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Co-Designing Personal Health? Multidisciplinary Benefits and Challenges in Informing Diabetes Self-Care Technologies

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Co-design is a widely applied design process with well-documented values, including mutual learning and collective creativity. However, the real-world challenges of conducting multidisciplinary co-design research to inform the design of self-care technologies are not well established. We provide a qualitative account of a multidisciplinary project that aimed to co-design machine learning applications for Type 1 Diabetes (T1D) self-management. Through retrospective interviews, we identify not only perceived social, technological and strategic benefits of co-design but also organisational, translational and pragmatic design challenges: participants with T1D experienced difficulties in co-designing systems that met their individual self-care needs as part of group design activities; HCI and AI researchers described challenges collaborating to apply co-design outcomes to data-driven ML work; and industry collaborators highlighted academic data sharing regulations as cross-organisational challenges that can impede co-design efforts. Based on this understanding, we discuss opportunities for supporting multidisciplinary collaborations and aligning individual health needs with collaborative co-design activities.

CCS Concepts: • **Human-centered computing** → **Collaborative and social computing**; *Empirical studies in collaborative and social computing*;

KEYWORDS: Co-design; participatory design; diabetes; t1d; personal health; self-care; self-management; HCI-AI; explainable artificial intelligence; XAI

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1 INTRODUCTION

Co-design is a widely applied design process that has been adopted and adapted in a variety of commercial and academic settings, from architecture to public health. Co-designers typically arrive from different disciplines and organisations: they share their domain knowledge, learn about design methods and collaboratively engage in iterative human-centred design cycles to achieve shared objectives. Co-design has been shown to be powerful in tackling wicked problems, exploring the design space of desirable technology, and fostering mutual learning between multidisciplinary team members [8,66,68]. For example, prior work has demonstrated the benefits of participatory approaches to exploring interactive machine learning [4,36], addressing ethical implications, such as AI fairness [50,73], and supporting people with health and wellbeing conditions in expressing and coping with their lived experiences [19,63,78]. The benefits of co-design, such as collective creativity and mutual learning, are well-documented. However, the real-world challenges of applying co-design within multidisciplinary project teams specifically for the design of self-care technologies are not well established.

This paper responds to recent calls for more reflective work to grow the understanding and transferability of co-design [9,66,69]. We contribute to health and design domains with a holistic account of the realities and practical challenges of an HCI-led multidisciplinary co-design project investigating the potential of machine learning (ML) for type 1 diabetes (T1D) self-management. We report the results of semi-structured interviews conducted with HCI researchers, AI researchers, industrial collaborators, and people living with diabetes who participated in the co-design project. We offer two primary CSCW contributions.

First, we describe differing social, technological, and strategic benefits held by different parties, and identify organisational, translational, and pragmatic design challenges in applying co-design within this context. We highlight difficulties in applying co-design outcomes to data-driven ML work and address research-practice gaps [58], such as cross-organisational data sharing barriers, that can impede co-design efforts. Furthermore, we draw attention to misalignments between scientific thinking and participants' lived experience and tensions between the collaborative mode of co-design and participants' individual self-care needs.

Second, we provide guidance and foster discussion on conducting multidisciplinary co-design research with people who live with an idiosyncratic health and wellbeing condition, such as T1D. We discuss how researchers and practitioners could foster translational knowledge work as part of multidisciplinary collaborations and support participants' individual (and often incompatible) self-care needs throughout collaborative co-design processes.

2 RELATED WORK

We first provide an overview of co-design research and then look at diabetes self-management literatures to provide background to this work.

2.1 Participatory Design and Co-Design

In the mid 1970's, participatory design projects were conducted as a response to a critique of how computer-based systems were being introduced into workplaces: workers and their unions were afraid that organisations installed computer-based systems to undermine their interests and even replace them [8]. The participatory design methodology was developed to empower people to

take an active role in the design process of interactive systems and organisational changes. The seminal Utopia project pioneered not only co-operative design methods [8], such as creating low-tech prototypes, but also helped frame participatory design principles, including: balanced power relationships; shared decision-making; mutual learning; and the exploration of alternative and holistic visions of technology use [74].

As participatory design matured, it became a widely used methodology not only in HCI but also in different research areas, including architecture and public health. Co-design is a contemporary approach that has been adopted and adapted in commercial and academic settings. While the terms participatory design and co-design are often interchangeably used, there are sources that present participatory design as a methodology and co-design as design process [68]. Co-designers typically arrive from different disciplines and organisations: they share their domain knowledge, learn about design methods, and collaboratively engage in iterative human-centred design cycles to achieve shared objectives. Research-focused projects have drawn on co-design to prioritise research agendas [62], review study proposals and material [20], and envision the design space of diverse technologies and services [70].

Prior work has explored design spaces and documented co-design outcomes [41,55,56,79], advanced existing co-design approaches [63,78], and investigated how to foster engagement during co-design activities. For example, researchers have not only acknowledged challenges of engaging with older adults but also proposed different strategies: while McGee-Lennon et al. [54] recommends paper-based design activities and “live coding” of interactive prototypes, Harrington et al. [32] suggest that encouraging older adults to use technologies over a longer period of time can lead to more detailed feedback as part of co-design sessions. Noergaard et al. [57] identified the challenges of conducting a series of co-design workshops with different stakeholders pointing to potential issues regarding longer-term participation: people with heart disease productively worked with health professionals as part of their first workshop, however, were not able to continue their fruitful collaboration since health professionals were not able to attend continuing workshops due to their job responsibilities.

2.3 Co-Design and Personal Health

Prior work has not only drawn on co-design approaches to understand how technologies could support health and wellbeing needs but also investigated how co-designers perceive and experience their roles in co-designing potential systems. For example, Revenäs et al. [64] motivate their reflective work with identifying a lack of research contributions on participants' experiences of taking part in co-design to inform the design for technologies for Parkinson's disease care. They identify a set of needs and challenges, including the desire to collaborate with additional stakeholders and challenges regarding providing appropriate guidance and realising desired workshop outcomes. Moreover, previous work has drawn attention to researchers' and participants' wellbeing needs during co-design sessions. For example, Linberg [46] found that working in pairs with children with cancer helped researchers to not only efficiently engage in co-design activities but also allowed them to gain awareness of the children's wellbeing as study participants. In the case of dementia, using simple games and realistic prototypes helped elicit care and technology needs [53], although researchers caution that co-design activities could cause emotional challenges for both people living with dementia and workshop organisers [33].

Prior co-design works have identified user needs and documented co-created design artefacts in different health and wellbeing domains [32,77,78]. However, there have been calls for not only methodological reflections [9,18,27,66] but also for explorations into the potential of co-design to inform emerging AI technologies [47,48,76] to grow the understanding of co-design and improve co-design research outcomes.

2.4 Diabetes Self-Management and Self-Care Technologies

In recent years there has been much interest in using AI/ML for supporting diabetes management decision-making, e.g. improved glucose prediction [22], classification of the impact of specific behaviours on health [23], or association of GPS location with blood glucose level variability [21]. Such innovation is necessary as diabetes self-management, especially for Type 1 Diabetes (T1D), is cumbersome and time-consuming. As T1D is an auto-immune condition whereby the body doesn't produce enough insulin, people with diabetes need to take daily insulin injections, and insulin doses rely on complex interdependent factors, including exercise, diet, stress, and others [1]. AI/ML based approaches could help overcome some of the barriers to adoption of current diabetes self-management apps through increased use of networked sensors to reduce the burden of data collection [12,16,38], combined with analytics to reduce the cognitive effort needed to gain actionable insights from complex data [39], thereby increasing efficacy.

As T1D management depends primarily on self-care, it is crucial that systems are oriented towards people's needs [15,28,52,61,71]. In particular, ethnographic research studies of diabetes self-management have drawn attention to the individual experience, idiosyncratic character, and open-ended nature of self-care practices and the ways in which people develop unique skills in managing their health and wellbeing over time [71]. For example, Chen [15] sheds light on people's varied health information management practices and the need for personalised self-care technologies. Mamykina et al. [51,52] describe how participants appropriated the self-tracking application MAHI to document routines, reflect upon their personal stories, and construct their own identities. Their analysis of the long-term use of MAHI identifies people's individual needs to maintain a positive self-image, demonstrate competence in managing their health and wellbeing and sustain their constructed self-image. O'Kane et al. [61] has documented not only on the individual use of diabetes technologies but also contextual influences in everyday life. Their situated study illustrates that medical technology use in familiar situations shows large individual differences. Participants tended to conceal and reveal their mobile medical devices in different situations to protect and manage the impression they make on others.

2.5 Towards Collaborative Co-Design for Personal Diabetes Self-Care

Design approaches which integrate end-users as contributors of design ideas and solutions provide a promising conceptual and methodological framework for diabetes system development. Diverse user centred design methodologies have often been applied to diabetes technologies, with researchers reporting that such methods provided positive results and helped answer research questions, as well as knowledge on user mental models, helped design better products and clarified misconceptions [43]. Such studies affirm the importance of including stakeholders in the development process, allowing them not only to comment on existing products, but also to drive the direction and approach taken. Although there is a significant body of literature on the use (and importance) of human-centred design approaches, there is little research taking a critical view on the process of engaging a multi-disciplinary group of co-designers to collaborate on the design of technology to support personal and often idiosyncratic self-care practices. This is especially important considering technology innovation includes many different stakeholders and diverse expertise, such as the move towards using AI and ML personalised self-care technologies for chronic conditions such as T1D. In this paper we provide a holistic account of the perceived values and practical challenges of a multidisciplinary collaboration involving HCI and AI researchers, industry practitioners and people living with diabetes to co-design ML-based self-care technologies.

3 METHODOLOGY

3.1 Co-Design Project Background

For context we provide here an overview of the 18-month long co-design project. Its aim was to co-design ML-based decision support concepts and co-create suitable machine learning approaches. The co-design project was funded by a scheme with a focus on fostering collaborations between businesses and academic organisations. The project involved HCI researchers, AI researchers and industry collaborators. The industry collaborators worked at a T1D start-up. A shared objective was to co-design ML-based decision support concepts and co-create suitable machine learning approaches. Fifteen participants with T1D (aged 24-69; 3-34 years since T1D diagnosis; 11 were male) were recruited. Participants received an Apple Watch, a 12-months Dexcom Continuous Glucose Monitor (CGM) subscription, and access to an app provided by the start-up for their participation.

A series of workshops were conducted between August 2019 and February 2020 (see Table 1). Participants unable to attend workshops were interviewed over the phone about the workshop topics. Co-design methods included scenarios, storyboards, mock-ups as well as tailored templates to help understand participants' data collection needs and empower participants to create their own self-care systems. In addition, researchers conducted simple sketching exercises with participants and provided example storyboards and mock-ups to scaffold co-design activities. In preparation for workshop activities, participants were asked to use the beta version of the app provided by the industry partners to track their meals and use their Apple Watch for tracking other health and wellbeing factors.

Table 1. Workshop details

#	Workshop type	# of attendees	Topics covered	Research Methods
1	Evening, 2 hrs	7 attendees	Identifying meaningful factors that influence diabetes	Ideation, sketching
2	Evening, 2 hrs	8 attendees, 6 phone interviews	Impact of technology on diabetes management; automated tracking	Scenarios
3	Weekend, 4 hrs	10 attendees	Designing a personalised decision-support prototypes	Storyboards, mock-ups
4	Evening, 2 hrs	3 attendees 3 phone interviews	Understanding the decision-making process	Scenarios
5	Weekend, 4 hrs	7 attendees	Understanding the role of context and tracking non-routine situations	Sketches, mock-ups

3.2 Research Questions

The objective of the interview study reported in this paper was to provide a retrospective and critical account of the co-design project with a focus on the personal experiences of all actors involved; we did not aim to evaluate its effectiveness or efficiency. We investigated the following research questions:

- What are the perceived benefits and challenges of co-design to inform T1D technologies from the points of view of the multidisciplinary team?
- What are the transferable lessons learned for future multidisciplinary co-design projects that focus on self-care technologies?

3.3 Data Collection and Analysis

The first author was appointed at the end of the co-design project to conduct this semi-structured interview study in order to provide some critical distance from the project. The first author conducted 17 interviews (see Table 2). Due to the COVID-19 pandemic, the interviews were conducted via phone and video conference systems. Interviews involved eight people with T1D who participated in the co-design project (referred to as P1, P2, etc.), three HCI researchers (e.g. HCI1), three AI researchers (e.g. AI1), as well as three industry collaborators (e.g. IC1). To support recollection before the interviews, a slide deck was shared with participants including photos of co-design outcomes and materials used throughout the workshops. Interview topics covered prior experiences with AI/ML, experiences of co-design activities, perceived challenges, views on workshop outcomes, and suggestions for future projects. Interview questions were adjusted for each group of interviewees and lasted approximately 30-90 minutes. The audio recordings were transcribed verbatim. As each person with T1D who participated in the project received an Apple Watch and a 12-month Dexcom CGM subscription, we did not provide additional incentives for this interview study. Researchers and industry collaborators did not receive any incentives. This interview study received an ethical approval from our institutional Faculty Ethics Committee.

Data collection and analysis was conducted in a staggered way according to project roles. As some participants were authors, each interviewee was sent the representative quotes for the codes and explicitly agreed to their use before group analysis was conducted. In this way, participants had the option to double-check their quotes and decide whether they felt comfortable to reveal their perceived benefits and challenges of taking part in the co-design sessions within the project team. All quotes were signed off and none were edited or removed. A qualitative data analysis software was used by the first author to thematically code data [10]. The data corpus was iteratively analysed in an inductive fashion drawing on open and axial coding [14]. Codes and findings were iteratively shared and discussion within the academic project team. We initially focused on the individual experience of each participant and cross-cutting themes within each participant group. At later stages, we created tables showing benefits and challenges of co-design activities to understand similarities and differences across participant groups.

Table 2. Interview study participants

#	Key	Role	#	Key	Role
1	P1	Participant with T1D	9	HCI1	HCI Researcher
2	P2	Participant with T1D	10	HCI2	HCI Researcher
3	P3	Participant with T1D	11	HCI3	HCI Researcher
4	P4	Participant with T1D	12	AI1	AI Researcher
5	P5	Participant with T1D	13	AI2	AI Researcher
6	P6	Participant with T1D	14	AI3	AI Researcher
7	P7	Participant with T1D	15	IC1	Industry Collaborator
8	P8	Participant with T1D	16	IC2	Industry Collaborator
			17	IC3	Industry Collaborator

4 FINDINGS

This interview study provides a qualitative account of a completed co-design project that explored the potential of machine learning for type 1 diabetes self-management. This account centres on the personal experience of the co-design project team members including academic researchers, industrial collaborators and workshop participants. We first report on perceived social, technological, and strategic benefits and then describe organisational, translational and pragmatic design challenges of applying co-design within this research context.

4.1 Perceived Benefits of Co-Design

Co-designers with T1D prioritised immediate social benefits of sharing personal self-care experiences in-situ over learning about design practices and technological concepts as part of co-design workshops. Researchers and industry collaborators appreciated mutual learning benefits and particularly valued prospective, strategic and economic benefits of co-design outcomes.

4.1.1 Social Benefits: Learning about Diabetes Self-Care from Co-Designers

HCI and AI researchers especially valued being able to have conversations with people living with type 1 diabetes and learning about what it is like to self-manage an idiosyncratic health condition in daily life, which was more engaging and informative than “*just looking through NHS web pages*” (AI1). They enjoyed the supportive and participative nature of co-design when “*getting people involved and helping them design things that are meaningful to them and learning from them as well rather than being like, ‘I’m a researcher, I know things.’*” (HCI1). As the co-design objectives were primarily design-led and technology centric, researchers anticipated that participants would particularly value the benefits of learning about novel technological approaches and engaging in creative design practices. However, research participants valued, above all, being able to appropriate co-design activities to their personal communication and care needs. This involved sharing their individual self-management experiences and receiving self-management advice from their peers during and after co-design activities:

“There was always a strong pull on talking about their own self- management, in any of the activities that we ran. Everything was a prompt for them to talk about some of the details of their own self- management.” (HCI3)

Participants contrasted their social experiences of taking part in co-design workshops and sharing their self-care narratives with their experience with clinical trials, where they took on prescribed and often distant research roles. For example, P8 highlighted that there is typically a lack of shared decision making and social exchange between participants in clinically informed research studies. In contrast to clinical trials, participants explained that co-design workshops provided space and time to meet and talk with other people living with T1D, a novel experience for some participants. They appreciated being able “*...to actually just sit in a group and hear people talk and laugh and joke about things that they’re doing.*” (P3). Through appropriating co-design activities to personal communication needs, participants recognised commonalities and differences in the ways they self-manage their health and wellbeing. For example, P1 explained:

“Useful insight around broader diabetes management came out of that exercise, not just about kind of how to design an app but about some of the struggles people face with different elements of their diabetes management.” (P1)

While researchers have described individual differences in diabetes self-management in prior work [15,71], research participants in this study identified individual differences across people with T1D themselves and, importantly, highlighted these co-constructed insights as beneficial. They reported that recognising that people with T1D at these group workshops have very

individual perceptions and self-care preferences helped rethink their own struggles and reassess their own self-care agency:

“It was interesting to see what we had in common and also the differences. [...] some things that really affected some people and didn’t seem to affect other people as much, like some people, the amount of sleep and stress [...] other different factors that came into it and how they dealt with it.” (P5)

Even for a person with higher self-care agency and expertise such as P6, it was beneficial to share and learn about different self-care routines from the group and potential contributors to blood sugar levels:

“I think I’m very narrow-minded. I feel like I know everything about diabetes so I know everything about my diabetes so it was very interesting to learn about other people and other things that people might consider to be issues with their diabetes.” (P6)

4.1.2 Technological Benefits: Learning about Self-Care Technologies and Machine Learning

Participants explained that just being with other workshop participants at the same time and place provided a learning opportunity. For example, P3 detailed how he passively observed what injection tools people used and how they go about using their medical devices in practice. An HCI researcher characterised some of these in-situ care practices as performative:

“It was really cool watching people talk about their different personal practices and challenging each other on it, like pulling out kits to show off and shaming people who didn’t bring their kits with them. Then you could see that the observations of what people were doing before eating as well and they’re actually trading opinions on how much that sandwich had carb-wise, and so not only did we observe self-management practices, but we saw how self-management practices were being slightly influenced by the nature of just having a bunch of people with diabetes in the room eating the same thing at the same time.” (HCI2)

During co-design activities and breaks, participants reported proactively asking for and receiving personal self-management technology advice from their peers. For example, P10 used the co-design workshops to validate her experiences with the use of a continuous glucose monitoring device that caused skin irritation: *“I thought that was just me, but I was able to find out from the other team members that they experienced the same thing. [...] It was small little things like that that I gained knowledge of.” (P10)*. Furthermore, participants shared their perceptions of and experiences with consumer health technologies. For example, P9 valued being able to learn more about potential unintended effects of technology providing immediate accessibility to health data:

“they’re getting their phone out or looking at their Apple Watch for their glucose reading religiously every couple of minutes, whereas other people would say that they tend not to stress over looking at it so often [...] their use of technology was quite interesting.” (P9)

Participants appreciated not only learning about the perceived benefits and limitations of existing self-care apps and devices as part of the co-design session but also valued learning about the process and methods of iteratively designing potential self-care technologies. For example, P6 emphasised her experience of being able to articulate her technology needs in relation to being able to take a proactive role in informing the design of diabetes applications:

“I use CGM and I use a lot of like apps to manage my diabetes it was good to like actually try and get a say in what goes into one of those apps that I might potentially use in the future to get to say what I would find useful personally rather than trying to use like five different apps, I could say like we could take all these aspects and put them into one app.” (P6)

Mutual learning is a long-lasting benefit of bringing together people with different expertise during co-design activities, and this was captured in this research in relation to ML. Data science machine learning, and AI were familiar to participants with T1D, but they were able to learn more in depth about potential ML concepts that were specific to their interest in diabetes technologies: “Before, it was kind of like, you know, computers being able to think for themselves or like have a sentience,” explained P8, showing the development of understanding of intelligent systems past a science fiction narrative. Reflecting back on their learning about ML approaches, participants described how this knowledge enhanced their understanding of other technologies that were in their lives, including popular consumer devices and platforms:

“I think the term ‘artificial intelligence’ is a bit more specific than that, I think. It’s more to do with machine learning, [...] So it’s things like, you know, how Netflix decides what you watch, kind of thing, or how you choose your recommendation. I think it’s algorithms, really.” (P3)

Participants were also able to explain complex aspects of machine learning in simple terms related to human cognition, including knowledge and learning, and also were able to understand where AI researcher and the industrial partners might fit into the technology development: “AI is computers that learn, that once you set certain criteria up or whatever, they can gain knowledge themselves without being told to gain knowledge, yeah. I think that is the simplest form,” (P10). Beyond a general understanding of AI and ML concepts, participants were also able to reflect on the challenges and opportunities surrounding the technology. This included limitations specifically related to ML enhanced T1D self-care technologies, such as the credibility of predictions, manual data entry vs automatic data capture, and data quality issues:

“If it’s showing information based on weeks and weeks of data-gathering and it’s basically giving you your average day, I mean, I suppose that could be useful. But then, if you suddenly change your physical activity, or you’re eating something at a time that you don’t usually eat something, then I guess that could disrupt it, in a way.” (P8)

4.1.3 Strategic Benefits: Learning about Multidisciplinary Differences and Informing Prospective Collaborative Work

Researchers and industry collaborators acknowledged the benefits of mutual learning within the multidisciplinary team. Their perceived benefits were particularly strategic and economic. For example, an HCI researcher reported learning more about how to manage the need for all academics to contribute to their own subdiscipline and their own publication venues, ultimately feeling better-equipped to investigate emerging research questions as part of future collaborations:

“I suspect what we will do, will be to write another project where we’re actually able to follow up on some of the emergent questions that are only really now, so we’ve gone through that process of learning a little bit about each other [...] I mean, it almost feels like a sort of pilot project.” (HCI3)

Industry collaborators valued learning more about co-design, as opposed to user-centred design approaches that are commonly applied in industry settings. Furthermore, they particularly valued the constructive feedback on their beta app that academic researchers forwarded from the co-design workshop participants:

“People just being very brutally honest about the app and saying ‘I don’t understand this, I don’t get it to be honest, I’m not using it, I don’t find it useful,’ I mean to me those are very helpful, that’s helpful information that people won’t say to us directly.” (IC4)

Reviewing co-design workshop outcomes also helped the industry partners to validate their internal user research findings. The lens of co-design offered an alternate design methodology which helped them to gain a more holistic view and to prioritise development tasks. IC2 stated

that external validation of their previously identified diabetes self-management concerns helped them gain confidence about people's technology needs as well as providing regulatory benefits.

"[It made us] Definitely more confident...less biased...because in industry you make decisions so quickly...having someone like the university finding the same kind of thing, goes like, maybe it's not that biased. And you know, in regulatory you actually have to show your design process too and you have to show that you actually investigated this, so to be able to show like, we've investigated this and the university investigated this and they have also found this, that creates gravitas." (IC2)

4.2 Perceived Challenges of Co-Design

While the previous section presented social, technological, and strategic benefits of co-design, we describe organisational, translational, and pragmatic design challenges to help inform researchers in the design of future co-design projects.

4.2.1 Organisational Challenges

Organisational challenges illustrate how funding requirements and multidisciplinary objectives can impact co-design processes, co-design roles, and cross-organisational data sharing practices.

Managing Formal Requirements and Organisational Barriers

The workshops were designed to support the commercial objectives of the industry collaborator, which was a condition of the initial project funding. However, this requirement led to barriers to the research objectives of other partners. The academic AI researchers wished to analyse the usage data of the commercial app to inform their research. However, the research team faced challenges in resolving the anonymisation requirements as well as implementing a process that would allow sharing sensitive health and wellbeing data across organisations. An HCI researcher explained: *"there was no way that we could anonymise the participants we would be interviewing and working with, and share that data with [the industry collaborator], and we kept hitting up against GDPR issues with regards to the data sharing and with consent."* (HCI3)

Overcoming the complexities of sharing and receiving highly sensitive data with external team members had to be negotiated in detail during the project launch. However, when it became clear that some data sharing challenges were insurmountable, industry collaborators and academics decided to restructure the project such that the co-design work that the academic researchers led was aimed to inform near future directions for the start-up rather than directly informing ongoing design and development cycles. Instead, workshop participants were given access to the commercial app and asked to freely share and discuss their experiences as part of the co-design workshops as industry collaborators kept their distance from the participants. While these arrangements supported researchers in contributing to the objectives of the industry collaborator, they altered the original goal of the project, which had been to apply a bottom-up co-design approach that directly involved all actors in exploring the potential of ML in diabetes self-care because of the *"pretty major issue with regards to the sharing of data."* (HCI3).

Managing Multidisciplinary Objectives, Expectations and Roles

While multidisciplinary team members managed to pursue their domain-specific objectives, some workshop participants perceived a lack of sufficient structure inherent in a user driven co-design project. For example, although P1 was able to achieve his intention of increasing his knowledge about diabetes care, he explained that a clearly articulated research objective could have improved co-design experiences and outcomes:

“... having a very clear objective right from the start and almost setting the flow of the workshops to try and achieve that objective through the course of them...I thought [the workshops were] very useful for the objective that I had which was to try and understand how other T1 diabetics manage their diabetes. I think [the workshops] would have probably been more useful for you guys if the objectives had been clearer from the start and therefore, we as participants could have helped you meet those objectives better.” (P1)

The iterative and open-ended nature of co-design made it difficult to detail specific objectives and workshop agendas. “*The participants would say, well no, we don’t want to focus on that, we’ll focus on something else,*” reported HCI2, highlighting challenges of designing workshops according to participants’ needs. It became clear that planning and conducting co-design processes required flexibility, for example, when assumptions based on previous workshops turned out to be false:

“*there was a design exercise to explore how an app could work in a sort of non-routine situation [...] it turns out that basically it would work the same. They didn’t need a special mode or anything like that and that was like half of the workshop gone, so I had to improvise.*” (HCI1)

Furthermore, participants’ accounts highlighted the importance of consistently managing expectations and responsibilities of all actors throughout the course of the workshops. Accepting that HCI and AI researchers were not experts in diabetes care was challenging for some participants and they felt it detracted from the workshop objectives. For example, P3 seemed to be surprised by the focus on mutual learning and the lack of the research team’s diabetes knowledge: “*I felt like they didn’t have a very good understanding of some aspects of type one diabetes. I felt a bit surprised by that, that the whole thing was about the learning.*” (P3).

4.2.2 Translational Work Challenges

We identified translational work challenges between HCI and AI academics and participants living with type 1 diabetes. The terms *translational research* and *translational work* are being used, in particular, in the biomedical domain to refer to the *translation* of scientific findings into medical practice [6,13]. Norman highlights the need for *translational developers* who can mediate between academia and industry [58]. Based on this understanding, we use the term *translational work* to describe how HCI researchers, AI researchers, industry collaborators, and people with T1D attempted to bridge theory-practice gaps as part of a multidisciplinary co-design collaboration.

Translational Work Challenges within a Multidisciplinary Research Team

HCI researchers intended to inform ML research based on co-design outcomes. However, both HCI and AI researchers reported challenges in intertwining their work cultures. They identified different factors that have led to disparate and parallel work streams within the multidisciplinary team. Academics highlighted the importance of developing a common language, mutual appreciation for methodological differences between HCI and AI, and iteratively investigating real-world data to identify signals and potential patterns in tandem with participants (rather than drawing on ML approaches as a solution from the start).

Prior work has documented how user experience designers adopt the data-centric culture of ML practitioners as part of successful collaborations [82]. Researchers’ accounts suggest that the infrastructure for collecting and analysing data was established during the course of the project rather than being an integral part of the HCI research agenda and ethical arrangements from the beginning of the project:

“*they couldn’t do anything without data from participants and initially we didn’t even plan to collect any data. So that’s why we had to get an ethics amendment and get people’s permission to collect the data.*” (HCI1)

The delay in being able to collect health and wellbeing data led to a two parallel work streams: ML researchers investigated how predictive model-based reinforcement learning approaches could offer suggestions and uncertainty indicators based on simulated data and HCI researchers focused on participants' personal data tracking preferences at the co-design workshops. When aligning HCI and AI work streams, tensions became evident between the need to provide real-world data sets for AI researchers and participants' self-tracking priorities.

As part of co-designing possible data-driven applications to support ML-based decision support, participants preferred automated tracking approaches. *"It turns out no-one wanted to track those things,"* explained HCI1, revealing participants' reluctance to manually collect data when designing and discussing their mock-ups. However, interview study findings clarified that participants would be willing to manually collect and annotate their health and wellbeing data for the purpose of supporting ML researchers in understanding potential relationships between health behaviour and blood glucose levels and the feasibility of ML approaches. Reflecting on discussions between HCI and AI researchers, an AI academic encouraged finding a compromise between participants' self-tracking preferences and ML research data requirements:

"For example, [an HCI colleague] said, well, you know, anything that asks me to input what I ate is out of the question, and you think, oh okay. That's quite a big, you know – can we maybe navigate that a little bit and can we sort of make suggestions or gamify it?" (AI2)

Acknowledging their limited knowledge about ML, HCI researchers reported facing challenges in synthesising qualitative co-design findings to inform ML practices. Reflecting on meetings with AI colleagues, an HCI researcher explained attempts to interlink scenarios informed by workshop findings with potential ML concepts to derive feasible implications:

"I think we present them very differently when it's just the HCI people because we're trying to package a qualitative theme in a way that a quantitative AI person might get something out of. So I guess, to some extent, we're doing what we did in the co-design workshops, where we're kind of presenting little hooks of possibilities and things, we can throw in terms like 'expert systems' and 'unsupervised learning' and then see how that pings with them, and we don't really know what these things are to the same extent, but we have an inkling." (HCI3)

Scenarios and storyboards reminded AI researchers of use cases that are common in software engineering. They found that co-designed storyboards in particular can help understand self-care challenges and ideate on potential ML approaches. However, AI researchers described challenges in applying co-design outcomes to their algorithmic ML work. *"I think the challenge here is that these mock-ups are not just user interface, they also express desired functionality and that functionality may be unachievable,"* noted AI2, highlighting fundamental differences between the desirability and feasibility of workshop outcomes, such as mock-ups that visualised participants' desire to engage with technology that predicts blood glucose values. AI researchers critically reflected on the ethical implications of presenting results of predictive ML approaches to participants: *"Prediction is not what is going to happen, it's what we think will happen and that needs to be clear for the user. If there are errors and, in this case, big errors can cost lives."* (AI3). Rather than predicting specific primary disease indicators, AI researchers and industry collaborators with a technical background suggested focusing on basic data analysis and visualisation methods that centre on detecting reoccurring health patterns.

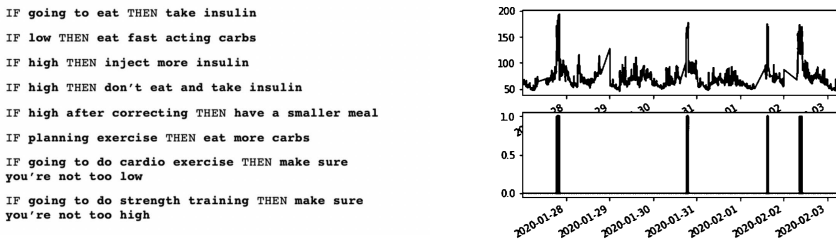
Challenges of Aligning Scientific Models with Participants' Lived Experiences

We identified misalignments between applied co-design methods that embodied scientific models and participants' lived self-care experiences. For example, researchers asked participants to complete and discuss if-then templates as part of the fourth co-design session (e.g., IF going to eat THEN take insulin; IF low THEN eat fast acting carbs). The objectives of using the if-then

templates were to better understand participants' decision making in diabetes self-care, explore the potential of rule-based recommender systems, and to prepare participants to create scenarios. Participants valued that this exercise helped simplify and articulate complex mental models (e.g., P8: "I think that's pretty much sort of what goes through our minds when we need to make a decision, and that's a really simple way of presenting that."). However, participants also made clear that the if-then templates were at odds with their lived experience of managing their health and wellbeing in everyday life. For example, P5 highlighted that the if-then rules are individual and not transferable, and P3 pointed to the lack of granularity and clarification of the if-then rules:

"I think it's a nice idea but there's so many 'if' statements that you'd have to include in it, or sort of clarifications. [...] The first one is – if you're going to eat, then take insulin. But even that is flawed because you'd have to clarify – if you were just to eat an omelette and some salad, then you wouldn't need to take insulin but if what you're eating qualifies as carbs, then... so you have to change that to – if you're going to eat carbs then take insulin." (P3)

Figure 1: Left: If-Then Statements; Right: Anomaly Detection Visualisation



With participants with T1D making an effort to collect data that was relevant to AI researchers, the researchers were then able to use this data to visualise trends and prediction and ultimately explain ML concepts in relation to T1D care during the workshops. Figure 1 right is a visual example to aid in the explanation of anomaly detection. In the two line graphs, the first showed blood glucose levels from the worn CGM over time and the second showed four blood glucose anomalies above in the first line graph. Although participants displayed familiarity with line graphs representing health data, particularly with regards to blood glucose over time, these were insufficient to reflect on self-management practices. Real world ups and downs with blood glucose levels are associated with the context, the situation and the person, and they wanted to know more about who and what was being represented by these line graphs: qualitative lived experiences were how they understood anomalies in everyday life, so they needed more context to interpret this quantitative representation. P8 described the importance of understanding "the why" behind these numbers in order to address anomalies:

"What you're not really seeing is why those anomalies are happening. [...] if we're talking about diabetes as an example, I think the 'why' is just as important in order to understand how to tackle those anomalies." (P8)

Participants also discussed the characterisation of anomalies as something that could be quantified or represented in a binary way. For instance, high blood glucose values were not always out of control – situations and contexts sometimes meant that these blood glucose levels were not anomalies and indeed were expected and managed. Overall, anomaly detection represented in this way (Figure 1 Right, second line graph) was not supportive of their choices

around self-care and their agency in dismissing these incidents based on their everyday lived experiences and self-management expertise.

4.2.3 Pragmatic Design Challenges

Apart from organisational and translational challenges, we identified pragmatic design challenges as part of co-design activities where participants experienced difficulties in overcoming tendencies to draw on existing design concepts and co-designing systems that met their personal, idiosyncratic self-care needs.

Challenges of Supporting Participants in Diverging Design Spaces

Reflecting on workshop design outcomes, researchers identified the challenge to inspire participants to think outside the box to explore design spaces for decision support systems that go beyond incremental improvements of existing solutions. An HCI academic tried to strike a delicate balance of providing scaffolding without leading the participants, but the participants still ended up with screens:

"I found it difficult to make them almost like take a step back– I think my first impression was that maybe that was because I gave them stencils [templates with mobile phone screens], but I'm just looking and one of those designs is on flipchart paper so there was no like stencil restricting them and it is still a screen. So, I think it was useful to use this to kind of help and narrow down the factors that people care about and want to track, but there's nothing new in this. [...] I guess because people started copying potential solutions." (HCI1)

Indeed, workshop participants explained that they drew on their prior experience of using existing apps when creating storyboards and mock-ups. *"I think also because other people had used different apps in the past before, I think in some way we were guided by the apps we'd used previously and how things were displayed and done on those,"* realised P5, when describing how her group aimed to design an app that would be able to seamlessly work with a popular food self-tracking service. Based on this understanding, participants explained looking at existing app design approaches that they particularly valued as a starting point to co-design potential alternatives and realised thinking outside of the box was difficult because of prior experience. For example, P6 thought:

"I'd used Dexcom for a long time, probably like three years now, I was very like led towards using some sort of Dexcom screen whereas I think some people had never used a CGM before, so they probably were thinking probably a bit more outside the box than I was. Whereas I went with a system that I knew and that I knew what worked, that like modelled around that so yes, I mean that was difficult." (P6)

Furthermore, participants discussed not only desirable design patterns but also existing app functionalities that they particularly disliked and critical incidents that they experienced using existing apps. P8 suggested that identifying specific limitations of the industrial collaborator's app encouraged them to explore how those limitations could be overcome:

"I think it was more of an example of what not to do, I guess, at the time, rather than giving sort of positive inspiration. It was kind of like, 'This thing doesn't really work, so how can we make it work?' Like, 'How can we present that in a way which would work?'" (P8)

Challenges of Supporting Idiosyncratic Self-Care Needs when Converging Design Spaces

Exploring a variety of design alternatives and converging on a design solution is a common design challenge that requires synthesis, prioritisation and agreement [11]. However, our findings suggest that the individual nature of type 1 diabetes and people's idiosyncratic self-care needs made co-design team activities particularly difficult: *"It's very, very hard to individualise type one diabetes so to do it in a group it's very difficult to get a system that would work for everyone,"* P6 said, highlighting participants' contrasting illness experiences and technology needs. While participants seemed to find agreement regarding their primary self-tracking priorities which involved blood glucose levels and carbs, they realised significant differences in terms of potential contributing factors which were very individual:

"It got difficult because people were saying different things. [...] So, I think, trying to come up with a simple interface and trying to figure out what those priorities are and present it in an easy- to-read way, was quite difficult." (P8)

It became evident that reaching consensus in creating mock-ups was difficult as participants expressed different self-tracking priorities when discussing what health and wellbeing data should be tracked to inform ML approaches. In addition, participants shared different self-tracking preferences regarding the granularity of tracking parameters and temporality of tracking. P10 reported that many self-tracking parameters that her co-design team wanted to put on paper were not relevant to her. Self-tracking priorities change over time, months and years as personal living circumstances change and one's bodily capacities change, she explained:

"Well a lot of it wasn't relevant to me because a lot of them used things for measuring exercise. I don't do a lot of exercise. I mean I'm 70 now. I walk the dogs, that's about it. I used to cycle a lot [...] in [a city in the UK], but I never really took much note of the burning of calories as it were. They were much more on the ball about that." (P10)

P5 described the design process of his team that started with visualising core functionalities rather than deciding what and how personal health and wellbeing data should be collected, including a predictive line graph to support decision making. However, they faced similar challenges as other co-design teams when it came to translating their different self-tracking priorities into a design structure:

"I mean, that's what we all struggle with, so to see a predictive graph of some sort is really useful, but quite how to do it and what impacts on it, like your carbs, your exercise, your insulin, and then... was there about fifty factors we decided could affect your blood sugars, and it's like, which ones to put in and how? I think that was probably one of the hardest bits to do, was designing that bit." (P5)

Highlighting that designing technologies to support people's individual self-care needs certainly requires personalisation and customisation, P8 summarises: *"We kind of came to the conclusion that it would have to be personalised in some shape or form."* However, participants reported that it was unclear how a customisable system could be designed in practice and their mock-ups did not illustrate any customisable features that visualised how their idiosyncratic self-care needs could be supported. Although researchers joined co-design activities as coaches and provided example sketches and data visualisations, *"it was too much of a blank canvas."* (P11). Participants wished to receive more guidance on how to manage their idiosyncratic self-care preferences and different technology needs when creating storyboards and mock-ups as a team: *"We did get guidance, but sometimes it was like it sort of sat there, a little bit lost as to how to go about putting down on paper what we actually wanted, and we had different ideas on it as well."* (P5)

5 DISCUSSION

We have investigated an HCI-led collaboration between AI researchers, industry collaborators, and people with T1D. We have reported on perceived social, technological, and strategic benefits and described organisational, translational, and pragmatic design challenges of applying co-design within this context. To support researchers and practitioners from different disciplinary backgrounds in conducting co-design to inform self-care technologies, we focus attention to (1) fostering mutual learning within multidisciplinary collaborations; (2) prioritising social over strategic co-design benefits; and (3) supporting participants' individual self-care needs throughout the collaborative co-design process.

5.1 Fostering Mutual Learning within Multidisciplinary Collaborations

Recent work has investigated how HCI researchers and UX professionals collaborate with engineers on AI-driven systems and identified a set of challenges, including difficulties in understanding AI capabilities and prototyping AI solutions [24,25,29,82,83]. For example, design professionals report difficulties in understanding ML capabilities, and recommend adopting data science jargon, including the use of quantitative evaluation methods, to be able to contribute to a data-centric work culture [82], which we also saw with the language HCI researchers were adopting in this co-design. HCI researchers acknowledged their limited understanding of ML and found it challenging to translate speculative co-design outcomes to feasible ML problems. Envisioning a variety of feasible AI experiences and rapidly prototyping realistic human-AI interactions are further challenges that designers are faced with, considering time extensive ML training workflows and a lack of data to design with [25,81,83]. This was an early stumbling block with the co-design, with the lack of data causing AI researchers to pursue reinforcement learning academic contributions. Furthermore, designers can find it difficult to productively collaborate with AI engineers because of a lack of a shared language and methodologies that help align human-centered design and machine learning work streams [29].

In our findings, AI researchers valued the sensitising benefits of co-designed storyboards and low-fidelity mock-ups that visualised predictive ML approaches. However, we have observed that co-design outcomes can require translational work to inform algorithmic ML research. To improve the transferability of co-design outcomes and foster mutual learning as part of HCI-AI projects, researchers and practitioners could combine co-design methods with established software engineering methods. For example, co-designed storyboards could inform the co-production of use cases. Software engineering methods, such as use cases and user requirement specifications, are used to communicate potential user needs, goals, and actions. Alternatively, concepts, such as “*intermediaries*” [3] and “*boundary objects*” [17,40,67], could help develop new approaches and align HCI and AI methodologies based on a shared language and principles. In these ways, co-design processes and outcomes could become more applicable to the design of ML-based applications.

Furthermore, AI researchers and industry collaborators highlighted fundamental differences between the desirability and feasibility of ML and potential tensions between people's idiosyncratic self-care practices and theoretical ML contributions. These observations suggest acknowledging methodological differences and making space for collaborators to pursue their research objectives alongside co-design objectives. For example, as part of this multidisciplinary co-design project, AI researcher conducted ML-centred studies on model-based reinforcement learning for T1D in parallel to co-design sessions.

To inform productive HCI-AI collaborations we can look to transferable best practices, such as committing to shared common goals [7,30]. Our lessons learned for HCI-AI collaborations are pragmatic. Mutual learning is not only a seminal participatory design principle but should also be a clearly defined and articulated objective as part of co-design processes. As Harper [31] puts it, “*HCI researchers need to stand up and take on that labor*” to be able to contribute to AI. Taking

on labour entails not only exploring ML as a design material [24,34] but also “*embrace[ing] a data-centric culture*” [82] to engage with ML approaches, workflows, and implementations in collaboration with AI researchers. Another lesson learned is to allocate time and resources to support upskilling of project team members and structure multidisciplinary co-design projects with an explicitly educational purpose. In particular, supporting junior co-design team members, such as research students and postdoctoral researchers, in becoming “*translational developers*” [58] who can learn how to navigate research-practice gaps and bridge HCI and AI disciplines.

5.2 Prioritising Social over Strategic Co-Design Benefits

Participants of this multidisciplinary co-design project reported social, technological, and strategic benefits. These perceived benefits seemed to be not only personal but also collective and shared across different stakeholders. For example, participants with T1D described benefits, such as receiving new self-care technologies for taking part in this experience-based co-design project [32], learning about new self-care strategies from their peers, and getting support on how to use new self-technologies. Researchers particularly valued learning about T1D from people with lived experience, improving their knowledge about HCI and AI methodologies, and finding new ways of informing future collaborations. These findings exhibit co-design as a mutual learning process that can support people’s personal values [42]. While perceived benefits are perceptions of positive outcomes caused by specific actions [44], personal values can involve different dimensions [45], from actions (e.g., engaging in self-care) and emotions (e.g., feelings of joy) to principles (e.g., gaining autonomy), abilities (e.g., physical and mental capacities), relationships (e.g., connecting with peers), and possessions (e.g., tangible things, such as technologies, and spaces). Berry et al. [5]’s two-part co-design study with people with chronic conditions, carers, and providers offers guidance on supporting conversations about personal values between different parties by identifying design dimensions (e.g., guidance) and tensions (i.e., disclosure vs. effort). Our co-design project was not “values-led” [35,42]. However, our methodological reflections highlight the importance of considering perceived co-design benefits and personal values of people with T1D throughout a technology-driven project.

Despite the personal nature of self-care, our findings show that a co-design process can support co-designers living with a chronic condition in sharing personal self-care experiences and learning from the experiences of their peers, both, during and after engaging in design activities. Importantly, co-design participants prioritised the immediate benefit of being able to share self-care experiences in-situ over the benefits of learning about design practices and ML concepts. This insight has important implications for planning co-design projects that are inherently technology and data centric.

Considering ethical aspirations of equalising power relationships and empowering co-design actors in expressing and pursuing their personal needs and values [8,68], we highlight the importance of prioritising the social experiences of co-design over potential strategic goals and anticipated benefits, especially, in the beginning of a research project. Creating opportunities for peer-to-peer interaction for social exchange and learning could enhance the co-design process and help drive the acceptance of the co-design process for all those involved. Creating such opportunities during online and offline co-design sessions can involve not only coffee breaks but also scaffolded methods to support participants in sharing lived experiences (e.g. [26]). A lesson learned is to iteratively redefine co-design agendas according to people’s needs, rather than desired workshops outcomes (e.g. number of design ideas, feasible implications for ML, desirable academic knowledge contributions). We acknowledge that prioritising social sharing and learning needs of co-designers can be at odds with desired strategic goals and tangible co-design outcomes, including the design of prototypes and applied ML approaches. This could even lead to co-design artefacts that centre on social engagement and social connectedness. However, considering social benefits does not necessarily need to lead to adverse experiences within a multidisciplinary co-

design team if, for example, researchers and industry collaborators recognise strategic and prospective benefits, such as informing future collaborations. Through systematically capturing feedback on perceived co-design benefits from all parties involved, the focus could be iteratively expanded over the course of a co-design research project.

5.3 Supporting Individual Self-Care Needs in Collaborative Co-Design

Realising participatory design and co-design principles, including mutual learning and diversity, involves striking a delicate balance between individual and collective needs [37,68]. As part of this project, we applied an experienced-based co-design approach [32] and providing a set of self-care technologies to participants, including an Apple Watch and a Continuous Glucose Monitor (CGM) subscription. While this approach supported mutual learning experiences, such as receiving informal peer support on how to adapt these technologies according to personal needs [60], the use of existing technologies seemed to have limited participants in thinking outside of the box when envisioning and co-designing novel self-care technologies.

Furthermore, we have identified tensions between the idiosyncratic self-care needs of people living with T1D and the collaborative modes of co-design: participants reported challenges of co-designing systems that met their individual and often incompatible illness experiences and technology needs. While prior work has effectively documented people's idiosyncratic self-care practices and has highlighted the importance of supporting personalisation and customisation [2,59,65], there is a lack of guidance on how people's idiosyncratic self-care needs could be supported as part of collaborative co-design activities, where people take the roles of co-designers to collectively converge on design ideas and materials.

We do not suggest that co-design is not a suitable process for people with idiosyncratic health and wellbeing needs; instead, we lay bare the benefits and challenges related to this collaborative approach to personal health technologies. We aim to raise awareness for an issue that we overlooked when conducting co-design workshops, but which participants highlighted repeatedly when reflecting on their co-design experiences as part of this interview study. A lesson learned is to shift the focus from user-interface co-creation to co-design activities that centre on people's individual health and wellbeing experiences. To introduce the roles of lived experience of health conditions and the complexities therein, co-design organisers can use different scaffolding tools, such as literature-based health experience insight cards [75]. Inspiration is further provided through Piper and Lazar's work [63] on what co-designers can learn from art therapy. They critique views that frame illness experiences as problems that need solving and encourage researchers to take observation roles to support participants in expressing their lived experiences. Art therapy approaches suggest working in smaller groups and in pairs, which has also been shown to be beneficial in participatory design sessions with children living with cancer [46]. At later stages, co-design activities can focus on developing multiple idiosyncratic design proposals before looking for any consensus, rather than looking for consensus from the outset [80]. Our findings suggest that a focus on people's idiosyncratic health and wellbeing needs does not necessarily need to be at odds with co-design activities around AI/ML technology.

Our study has identified not only potential tensions between participants' individual needs and the collaborative mode of co-design, but also tensions between participants' lived experience and scientific models (i.e., If-Then templates and anomaly detection explanation [see Figure 1]). Exploring the design space of user-centred ML explanations specifically for co-design projects is a promising research direction, considering that designing tools to support co-design are established methodological contributions [8,37]. Such design-led inquiries could investigate the ways in which algorithmic concepts might be intertwined with people's individual self-care experiences and information needs as co-designers. User-centred explanation instruments could not only make sense of abstract AI/ML algorithms and but also help visualise exactly what AI/ML can do, but also importantly, what it cannot. Prior work provides inspiration, such as the creative

presentation of AI as a monster metaphor [24], the use of tangible cards to foster discussion on data protection regulations [49], and “inspirational bits” [72] that reveal the properties of sensors. Through exposing the benefits and challenges in co-designing for T1D self-care, we propose practices for co-designing personal health and also highlight opportunities for co-designing more complex technical systems, that might require more varied multi-disciplinary teams.

6 LIMITATIONS

The fact that this interview study was conducted at the end of an 18-month long co-design project might be considered a limitation. However, a slide deck, including photos of co-design outcomes, seemed to help participants recall and reflect on their co-design experiences during interviews and we were able to capture longer term benefits and challenges of co-designing for personal health. Situated data, such as video recordings of workshop activities, could have strengthened findings and a mixed method approach could have provided more detailed insights regarding people’s immediate experiences with different co-design methods. Although the interviews were conducted by a researcher appointed specifically to conduct this study, it should be considered that presented views are influenced because several authors took part in this study as research participants. Overall, the strength of this study is that it provides a holistic account of a multidisciplinary co-design self-care project with a thematic analysis that identifies perceived benefits and challenges of co-design within this personal health context.

7 Conclusion

Research and development for human-centred health and wellbeing technologies requires domain knowledge and multidisciplinary expertise [31]. With key principles of diversity, collective creativity, and mutual learning, co-design approaches have significant potential of help address multidisciplinary challenges and inform innovative futures [47,48]. This interview study provides a qualitative account of a multidisciplinary project that aimed to co-design ML applications for T1D self-management. We have identified not only social, technological, and strategic benefits of co-design but also organisational, translational and pragmatic design challenges within this context: participants with T1D experienced difficulties in co-designing systems that met their individual self-care needs as part of group design activities; HCI and AI researchers described challenges applying co-design outcomes to data-driven ML work; and industry collaborators highlighted data sharing regulations as cross-organisational challenges. To support researchers and practitioners from different disciplinary backgrounds in conducting co-design to inform what can be very personal self-care and self-management systems, we contribute lessons learned on how co-designers could foster translational knowledge work as part of HCI-AI collaborations and support participants’ individual (and often incompatible) health needs throughout the co-design process.

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9 REFERENCES

- [1] American Association of Diabetes Edition. 2009. AADE Guidelines for the Practice of Diabetes Self-Management Education and Training (DSME/T). *Diabetes Educ* 35, 3_suppl (November 2009), 85S-107S. DOI:<https://doi.org/10.1177/0145721709352436>

- [2] Amid Ayobi, Paul Marshall, and Anna L. Cox. 2020. Trackly: A Customisable and Pictorial Self-Tracking App to Support Agency in Multiple Sclerosis Self-Care. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20)*, ACM Press. DOI:<https://doi.org/10.1145/3313831.3376809>
- [3] Pascal Béguin. 2003. Design as a mutual learning process between users and designers. *Interacting with Computers* 15, 5 (October 2003), 709–730. DOI:[https://doi.org/10.1016/S0953-5438\(03\)00060-2](https://doi.org/10.1016/S0953-5438(03)00060-2)
- [4] Francisco Bernardo, Michael Zbyszynski, Rebecca Fiebrink, and Mick Grierson. 2016. Interactive machine learning for end-user innovation. American Association for Artificial Intelligence (AAAI).
- [5] Andrew B. L. Berry, Catherine Y. Lim, Tad Hirsch, Andrea L. Hartzler, Linda M. Kiel, Zoë A. Bermet, and James D. Ralston. 2019. Supporting Communication About Values Between People with Multiple Chronic Conditions and their Providers. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, ACM, Glasgow Scotland Uk, 1–14. DOI:<https://doi.org/10.1145/3290605.3300700>
- [6] Robert D. Black. 2011. Recent advances in translational work on implantable sensors. *IEEE Sensors Journal* 11, 12 (2011), 3171–3182.
- [7] Ann Blandford, Jo Gibbs, Nikki Newhouse, Olga Perski, Aneesha Singh, and Elizabeth Murray. 2018. Seven lessons for interdisciplinary research on interactive digital health interventions. *DIGITAL HEALTH* 4, (January 2018), 205520761877032. DOI:<https://doi.org/10.1177/2055207618770325>
- [8] Susanne Bødker, Pelle Ehn, Dan Sjögren, and Yngve Sundblad. 2000. Co-operative Design—perspectives on 20 years with ‘the Scandinavian IT Design Model.’ In *Proceedings of NordiCHI, 22–24*.
- [9] Claus Bossen, Christian Dindler, and Ole Sejer Iversen. 2016. Evaluation in participatory design: a literature survey. In *Proceedings of the 14th Participatory Design Conference on Full papers - PDC '16*, ACM Press, Aarhus, Denmark, 151–160. DOI:<https://doi.org/10.1145/2940299.2940303>
- [10] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (January 2006), 77–101. DOI:<https://doi.org/10.1191/1478088706qp0630a>
- [11] B. Buxton. 2010. *Sketching User Experiences: Getting the Design Right and the Right Design*. Elsevier Science. Retrieved from <https://books.google.co.uk/books?id=2vfPxocmLh0C>
- [12] Betty P. I. Chang, Thomas L. Webb, and Yael Benn. 2017. Why Do People Act Like the Proverbial Ostrich? Investigating the Reasons That People Provide for Not Monitoring Their Goal Progress. *Front. Psychol.* 8, (February 2017). DOI:<https://doi.org/10.3389/fpsyg.2017.00152>
- [13] F. Charles Mace. 2018. Tony Nevin: The embrace of translational work by a basic scientist. *Journal of the experimental analysis of behavior* 109, 1 (2018), 56–65.
- [14] Kathy Charmaz and Richard G. Mitchell. 2001. Grounded theory in ethnography. *Handbook of ethnography* (2001), 160–174.
- [15] Yunan Chen. 2010. Take It Personally: Accounting for Individual Difference in Designing Diabetes Management Systems. In *Proceedings of the 8th ACM Conference on Designing Interactive Systems (DIS '10)*, ACM, New York, NY, USA, 252–261. DOI:<https://doi.org/10.1145/1858171.1858218>
- [16] Eun Kyoung Choe, Saed Abdullah, Mashfiqui Rabbi, Edison Thomaz, Daniel A. Epstein, Felicia Cordeiro, Matthew Kay, Gregory D. Abowd, Tanzeem Choudhury, James Fogarty, Bongshin Lee, Mark Matthews, and Julie A. Kientz. 2017. Semi-Automated Tracking: A Balanced Approach for Self-Monitoring Applications. *IEEE Pervasive Computing* 16, 1 (January 2017), 74–84. DOI:<https://doi.org/10.1109/MPRV.2017.18>
- [17] Chia-Fang Chung, Kristin Dew, Allison M Cole, Jasmine Zia, James A Fogarty, Julie A Kientz, and Sean A Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. ACM Press, 768–784. DOI:<https://doi.org/10.1145/2818048.2819926>
- [18] Luigina Ciolfi, Gabriela Avram, Laura Maye, Nick Dulake, Mark T. Marshall, Dick van Dijk, and Fiona McDermott. 2016. Articulating Co-Design in Museums: Reflections on Two Participatory Processes. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*, ACM, San Francisco California USA, 13–25. DOI:<https://doi.org/10.1145/2818048.2819967>
- [19] Aurora Constantin, Jessica Korte, Cara Wilson, Cristina Adriana Alexandru, Judith Good, Gavin Sim, Janet Read, Jerry Alan Fails, and Eva Eriksson. 2020. Planning the world’s most inclusive PD project. In *Proceedings of the 2020 ACM Interaction Design and Children Conference: Extended Abstracts*, ACM, London United Kingdom, 118–125. DOI:<https://doi.org/10.1145/3397617.3398066>
- [20] Daniel Cukor, Lewis M. Cohen, Elizabeth L. Cope, Nasrollah Ghahramani, S. Susan Hedayati, Denise M. Hynes, Vallabh O. Shah, Francesca Tentori, Mark Unruh, Jeanette Bobelu, Scott Cohen, Laura M. Dember, Thomas Faber, Michael J. Fischer, Rani Gallardo, Michael J. Germain, Donica Ghahate, Nancy Grote, Lori Hartwell, Patrick Heagerty, Paul L. Kimmel, Nancy Kutner, Susan Lawson, Lisa Marr, Robert G. Nelson, Anna C. Porter, Phillip Sandy, Bruce B. Struminger, Lalita Subramanian, Steve Weisbord, Bessie Young, and Rajnish Mehrotra. 2016. Patient and Other Stakeholder Engagement in Patient-Centered Outcomes Research Institute Funded Studies of Patients with Kidney Diseases. *Clin J Am Soc Nephrol* 11, 9 (07 2016), 1703–1712. DOI:<https://doi.org/10.2215/CJN.09780915>

- [21] Sean T. Doherty and Stephen P. Greaves. 2015. Time-Series Analysis of Continuously Monitored Blood Glucose: The Impacts of Geographic and Daily Lifestyle Factors. *Journal of Diabetes Research* 2015, (2015), 1–6. DOI:<https://doi.org/10.1155/2015/804341>
- [22] Klaus Donsa, Stephan Spat, Peter Beck, Thomas R. Pieber, and Andreas Holzinger. 2015. Towards Personalization of Diabetes Therapy Using Computerized Decision Support and Machine Learning: Some Open Problems and Challenges. In *Smart Health: Open Problems and Future Challenges*, Andreas Holzinger, Carsten Röcker and Martina Ziefle (eds.). Springer International Publishing, Cham, 237–260. DOI:https://doi.org/10.1007/978-3-319-16226-3_10
- [23] Afsaneh Doryab, Mads Frost, Maria Faurholt-Jepsen, Lars V. Kessing, and Jakob E. Bardram. 2015. Impact factor analysis: combining prediction with parameter ranking to reveal the impact of behavior on health outcome. *Pers Ubiquit Comput* 19, 2 (February 2015), 355–365. DOI:<https://doi.org/10.1007/s00779-014-0826-8>
- [24] Graham Dove and Anne-Laure Fayard. 2020. Monsters, Metaphors, and Machine Learning. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, Honolulu HI USA, 1–17. DOI:<https://doi.org/10.1145/3313831.3376275>
- [25] Graham Dove, Kim Halskov, Jodi Forlizzi, and John Zimmerman. 2017. UX Design Innovation: Challenges for Working with Machine Learning as a Design Material. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, ACM, Denver Colorado USA, 278–288. DOI:<https://doi.org/10.1145/3025453.3025739>
- [26] Chris Elsdén, Bettina Nissen, Andrew Garbett, David Chatting, David Kirk, and John Vines. 2016. Metadating: Exploring the Romance and Future of Personal Data. ACM, 685–698. DOI:<https://doi.org/10.1145/2858036.2858173>
- [27] Chris Elsdén, Ella Tallyn, and Bettina Nissen. 2020. When Do Design Workshops Work (or Not)? In *Companion Publication of the 2020 ACM Designing Interactive Systems Conference (DIS '20 Companion)*, Association for Computing Machinery, New York, NY, USA, 245–250. DOI:<https://doi.org/10.1145/3393914.3395856>
- [28] Martha M. Funnell and Robert M. Anderson. 2004. Empowerment and Self-Management of Diabetes. *Clinical Diabetes* 22, 3 (July 2004), 123–127. DOI:<https://doi.org/10.2337/diaclin.22.3.123>
- [29] Fabien Girardin and Neal Lathia. 2017. When User Experience Designers Partner with Data Scientists. In *AAAI Spring Symposia*.
- [30] Richard Grant and Len Finocchio. 1995. *Interdisciplinary collaborative teams in primary care: A model curriculum and resource guide*. Pew Health Professions Commission.
- [31] Richard H. R. Harper. 2019. The Role of HCI in the Age of AI. *International Journal of Human–Computer Interaction* 35, 15 (September 2019), 1331–1344. DOI:<https://doi.org/10.1080/10447318.2019.1631527>
- [32] Christina N. Harrington, Lauren Wilcox, Kay Connelly, Wendy Rogers, and Jon Sanford. 2018. Designing Health and Fitness Apps with Older Adults: Examining the Value of Experience-Based Co-Design. In *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '18)*, Association for Computing Machinery, New York, NY, USA, 15–24. DOI:<https://doi.org/10.1145/3240925.3240929>
- [33] Niels Hendriks, Liesbeth Huybrechts, Andrea Wilkinson, and Karin Slegers. 2014. Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference on Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - PDC '14 - volume 2*, ACM Press, Windhoek, Namibia, 33–36. DOI:<https://doi.org/10.1145/2662155.2662196>
- [34] Lars Holmquist. 2017. Intelligence on tap: AI as a new design material. *Intelligence* (2017).
- [35] Ole Sejer Iversen, Kim Halskov, and Tuck W. Leong. 2012. Values-led participatory design. *CoDesign* 8, 2–3 (June 2012), 87–103. DOI:<https://doi.org/10.1080/15710882.2012.672575>
- [36] Simon Katan, Mick Grierson, and Rebecca Fiebrink. 2015. Using Interactive Machine Learning to Support Interface Development Through Workshops with Disabled People. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, ACM Press, Seoul, Republic of Korea, 251–254. DOI:<https://doi.org/10.1145/2702123.2702474>
- [37] Finn Kensing and Jeanette Blomberg. 1998. Participatory design: Issues and concerns. *Computer Supported Cooperative Work (CSCW)* 7, 3–4 (1998), 167–185.
- [38] Young-Ho Kim, Jae Ho Jeon, Bongshin Lee, Eun Kyoung Choe, and Jinwook Seo. 2017. OmniTrack: A Flexible Self-Tracking Approach Leveraging Semi-Automated Tracking. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies* 1, 3 (September 2017), 28. DOI:<https://doi.org/10.1145/3130930>
- [39] David C. Klonoff and David Kerr. 2018. Overcoming Barriers to Adoption of Digital Health Tools for Diabetes. *J Diabetes Sci Technol* 12, 1 (January 2018), 3–6. DOI:<https://doi.org/10.1177/1932296817732459>
- [40] Charlotte P. Lee. 2007. Boundary Negotiating Artifacts: Unbinding the Routine of Boundary Objects and Embracing Chaos in Collaborative Work. *Comput Supported Coop Work* 16, 3 (June 2007), 307–339. DOI:<https://doi.org/10.1007/s10606-007-9044-5>
- [41] Min Hun Lee, Daniel P. Siewiorek, Asim Smailagic, Alexandre Bernardino, and Sergi Bermúdez i Badia. 2020. Co-Design and Evaluation of an Intelligent Decision Support System for Stroke Rehabilitation Assessment. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW2 (October 2020), 1–27. DOI:<https://doi.org/10.1145/3415227>

- [42] Tuck Wah Leong and Ole Sejer Iversen. 2015. Values-led Participatory Design as a Pursuit of Meaningful Alternatives. In *Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction*, ACM, Parkville VIC Australia, 314–323. DOI:<https://doi.org/10.1145/2838739.2838784>
- [43] Cynthia LeRouge and Nilmini Wickramasinghe. 2013. A Review of User-Centered Design for Diabetes-Related Consumer Health Informatics Technologies. *J Diabetes Sci Technol* 7, 4 (July 2013), 1039–1056. DOI:<https://doi.org/10.1177/193229681300700429>
- [44] Yvonne Leung. 2013. Perceived Benefits. In *Encyclopedia of Behavioral Medicine*, Marc D. Gellman and J. Rick Turner (eds.). Springer New York, New York, NY, 1450–1451. DOI:https://doi.org/10.1007/978-1-4419-1005-9_1165
- [45] Catherine Y. Lim, Andrew B. L. Berry, Tad Hirsch, Andrea L. Hartzler, Edward H. Wagner, Evette J. Ludman, and James D. Ralston. 2017. Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients’ Perspectives. *J Gen Intern Med* 32, 12 (December 2017), 1278–1284. DOI:<https://doi.org/10.1007/s11606-017-4154-3>
- [46] Susanne Lindberg. 2013. Participatory design workshops with children with cancer: lessons learned. In *Proceedings of the 12th International Conference on Interaction Design and Children - IDC '13*, ACM Press, New York, New York, 332–335. DOI:<https://doi.org/10.1145/2485760.2485840>
- [47] Daria Loi, Thomas Lodato, Christine T. Wolf, Raphael Arar, and Jeanette Blomberg. 2018. PD manifesto for AI futures. In *Proceedings of the 15th Participatory Design Conference on Short Papers, Situated Actions, Workshops and Tutorial - PDC '18*, ACM Press, Hasselt and Genk, Belgium, 1–4. DOI:<https://doi.org/10.1145/3210604.3210614>
- [48] Daria Loi, Christine T. Wolf, Jeanette L. Blomberg, Raphael Arar, and Margot Brereton. 2019. Co-designing AI Futures: Integrating AI Ethics, Social Computing, and Design. In *Companion Publication of the 2019 on Designing Interactive Systems Conference 2019 Companion - DIS '19 Companion*, ACM Press, San Diego, CA, USA, 381–384. DOI:<https://doi.org/10.1145/3301019.3320000>
- [49] Ewa Luger, Lachlan Urquhart, Tom Rodden, and Michael Golembewski. 2015. Playing the Legal Card: Using Ideation Cards to Raise Data Protection Issues within the Design Process. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, ACM Press, Seoul, Republic of Korea, 457–466. DOI:<https://doi.org/10.1145/2702123.2702142>
- [50] Michael A. Madaio, Luke Stark, Jennifer Wortman Vaughan, and Hanna Wallach. 2020. Co-Designing Checklists to Understand Organizational Challenges and Opportunities around Fairness in AI. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, Honolulu HI USA, 1–14. DOI:<https://doi.org/10.1145/3313831.3376445>
- [51] Lena Mamykina, Andrew D. Miller, Elizabeth D. Mynatt, and Daniel Greenblatt. 2010. Constructing identities through storytelling in diabetes management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, ACM, 1203–1212. Retrieved January 31, 2016 from <http://dl.acm.org/citation.cfm?id=1753507>
- [52] Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '08)*, ACM, New York, NY, USA, 477–486. DOI:<https://doi.org/10.1145/1357054.1357131>
- [53] Julia M. Mayer and Jelena Zach. 2013. Lessons learned from participatory design with and for people with dementia. In *Proceedings of the 15th international conference on Human-computer interaction with mobile devices and services - MobileHCI '13*, ACM Press, Munich, Germany, 540. DOI:<https://doi.org/10.1145/2493190.2494436>
- [54] M. McGee-Lennon, A. Smeaton, and S. Brewster. 2012. Designing home care reminder systems: Lessons learned through co-design with older users. In *2012 6th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops*, 49–56. DOI:<https://doi.org/10.4108/icst.pervasivehealth.2012.248684>
- [55] Oussama Metatla, Alison Oldfield, Taimur Ahmed, Antonis Vafeas, and Sunny Miglani. 2019. Voice User Interfaces in Schools: Co-designing for Inclusion with Visually-Impaired and Sighted Pupils. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19)*, Association for Computing Machinery, New York, NY, USA, 1–15. DOI:<https://doi.org/10.1145/3290605.3300608>
- [56] Timothy Neate, Aikaterini Bourazeri, Abi Roper, Simone Stumpf, and Stephanie Wilson. 2019. Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, ACM, Glasgow Scotland Uk, 1–12. DOI:<https://doi.org/10.1145/3290605.3300880>
- [57] Birgitte Noergaard, Marianne Sandvei, Nina Rottmann, Helle Johannessen, Uffe Wiil, Thomas Schmidt, and Susanne S Pedersen. 2017. Development of a Web-Based Health Care Intervention for Patients With Heart Disease: Lessons Learned From a Participatory Design Study. *JMIR Res Protoc* 6, 5 (May 2017), e75. DOI:<https://doi.org/10.2196/resprot.7084>
- [58] Donald A. Norman. 2010. The Research-practice Gap: The Need for Translational Developers. *interactions* 17, 4 (July 2010), 9–12. DOI:<https://doi.org/10.1145/1806491.1806494>

- [59] Francisco Nunes, Nervo Verdezoto, Geraldine Fitzpatrick, Morten Kyng, Erik Grönvall, and Cristiano Storni. 2015. Self-Care Technologies in HCI: Trends, Tensions, and Opportunities. *ACM Trans. Comput.-Hum. Interact.* 22, 6 (December 2015), 33:1-33:45. DOI:<https://doi.org/10.1145/2803173>
- [60] Aisling Ann O’Kane, Sun Young Park, Helena Mentis, Ann Blandford, and Yunan Chen. 2016. Turning to Peers: Integrating Understanding of the Self, the Condition, and Others’ Experiences in Making Sense of Complex Chronic Conditions. *Computer Supported Cooperative Work (CSCW)* 25, 6 (2016), 477–501.
- [61] Aisling Ann O’Kane, Yvonne Rogers, and Ann E. Blandford. 2015. Concealing or Revealing Mobile Medical Devices?: Designing for Onstage and Offstage Presentation. In *Proceedings of the 33rd annual ACM conference on human factors in computing systems*, ACM, 1689–1698.
- [62] S. Oliver, L. Clarke-Jones, R. Rees, R. Milne, P. Buchanan, J. Gabbay, G. Gyte, A. Oakley, and K. Stein. 2004. Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. 8. Retrieved September 10, 2020 from <https://eprints.soton.ac.uk/62007/>
- [63] Anne Marie Piper and Amanda Lazar. 2018. Co-design in health: what can we learn from art therapy? *Interactions* 25, 3 (April 2018), 70–73. DOI:<https://doi.org/10.1145/3194353>
- [64] Åsa Revenäs, Helena Hvitfeldt Forsberg, Emma Granström, and Carolina Wannheden. 2018. Co-Designing an eHealth Service for the Co-Care of Parkinson Disease: Explorative Study of Values and Challenges. *JMIR Res Protoc* 7, 10 (October 2018), e11278. DOI:<https://doi.org/10.2196/11278>
- [65] John Rooksby, Mattias Rost, Alistair Morrison, and Matthew Chalmers Chalmers. 2014. Personal Tracking As Lived Informatics. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI ’14)*, ACM, New York, NY, USA, 1163–1172. DOI:<https://doi.org/10.1145/2556288.2557039>
- [66] Peter Slattery, Alexander K. Saeri, and Peter Bragge. 2020. Research co-design in health: a rapid overview of reviews. *Health Res Policy Sys* 18, 1 (December 2020), 17. DOI:<https://doi.org/10.1186/s12961-020-0528-9>
- [67] Susan Leigh Star and James R. Griesemer. 1989. Institutional ecology, translations’ and boundary objects: Amateurs and professionals in Berkeley’s Museum of Vertebrate Zoology, 1907-39. *Social studies of science* 19, 3 (1989), 387–420.
- [68] Marc Steen. 2013. Co-design as a process of joint inquiry and imagination. *Design Issues* 29, 2 (2013), 16–28.
- [69] Marc Steen, Jenny de Boer, Lilliane Kuiper-Hoyng, and Froukje Sleswijk Visser. 2008. Co-design: practices, challenges and lessons learned. In *Proceedings of the 10th international conference on Human computer interaction with mobile devices and services (MobileHCI ’08)*, Association for Computing Machinery, New York, NY, USA, 561–562. DOI:<https://doi.org/10.1145/1409240.1409350>
- [70] Marc Steen, Menno Manschot, and Nicole De Koning. 2011. Benefits of co-design in service design projects. *International Journal of Design* 5, 2 (2011).
- [71] Cristiano Storni. 2013. Design challenges for ubiquitous and personal computing in chronic disease care and patient empowerment: a case study rethinking diabetes self-monitoring. *Pers Ubiquit Comput* 18, 5 (August 2013), 1277–1290. DOI:<https://doi.org/10.1007/s00779-013-0707-6>
- [72] Petra Sundström, Alex Taylor, Katja Grufberg, Niklas Wirström, Jordi Solsona Belenguier, and Marcus Lundén. 2011. Inspirational bits: towards a shared understanding of the digital material. In *Proceedings of the 2011 annual conference on Human factors in computing systems - CHI ’11*, ACM Press, Vancouver, BC, Canada, 1561. DOI:<https://doi.org/10.1145/1978942.1979170>
- [73] Shari Trewin, Sara Basson, Michael Muller, Stacy Branham, Jutta Treviranus, Daniel Gruen, Daniel Hebert, Natalia Lyckowski, and Erich Manser. 2019. Considerations for AI fairness for people with disabilities. *AI Matters* 5, 3 (December 2019), 40–63. DOI:<https://doi.org/10.1145/3362077.3362086>
- [74] Maja Van der Velden, C. Mörtberg, J. Van den Hoven, P. E. Vermaas, and I. Van de Poel. 2014. Participatory design and design for values. *Development* 11, 3 (2014), 215–236.
- [75] Clare Villalba, Anjali Jaiprakash, Jared Donovan, Jonathan Roberts, and Ross Crawford. 2019. Testing literature-based health experience insight cards in a healthcare service co-design workshop. *CoDesign* (January 2019), 1–13. DOI:<https://doi.org/10.1080/15710882.2018.1563617>
- [76] Greg Walsh and Eric Wronsky. 2019. AI + Co-Design: Developing a Novel Computer-supported Approach to Inclusive Design. In *Conference Companion Publication of the 2019 on Computer Supported Cooperative Work and Social Computing*, ACM, Austin TX USA, 408–412. DOI:<https://doi.org/10.1145/3311957.3359456>
- [77] Chelsea-Joy Wardle, Mitchell Green, Christine Wanjiru Mburu, and Melissa Densmore. 2018. Exploring Co-design with Breastfeeding Mothers. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI ’18)*, Association for Computing Machinery, New York, NY, USA, 1–12. DOI:<https://doi.org/10.1145/3173574.3174056>
- [78] Cara Wilson, Margot Brereton, Bernd Ploderer, and Laurianne Sitbon. 2019. Co-Design Beyond Words: “Moments of Interaction” with Minimally-Verbal Children on the Autism Spectrum. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI ’19*, ACM Press, Glasgow, Scotland Uk, 1–15. DOI:<https://doi.org/10.1145/3290605.3300251>

- [79] Julia Woodward, Zari McFadden, Nicole Shiver, Amir Ben-hayon, Jason C. Yip, and Lisa Anthony. 2018. Using Co-Design to Examine How Children Conceptualize Intelligent Interfaces. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*, Association for Computing Machinery, New York, NY, USA, 1–14. DOI:<https://doi.org/10.1145/3173574.3174149>
- [80] Niels Wouters, Jonathan Huyghe, and Andrew Vande Moere. 2014. StreetTalk: participative design of situated public displays for urban neighborhood interaction. In *Proceedings of the 8th Nordic Conference on Human-Computer Interaction Fun, Fast, Foundational - NordiCHI '14*, ACM Press, Helsinki, Finland, 747–756. DOI:<https://doi.org/10.1145/2639189.2641211>
- [81] Qian Yang, Justin Cranshaw, Saleema Amershi, Shamsi T. Iqbal, and Jaime Teevan. 2019. Sketching NLP: A Case Study of Exploring the Right Things To Design with Language Intelligence. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, Glasgow, Scotland Uk, 1–12. DOI:<https://doi.org/10.1145/3290605.3300415>
- [82] Qian Yang, Alex Scuito, John Zimmerman, Jodi Forlizzi, and Aaron Steinfeld. 2018. Investigating How Experienced UX Designers Effectively Work with Machine Learning. In *Proceedings of the 2018 on Designing Interactive Systems Conference 2018 - DIS '18*, ACM Press, Hong Kong, China, 585–596. DOI:<https://doi.org/10.1145/3196709.3196730>
- [83] Qian Yang, Aaron Steinfeld, Carolyn Rosé, and John Zimmerman. 2020. Re-examining Whether, Why, and How Human-AI Interaction Is Uniquely Difficult to Design. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, Honolulu HI USA, 1–13. DOI:<https://doi.org/10.1145/3313831.3376301>

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