Extending Third Wave: Co-design and Participatory Design

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Slide credit: Ben Langston, Nicola Plant, Roisin McNaney

HCI Theory

Third Wave: Action Research

“Action Research (AR) is a class of methods and approaches for conducting democratic and collaborative research with community partners. AR has evolved over the last several decades and offers HCI researchers theoretical lenses, methodological approaches, and pragmatic guidance for conducting socially relevant, collaborative, and engaged research.”

Gillian Hayes, 2012

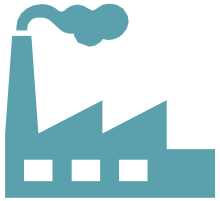
Action Research is one such socially responsible approach that is being promoted in HCI. It provides methods and approaches for conducting democratic and collaborative research with members of a community (Hayes, 2011). In particular, it offers theoretical lenses, methodological approaches, and pragmatic guidance for conducting socially relevant, collaborative and engaged research (Stringer, 2007). Where it differs from previous participatory design approaches, is that while primarily seeking to help with practical concerns, it also aspires to scientific rigor and the promotion of sustainable social change. To achieve these three goals, a cyclical methodology is followed, with an emphasis on problem formulation, intervention design, deployment (i.e., "action"), observation of the effects of the action, reflection and then redefinition of the problem. A further distinction is to come up with a solution that improves on previous ones and which helps all those engaged in the project learn through the actions they take.

Yvonne Rogers
May 2012

What are Participatory and Co-design approaches?

- Design approaches that are defined by the level of **involvement** and **engagement** from stakeholders
- Put users and the **core** of the design process: **involving end users** at multiple points- from idea formulation to evaluation
- Approach puts users on an **equal footing** with designers to develop artefacts or systems that they will use **themselves** (Shuler and Namioka, 1993)

Origins of Participatory Design



Movement that started in the 60's and 70's in Scandinavia

Gained popularity at this time when computerised versions of previously manual industrial processes or environments were being designed.

Promoted democratic engagement of those involved with the operation of the manual versions.

Emphasied cooperative and collaborative methods

Revolutionary approach truly bottom-up grassroots design process.

Empowered users to decide what is best for them.

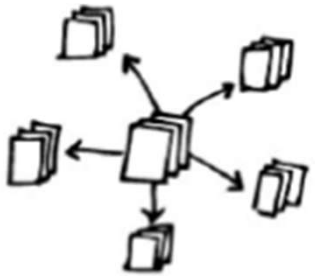
What is Co-design?

- Working **collectively** with stakeholders to design a system
- Users are seen to bring **skills** and **expertise** that a designer doesn't have but are required for the design of the system (e.g. knowledge of social structures within a community)
- "Co-designing threatens the existing power structures by requiring that control be relinquished and be given to potential customers, consumers or end-users." (Sanders & Stappers, 2008)

Is there a difference?

- Co-design and Participatory Design are terms often used interchangeably
- Both work with stakeholders to focus on gathering a range of experiences and needs
- Both emphasize a collaborative process to empower users

What is codesigned?



Systems

Products

Services

Spaces

Beware

Don’t claim you are doing co-design unless you are *actually* doing co-design

Why should we Co-Design?

Codesigning ML to Support Type1 Diabetes Care




Personal Benefits

Data

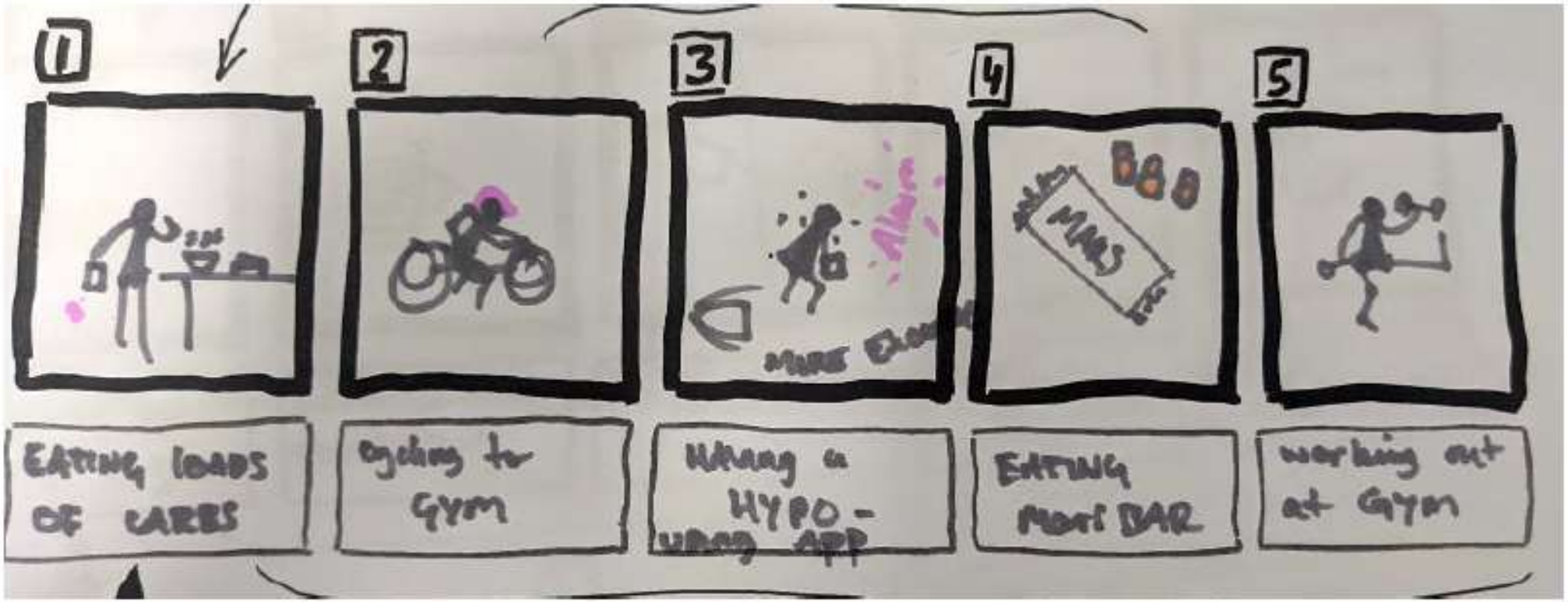
Data

Machine Learning Pipeline

Data

T1D Community Benefits

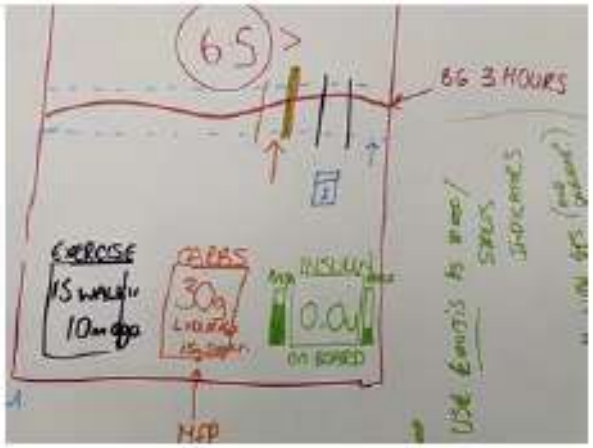
Where Could ML for Diabetes Help?

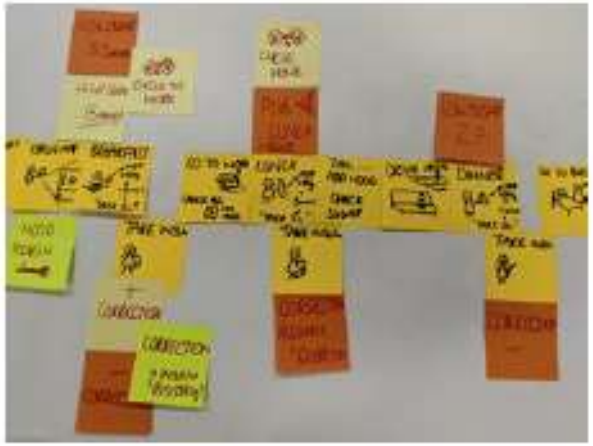


A. Ayobi, K. Stawarz, D. Katz, P. Marshall, T. Yamagata, R. Santos-Rodriguez, P. Flach and A.A. O'Kane. **Machine Learning Explanations as Boundary Objects: How AI Researchers Explain and Non-Experts Perceive Machine Learning**, IUI Explainable AI 2021

Workshop	Type	Attendees	Details
W1	Evening workshop, 2 h	7 attendees	**Theme:** Identifying meaningful factors that influence diabetes. **Discussion topics:** Current use of technology for supporting diabetes self-management, related challenges, participants' data needs. **Activities:** Group discussions, brainstorming. **Outputs:** List of factors that influence participants' self-management, sketches of an app for tracking them (see Fig. 1).
W2	Evening workshop, 2 h	8 attendees 6 phone interviews[a]	**Theme:** Impact of technology on diabetes management. **Discussion topics:** Using technology to support self-management, automated tracking and trade-offs of data capture. **Activities:** Group discussions, identifying situations where tracking is or is not useful, commenting on hypothetical scenarios. **Outputs:** A list of situations that would benefit from decision-support, types of data that could be shared.
W3	Weekend workshop, 4 h	10 attendees	**Theme:** Designing a personalised decision support app. **Discussion topics:** Ideal functionality, trustworthiness of recommendations provided by diabetes apps. **Activities:** Creating usage scenarios, designing an "ideal diabetes app", group discussions. **Outputs:** Sketches, storyboards, list of requirements for a diabetes decision support app.
W4	Evening workshop, 2 h	3 attendees 3 phone interviews[a]	**Theme:** Understanding the decision-making process. **Discussion topics:** Everyday decisions, understanding and visualising tracked data. **Activities:** Discussing diabetes decisions in hypothetical scenarios, commenting on visualisations of data collected by participants. **Outputs:** List of general "diabetes rules" to help deal with common situations.
W5	Evening workshop, 2 h	10 attendees 1 phone interview[a]	**Theme:** Exploring diabetes rules, routine/non-routine situations. **Discussion topics:** Diabetes management rules, non-routine situations, what if something goes wrong or routines change. **Activities:** Reviewing the list of diabetes rules created in W4, presentation on machine learning, translating diabetes rules into specific app features. **Outputs:** List of desirable features for decision-support systems.
W6	Weekend workshop, 4 h	7 attendees	**Theme:** Understanding the role of context and tracking non-routine situations. **Discussion topics:** Dealing with non-routine situations, identifying functionality that could support decision-making in such situations. **Activities:** Group discussions, brainstorming, sketching. **Outputs:** Requirements for an app that supports non-routine situations.

Initial Focus on Everyday ML4Diabetes

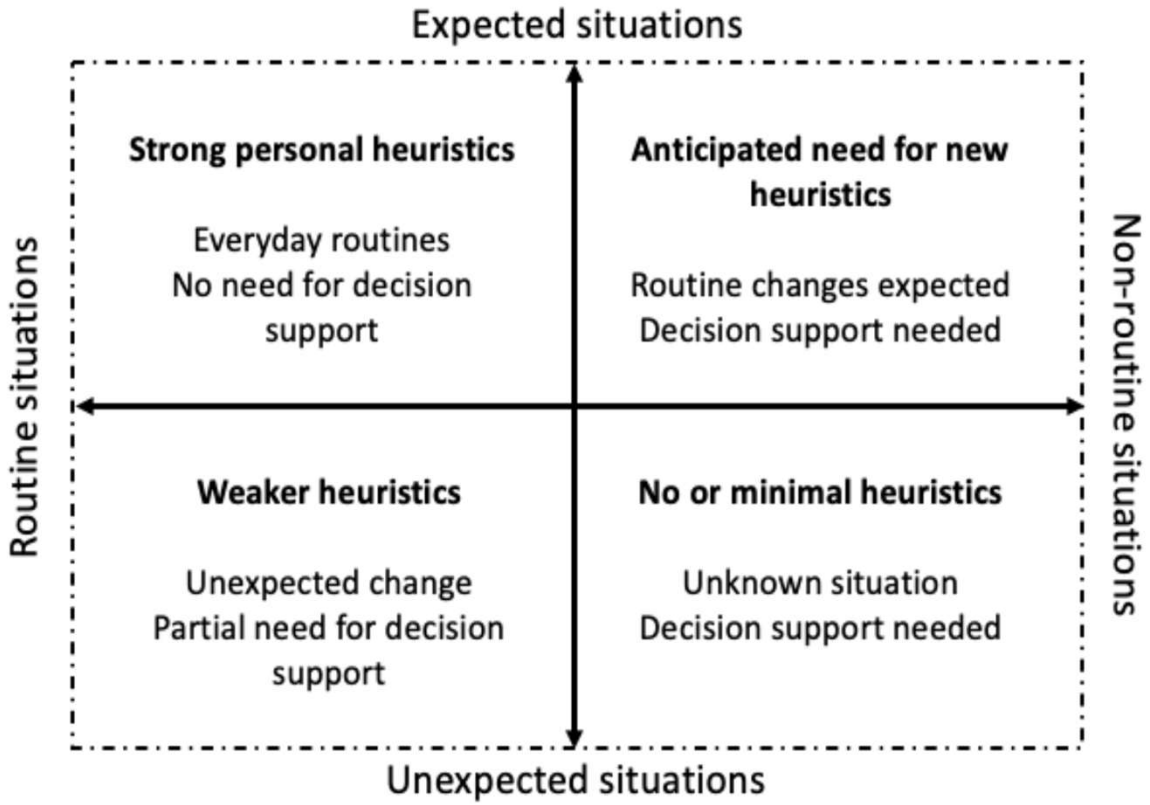




Left and upper-right: examples of interface designs showing key factors participants would like to track.

Lower-right: a story board presenting a typical day of a person with Type 1 diabetes.

Expert Systems For Unexpected, Non-Routines



K. Stawarz, A. Ayobi, D. Katz, P. Marshall, T. Yamagata, R. Santos-Rodriguez, P. Flach and A.A. O'Kane. **Co-Designing Opportunities for Human-Centred Machine Learning in Supporting Type 1 Diabetes Decision-Making**, IJHCS 2023

Towards Co-Designing ML for Diabetes

Co-design: end users are equal members of a design team

Challenges between stakeholders co-designing ML for diabetes

- Organizational issues to **directly feed into design process**
- Translational issues for **different backgrounds of co-designers**
- Pragmatic design challenges around **collecting manual logged data before the benefit can be realized**

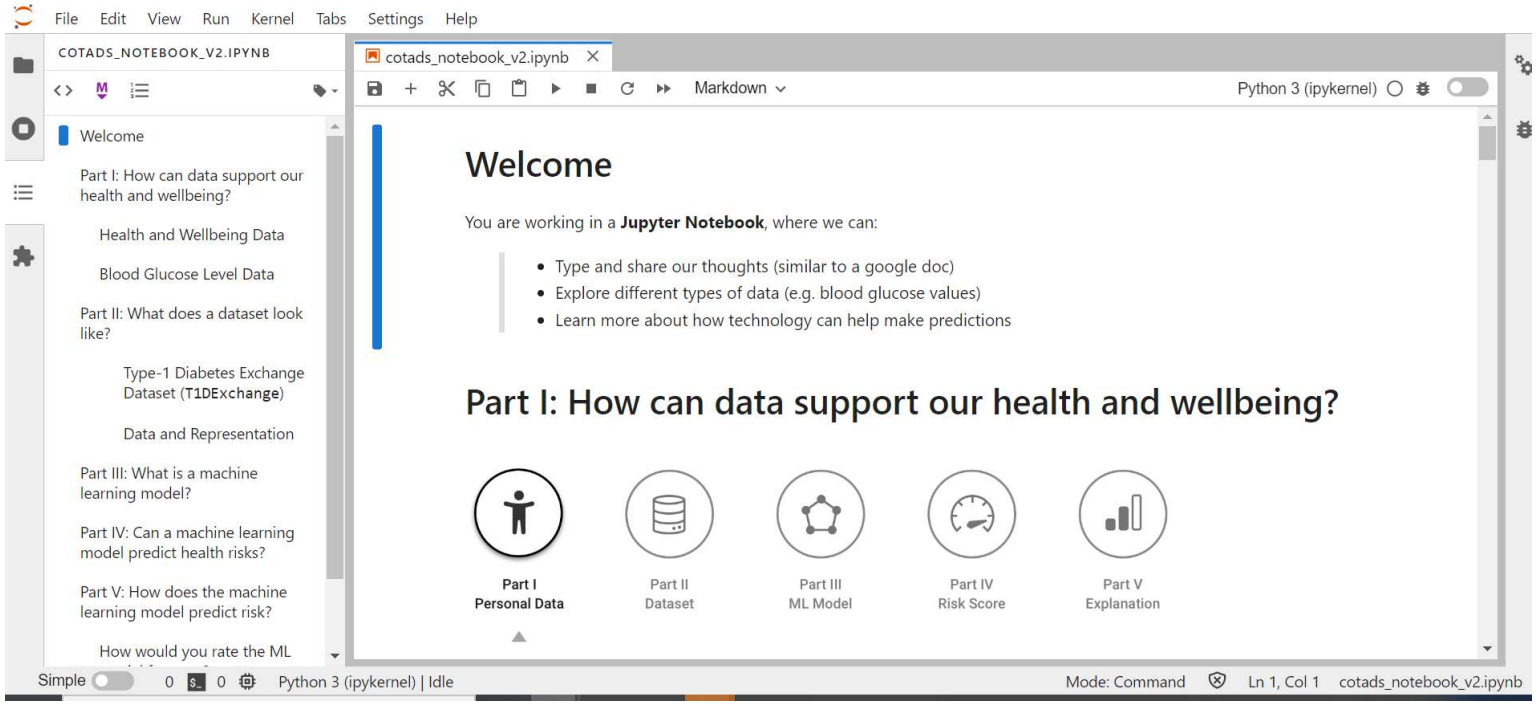
Prioritize **mutual learning**, benefit of participation

Need to align **lived self-care experience with scientific ML explanations**

A. Ayobi, K. Stawarz, D. Katz, P. Marshall, T. Yamagata, R. Santos-Rodriguez, P. Flach and A.A. O'Kane. **Co-Designing Personal Health? Multidisciplinary Benefits and Challenges in Informing Diabetes Self-Care Technologies.** CSCW 2021

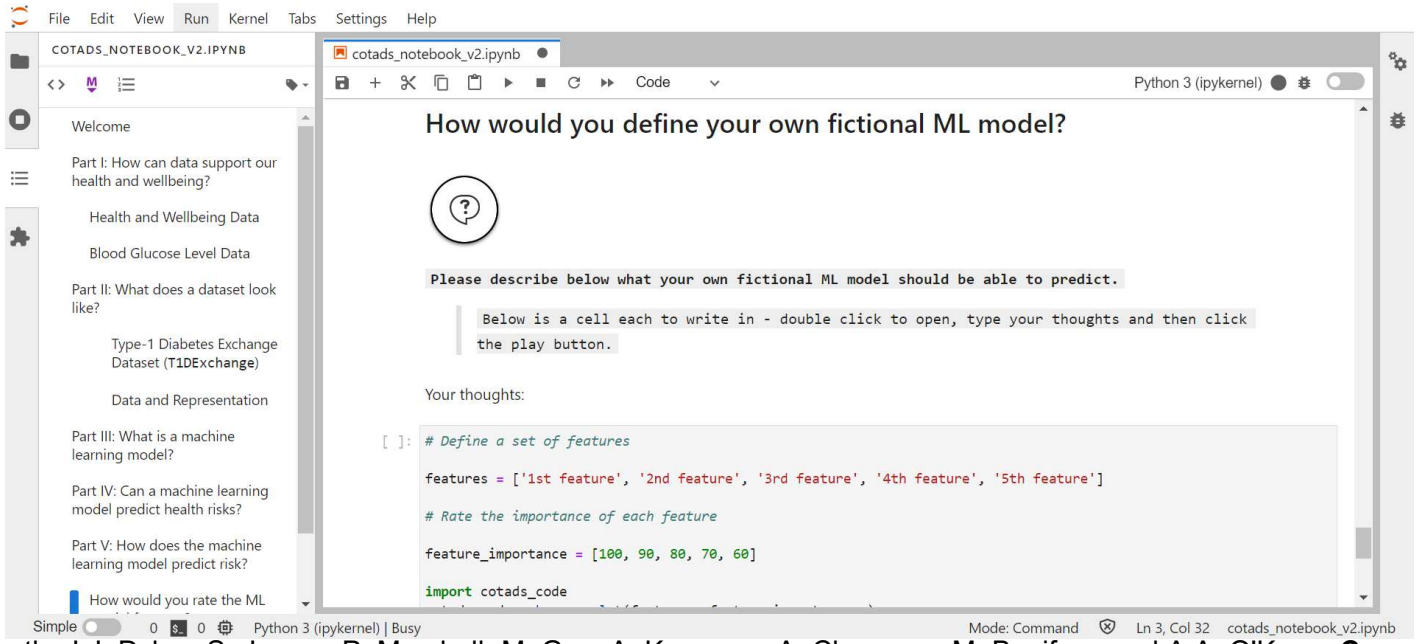
Computational Notebooks for Clinical T1D Risk

- User centred design with clinicians and carers for **ML-enhanced risk** score based on publicly available data set from US



Co-Designing ML for Clinical Diabetes Risk

- Powerful tool for **starting and directing discussion**, supporting individual ideas and collective co-design, and addressing stigma
- Still technical, but supported **learning of ML concepts and coding**



A. Ayobi, J. Hughes, C.J. Duckworth, J.J. Dylag, S. James, P. Marshall, M. Guy, A. Kumaran, A. Chapman, M. Boniface and A.A. O'Kane. **Computational Notebooks as Co-Design Tools: Engaging Young Adults Living with Diabetes, Family Carers, and Clinicians with Machine Learning Models.** CHI 2023

Towards Co-Designing Care Smarthomes

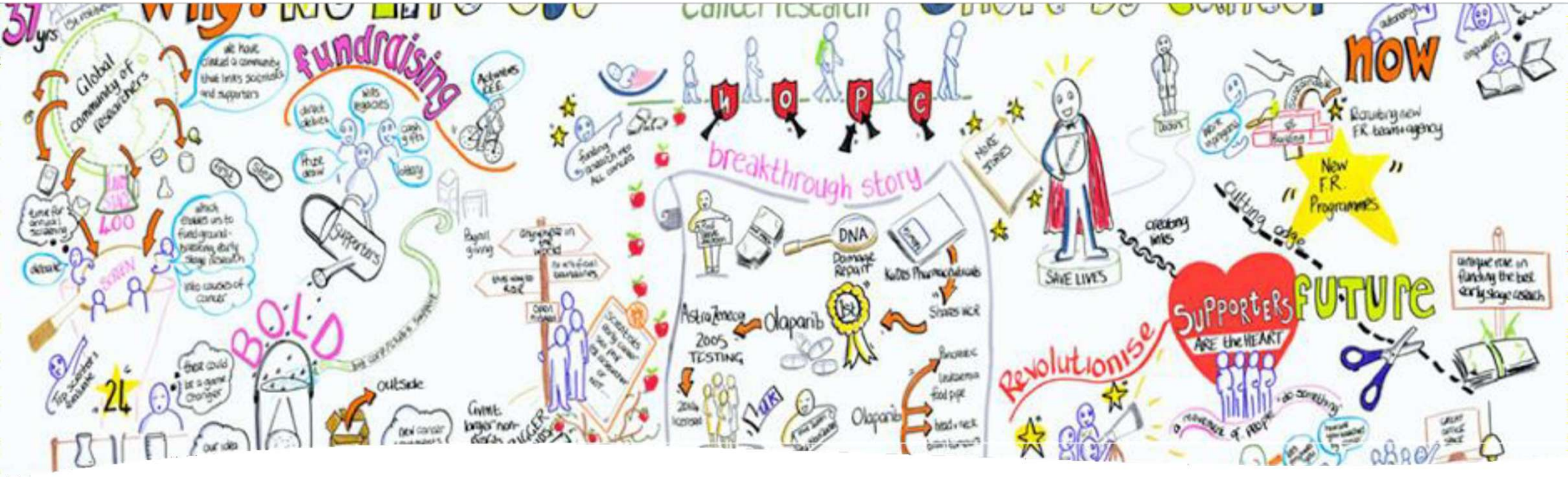
- **Complex smart home** technology, like the SPHERE house, has sensors, data fusion, machine learning, computer vision…
- User centred approach **BEFORE co-design to create companion book**

R. Eardley, S.W. Mackinnon, E. Tonkin, E. Soubutts, A. Ayobi, J. Linington, Z. Banks Gross, G. Tourte, D.J. Bailey, R. Knights, R. Gooberman-Hill, I. Craddock, A.A. O'Kane "A user centred and expert informed design process to explain complex IoT Machine Learning Platforms" **IMWUT 2022**

BREAST CANCER NOW The research & care charity

Case Study 1:

- Work conducted by Ben Langston
- Working with breast cancer patients to understand their experiences and support needs post-treatment
- Focus was on driving change in post treatment support through participatory design
- Worked with them for just over 2 years including engagement, co-design workshops, service delivery and refinement
- Developed a community based psychosocial service to support women after their treatment had ended



Phase 1: Discovering & conceptualising

- Session 1: Explored participant experiences of the support (or non-support) they had received after their treatment ended
- Session 2: Was about confirming understanding of what people had described and building personal stories
- Session 3: Used personal stories and art as prompts for developing concepts for how post-treatment support could be imagined

Phase 2: Refining ideas and co-production

- Session 4: Working in groups to refine concepts/ ideas into something tangible and feasible
- Session 5: Making decisions collectively on the structure and content of a pilot community support service
- Session 6: Building on session 5 to finalise pilot content and structure, as well as reaching out to other stakeholders

Phase 3: Delivery and learning

- Session 7: Focused training with volunteers.
- Piloting: The service was piloted in 4 locations in South London over a 6-month period. Included post delivery de-briefing with volunteers.
- Session 8: Post-pilot learning session with people who attended, to make recommendations for changes to the content
- Showcase: presenting the findings from the PD process and pilot service.

Why a participatory approach?

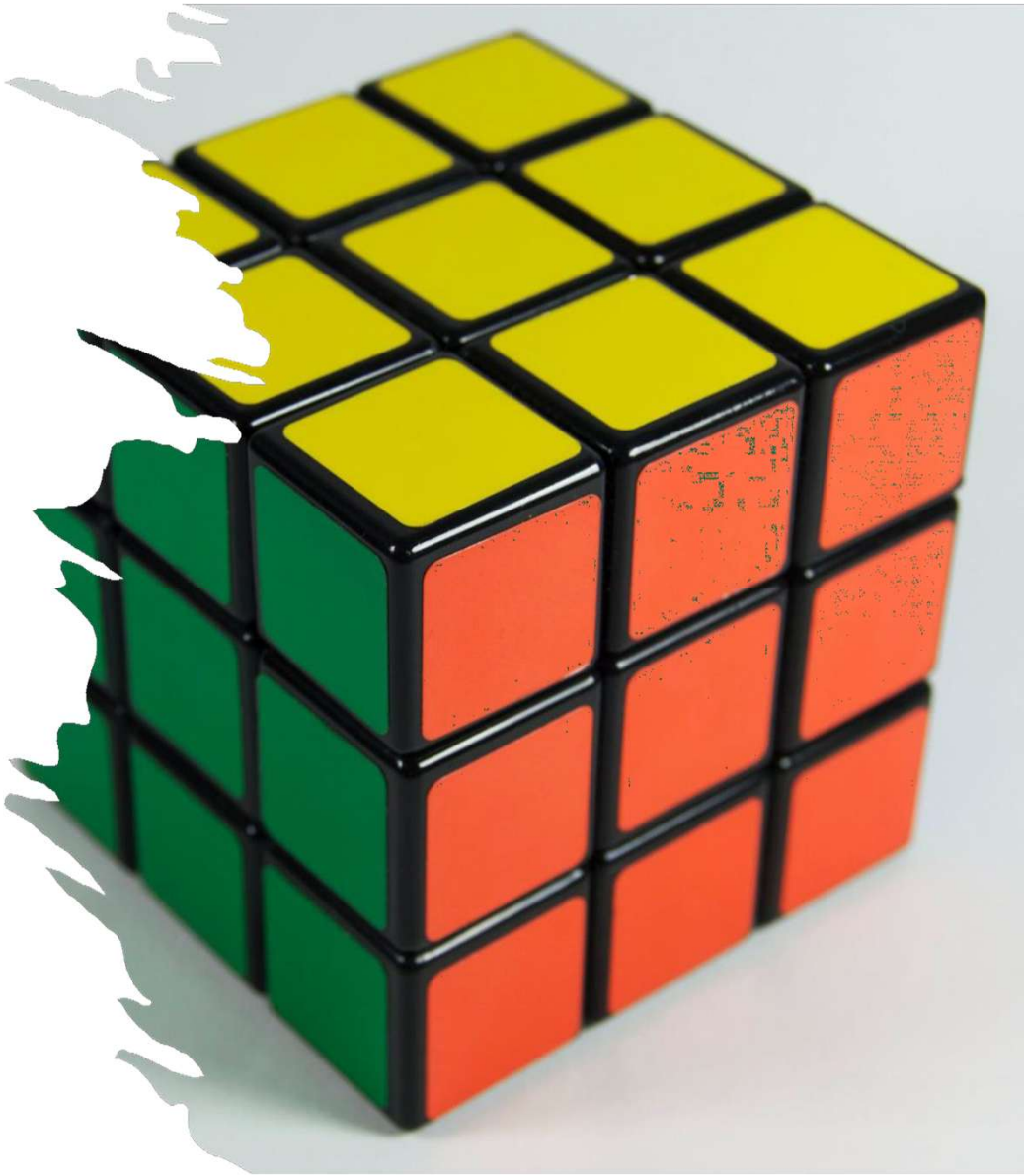
- **Who was involved?** People with lived experience, clinical experts, end users
- **Why was the approach appropriate?** Because they didn't yet know what the group needed or how to support their needs. All they knew was that women felt unsupported post-treatment
- **What specific methods were used?** Workshops, storyboarding, personal story videos, design prompts, priority setting, prototyping (piloting), design iterations
- **What were the benefits?** Deepened understanding of needs, multiple experiences and opinions represented, ownership over pilot, better support for women
- **What were the challenges?** Building trust, managing expectations (who would benefit), fatigue, highly emotional subject matter

Benefits of engaging users

- Engaging users throughout the design process
- Engaging different user opinions
- Helps get the design right
- (Usually) quick turnarounds on design and evaluation
- Democratic process
- Easier user acceptance in the marketplace
- More in depth knowledge of the context and the domain

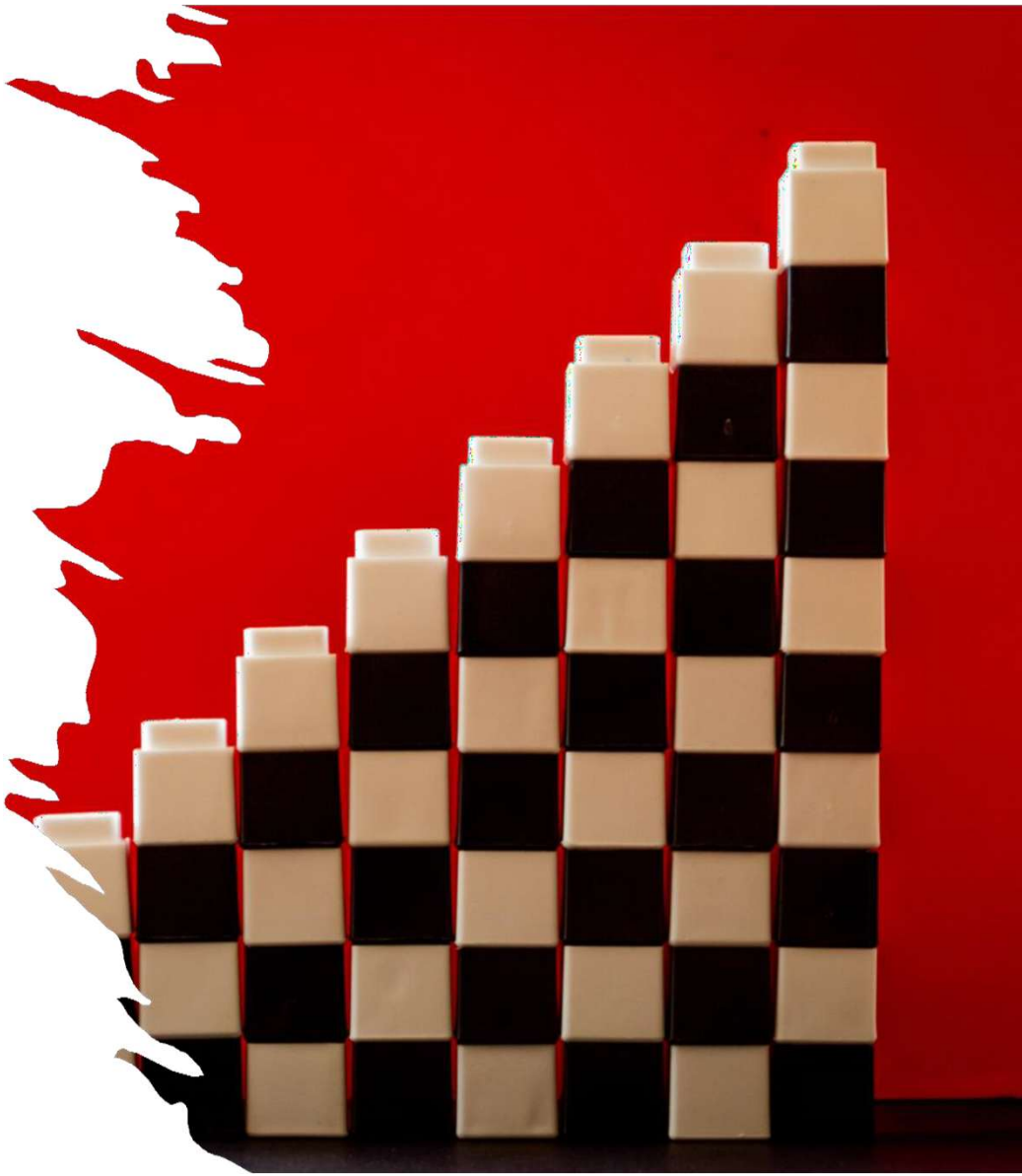
Challenges

- Time commitments from others
- Costly to engage many users many times
- Can privilege certain group
- Hard to get a wide range of experiences
- People who tend to engage in this research would not be average users
- Hard to manage expectations
- Hard to deal with complex technological constraints
- Not all users can give equal participation because of language and consenting reasons



When to use participatory approaches

- When we have less of an understanding of the user group
- When the user group might have a diverse range of opinions and experiences
- When there might be particular challenges with using a technology that require further exploration
- When the contexts that technology might be used in are less understood
- When technology use might be grounded in social, political, emotional contexts



When fully participatory approaches might not be appropriate

- With people who cannot consent (children, mental health issues, vulnerable people, etc)
- With people who do not communicate in ways the researchers do (different languages, people with vision issues, people with hearing issues)
- Contexts where people cannot invest time (single parents, frequent travellers)
- With non-people (animals)

Additional co-design reading

- Bødker, S., Ehn, P., Sjögren, D. & Sundblad, Y (2000): Co-operative Design perspectives on 20 years with the Scandinavian IT Design Model. Invited paper, Proc. NordiCHI2000, Stockholm, Oct 2000.
- McNaney, R., Vines, J., Mercer, J., Mexter, L., Welsh, D. and Young, T., 2017, May. DemYouth: Co-Designing and Enacting Tools to Support Young People's Engagement with People with Dementia. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (pp. 1313-1325). ACM.
- McNaney, R., Vines, J., Dow, A., Robinson, H., Robinson, H., McDonald, K., Brown, L., Santer, P., Murray, D., Murray, J. and Green, D., 2018, April. Enabling the Participation of People with Parkinson's and their Caregivers in Co-Inquiry around Collectivist Health Technologies. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (p. 491). ACM.
- Monk, A. and Howard, S., 1998. Methods & tools: the rich picture: a tool for reasoning about work context. *interactions*, *5*(2), pp.21-30.
- Odom, W., Zimmerman, J., Davidoff, S., Forlizzi, J., Dey, A.K. and Lee, M.K., 2012, June. A fieldwork of the future with user enactments. In *Proceedings of the Designing Interactive Systems Conference* (pp. 338-347). ACM.
- Sanders, E.B.N. and Stappers, P.J., 2008. Co-creation and the new landscapes of design. *Co-design*, *4*(1), pp.5-18.
- Schuler, D. and Namioka, A. eds., 1993. *Participatory design: Principles and practices*. CRC Press.