
CONFERENCE ABSTRACT

Warning: the Do-It-Yourself (DIY) wave will drastically change diabetes care!

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Introduction: Over the last few years, we have seen a rapid increase in patient-initiated activities, including software and hardware systems for diabetes self-management. Projects initiated by e.g. the Nightscout project, the *CGM in the Cloud* Facebook group (20.141 members, September 2016), have brought diabetes specific solutions to patients' doors. This is especially true for the demand to make use of continuous glucose monitors (CGM) more user-friendly for vulnerable patient groups. The authors urge the research society, as well as personnel and decision makers in health care, to be more aware of and open toward the opportunities this new situation brings.

Methods: This summary is based on the authors' active participation in relevant social media and long research experience within the chosen disease case. We also searched for information on PubMed.gov and Google.com, using keywords "do it yourself" and "diabetes".

Results: We observe that today's do-it-yourself trend for health is characterized by patients themselves building and sharing technologies and networks for self-management via social media, which are not available through the medical system. This is largely because there are few technological options that fit their or their family's precise needs, especially in the case of children with Type 1 diabetes or other health issues with a complex treatment regimen. So instead of operating several autonomous technologies, often requiring different service providers and systems, patients have built physical communication units for biological and medical sensors. By reverse-engineering or using known protocols of short- and long-range wireless communication systems, these patients can make the medical sensor units interoperable with the technologies that most people can access outside of healthcare, e.g. smartphones, tablets, smartwatches, servers and cloud solutions. In doing so, patients are able to access and share health information, mainly within families, thus making self-management and remote management easier. Some have even created tailor-made housing for the electronics using their own consumer-grade 3D-printers. We have tested and studied some of these relatively easy ways of creating user-friendly self-management tools and methods for diabetes. This includes using the smartwatch and smartphone interchangeably as a diabetes diary app, connecting these apps to continuous glucose monitors and other sensors, using color-changing light bulbs as

sensor value indicators, and integrating motivational elements like gaming, quizzes and social media. While these activities are highly visible on social media and the Internet in general – 547.000 hits for the keywords using Google search engine – there are hardly any results or discussions in the research literature, e.g. only 8 hits in PubMed. The trend does not stop with sharing tech designs. The patients in these communities have defined their own social media hashtag, #WeAreNotWaiting, to reinforce their statement of frustration as well as their declaration to take health matters into their own hands.

Discussion and Conclusion: Given the technical possibilities of building components, combined with the ease of sharing instructions and experience using social media, we see a future where patients have more and more influence over healthcare options in general. From the Norwegian part of the FI-STAR study, we experienced that while patients want to share their information with clinicians, the health care sector is not yet equipped or prepared. We suggest that relevant actors take advantage of all media outlets to invite patients and co-designers of future healthcare, in order to relate to this new situation and inform future decisions. Privacy and security are key issues for successful integration of private health data into clinical practice.

Keywords: #WeAreNotWaiting, mHealth, do-it-yourself, patient empowerment, diabetes
