

Real-World Use of Open Source Artificial Pancreas Systems

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Keywords

artificial pancreas, APS, OpenAPS, #WeAreNotWaiting, closed loop, DIY diabetes technology

Patient-designed and -driven research on hybrid closed loop was presented with outcomes on par with traditional closed loop studies at American Diabetes Association Scientific Sessions.

The #OpenAPS community (as of July 2016) consists of more than 100 individuals worldwide who self-built hybrid closed loop systems by pairing small computing hardware, open source software (OpenAPS), and existing diabetes devices (continuous glucose monitors [CGMs] and older insulin pumps). The community has used these systems in the real world for more than 250 000 hours at the time of this letter to the editor.

OpenAPS has been far safer than standard pump/CGM therapy, as measured by duration of hypoglycemia and hyperglycemia, with no reports of severe hypo- or hyperglycemic events. It has allowed patients and caregivers remarkable improvements in quality of life due to increased time in range, uninterrupted sleep, and peace of mind. OpenAPS users (18 respondents of the first 40 users, 67% male, 61% adults, median 27 years old, 15 years with diabetes, 10 years on pump, 3 years on CGM) were surveyed on quantitative and qualitative measures of their experience using their self-built artificial pancreas systems (APSs). While using OpenAPS, self-reported median HbA1c dropped from 7.1% to 6.2%, and median percent time in range (80–180 mg/dL) increased from 58% to 81%. All but one respondent reported some improvement in sleep quality, and 56% reported a large improvement. Users cautioned that APS cannot be considered a “technological cure,” but were extremely satisfied with the “life-changing” improvements associated with using an APS. These experiences are instructive for what patients can expect from commercial APS when they become available, and can help health care providers be prepared to set patients’ expectations properly.

There are limitations to this study, of course: outcomes are self-reported, each user’s self-built system may differ slightly, and patients who self-selected to spend time to build such a system may represent a more engaged subpopulation than average. The data shared above were presented by patients just a few feet away from traditional researchers presenting a device manufacturer’s pivotal hybrid closed-loop study results poster. Despite the study limitations and obvious differences in the size and type of trial, many physician attendees expressed

pleasant surprise at the comparability of results between the 2 systems.

The number of patients interested in directly improving diabetes technology is growing, and the scientific community should be challenging itself to find new ways to engage patients as researchers and designers, rather than solely as passive recipients of care. We challenge readers to find ways to engage patients in the design and at every stage of your research and product development, including in immediate sharing of results from research, and encouraging submission of patient-designed research to journals and for presentation at academic and scientific conferences. The patient community has valuable insight, data, and experiences that can help everyone (device manufacturers, health care providers, and patients) to build better tools to better manage life with diabetes.

Abbreviations

AP, artificial pancreas; APS, artificial pancreas system; CGM, continuous glucose monitor; OpenAPS, open source artificial pancreas system.

Acknowledgments

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