of a financial situation that makes them make a particular decision. So I think with regards to reporting issues, one of the things the community is designed around is safety. We care about our safety and the safety of the community so we have been fully transparent from day one, which includes reporting issues and concerns. That means you can report your issue or concern anonymously in the community; you can post it to GitHub; you can send an email or report within the community; but as a lot of people have learned this year, you can also report any problems with the system to your local regulatory body, even if it's an off-label use. And what was also interesting to learn this year is that a lot of the diabetes community didn't know that even with on-label commercial use of diabetes products if they have an issue, it can be reported to their doctor or regulatory body. Again, I think the question comes up of do we need more reporting? It seems to me that we need increased awareness about reporting, not only with DIY but within the diabetes community in general because so many people didn't realise that if that had an issue with a product they were using with on- or off-label use it could and should be reported to their local regulatory bodies.

**SH:** That's really true, and I think you're right that most healthcare professionals wouldn't have been aware that any issues that arise on even commercially approved systems have a certain reporting channel. I think what DIY has done is to bring that right to the forefront. You're right that if DIY is being put under

scrutiny then commercial systems should similarly also be subjected to the same standards and that any issues should be reported in the same manner. Certainly, in the UK we receive reports via the MHRA [Medicines and Healthcare products Regulatory Agency] and in the USA via the FDA [Food and Drug Administration], and those standards also need to be applied to commercial systems. The point you made about DIY/CGM and the use of Libre is absolutely spot on with respect to cost. Diabetes has always been deemed 'DIY' and that's the nature of it. Looking back 20–30 years, people I look after now tell me about their experiences of how they used blood glucose test strips, which was a new advancement almost 30 years ago. At that time, the cost of these strips was fairly high so you'd only get about one strip a week. So the way most people coped was that you cut the strip into 4 pieces. This was a very common situation, which again in this day and age would be viewed as complete 'DIY' as it was very cost driven. With the increasing availability of prescriptions, luckily that behaviour didn't have to continue as it exposes the user to potential errors. So, I think you're right, it is a cost-based thing, and we will reflect more on cost and accessibility in a little bit. I am grateful for your comment on that.

**DL:** Just one other comment I would make on DIY, I'm glad you brought up the test strip example. I think when people look at DIY/APS or closed looping they think 'oh my gosh this is completely new it's never been done before, patients are doing something that we didn't give them permission to do'. When you actually look back to home finger stick blood glucose monitoring, it originally elicited protests from healthcare providers who thought patients shouldn't have their blood glucose data because 'they might do something wrong' or that 'we didn't approve them to do it'. A movement was actually started by patients to have home blood glucose monitoring, which then became the norm. The original use of CGM was similar. The first CGMs were blinded, and the data were only available to healthcare providers; a lot of people said 'we don't want patients to have this data because they might do something with it'. Now, it's the norm for patients to have access to their

data in real time. I think APS and automated insulin delivery being DIY is just the latest in that series of examples where patients have really pushed for something that then becomes the standard of care for the next decade or 20–30 years after that.

**SH:** So true. So Dana, any concerns as we move forward for DIY use in the real world?

**DL:** I think a lot of my concerns have to do with the access and the affordability that we have talked about. I think people make different decisions based on the gaps that have been left by the healthcare system in terms of the coverage of insulin and CGM or things like that. Originally this [DIY/APS] all started because of the lack of customisable CGM alarms as the gap and no commercial solutions for closed looping. Now we're seeing different choices being made because the commercial technology, at least some of the first-generation technology, is not necessarily meeting people's expectations in terms of knowing what this technology is capable of doing. I'm excited to see more conversations and more partnerships between industry and the diabetes community, with industry and researchers learning from what we've shown to be possible and what the trade-offs are in terms of real life and this technology to make sure we can make this technology safe but effective, widely available and affordable.

**SH:** Absolutely. So, moving onto my final few questions Dana. Having changed the landscape for T1D for the better, what's next for you?

**DL:** I still think we have changes to do. I think we need to work with traditional researchers and industry to bring this technology to more markets, make it more widely available and make sure it's affordable and accessible. I also think we have work to do in terms of changing the healthcare system, so that when patients who are using this technology end up in the Emergency Room for whatever reason or they have surgery for something else they are able to use this technology while they are also addressing other healthcare issues. Routine diabetes care needs to evolve to match the potential of what this technology has to offer. I would say there is still work to be done and changes to be made. The community, and

myself included, still want to push in that direction because we see what is possible and we see it coming and I think we will get there in the next couple of years.

**SH:** I absolutely agree and it's really a positive step forward. I think for me as a healthcare professional it's also one of our big areas—how do we improve access to technology? With most people realising that it's not reachable to most, even in the UK with the free healthcare service. Certainly, when you look worldwide, having been raised in a third-world country myself, such technology is even more scarce, and even getting adequate insulin and testing strips is only possible to those who are privileged. A lot more needs to be done, and I hope that people like us who benefit from great healthcare systems can direct some of our energy into social agendas that are trying to address this issues. I hope that can come to the forefront. I know you have been involved in issues like this Dana, so it will be great to hear more about that from you if there are any aspects you want to emphasise.

**DL:** Yes I am glad you bring it up. This is exactly one of the reasons why I support the Life For A Child movement [3], because there are about 18,000 children or more worldwide who would die if we didn't get them insulin and blood glucose test strips. Working with the governments of different countries to educate healthcare providers [is important] so they can make the correct diagnosis because children would die without a diagnosis and without receiving insulin in time. It's challenging a lot of the time. We're talking about technology because a lot of people perceive diabetes as a solved problem or they think 'okay you just take insulin, everything is covered', but what we've realised is that there's still issues worldwide with regards to insulin coverage, access and affordability that need to be addressed. Again like we talked about at the beginning of this conversation, even for those who are privileged enough to have access to insulin and have access to some of these other technologies, diabetes is still hard and there's so much we don't understand about it and still learning about. It's important for us all to focus our energies constructively and collaborate on the problems we can solve, like getting insulin to kids in countries that are unable to survive without it,

and focus on pushing the technology forward as it continues to become more accessible and affordable. There's so much to be done, and it needs all of our hands and energy. I'm excited to see more collaborations heading in those directions because again I'd like to see these efforts in these areas be multiplicative and not just additive.

**SH:** Really positive stuff! Finally Dana, from your perspective, the future of diabetes, where is it going?

**DL:** I think the future of diabetes is going to a place where the biggest concern will be keeping your system running; with keeping your sensor going, keeping your pump site going; with glycaemic excursions being out of range being an occasional blip rather than an everyday constant frustration. I am looking forward to people having the perspective that diabetes is not something they feel that they need to see most cured, or ideally that we will have a cure. For example, I have T1D and I have had it for 17 years; but I have also been living with coeliac disease for 11 years. Given the current technology, I feel like my biggest health frustration is coeliac and finding access to gluten-free food. I would maybe rather have a cure for coeliac first because I think technology has come such a long way for T1D and I would like this technology to be accessible and the healthcare system be supportive enough so that everyone can feel that diabetes is not a hassle and a burden and doesn't bring pain and suffering in the way it brings to people today.

**SH:** Absolutely, I agree in terms of automating the whole process and getting access for people to use this and benefit from it.

**VG:** Dana, if it is possible I do also have some questions for you? What would be your top tips to somebody who was starting out on this process, to somebody who would like to adopt this management style?

**DL:** My tips would be to start reading and start listening in the communities because there are now thousands of people worldwide speaking multiple different languages who are sharing their experiences and documenting what their learning curve was like. Being the first in doing DIY can sometimes be hard, but now we're at the point where there are a lot of people to learn from and you can learn from their

mistakes and their learning curve to expedite your own learning curve. Also, learn to be comfortable asking for help; you don't have to do it alone [4]. DIY does not mean do it alone. There's absolutely a community of people who have worked with this technology and experienced this technology themselves who are happy to answer questions and happy to present themselves and share their experience and expertise with you [5].

**VG:** Can I also ask your opinion of patient inclusion within industry? Do you think enough is being done there?

**DL:** I think more can be done in patient inclusion. I think whether we are talking about industry developments or research there have always been things like focus groups and that is a way to include patients, but then is that the only way to include patients? I would like to see more inclusion at the start of the prioritization of deciding what to research, what to study and what problems to address in terms of development and design, and I think by having more patients take a bigger role earlier in those processes we will see better technology developed that more closely fits the users' needs in the real world.

**VG:** My final question—Community physicians and nurse practitioners don't get to go to conferences and aren't always at the forefront of education. How do you think we engage these members and how do you think we can educate them to make sure that they are educated and are able to help patients that are able to adopt this management style?

**DL:** I think that is a great question. I'm hoping for insight from endocrinologists who have managed T1D the longest and who the most closely associated with T1D patients to help figure out how to reach these healthcare providers in their local communities and share education with them [6, 7]. It could be sending them guidelines of best practice documents or sending them patient-built documentation or books like mine that are both for a patient and healthcare provider audience. I think it's a really important question as there are a lot of healthcare providers who already don't feel comfortable addressing diabetes even without this technology, and I think adding this level of

automated technology is going to further make them uncomfortable with managing it, which leaves a lot of patients unfortunately in a gap. I would love to see no more patients falling through the gap in health care because of the technology they use or because they have diabetes, but I think a lot of work still needs to be done in that space.

**SH:** So Dana, before I wrap up, any questions for me?

**DL:** I think that's it from me; thank you for having me on the podcast and thank you for raising a lot of really interesting questions.

**SH:** Dana's open access book on automated insulin delivery is available via [artificialpancreasbook.com](https://www.artificialpancreasbook.com) (<https://www.artificialpancreasbook.com/>) and will be available through the figshare link alongside this commentary. Dana, thanks a lot for joining us and giving your excellent insight and perspective. Having built the system, used it, being involved in the journey of implementing and researching it, insulin being regulated, influencing industry and influencing healthcare professionals, it's a really powerful story. I am sure there is still more to come, and I think the bit that always excites me is the attitude of paying it forward and the attitude that magnifies the actions that we are all doing and supporting each other in the community. Thank you so much for giving us your insight and time.

**DL:** My pleasure. Thank you for having this conversation and to everyone who is listening and doing their own work to move diabetes forward—thank you.

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