

Patient & Stakeholder Engagement in Digital Health

Katarina Braune, MD, T1D
BIH QUEST Seminar



Digital Clinician Scientist & Doctor/Patient Hybrid



Clinician

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

Scientist

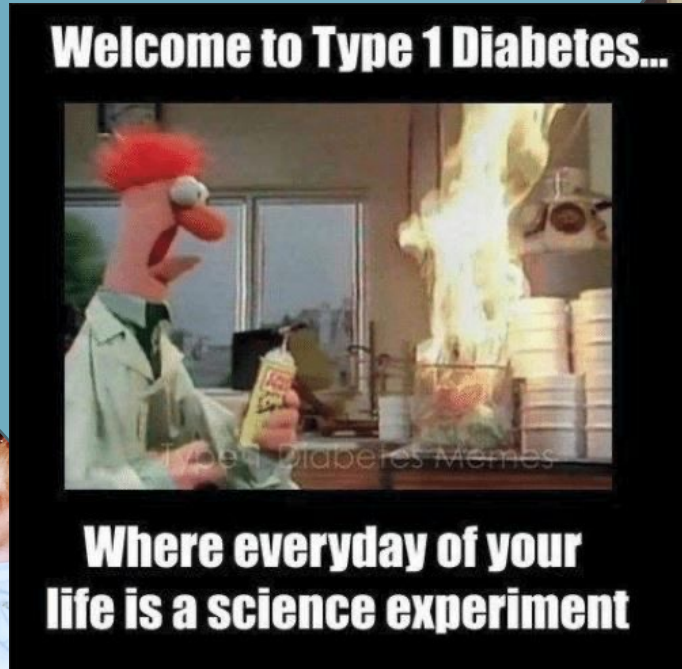
Diabetes Technology
Open-Source & Patient-Led Innovation
Habilitation in Medical Informatics
Visiting scholar, Stanford University &
Steno Diabetes Center Copenhagen
Research group co-lead
Digital Transformation & Apps
Falling Walls Female Science Talents
Intensive Track 2022



Digital Clinician Scientist & Doctor/Patient Hybrid

Person with Diabetes

Lived experience
for 20+ years



Patient & Stakeholder Engagement Projects



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

funded by



European
Commission

Horizon 2020
European Union funding
for Research & Innovation

BIH Berlin Institute
of Health
Charité & MDC

BIH CHARITÉ
CLINICIAN SCIENTIST
PROGRAM



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

funded by

BIH QUEST
Transforming Biomedical Research

BIH Academy
Biomedical Innovation Academy

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

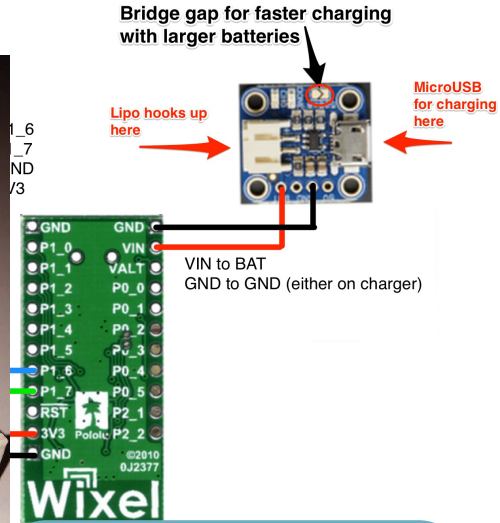


UNIVERSITY OF COPENHAGEN



KING'S
College
LONDON

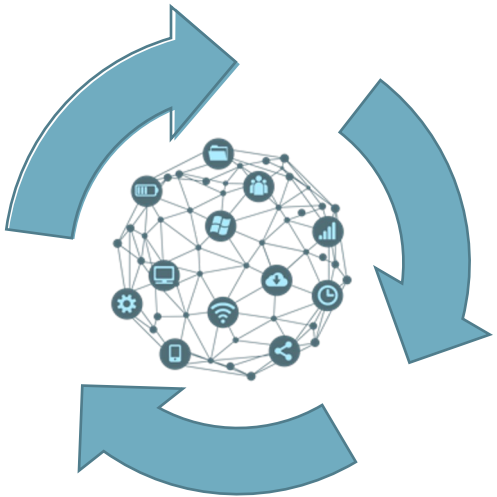
BIH Academy
Biomedical Innovation Academy



We know how to get sensor data in a cloud!



I know how to remote-control insulin pumps!



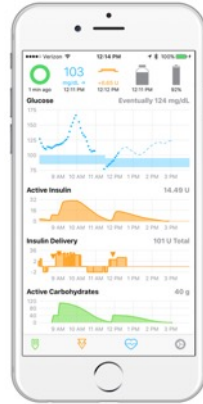
We already have all we need to build an AP. Let's close the loop!



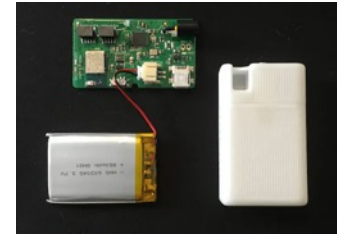
Components of an Open-Source Automated Insulin Delivery System



Continuous glucose monitoring sensor



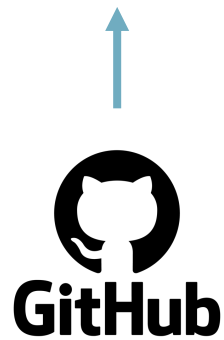
Smartphone app



Communication device



Insulin pump



**“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



What are we doing at OPEN?



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



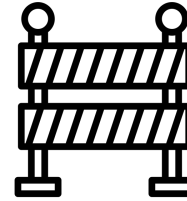
**Why
DIY?**



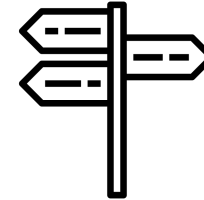
**Clinical
outcomes**



**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! 😊

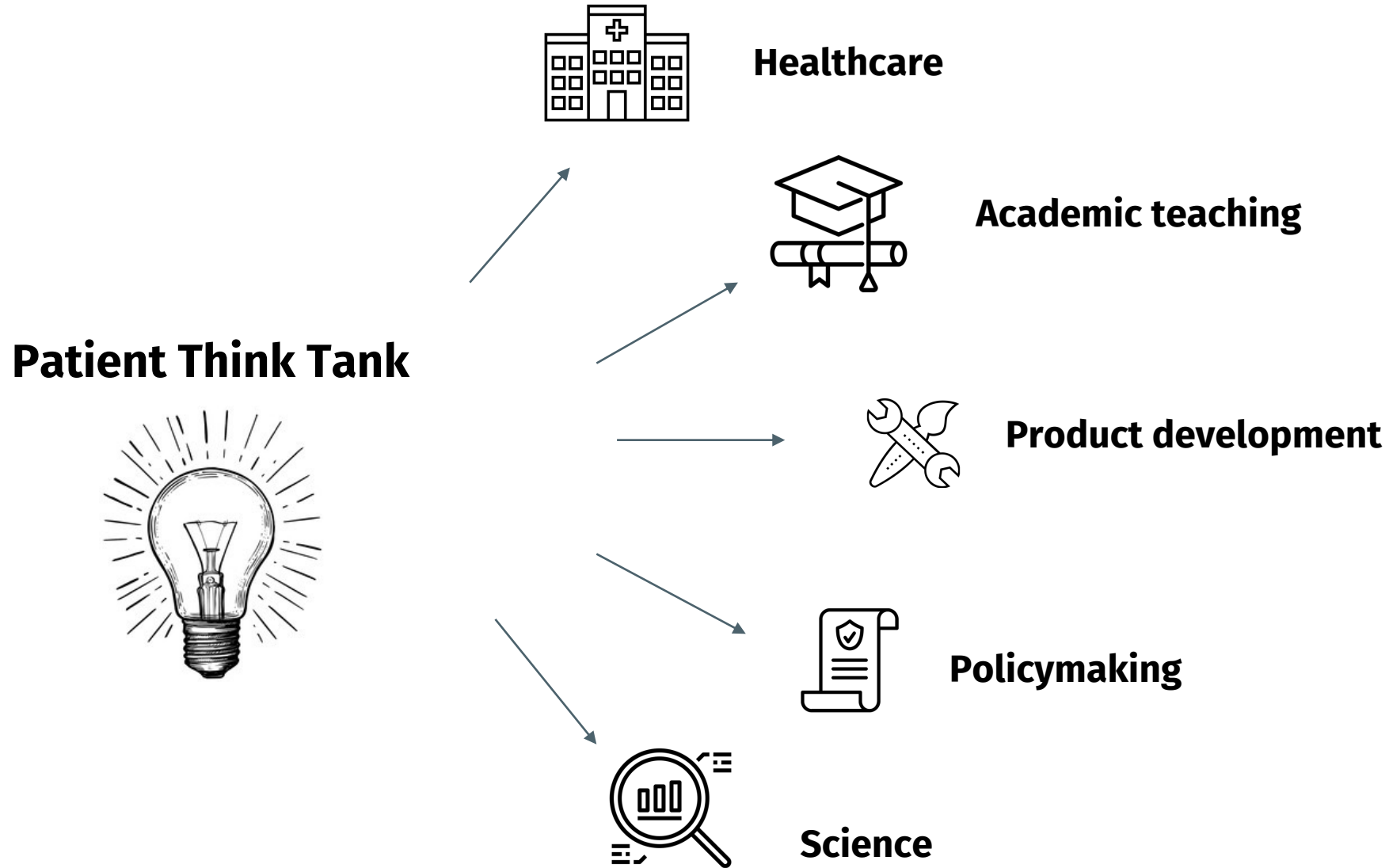


Patient Think Tank: #NothingAboutUsWithoutUs

Meanwhile, at today's meeting on feline healthcare...



Patient Think Tank: #NothingAboutUsWithoutUs





dedoc believes in the value diabetes advocates bring to scientific congresses. This is why we have created the #dedoc^o voices scholarship program.

The #dedoc^o 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”

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

← Tweet

 **Doc Frauke**
@DocFrauke

Der Diabetespatient, der schwer einzustellen ist und wieder einmal wegen seiner abgedreht hohen Zuckewerte zur Beratung einbestellt wurde, nimmt im Sprechzimmer Platz. Die ihn begleitende Literflasche Cola stellt er unbekümmert auf den Tisch. 😞

8:30 vorm. · 18. März 2021 · Twitter for Android

4 Retweets 2 Zitierte Tweets 278 „Gefällt mir“-Angaben

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 8.4 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: a German position statement paper



Language Matters Diabetes

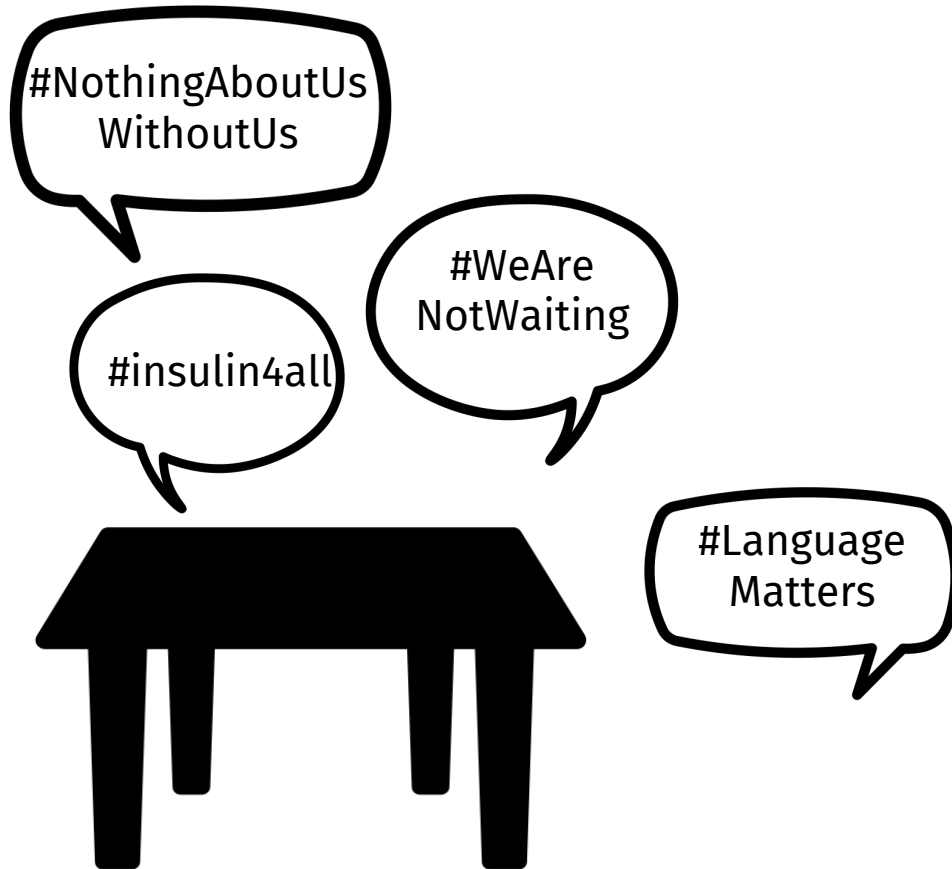
Language Matters Diabetes has slowly evolved into a global movement that discusses the language we use when dealing with different types of diabetes. These guides provide practical examples of language that will encourage positive interactions with people living with diabetes and subsequently positive outcomes.



Thank you!

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

*Tom Robinson
VP of Global Access, JDRF*



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