Patient & Stakeholder Engagement in Digital Health

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BIH QUEST Seminar
Digital Clinician Scientist & Doctor/Patient Hybrid

**Clinician**

Pediatrician & Diabetologist
Doctor/patient hybrid
Head of Medical, #dedoc°

**Scientist**

Diabetes Technology
Open-Source & Patient-Led Innovation
Habilitation in Medical Informatics
Visiting scholar, Stanford University & Steno Diabetes Center Copenhagen
Research group co-lead
Digital Transformation & Apps
Falling Walls Female Science Talents
Intensive Track 2022
Digital Clinician Scientist & Doctor/Patient Hybrid

Person with Diabetes

Lived experience for 20+ years

Welcome to Type 1 Diabetes...

Where everyday of your life is a science experiment
Patient & Stakeholder Engagement Projects

The OPEN project
Outcomes of Patients’ Evidence with Novel, Do-it-Yourself Artificial Pancreas Technology

Patient Think Tank
Stakeholder engagement of patients in Medicine on all levels

funded by

funded by
The OPEN project

- EU & BIH-funded
- Patient-led: by, with and for people with type 1 diabetes
- Interdisciplinary
- International
- All data = open data
- All outcomes = open source
We already have all we need to build an AP. Let’s close the loop!

I know how to remote-control insulin pumps!

We know how to get sensor data in a cloud!
Components of an Open-Source Automated Insulin Delivery System

- Continuous glucose monitoring sensor
- Smartphone app
- Communication device
- Insulin pump

GitHub

BIH Academy
“If I could give my pancreas to my son, I would. This is the next best available option.”

Parents of a 12-year-old boy, UK, using OpenAPS

Braune et al. 2022, Journal of Medical Internet Research.
What are we doing at OPEN?

Translating experience-based evidence from the patient community to academia and industry – and vice versa.

Why DIY?  
Clinical outcomes  
Lived experiences  
Barriers to scale  
Guidance for HCPs

What can academia, industry and people with diabetes learn from each other?

How can we improve representation of patients as stakeholders in research, device development and policymaking?
Milestones & highlights

- Enrolled >1500 people with diabetes (aged 2 to 80+ years) in our studies
- >40 invited talks
- 2 keynotes
- 3 conference chairs
- 2 satellite symposia at conferences
- 15 oral presentations, proceedings & posters
- 10 peer-reviewed articles (4 more under review)
- 1 invited commentary for The Lancet (in press)
- International consensus statement & clinical guidance
  - 48 co-authors from 25 countries
  - Endorsed by professional organizations
  - Published in 100 Years of Insulin Special Issue, The Lancet Diabetes & Endocrinology
  - Featured in “Paper of the Year”, American Diabetes Association
- BIH QUEST Award for Patient & Stakeholder Engagement
- Audience Award, Digitaler Gesundheitspreis

... many more to come! 😊
Patient Think Tank: #NothingAboutUsWithoutUs

Meanwhile, at today's meeting on feline healthcare...
Patient Think Tank: #NothingAboutUsWithoutUs

- Healthcare
- Academic teaching
- Product development
- Policymaking
- Science
believes in the value diabetes advocates bring to scientific congresses. This is why we have created the #dedoc° voices scholarship program.

The #dedoc° voices scholarship program grants diabetes advocates access to some of the world’s most renowned scientific conferences. It ensures the presence of the voice of people with diabetes, empowers a new generation of advocates and provides a dedicated platform for people with diabetes, healthcare providers and industry leaders to meet and exchange.
“Virtual fireside chats” instead of “bedside teaching”

- People with diabetes as co-lecturers in medical school
- Area of concern: language and stigma in communication

Lea Raak  
Blogger  
MSc in Gender & Disability Studies

Katharina Tugend  
Communication Scientist in Healthcare

Antje Thiel  
Freelance Journalist

Saskia Wolf  
Lawyer
“Virtual fireside chats” instead of “bedside teaching”

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Insulin therapy in poorly controlled type 2 diabetic patients: does it affect quality of life?

Background: Strict glycaemic control in type 2 diabetic patients is recommended in a number of treatment protocols. However, although better glycaemic control prevents or postpones chronic diabetic complications, it remains uncertain how this affects quality of life in the short and long term.

Aim: To study the impact of insulin therapy on glycaemic control and quality of life in type 2 diabetic subjects, with secondary failure on maximal oral medication.

Design of study: Two separate sets of analyses were performed: a longitudinal analysis of those patients converted to insulin therapy and a comparison of 12-week outcomes between the two randomisation groups.

Setting: Ten general practices, participating in the Nijmegen Monitoring Project.

Method: Patients, poorly controlled on maximal oral therapy, were stratified with respect to age and sex, and randomly allocated to insulin therapy in two different schedules: (a) after a 12-week period with enhanced compliance to diet and oral therapy; or (b) as soon as secondary failure was established. Patients were referred to a diabetologist to start insulin therapy and were referred back to their general practitioner (GP) as soon as glycaemic control was stable. We assessed fasting blood glucose, HbA1c functional health, and quality of life (Sickness Impact Profile, COOP/WONCA charts, Diabetes Symptom Checklist) at baseline, after the patient was referred back to the GP, and nine months later.

Results: Of the 38 included patients, three patients dropped out and seven patients were not switched over to insulin therapy. In patients starting insulin therapy, mean HbA1c and fasting blood glucose level decreased from 9.5% to 7.6%, and from 12.0 mmol to 6.4 mmol, respectively (P < 0.001). The better control was accompanied by a decrease in hyperglycaemic complaints (P = 0.01). No increase in hypoglycaemic complaints was found. There were no statistically significant changes in quality-of-life parameters. After 12 weeks, patients directly referred to insulin therapy showed a statistically significant improvement in HbA1c and fasting glucose level, in contrast to patients with enhanced compliance. Quality-of-life scores did not significantly differ statistically.

Conclusion: Insulin therapy in poorly controlled type 2 diabetic patients from general practice resulted in a significant clinical improvement of glycaemic control, accompanied by a reduction of hyperglycaemic complaints, without an increase in hypoglycaemic complaints or an adverse influence on quality of life.
Language matters: A new language for diabetes

- diabetic, sufferer, patient
- subject
- normal, healthy people
- poorly controlled
- failed

- person (living) with diabetes
- participant
- people without diabetes
- optimal outcomes, within range
- did not, has not, is not ...
Language Matters Diabetes has slowly evolved into a global movement that discusses the language we use when dealing with different types of diabetes. These guides provide practical examples of language that will encourage positive interactions with people living with diabetes and subsequently positive outcomes.
Thank you!

“It is not about a seat at the table. This IS the table.”

Tom Robinson
VP of Global Access, JDRF

#NothingAboutUsWithoutUs
#WeAreNotWaiting
#LanguageMatters

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