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Abstract

While many have argued that disabled users should be more involved in the design of assistive technology, these users continue to have limited influence over such design. As a

consequence, assistive devices are generally designed in response to those needs defined by medical practitioners, industry experts, and governmental agencies, and do not always take into account the priorities of individuals with impairments. In recent years, however, care for type 1 diabetes has been revolutionized by user-driven innovations. Two such innovations are the #OpenAPS project, which aims at building an open-source artificial pancreas, and the related Nightscout project, which enables those with type 1 diabetes to transmit blood glucose data remotely. In this article, I examine these innovations as case studies for user-driven participatory design, weighing its various benefits. I then highlight the ways in which this approach to design transforms traditional models of medical research, and propose ways of addressing educational barriers to this kind of design.

Introduction

Stuart Blume (2012) recently observed that although those working in the field of science and technology studies have for many years stressed the importance of involving the users of technology in its design (Oudshoorn and Pinch 2003), users continue to have little influence over the development of accommodation technology (Blume 2012, 350). In general, medical practitioners, industry experts, and governmental agencies continue to dictate the goals for the design of assistive technology, and these may not be in line with the needs of users (*ibid.*).

Irving Kenneth Zola (1977), among others, has pointed out that, traditionally, medical and governmental groups have approached impairment as a problem that must be solved. Assistive technology developed under the traditional model is

primarily aimed at correcting an impairment (Johnson and Moxon 1998, 243). This approach can be problematic, as it sends a message that disabled bodies are wrong and promotes the normalisation of certain bodies. In addition to the problem of normalisation, the traditional medical approach to assistive technology creates a divide between the user and the designer-as-expert. This can leave the user with a sense of being dependent on the designer or device (Zola 1982; Johnson and Moxon 2010, 246).

In recent years, scholars have identified another significant limitation with the medical approach. In its focus on solving impairment, the medical approach does not address the concerns and interests of users that go beyond functionality—what Blume has termed "those elements of experience that lie beyond the compass of medical practice" (Blume 2012, 356). Key among these are the aesthetic aspects of an assistive device. Graham Pullin explains that bodies are not just functional, they can be used to negotiate a place within culture and shape self-image (2009, 40). For example, Pullin writes that "any hand is more than a tool—it becomes part of a wearer's body image, a visual as well as functional termination of the arm" (*ibid.*). Pullin argues convincingly that, given the importance of these visual and cultural aspects of assistive technology, designs that focus exclusively on function are of limited success.

Participatory design, which involves the disabled individual at every stage of the design process, has been forwarded as a preferable alternative to traditional models of design for disability. Through its emphasis on user involvement, participatory design promotes technology that is responsive to the actual needs of users, as opposed to those determined exclusively by the medical industry. Of course, not all users will

be able to participate in the design process to the same degree or in the same way, and scholars of participatory design stress the importance of taking these differences into account (Newell et al. 2010, 235; Oswal 2014, 14). We are currently in need of more models of design that allow users to contribute to the design process and to determine their roles in this process.

The past decade has witnessed the emergence of new opportunities for users to dictate their roles in the design of assistive technology. Particularly relevant here is the increasing accessibility of design tools, such as programming and 3D printing (Rao 2012; Sharma 2013). As the tools of technological development become more accessible, a greater number of disabled users will be able to develop and modify technology at some remove from medical and industry experts. Already, some hearing aid manufacturers are using 3D printing as a means of creating devices to meet the needs of individuals' unique bodies (Sharma 2013), and it is not hard to imagine a future in which someone who wears one of these devices will be able to design it independently.

It is worth keeping in mind that not everyone wants to be involved in the design of assistive technology. But these technological innovations are nevertheless valuable because, by potentially reducing the need for other designers, they can give users a greater say both in the development of assistive technology, and, through this, in the role they wish to play in this process. Yet, as discussed below, not all disabled individuals can use these new design tools, and in order for these tools to support participatory design, we must strive to remove existing barriers to learning these technologies.

In this article I will explore both the benefits and the challenges of user-driven participatory design, specifically by considering

recent examples of it within the context of type 1 diabetes care. I begin with an overview of type 1 diabetes in order to establish the reasons why technology is often used in managing the disease. After then describing existing technology for regulating glucose levels, I examine two projects, #OpenAPS and Nightscout, that illustrate various aspects of user-driven participatory design and innovation. Finally, I draw on these two case studies to suggest ways that designers and agencies can lower the barriers to community access and increase user involvement in all stages of design.

Yet, while these case studies contain valuable lessons for future approaches to assistive technology, it is important to stress that these are just two among many potential models. Just as a one-size-fits-all approach to assistive devices must be discarded, so, too, must be a one-size-fits-all approach to the development of these devices.

Type 1 Diabetes: "A Data-Intensive Disease"

Type 1 diabetes presents itself when the body's immune system begins to attack the pancreatic cells that are responsible for producing insulin. There is currently no known way of preventing this attack, or of halting pancreatic damage once it begins to occur (Couzin-Frankel 2011, 819). In most individuals, the pancreas maintains a longevity-promoting equilibrium of glucose in the blood by releasing insulin in response to fluctuations in glucose levels. But for those with type 1 diabetes, the pancreas does not produce this insulin. To achieve homeostasis, those with type 1 diabetes must monitor their glucose levels through multiple daily blood tests and the administration of exogenous insulin. Achieving optimal blood glucose levels for long-term health is a delicate balance. Levels

that are too high can lead to significant long-term complications, including neuropathy and cardiovascular disease (Atkinson, Eisenbarth, and Michels 2014, 74), while levels that are too low can quickly turn fatal (Seaquist et al. 2013, 1386).

Since the discovery of insulin in the 1920s, it has been possible for a person with type 1 diabetes to regulate his or her blood glucose levels, but available management techniques have severe limitations (Atkinson, Eisenbarth, and Michels 2014, 72-73). For most individuals, the pancreas releases insulin based on fluctuations caused by food, exercise, and other factors, but a person with type 1 must make these adjustments using limited information and blunt tools. For many people with type 1, this means multiple daily finger blood tests to determine glucose levels, and multiple daily injections in response to these levels and other factors (Atkinson, Eisenbarth, and Michels 2014, 74). It is these constant measurements and adjustments that led one journalist to describe diabetes as a "data-intensive disease" (Swanson 2015).

Over the past thirty years, technological advancement has led to new options in terms of both insulin delivery and glucose testing. Insulin pumps offer the option of ongoing insulin delivery, and continuous glucose monitoring devices (CGMs) give their users access to real-time data on blood glucose levels. The former have, according to trials, enabled better management of the disease (Atkinson, Eisenbarth, and Michels 2014, 74). The latter have given those with type 1 unprecedented insight into glucose levels.

However, the strategies for diabetes management enabled by these two developments are expensive, and their efficacy is limited. Many people with diabetes are prevented from accessing these devices by geographical and financial barriers

(Clarke and Foster 2012, 91). Indeed, in many parts of the world, access to insulin itself is limited, rendering pumps and other assistive technology widely inaccessible (Gale 2006, 11). Moreover, although some glucose monitors have been created for those with visual impairments (Clarke and Foster 2012, 90), insulin pumps and CGMs continue to present accessibility problems to people with these and other impairments. Those who can access these devices can continue to face challenges with their diabetes management; typically, a person wearing both a CGM device and an insulin pump must mediate between the two, making manual insulin adjustments based on fluctuations in blood sugar. Children and others who cannot monitor their blood sugar levels and make these adjustments must rely on caregivers to monitor them directly, and this can limit independence.

Remarkably, technology has developed to the point that it is possible to produce a closed-loop pancreas system, which uses computer algorithms to make precise adjustments to insulin levels in response to blood sugar fluctuations (Atkinson, Eisenbarth, and Michels 2014, 74). To promote longevity, the system would make these adjustments continuously and automatically based on real-time blood glucose readings from a CGM. Eventually, these devices could incorporate heart rate monitors, sleep monitors, accelerometers and other devices, leading to even more refined control.

In recent years, medical researchers have taken steps toward this goal of an artificial pancreas. A pump that suspends insulin delivery in response to glucose levels is already on the market. Researchers have been testing prototypes for a fully-integrated artificial pancreas with significant success (Breton et al. 2012, 2236; Haidar et al. 2014). The JDRF, a charity aimed at reducing

the impact of type 1 diabetes, describes the artificial pancreas as "the most revolutionary development in diabetes care since the discovery of insulin" (JDRF 2015). However, even the most optimistic estimates acknowledge that it will be years before these devices will be available to consumers. One of the main reasons for this is the length of the FDA approval process. While this process is obviously important for ensuring the safety of a device, for those who live with the fear of potentially-fatal glucose levels and long-term complications, these delays can be frustrating. This extended wait for this new technology is a key motivator behind the user-driven developments in diabetes care discussed below.

In sum, while the technology for diabetes management has progressed significantly in the past few decades, with pumps offering ongoing insulin delivery and CGMs providing real-time access to glucose levels, these tools are nevertheless limited. Although an artificial pancreas which links these tools together has been developed which could offer significant benefits to people with type 1 diabetes, this technology is not yet available, and this has motivated several user-driven innovations.

The #OpenAPS and Nightscout Projects

One of these user-driven innovations is the Open Artificial Pancreas System (#OpenAPS) Project. The project is led by a group of independent researchers, united by the hashtag #wearenotwaiting, with the goal of producing a fully-automated artificial pancreas using already existing technology, including CGMs and insulin pumps. According to one of the lead developers, Dana Lewis, the project was started, in part, due to the long wait for the development of an FDA-approved artificial pancreas (Lewis 2015). The project is "founded on open-source

and open-science principles" (Lewis 2015), and therefore represents a challenge to traditional biomedical research models, in which technology is developed by a small team of experts exclusively.

According to its site, the project began almost two years ago when Dana Lewis and Scott Leibrand decided to try building a preliminary closed-loop pancreas system using existing FDA-approved technology and readily available parts (OpenAPS 2015). This initiative was termed the #DIYPS (Do-It-Yourself Pancreas System). Since the project began, a number of other developers have begun sharing their own DIY pancreas systems, and according to the #OpenAPS site there are now "up to a dozen independent researchers" running their own DIY systems (*ibid.*). The #OpenAPS project is aimed at bringing together these innovators to develop a blueprint for an FDA-approved, fully-automated artificial pancreas system (*ibid.*).

One of the key developments related to the #OpenAPS movement is the Nightscout project. This initiative was launched when John Costik, whose son has type 1 diabetes, discovered a way to transmit glucose levels over the internet using widely-available parts, a CGM, and a remotely-run app (Linebaugh 2014). Along with other innovators, Costik developed a system that allows a caregiver to monitor a child's glucose levels remotely, thereby giving more independence to children and others with type 1 diabetes who rely on caregivers. The developers made the blueprints and software for this system open access, allowing others to replicate it at a low cost (*ibid.*). Upgrades to this system are discussed and implemented by a community of developers using Github, a collaborative coding platform (Nightscout Contributors 2014). To participate directly in the development of the project, a person must be able to read

and write in several programming languages. However, users who do not know these languages can still have some impact on the development of the technology by making suggestions on Github (*ibid.*). The system has received a groundswell of support from the type 1 diabetes community. The Facebook Group dedicated to transmitting glucose monitor data remotely has grown rapidly in the past year, from 7000 members in October of 2014 (Leibrand 2014), to nearly double that in August of 2015. While most users are from North America and Europe, there are, according to the Nightscout site, users in every continent save Antarctica (Nightscout Project "Map" 2015).

The Nightscout project addresses many of the problems with traditional models of assistive device research. As already noted, assistive devices are often created at some remove from users, but the Nightscout project allows the individual with type 1 diabetes to have direct influence on the development process in a way that is self-determined. Although knowledge of multiple programming languages is required for a person to have a direct influence on the system, anyone with web access is able to make suggestions for the project. This means that the technology develops in direct response to the needs identified by those living with the disease. In addition, the Nightscout project emphasizes user agency by allowing many users to define the parameters of their involvement in the design process. This mitigates some of the problems with the predominant models of design for disability which, as already noted, can render a user dependent on designers or on their devices.

Rather than approaching design through the traditional aim of fixing an illness, the Nightscout development community has created technology that takes into account the multiplicity of

roles that assistive devices play in an individual's life. So, the developers of the Nightscout project have programmed aspirational messages into the remote app interface. For example, when a user achieves optimal glucose numbers, a smiley face appears on the interface with the words "happy dance!" Messages such as this one add an element of fun into diabetes management and the technology therefore eschews the traditional model of medical devices, which focuses almost exclusively on functionality. Moreover, the developers have created apps for a variety of different devices with the aim of meeting users' aesthetic preferences. By taking aesthetics into account, the project exemplifies one way of dealing with the challenge, identified by Blume, of making assistive technology reflect the multivalent range of meanings that these devices hold for their users (Blume 2012, 356-7).

The community has contributed not only to Nightscout's design, but also to its troubleshooting. In the "CGM in the Cloud" Facebook community, users receive technical support from peers. Like the technology itself, this support emerges in response to actual user needs, as opposed to the needs defined exclusively by the medical industry. Traditionally, troubleshooting for a device focuses on the mechanical aspects of it, but the troubleshooting that takes place in the Nightscout forum covers some of the non-technological challenges of living with a medical device, such as what to do when exercising, and how to work with schools to ensure that students have access to their devices.

Aside from the advantages of its user-driven participatory model, the Nightscout project also highlights some benefits of collaborative research more generally. Since its developers collaborate online, they can come from different parts of the

world. Thanks to this geographical diversity, developers bring to the project a wide range of skills and talents, since training and approaches to technological development vary significantly between regions. Developers also bring diverse experiences with diabetes technology, since many existing devices are limited to certain geographical areas. This means that developers can compare a wide range of existing technology to identify what works best.

While the principles of user-driven participatory design that lie behind Nightscout are admirable, it is worth noting some limitations to the project as it currently exists. Currently, not all roles in the development process are available to all users. As noted, those who wish to have direct influence over the development of the project must first develop some programming skills, and there are various barriers to learning these. While in theory all users can contribute to the project through less direct means, such as the "CGM in the Cloud" group or Github, it is important to keep in mind that online communities such as these remain inaccessible to some, as Katie Ellis and Mike Kent have argued (Ellis and Kent 2011, 1-11).

At this stage, both the #OpenAPS and the Nightscout projects are based on devices that can be difficult to use. As already noted, CGMs continue to present accessibility problems to people with visual and other impairments. Moreover, the CGM sensors that are key to the Nightscout project are not available in many countries. Even where these devices are available, they are, for many, prohibitively expensive, and some insurance plans do not cover them. The Nightscout community is generally sensitive to these financial and geographical problems, and there have been some steps taken to mitigate the costs of running the system. For example, the project requires a cloud

platform to run, and the Nightscout developers have provided instructions for ensuring that use of this platform remains free (Nightscout Project "Azure" 2015). Although users do not yet have equal access to, or control over, the design process of Nightscout, the project nevertheless represents a significant innovation in this respect, and it is valuable for highlighting many of the benefits of user-driven design.

Implications for User-Driven Participatory Design

The #OpenAPS and Nightscout projects provide insight into the current state of participatory design. They show how this kind of design can address some of the problems that scholars of design for disability have identified with traditional models of development. Where these traditional models approach design with the primary aim of correcting an impairment, user-driven models, such as Nightscout and #OpenAPS, can take into account more multivalent user goals. And where traditional models sometimes give the disabled community a sense of dependence on the medical industry by sidelining disabled users during the design process, participatory design models give users greater agency. This is illustrated by the Nightscout project. Moreover, in the case of the Nightscout project, the increasing democratization of programming skills has allowed for even greater possibilities for user control, as users now have more options in terms of how much they want to engage with the design process.

At the same time, the Nightscout project in particular has highlighted some of the roadblocks to further user- and community-driven developments. One of these is the lack of models for cooperation between governmental regulatory agencies and community developers. The Nightscout project has

largely developed independently of regulatory agencies, but this is obviously not ideal, as these agencies are crucial for providing arm's-length oversight. In the case of the Nightscout project, core developers have been working on establishing frameworks for evaluating the project's success and for ensuring its continued safety (Nightscout Contributors 2014). In addition, several core Nightscout developers have chosen to work with the FDA in establishing a set of best practices for user-driven innovations going forward (Leibrand 2014). The Nightscout project therefore underlines the need for agencies to establish guidelines and frameworks for community-driven assistive technology—ones that reinforce and supplement the checks put in place by independent design groups. In this way, agencies can support the role suggested by Vic Finkelstein in 1991, who argues that medical professionals should think of themselves as "a resource to be tapped by disabled clients, rather than as professionals trained to make highly specialised assessments of what is appropriate for individual disabled people" (Finkelstein 1991, 36).

In addition, while several of the users of the Nightscout project have the programming skills to have direct influence over the development of the project, many do not, and this disparity highlights another roadblock to user-directed participatory design for accommodation technology: that it requires technological skills that many lack. People with disabilities can face any number of barriers to becoming proficient in these skills. The Nightscout project should therefore prompt us to consider more ways of allowing users to direct their own involvement in design. More designers could create devices that emphasize customization and self-directed modification, as this would give people with disabilities greater control over their

devices. Going forward, research centers, grassroots organizations, and governmental agencies could make training in skills such as programming and engineering more accessible to those with disabilities; this would allow more people with disabilities to fruitfully gain control not only of their devices, but also of their roles in design.

#OpenAPS and Nightscout are suggestive of the new possibilities for user-driven design enabled by the greater accessibility of tools for technological development. These developments can be decentralized to an unprecedented degree and, concomitantly, can be made to respond more directly to the needs and interests of those with disabilities. While there are still barriers to this kind of participatory design for many, it is to be hoped that agencies, community groups and grassroots organizations will find ways of making these models of development more accessible going forward.

Acknowledgments

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About The Author

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