Values Before Variables: Why HCI Should Design “Boring” Digital Health Infrastructure

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Human-Computer Interaction (HCI) in digital health frequently focuses on designing decision aids and interfaces to solve complex frictions. Yet, in paediatric type 1 diabetes, deploying a beautifully designed Shared Decision Making (SDM) tool into rigid, linear clinical pathways leads to an illusion of choice. Our objective is to provoke the HCI community to look beyond the user interface and engage with the messy, “boring” hidden work of clinical service design by establishing a continuous, values-based SDM architecture. Co-design with 90 young people, their families and healthcare team took place within a hectic clinical environment, blending methodologies in response to resources and needs. A “Dual-Loop” architecture replaced a conventional pathway: an initial cycle ensuring values precede choice, followed by ongoing optimisation accommodating shifting clinical and personal realities. The dual-loop changed behaviours: 38% of families reconsidered their initial technology choice, shifting away from assumption-based decisions to those matching their values. HCI must stop treating clinical workflows as unchangeable or out of scope. Rigid clinical norms and activities can be separated and rebuilt as adaptable systems that survive the messy realities of young lives. The Dual-Loop generates space for effective communication and sustainable technology adoption, transferable to other self-managed chronic conditions.

Shared Decision-Making. Co-Design. Human Values.

1. INTRODUCTION

1.1. Shared Decision Making

In recent years, Shared Decision Making (SDM) has gathered momentum as an effective mechanism for collating evidence-based information and patient views, and bringing them into a conversation with healthcare professionals (HCPs) as well as tackling health inequalities (Elwyn *et al.*, 2012; Dennison Himmelfarb *et al.*, 2023). Kunneman et al describe SDM as a “process, a conversation between clinicians and patients in which they think, talk, and feel through the situation of each patient” (Kunneman *et al.*, 2016). Within this process, SDM offers the opportunity to align individual preferences alongside clinical counsel, whilst making high-quality medical evidence accessible.

Different SDM tools may be used depending on the context of the decision to be made. If a specific problem / decision can be defined and supported by evidence-based information, decision aids, such as pamphlets or digital information, may be made available to allow patients to prepare for clinical consultations (Stiggelbout *et al.*, 2012). Conversation aids have also been developed to encourage high-quality conversations (Zeballos-Palacios *et al.*, 2019). These aids may be present in some SDM scenarios but are not essential for SDM. However, access to high-quality SDM training and tools is incomplete (Légaré and Witteman, 2013), generating the risk of inadequate conversations, poor decisions and a tick-box exercise (Boland *et al.*, 2019).

1.2. Self-Managed Chronic Conditions

For those living with life-long chronic conditions, such as type 1 diabetes (T1D), individuals often navigate hundreds of self-management decisions every day, outside of direct clinical care.

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Reconnecting patients, families and HCPs around the most significant of these, such as choosing or optimising their diabetes technology choices, is an opportunity for SDM. This is illustrated by the availability of SDM tools such as the SDM Tool for Hybrid Closed Loop (HCL) system used in the UK's National Health Service (NHS) (NHS England, 2025). Whilst many of these available tools are excellent at summarising and presenting medical information to the target patient population, there are nuanced, complicated, and potentially conflicting decision drivers across individuals, families and HCPs that may not be captured. The significance of this diversity is recognised in human-centred design (Flood *et al.*, 2021) and human computer interaction methods (Balcombe and De Leo, 2022). As Katz wrote "No single right decision exists for how the life of health and illness should be lived […] Physicians and patients bring their own vulnerabilities to the decision-making process. Both are authors and victims of their own individual conflicting motivations, interests, and expectations. Identity of interests cannot be presumed. It can only be established through conversation" (Katz, 1984).

Similar to other research within HCI, we use T1D as an exemplar of a self-managed chronic condition because of the significant amount of technology already embedded in self-management (e.g. glucose meters, insulin pumps, etc) (Shin and Holtz, 2020; Gordon James *et al.*, 2023; Gerstenberg *et al.*, 2025). The standard model of care for living with T1D increasingly involves using HCL systems, which attempt to titrate automated insulin delivery to keep blood glucose levels in a safe range (Griffin *et al.*, 2023). Within this context, our objective was to go beyond blood glucose control to encompass diverse and individual factors such as quality of life, emotional well-being, and lifestyle as part of the technology choice. From the HCP perspective, our aim was to connect this subjective, qualitative data about values and experiences to help identify and mitigate clinical risks for individual patients on HCL systems. This is in line with moves towards 'person centred care' being rolled out in the NHS (*Fit for the future: 10 Year Health Plan* for *England*, 2025). Capturing "What Matters to You" (WMTY) allows clinical teams to focus on person-centred care, prioritising the individual's experience and values alongside their clinical, disease-centric requirements (Elwyn *et al.*, 2012).

1.3. HCI and Device Choice

The selection, adoption and optimisation of medical devices for chronic condition self-management is increasingly understood not as a single decision, but as a complex, ongoing negotiation with evolving personal and clinical needs. Contemporary human-centred design emphasises the lived experience and the reality of integrating technology into the often messy context of daily life. Research indicates many healthcare technology failures stem from a misalignment with users real-world needs and expectations, generating excessive cognitive load, rather than due to technical issues (Wang *et al.*, 2023; Tzimourta, 2025).

Thinking more broadly, frameworks such as the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) model highlight that health technology adoption can fail when complexity is too high, or a mismatch between the technology, its perceived value proposition, and the realities of its use in the real world (Greenhalgh *et al.*, 2017, 2020). Medical device choice must move beyond standard clinical information provision and explicitly align to an individual's unique values, privacy preferences, and tolerance for device burden (Winter and Chico, 2023). Whilst HCI has historically focused on tools and interfaces that facilitate this aim, little interest appears to have been given to the context that they will be deployed in (Ackerman, 2000; Harrison, Koppel and Bar-Lev, 2007; Lyon *et al.*, 2023; Waddell *et al.*, 2024).

Despite the complexities of medical device adoption, ongoing burden and related abandonment, there remains a gap in practical HCI research designed to build the systems and frameworks that these devices and tools will fit into. Perhaps this is due to the messiness and complexity of health systems, that can require compromise in academic methodologies in order to fit into the tight resource and regulatory boxes provided. Perhaps it is due to the perceived distance from most HCI interventions. But without tackling and updating the pathways that patients, families and HCPs are travelling on, HCI work in healthcare risks remaining on the shelf and not in the hands of those who might benefit. The most urgent HCI intervention in digital health right now isn't on the screen; it is in the "boring," hidden work of clinical service architecture. Our provocation is that HCI needs to stop treating clinical pathways and systems as work for others and start designing the workflow itself. To demonstrate this, we present an exemplar of shifting a paediatric diabetes unit from a linear prescribing model to an enabling "Dual-Loop" SDM architecture.

2. INTERVENING IN THE CLINICAL PATHWAY

2.1. Needs Discovery

As part of a larger Quality Improvement (QI) project, patients (between 4 – 18 years of age) and parents from within the Paediatric Diabetes Unit (PDU) at University Hospital Southampton (UHS) were invited to share their expert opinions and preferences. All participants were informed that taking part in this work would not impact their individual clinical care and that there was no obligation to contribute.

Healthcare Professionals (HCP) from across the PDU Multidisciplinary Team (MDT) at UHS were invited to share their specialist perspectives. Opinions were captured from paediatric specialist diabetes nurses, endocrinologists, phycologists, pharmacists, dieticians and clinical scientists.

Following the principles of the double-diamond design process, it was important to establish and validate the broad patient, family and MDT needs around selecting and using insulin pump technologies, including HCL systems. Although anecdotal information was available via clinic interactions and UHS has a track record of proactively offering diabetes technologies, two survey activities were undertaken to establish key perceptions, experiences and concerns, including hidden burden, from existing patients, families and staff.

2.2. Prototyping Core Components

Based on our initial design needs activities, preliminary components of the SDM pathway were prototyped and shared across the MDT for feedback. Digital assets were created that could potentially be used in family's own time or face-to-face with a keyworker from the PDU. These were focused on an interactive shared decision aid and a package which aimed to identify patient and family preferences and values. An in-person information sharing event agenda was also generated as part of the planned pathway.

Families and patients were invited to attend two focus groups, facilitated by a member of the project team. The prototype core components were shared in advance, and participants were invited to talk, as a group, about the prototype tools, with minimal facilitation to ensure all voices were heard and all aspects of the prototype tools were reviewed by the groups.

Initial testing took place in a live clinical environment, with these early prototype components as part of a linear (single loop) pathway (Table 1) prescribing the flow of patients through their shared HCL decision.

2.3. Dual-Loop: Incorporating Clinical Norms

In response to feedback from the focus groups, as well as coming back to the initial design needs outputs, the SDM scope was expanded to include ongoing HCL optimisation and incorporation of clinical norms, resulting in a dual-loop pathway architecture, released as part of an expanded dual-loop pathway. Evaluation of this dual-loop pathway was undertaken within the PDU clinical environment. Insights and experiences were captured during an immediately after completing the pathway.

3. DISRUPTING THE ILLUSION OF CHOICE

3.1. The Illusion of Choice

Whilst the majority of respondents (86%) reported that their previous HCL choice was discussed within an existing clinic appointment, but only 32% said they had the opportunity of hands-on experience of a system and 21% said they'd reconsider their decision if they could. In terms of their perception of the involvement of the young individual living with diabetes, 19% felt the child was either "Not very involved" or "Not involved at all." For those who had previously chosen a system, 42% said that they found the decision "Hard" or "Very Hard" and 12% felt "Unable to weigh the options." These responses confirm that although choice is visible in the system pathway, for many individuals it remains an illusion of choice. This is not a patient (or HCP) failure, but a system failure. The conventional pathway forces assumption-based choices masquerading as patient agency. Building beautifully designed decision aids to slot into these rigid clinical norms has unintentionally upheld this illusion.

3.2. Prototyping Initial Framework

When asking participants to project what they'd like to see looking forward, responses included functional aspects of using HCL systems during their journeys, environmental context, such as use outside of the home and whilst at school, but also interface and communication preferences.

When it came to communication preferences, and contextual information around living with HCL, key insights led to the expansion of scope of some of the prototype components, in particular around producing interactive tools that layered information and focused on simple, visual information where possible to prevent "information overload" reported (Table 1).

Table 1: Core initial prototype components and key features

Core Prototype Components	Key Features
HCL Discovery Event	*In person* *Introduction to HCL* *Overview of all available HCL systems* *Hands-on opportunity with every HCL* *Meeting / hearing from CYP on HCL*
Interactive HCL SDM Aid	*Interactive digital tool* *Dynamic to avoid overload* *Visually engaging and multimedia* *MDI vs HCL overview* *Overview -> detail* *independently curated for all HCL systems*

	Covers sport with individual systems
What Matters to You Questionnaire	*Across multiple environments / scenarios (overnight, school and exercise)*
Features Table (Red-Amber-Green)	*Visually highlights differences across all systems* *Mixture of practical and functional (e.g. size, sport, interaction)*

3.3. Dual-Loop Architecture

Participants at both stages highlighted the dynamic nature of living with T1D, in terms of technology, growing children and young people (CYP) and potentially changing family situations. Patients, families and their PDU have to navigate these changes in terms of needs, expectations and risks. With all but one of the HCL systems available requiring a 4-year commitment within the NHS, significant changes need to be allowed for. Although many of these can be predicted in broad-brush terms, for example, physiological changes around puberty, the menstrual cycle for girls and young women, and the shift from parent-led to young-person-led care, predicting the exact impact of these, as well as individual patient interests and preferences, four years in advance can be extremely challenging. All stakeholder groups were aware of these challenges, as demonstrated in the following quotes (Textbox 1.)

Textbox 1. Dynamic challenges around choosing an HCL system: participant insights

Puberty and Hormones: "[We now find] profiles are handy for … their cycles and keeping them more in range" – parent of CYP

Shifting Independence: "Seeing other types of pump may have been helpful to [us] due to the age of [the child], but now [the child] is older would be nice for them to see in real life… help them make a more informed choice about how they want to care for themselves" – parents of CYP; "My parents decided" - CYP

Shifting Priorities and Agency: "She would now love a patch pump" – parents of CYP; "[My child's] confidence and understanding grows quickly! ... It's hard when you then see other systems which are probably better suited but can't change" – parents of CYP

In order to address these challenges, we elected to move to a dual-loop architecture and capture both the initial HCL decision, but also ongoing optimisation opportunities and balancing with clinical norms and risks. Crucially this architecture is continuous, allowing for movement between the two loops, ensuring capture of knowledge transfer (for all stakeholders) is feasible. An overview of this architecture is shown in Figure 1. Where possible, existing clinical resources and events are placed into this architecture, with the pathway for each individual able to adapt to meet evolving needs.

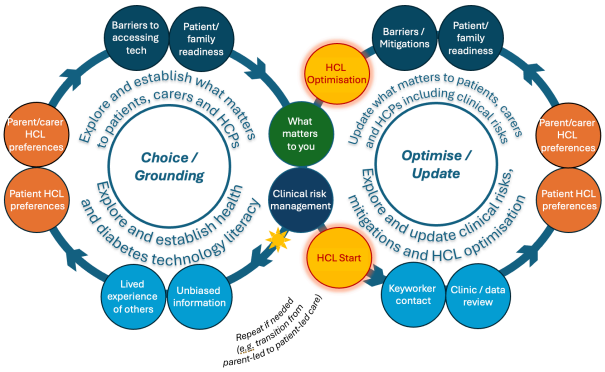


Figure 1. Dual-loop HCL SDM architecture

Loop 1 of the dual-loop system architecture contains the initial decision-making cycle focusses on starting well and sharing values and preferences. It contains HCL Discovery events, the HCL SDM Aid, What Matters to You tool, face-to-face contact and conversations, as well as core pre-HCL start training when required. It generates space to identify values and drivers, expectations of involvement and input required to successfully and effectively use HCL systems. With the overarching aim to start well, it leans into the COM-B behaviour change model (Michie, van Stralen and West, 2011), giving some visibility of their capability and capacity as well as the opportunity to develop skills, experience and confidence around using HCL in specific scenarios that are most important for each individual.

Presenting this as a loop allows stakeholders the freedom to adjust to family or clinical needs, by repeating or extending various components if necessary (or skipping those known). This was acknowledged by a parent in one of the focus groups: "Change is difficult… [we] inch along. [we see] dummy pumps, seeing it, making it real, but not scary as in [it's] happening tomorrow has been vital to us."

Loop 2, focuses on optimisation and balancing these with clinical risks and norms, drawing heavily on existing clinical resources (e.g. routine outpatient clinics), but also including reference (and, if required updates) to the "What Matters to You" conversation. It brings together routine data review with re-evaluation of patient and clinical needs, driving optimisation or, even, technology choice when applicable. Routine HCL optimisation may be handled within this second loop, but bigger changes and challenges may involve revisiting Loop 1 to boost knowledge, experience and insights across patients, families and the MDT (even if a change of HCL is not feasible under local procurement rules).

For those who had access to the dual-loop architecture when deployed as part of their routine care, 38% reconsidered their initial choice, compared to 17% for those exposed to the single-loop structure. This may indicate that the shift to the broader redesign of the workflow has redistributed power and changed behaviours beyond that achieved by the addition of the tool alone and illustrates the architectural consequences.

4. DISCUSSION AND CONCLUSIONS

During the prototyping phase, the mapping of lived components – in the case of T1D, examples include school anxiety, sports stigma, alarm fatigue – was crucial. This is the invisible, messy task of aligning medical devices with lives. The most critical design feature wasn't a digital intervention but the introduction of independent information events without industry presence, prioritising values before choice.

The transition from single-loop to dual-loop SDM is our core HCI intervention, with the doubling of reconsideration of initial device choice indicative of a redistribution of power in the clinic. The dual-loop architecture respects the expert input of both patients and families as well as their clinical teams. It forces the clinical system to continuously confront the messy reality of growing children, changing hormones and shifting independence. Whilst this paper doesn't prove effectiveness of this intervention, it demonstrates that by designing space for decision-making rather than just the tool, behaviour fundamentally changes.

Many of the components of this dual-loop SDM framework may appear to be boring from an HCI perspective; service architectures, information events, clinical pathways are usually left to others. However, we suggest that the exemplar presented here, essentially a structural hack to close the gap and tension across procurement and budget boundaries, with a rigid 4-year funding cycle, and the chaotic reality of puberty, school anxiety and shifting independence, demonstrates that these are essential and prerequisite for any sustainable HCI-driven digital health intervention. They confirm the immense, often invisible, work individuals living with self-managed conditions such as T1D, their families and healthcare teams do to make rigid technology fit chaotic lives.

The challenge for HCI researchers laid out in this paper is to embrace the messy, systemic work of designing infrastructures, rather than just adding interfaces. This approach creates space for decisions whilst also tackling inequalities and access, as well as reducing burden. Prioritising values before variables should be a prerequisite for any digital health intervention.

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