

# Training for patients and public contributors in clinical trial methodology

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EUPATI Sweden



# Who we are



**EUPATI Sweden** is an independent, non-profit association with a vision to drive positive change in health innovation by increasing meaningful patient partnership.

- We offer **training for patients**
- We offer **training for professionals**
- We are a **neutral platform** for collaboration between patients, industry, academia and the public sector



# Our members

abbvie



Funktionsrätt  
Sverige



sanofi

SÄLLSYNTA  
DIAGNOSER  
RARE DISEASES SWEDEN

Apotekarsocieteten  
Vi gör Sverige kunnigare om läkemedel



Reumatiker  
förbundet



AstraZeneca



Svenska  
Covidföreningen



BARNCANCER  
FONDEN



Johnson & Johnson  
Innovative Medicine



Svenska  
Diabetesförbundet



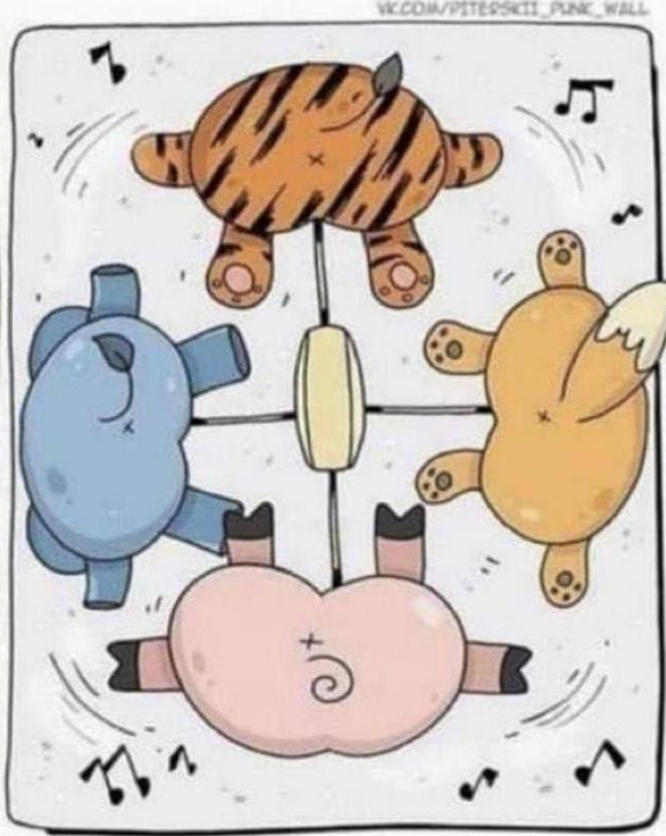
SWEDISH  
Medtech

Vetenskap & Allmänhet  
PUBLIC & SCIENCE SWEDEN

# Clients



# Users



# How patient involvement increases efficiency



New research questions



Faster recruitment



Endpoints relevant to patients



Protocols with fewer drop-outs

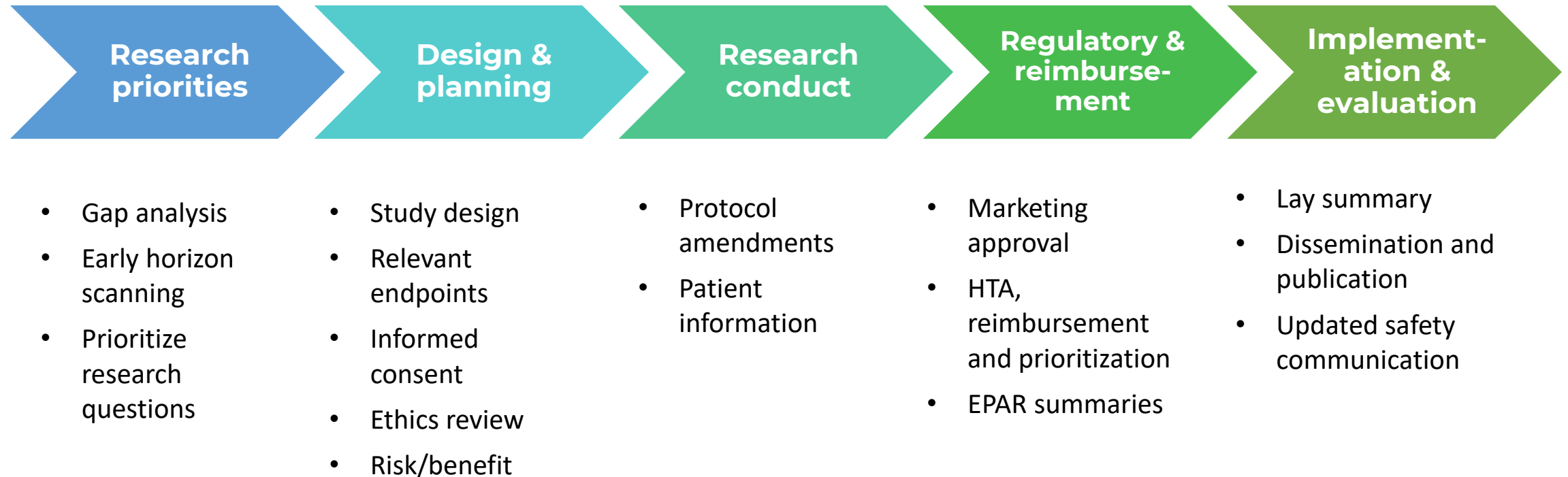


Increased trust and accessibility



Opens doors for financing

# Patient involvement along the research process



# Patient involvement – example



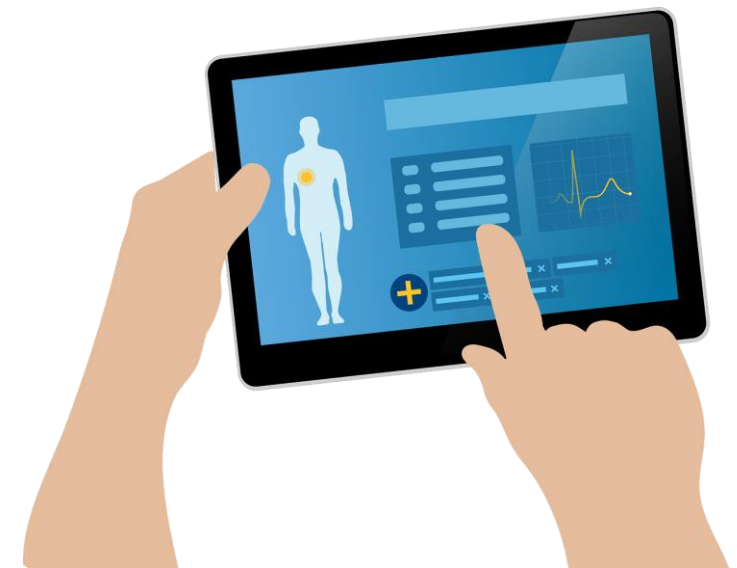
**Study:** Clinical trial for ADHD and substance abuse

**Action:** Research team contacted a national patient organisation for input

**Patient feedback:** Too many and too long self-assessments and instruments

**Result:** Research team removed several self-assessments thereby shortening clinical visits

”It was so obvious as soon as they said it. Why hadn’t we realized it sooner?”



# Patient stages and the role of training



Patient's stage	Accessible for research through
1. Newly diagnosed, recent authentic experience	Interview, focus group, survey
2. Has lived with chronic condition for several years. Has insights related to their condition, moving beyond their immediate, lived experience	Patient story at conference or in education
3. Has begun to connect their personal story with the broader experiences of other patients, recognizing common themes and patterns within a community	Representing a group; providing advice
4. Is (becoming) an equal partner in the research process, contributing their unique knowledge and experiences to research teams to improve the lives of others	Patient partner, bridge between researchers and patients: open to collaboration as equal partner

# EUPATI Sweden's patient training



- Digital platform – films, links, quiz
- Free and open to everyone
- Diagnosis agnostic
- Co-created with patients, researchers, industry and authorities – including UU!
- Over 160 trained so far

## What can patients learn?

- Medicines and medtech R&D
- Precision medicine
- Regulatory affairs and HTA
- Ethical frameworks of partnership
- Practical examples
- National authorities and their roles

Having a specialist training gives me a sense of legitimacy

# EUPATI Sweden's training for research groups



## Introductory training for research groups

- The what, why and how of patient involvement
- Involving patients along the entire process
- Roles and methods
- Creating conditions for meaningful involvement
- Case discussions, good examples
- Planning the team's involvement and next steps

For research teams in Region Stockholm-Gotland



# Tensions we might meet along the way



## On the one hand

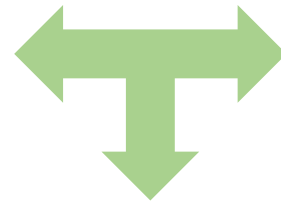
Wanting clarity

Needing efficiency

Showing impact

Treating health as biological

Researcher as expert



## On the other hand

Living with ambiguity

Making time for relationships

Acknowledging invisible labor

Understanding health as relational and contextual

Knowledge emerging through shared inquiry



# Thank you!

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