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## **Breaching, Bridging, and Bonding:**

### **Interweaving Pathways of Social-symbolic Work in a Flanked Healthcare Movement**

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**MANUSCRIPT ACCEPTED AT JOURNAL OF MANAGEMENT STUDIES**

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This project has received full ethics approval by University College Dublin's Humanities and Social Sciences Research Ethics Committee, approval no. HS-19-19.

## **Abstract**

This article explores how heterogeneous and distributed forms of social-symbolic work combine over time to yield synergistic relationships that precipitate institutional change. We study a collective effort by patient activists to change the technological and regulatory standards of Type-1 diabetes care. We offer contributions to radical flank theory by conceptualizing radical and moderate flanks as dynamic and overlapping pathways of action rather than fixed actor positions, and we show how a medial ‘bonding’ pathway can provide important social glue to connect the radical and moderate flanks. While in our case the material and discursive ‘hacking’ work in the breaching pathway disrupted institutions, triggered technology innovation, and created momentum for change, material and relational ‘bridging’ embedded these efforts into existing institutional structures and longer-term innovation trajectories. Values and amplification work in the bonding pathway served to keep the two other pathways aligned over time. By addressing how a complex social problem – patient-centric innovation - may be affected through heterogeneous social-symbolic work that leads to institutional accommodation, our study holds considerable policy and societal relevance.

**Keywords:** social-symbolic work; institutional change; social movements; radical flank theory; patient entrepreneurship; material work.

## INTRODUCTION

How disruptive do institutional challenges need to be to effect change? For instance, is the institutionally accommodating approach of Fridays for Future more or less likely to help thwart the climate catastrophe than Extinction Rebellion's more disruptive activities? And if both approaches serve different purposes toward a common goal, how can they fruitfully be combined? Answering these questions is particularly important when challengers tackle highly entrenched or dominant institutions and/or in situations where institutional change is of great societal relevance (Chimenti and Geiger, 2023; Claus and Tracey, 2020; Grodal and O'Mahony, 2017; Wijen and Ansari, 2007). On the one hand, change needs to be acceptable to institutional incumbents or it may be quashed, so too much disruption is likely counterproductive. On the other hand, if the disruption can easily be absorbed or ignored by institutional incumbents, real change may never happen. In some cases, the use of radical approaches by challengers may help the overall cause by making the moderate voices more palatable to the status quo; a phenomenon that social movement theory has termed the 'radical flank effect' (Downey and Rohlinger, 2008; Ellefsen, 2018; Haines, 1984; Schifeling and Hoffman, 2019). However, research in this area has little to say about how more or less radical practices might intertwine in realizing these positive effects. We turn to the recently consolidated notion of social-symbolic work (Barberá-Tomás et al., 2019; Claus and Tracey, 2020; Lawrence and Phillips, 2019; Mantere and Whittington, 2021) to shed light on the interweaving repertoires of action that different movement actors pursue in institutional change projects over time. Specifically, we lean on Lawrence and Phillips' (2019) three dimensions of social-symbolic work – material, discursive, and relational – to interrogate the sequencing, aligning, and integrating of different types of work embedded in more or less disruptive pathways of change (Micelotta et al., 2017). Cross-fertilizing the social-symbolic work and radical flank literatures, we ask: How can different, and more or less radical, forms

of social-symbolic work interweave over time to effect institutional change, and what type of change may be achieved through such interweaving?

We studied a group of patients and parents of children with Type 1 diabetes (T1D) who, in the early 2010s, started to challenge the technological and regulatory standards of T1D healthcare, which they felt were not only outdated but more importantly inattentive to the experiences of persons living with the chronic condition (Vidolov, Geiger, and Stendahl, in press). We leverage a longitudinal and multi-method research design through four complementary sets of data: Twitter posts, semi-structured interviews, observations, and archival documents. Our analysis reveals three broad social-symbolic work ‘pathways’ among these patient entrepreneurs and activists, which proved highly complementary over time. The ‘breaching’ pathway included activities that disrupted industry incumbents and regulators and created pressure on them through material breach work and discursive breach work – in our case, ‘hacking’ commercial T1D technology, risking legal persecution. Those who engaged in the ‘bridging’ pathway seized on this institutional breach but pursued a more moderate pathway to change; this pathway saw members collaborating with industry incumbents and regulators to co-develop T1D technology through material and relational bridge work. Situated between these two pathways and keeping them aligned around shared goals, the ‘bonding’ pathway included values work and amplification work (Bertels, Hoffman and DeJordy, 2014; Gehman, Trevino and Garud, 2013), which corralled and sustained the collective effort.

Being at once sensitive to the “complex (and typically collective) nature of institutional change” (Micelotta et al., 2017, p. 1893) and to the dynamic interrelationships between more or less radical forms of work allows us to hypothesize the type of change that such interweaving is likely to lead to. In our case, we observed institutional accommodation in Micelotta et al.’s (2017) vocabulary: change that is revolutionary in pace and

developmental in scope. Where work in the radical ‘breaching’ pathway provides the impetus for change and keeps its momentum up, work in the moderate ‘bridging’ pathway continually reinserts this change into institutional givens, preventing it from becoming too institutionally disruptive. Our process model thus adds important granularity to Micelotta et al.’s (2017) pathways of change framework by starting to uncover the varied micro-processes involved in achieving particular types of change. It also offers novel insights into social-symbolic work by demonstrating how more or less disruptive combinations of material, discursive, and relational work can beneficially combine over time, with one type of work becoming a vital resource for others as the change process unfolds. Our case lends itself particularly well to moving beyond the field’s emphasis on discursive change strategies (Schifeling and Hoffman, 2019) by emphasizing the importance of material breach work to trigger institutional change. We define material breach work as the illicit altering of material artifacts that are central to an institution’s or organization’s practices. At the same time, we highlight how this work needs to be framed by other types of work to achieve its intended effects.

Our study refocuses radical flank theory from structural concerns to the manifold repertoires of action challengers deploy. Asking what exactly it is that ‘radicals’, ‘moderates’, or other movement actors do and how these activities interlink, our perspective opens up the possibility that the ‘radical’ and ‘moderate’ approaches in a flanked movement are in fact bundles of dynamic and at times overlapping practices rather than fixed actor positions. We highlight the importance of the ‘bonding’ pathway as an important social glue that prevents such bundles of practices from drifting apart over time. Most importantly, we claim impact beyond the academic setting (Wickert et al., 2021) by demonstrating how relatively small and resource-poor movements can impact societal challenges through distributed and heterogeneous social-symbolic work, even in traditionally change-resistant contexts such as healthcare (Bartram et al., 2020).

## THEORETICAL BACKGROUND

In the social movement literature, one long-standing conundrum has been to establish whether and in what contexts radical and moderate collective action can combine to change a societal status quo (Bertels et al., 2014). According to the radical flank perspective (Downey and Rohlinger, 2008; Haines, 1984; Schifeling and Hoffmann, 2019), actors' ability to mobilize and enact change can be influenced by the presence of other, more or less radical groups that shift the focus and content of debate (Haines, 1984). The concept of radical flanks was first introduced in Freeman's (1973) study of the women's liberation movement in the U.S. in the 1960s and 70s. Freeman claimed that the arguments brought forth by reformist women's organizations would have been dismissed but for the existence of more radical feminist groups. In comparison to the latter's radical stances, the National Organization for Women appeared as an acceptable negotiation partner – the existence of the radical flank softened opposition to the organization's arguments and shifted the entire field's debate. A similar effect was detected by Haines (1984) in the Civil Rights Movement where the Black Panthers' deployment of radical and at times violent tactics first met with a staunch rejection of the entire movement but over time made change seem inevitable. Positive flank effects thus typically occur when moderates gain support from institutional incumbents because the radicals' extreme stance puts moderates in a more favorable light and/or makes incumbent action necessary.

Positive flank effects have since been demonstrated in various collective action contexts – though Schifeling and Hoffman (2019, p. 229) lament that the concept still “has received far too little empirical development to date”. It is notable that in line with the original studies, the bulk of this literature has focused on structural explanations to address why and under what conditions flank effects may occur. Baron, Neale, and Rao (2016) for instance demonstrated that in self-regulating contexts, the threat emanating from

confrontational activists makes cooperative activists attractive partners, especially if they can provide a shield against the confrontational activists. Truelove and Kellogg (2016) observe a positive flank effect inside a car-sharing firm, where in response to one occupational group's more extreme strategic demands opponents formed a coalition with more moderate challengers. In both cases, positive flank effects depended on moderates' willingness to engage in coalition-building with opponents. Such dialogues can increase moderates' own power within the broad collective but may also engender tensions with the movement's less compromising flank, who may regard such strategies as a "sucker's game" (Snow and Cross, 2011, p. 124). Schifeling and Hoffman's (2019) analysis of the debate on fossil fuel divestments highlights two crucial conditions for positive flank effects to occur: the importance of synchronization between challengers and moderates; and the ability of moderates to translate the radical challengers' goals to opponents. By contrast, negative radical flank effects are likely when radical and moderate groups become associated in opponents' minds (Haines, 1984). Ellefsen (2018) describes the case of an animal justice campaign that consisted of a moderate 'aboveground' and a radical underground flank, both of which eventually suffered from strong media backlash.

It should be noted that the term 'radical' in this literature does not necessarily refer to violent tactics but rather describes a contextual attribute of one group or one type of strategy relative to others. While the term is sometimes employed to describe challengers' contempt for institutions or authority more broadly, radicals are often seen as those collective actors who are willing to engage in direct action (Snow and Cross, 2011) and/or as those whose discursive demands "are on the extreme end of the debate spectrum" (Schifeling and Hoffmann, 2019, p. 216). On this latter basis, Truelove and Kellogg (2016) diagnosed a radical flank in a professional department that pushed for change within its firm's business model, and Schifeling and Hoffmann (2019) detected the advent of a discursive radical flank



in the fossil fuel divestment campaign that enlivened an ossified debate. McCammon, Arch, and Bergner (2014) further argue that positive radical flank effects are not limited to situations in which there is a strong divide between radicals and moderates; they can also occur in collective action movements that are less divided. Studying a case where actions by moderates and radicals were tightly coordinated, Ellefsen (2018) theorizes that flanks may be present as long as there is movement fragmentation (of different actors, strategies, or goals) and where movement actors themselves and/or other field actors perceive and react to this fragmentation.

While the radical flank literature has yielded important insights into the structures and conditions of social movement success, it tends to remain at a meso-level of analysis, thus obscuring a finer-grained view of what exactly ‘radical’ or ‘moderate’ strategies may consist of and, importantly, how they may or may not align. Beyond recommending frequent interactions, the literature has so far only hinted at the “possibilities for a more symbiotic dynamic” (Schifeling and Hoffman, 2019, p. 228). It has also remained relatively silent on what may keep a flanked movement together over time and how actors who do not form part of either ‘flank’ contribute to achieving cohesion. Bertels et al. (2014) have made early inroads into this latter question by identifying that some organizations in a social movement specialize in ‘indirect’ or supporting work, but they retained a structural perspective in their analysis of board interlocks of U.S. environmental organizations. Insights into the diverse practices actors engage in and how these may interact, synchronize, or diverge over time could however prove crucial in establishing how to combine radical and moderate activities to achieve institutional change (Ellefsen, 2018).

We thus propose a shift away from examining the structural positions of radical or moderate actors and toward interrogating the practices or ‘work’ involved in these flanks, which we explore by leaning on Lawrence and Philips’ (2019) social-symbolic work concept.

We see two crucial additions to radical flank theorizing in doing so. For one, Lawrence and Philips' concept of work is multidimensional and focuses on patterns of action rather than on the question of 'who' carries these out. It thus allows the possibility that different types of work are distributed among different actors, either strategically or through an implicit division of labor, and that actors may shift between types of work. And two, in line with other practice-based approaches, their framework entails a process orientation, where heterogeneous types of work might be distributed not just among various actors but also over time, which opens up a longitudinal and dynamic perspective into the micro-processes that constitute the flanks.

Consolidating various bodies of organizational literature that have 'turned to work' to establish how individuals and groups create, disrupt, or maintain organizations, Lawrence and Philips highlight the multidimensional nature of social-symbolic work - or the "purposeful, reflexive efforts to change social arrangements" (ibid., p. 15). Social-symbolic work, in their definition, may be discursive, relational, or material. The discursive dimension allows actors to shape their social worlds through language, narratives, and symbols. The relational dimension refers to the interactions, networks, and collaborations actors forge to shape social-symbolic objects (Girschik, 2020). The material dimension in turn is focused on how humans mobilize infrastructures, technologies, or other elements of the physical environment. Several authors noted that this last dimension has been particularly neglected in the institutional work literature, which typically focuses on discursive work when studying institutional or organizational change (Monteiro and Nicolini, 2015; Raviola and Norbäck, 2013).

Importantly for our purpose, beyond categorizing different types of work in a coherent framework, Lawrence and Philips (2019) pay attention to the dynamic interactions between the types of work actors engage in. They propose three ways in which forms of work may relate over time: sequencing, or the temporal stacking of types of work; aligning, or

work done in parallel; and integrating, that is intertwining forms of work aimed at different social-symbolic objects. However, they also point to the scarcity of research engaging with such temporal issues, with few exceptions. Lawrence (2017) investigates how material and discursive work interact over time in ‘high-stakes’ institutional translation, but his account lacks detail on the different tonalities of this work along the radical-to-moderate continuum. A recent study by Zara and Delacour (2021) on the Serbian transition is the first to focus on the feedback loops between distributed work. By demonstrating how these interrelations affect institutional change, their study is a clear call for the benefits of a perspective that can capture the sequencing of distributed work.

In summary, we suggest that the social-symbolic work perspective can bring nuance and a dynamic perspective to the radical flank perspective by offering a fine-grained view of the micro-level repertoires of action, their dynamics, and how different action repertoires or ‘pathways’ (Ellefsen, 2018) interplay over time to effect change. Conversely, the radical flank perspective holds valuable opportunities to deepen insights into social-symbolic work by focusing researchers on the collective but not always fully synchronized work needed to affect institutional change. The radical flank perspective suggests that certain types of work may become important resources for other types, but it also highlights that different types of work may become misaligned or may even be in conflict.

Perhaps most crucially, the focus on the heterogeneity and sequencing of such ‘divisions of labor’ may encourage social-symbolic work researchers to consider in more detail the outcomes of the work they study, which is one of the strengths of the radical flank literature. This could include further demystifying the broad rubric of ‘institutional change’, a task that Micelotta et al. (2017) have recently tackled. Micelotta et al. (2017) distinguish between four ‘pathways of change’ - institutional accommodation, alignment, displacement, and accretion - depending on the pace (evolutionary or revolutionary) and scope of change

(developmental or transformational). They urgently call for studies into the micro-level practices underlying these four pathways. Adopting their vocabulary of ‘pathways’, which is also in line with Ellefsen (2018), we seek to add further processual detail to their categorization by combining a radical flank with a social-symbolic work perspective.

## METHODS

### Data Collection

We adopted an exploratory longitudinal research design (Pettigrew, 1990), centering on a single case study – the #WeAreNotWaiting community. Our primary data collection focused on the micro-level practices undertaken by members of this community to change the technological and regulatory standards of T1D healthcare. We studied this process using retrospective data from its creation in late 2013 to 2018 and through real-time data collection from 2018 until the mainstream commercialization of artificial pancreas systems (APS) in 2020 (Medtronic, 2020). While the community eventually stretched across the globe, we focus on the community’s activities on affecting institutional changes in the USA. To aid triangulation of insights, we collected data from several sources: Twitter posts, semi-structured interviews, observations at public events, and archival material (Table 1).

#### TABLE 1 HERE

*Twitter posts.* Much of the community’s ‘life’ happened on Twitter, which was the community’s primary internal and external communication forum. In 2018 we started to follow a set of active users (n=200) tweeting with the hashtag #WeAreNotWaiting. Following the active users provided first insights into the community and allowed us to comprehend its norms of following, sharing, and liking (Postill and Pink, 2012). The field researcher checked updates from the #WeAreNotWaiting hashtag feed several times a day for the duration of the fieldwork period and took notes on (1) who used the hashtag, (2) popular

topics and discussions, (3) events, news, or activities relevant to the community, (4) interactions between community members and between members and external stakeholders.

Once we had familiarized ourselves with community interactions on this platform, we collected the entire set of 18,600 tweets containing the hashtag #WeAreNotWaiting published on Twitter from the hashtag's first appearance in January 2014 to December 2018. Tweets were collected using Twitter's Application Programming Interface, which returned tweets matching the #WeAreNotWaiting hashtag. We removed any information that could be directly tied to an individual's identity before the dataset was analyzed (Townsend and Wallace, 2016). Collecting a full set of Twitter posts during this lengthy time period facilitated a better understanding of changes in the network of users, community dynamics, and the evolution of community activities.

**Interviews.** We conducted 31 semi-structured interviews with community members. We identified participants through their public profiles, by compiling frequency data for tweets (number of tweets, likes, and retweets), or through snowball sampling. The interviews took place in 2019 and 2020, lasted between 45 and 60 minutes, and were conducted in person or via video call, per the participant's preference. Interviews were recorded with participants' permission and fully transcribed, yielding 390 single-spaced pages of text. Participants were given pseudonyms to protect their identities. Our interview questions focused on how the #WeAreNotWaiting community emerged and evolved, reasons for participating in the community, and different activities undertaken by community members. We ensured that the interviews remained open to issues that were particularly important to participants. The interviews provided rich detail on the community's history, activities, and dynamics between different parts of the community. While we did not interview external stakeholders, we used other data collection methods – particularly observations and archival materials - to fill this gap in our understanding (Miles and Huberman, 1994).

*Observations.* During 2019 and 2020, the field researcher attended seven diabetes conferences and innovation workshops, totaling 78 hours of participant observation. Five of these events were organized by the #WeAreNotWaiting community and the other two by medical and academic researchers. These events attracted community members, other diabetes advocates, entrepreneurs, device manufacturers, regulators, and healthcare providers. Observations provided us with an understanding of the interactions between the community and external stakeholders, technological and regulatory developments, community priorities as well as key challenges.

*Archival material.* We collected 90 archival documents including company newsletters, press releases, blog posts, presentations, news media articles, research articles, mission statements, business plans, and regulatory guidelines related to T1D technology. Documents spanned from 2013 and 2020 and provided us with further insight into the early history, regulatory and technological context, and public reception of the #WeAreNotWaiting community. Importantly, these documents gave us extensive insights into stakeholders' evolving responses to the community's efforts, in particular technological and regulatory ones.

## **Data Analysis**

We inductively analyzed the community's efforts to change the technological and regulatory standards in T1D healthcare, meaning that our theorizing around the flank pathways and sequencing of work emerged mainly from the data. We iterated between field data and existing ideas, constructs, and findings in three recursive stages (Miles and Huberman, 1994).

*Stage 1: understanding temporal patterning of community activities and stakeholder reactions.* Based on an in-depth reading of our interviews, observation notes, and secondary data, we compiled a detailed chronological account of the #WeAreNotWaiting community, amounting to 87 single-spaced pages. This gave us an early understanding of the evolution of

the #WeAreNotWaiting community, their motives, the different activities they engaged in as well as reactions from institutional stakeholders. To increase the granularity of these insights, we conducted a pattern and frequency analysis on all 18,600 tweets. We identified patterns of activity over time, including peaks in the use of the hashtag, which may point to important community events, the most active users by tweet frequency, and the most retweeted and favorited users (Christensen, 2013), giving us a steer on the distribution, centrality and closeness of actors. As this analysis gave us insights into membership dynamics but not necessarily into the content of the Twitter conversations, we decided to read each tweet and manually code relevant ones for conversations related to: closed-loop technology (codes: DIY, commercial systems, regulation, other), the community itself (codes: objectives, values, information sharing, support, other), stakeholder interactions and reactions (codes: industry, regulators, healthcare providers, other patient organizations, other), and any events or news announced or discussed. This was done to detect shifts and patterns in community conversations. Combining insights from the case chronology and the Twitter analysis, we produced a dense timeline depicting all key events and activities in the collective's institutional change project (Gehman et al., 2013; Figure available from the authors).

*Stage 2: differentiating types of social-symbolic work.* In the second stage, we returned to our interviews, documents, and observational data to gain a more practice-based understanding of who was doing what and when in the #WeAreNotWaiting community. We inductively coded data for empirical descriptions related to members' activities to drive institutional change, combining similar empirical descriptions into preliminary themes (Miles and Huberman, 1994). It was at this point that we noticed a certain distribution of labor within the community's activities, a reflection that prompted a further categorization of different types of 'work' (see Table 2). We also noted that within the same interview or document, several types of such work may be mentioned, and we coded these data sources

accordingly. Comparing and contrasting these themes with insights from social-symbolic work and radical flank theory led us to conceive of the ‘radical’ and ‘moderate’ approaches less as a role-based distinction and more in terms of patterns or bundles of work. Further, beyond radical ‘breaching’ work and more moderate ‘bridging’ work, we detected a third bundle of work, mainly around community-building efforts and amplification of the community’s activities to a broader set of stakeholders. An iterative back and forth between the literature and our data helped us finally distinguish six broad forms of social-symbolic work: material breach work, discursive breach work, material bridge work, relational bridge work, values work, and amplification work. Table 2 is the outcome of this analysis stage.

*Stage 3: combining analytical insights and building a process model.* We were mindful of Pettigrew’s (1990) admonition to understand analytical themes dynamically. We thus focused this stage of the analysis on the interactions, dynamics, and effects between three broad pathways of work. We sought to generate “plausible explanations” for the dynamic patterns we detected (Mees-Buss, Welch and Piekkari, 2022, p. 418), which we then repeatedly discussed and triangulated across Twitter, interview, observation, and archival data. While the radical flank literature had acted as a useful sensitizing device to analyze the differences in members’ approaches in the previous analysis rounds, we also observed that some members engaged in more or less radical activities at different moments in time. We further noted that despite the differences in work done, the community remained relatively united in its objectives and change targets. Using the notion of pathways (Ellefsen, 2018; Micelotta et al., 2017) as a heuristic device, we traced how the six types of work and three pathways categorized in stage 2 combined to achieve this outcome by cross-coding the events, activities, and milestones established in stage 1 with the six types of work. This yielded an analytically enhanced version of our initial chronological timeline, which represents the dynamic interrelationships between types of work, based on our categorization



of the main types of work evident in the document, event, or activity in question (Figure 1a and 1b). In a final analytical step, comparing our findings with existing research insights and in particular with Micelotta et al.'s (2017) categorization of pathways of change, we identified the institutional change effected by the community over time as institutional accommodation, and we traced back from this outcome to the dynamic patterning of the bundles of work. Drawing this insight together with our previous analysis stages finally allowed us to build a process model, illustrated in Figure 3.

===TABLE 2 and FIGURES 1a & 1b HERE===

## **FINDINGS**

### **Research context**

The #WeAreNotWaiting community emerged in 2013 on the U.S. West Coast as a loose collective of around 20 patients and parents of children with T1D (Healthline, 2019). T1D is an autoimmune chronic condition characterized by deficient insulin production, which requires daily administration of insulin and management of blood glucose levels. A host of medical devices such as insulin pumps, continuous glucose monitors (CGM), and blood glucose meters are daily essentials for managing T1D (Diabetes UK, 2022). However, despite significant advances in sensor technology in other areas, the technology offered by multinational T1D device makers had not seen major innovative leaps in years and was often cumbersome to use. Specifically, medical device manufacturers had made no apparent effort to ‘close the loop’, that is to automate the communication between blood glucose monitors and insulin pumps, which would significantly reduce the cognitive and physical burden on T1D patients (Figure 2). The #WeAreNotWaiting community set out to change this status quo: to create interoperability in T1D technology, to ‘close the loop’ between separate devices, and more broadly to show industry and regulators that they had to innovate “alongside patients” to help improve their lives, as one interviewee put it.

Around 2010, a small number of T1D patients in the US started to explore the possibility of improving T1D technology themselves by reverse-engineering existing medical devices. There were two catalyzing moments that helped these individual efforts to converge into a collective. The first was when a self-identifying ‘hacker’ patient published a blog post in June 2012 about the ‘Sad State of Diabetes Technology’ (archival material, 2012). It was through the blog post’s comment section that other T1D ‘hackers’ started to connect around how to change this ‘sad state’ of an innovation gap. The second catalyzing moment took place in 2013 when a parent tweeted an image of his iPad demonstrating how he had managed to achieve remote monitoring of his son’s blood glucose, which galvanized others into exploring ‘DIY’ (do-it-yourself) technology innovation (interview P4, 2019). These burgeoning community links happened shortly after the first Quantified Self conference had opened up a public discussion over the potential of self-tracking technologies for patient- and self-empowerment (Geiger and Gross, 2017). After several individual meetings and online conversations, the patient hackers organized a mini-conference in 2013 in San Francisco to present their projects and discuss the potential of open-source T1D innovation. It was at this conference that the #WeAreNotWaiting community crystallized - and found its name when one of the core instigators exclaimed:

It sounds like, if I sum up what has happened today, that we are not waiting for the industry, we are not waiting for the FDA, or waiting for anyone to tell us that it is ok, we have to keep going, we have the passion and we are moving ahead and we are doing it! (interview P2, 2019)

Change was seen as necessary and urgent in several areas. First, patients shared a deep sense of frustration with the slow pace of innovation in T1D technology that seemed to be “stuck in a time loop”, according to one interviewee, which directly affected patients’ quality of life. Second, patients were angry at the dominance of a few medical device makers whose proprietary technology and data protocols prohibited patients to access and share their blood glucose data (interview P3, 2019). Third, patients were fed up with what they saw as wholly

outdated regulatory frameworks for innovating T1D technology that slowed down the pace of innovation and that had little to no patient involvement (interview P7, 2019). Feeling unheard by the powerful institutional actors in industry and regulation, the #WeAreNotWaiting community turned their frustrations into collective action to “put a fire under the industry to realize what is happening” (interview P2, 2019). Their manifesto, depicted in Table 3, vividly illustrates the urgency and passion the community felt in affecting this change. Yet, for these goals to be reached, a great deal of technological development work was needed beyond the tentative hacks a few parents had produced thus far. Work was needed to convince industry players to permit access to data protocols. Work was also needed to embed community values into the existing innovation ecosystem and to access funding and operational infrastructure that would enable faster advancement of interoperable technology. Work was further needed to convince the FDA to update its regulations regarding open device data and interoperability. Finally, work was needed around building an evidence base to manage healthcare providers’ safety concerns so that they would feel comfortable supporting the open-source technology. Above all, this work would eventually have to connect to the larger vision of a more patient-centric medical innovation system.

Before tracing this heterogeneous work in detail, we briefly pre-empt the resulting technological and institutional changes. When, in late 2014, some patients succeeded in ‘closing the loop’ by automating the connection between their T1D devices, the world’s first artificial pancreas system (APS) was built – in a patient’s garage rather than the lab of a large medical device manufacturer. At that time, no medical device manufacturer seriously pursued R&D on these systems, and regulations did not accommodate patient-developed applications. The community grew considerably during its early years, with an ever-greater number of ordinary patients learning to ‘loop’ their T1D devices and popular media starting to report on these patient DIY efforts; eventually, they formed a community of over 30,000 people

(Healthline, 2019). Naturally, their efforts did not remain invisible to industry and regulators. Yet, somewhat surprisingly, rather than shutting hackers down through legal proceedings or other repressive actions (Ellefsen, 2018), these incumbents slowly opened up to movement members' efforts at reaching out. In fact, fast-forwarding through technology partnerships between patient entrepreneurs and industry incumbents, data-sharing agreements, and joint research papers, by 2017, the FDA had made the “revolutionary move” (Healthline, 2019, n.p.) to develop new regulatory guidelines for fast-tracking digital health technology and ensuring interoperability. They had also included #WeAreNotWaiting members to co-create this new regulatory pathway. That same year, the first multinational company – Dexcom – launched an open Application Programming Interface to accelerate open-source innovation. By 2020, artificial pancreas systems and closed-loop technologies were commercially available on the market, allowing patients to choose among different systems to suit individual needs. As a Healthline article (2019, n.p.) stated: after decades of stagnating technology innovation, “due in large part to the grassroots #WeAreNotWaiting movement, times are changing”. While the community continues to fight for patient-centric healthcare innovation, it had achieved its main technological and regulatory change mandate within a space of time and pace that even surprised industry insiders.

===FIGURE 2 and TABLE 3 HERE===

### **Interweaving pathways of social-symbolic work**

Our findings offer unique insights into the mechanisms and dynamics of heterogeneous forms of social-symbolic work in an institutional change project. In this section, we present the three pathways of work we identified, detailing rationales and activities associated with different forms of work in each pathway (Table 2). We subsequently show how these pathways interweaved over time to contribute to technological and regulatory change in T1D healthcare (Figures 1a and 1b).

The #WeAreNotWaiting community developed without a formal organizational structure or strategic masterplan for bringing about change, beyond the manifesto in Table 3. As in many collective action projects, while there was broad agreement on the movement's goals, community members had differing views on how to achieve those:

Different people had very strong ideas. I wanted to get into the business of selling. I had a very different perspective, I said that I think [open source development] had served its original purpose of demonstrating an unmet need in an unambiguous way to the companies who should have been doing this in the first place and now we are coming to do that (interview P1, 2019).

Although the community was initially known as the 'patient hacker community' (Vidolov et al., in press), our data indicate that from early on, different ways to drive change through technology innovation were discussed and practiced. As the quotation above indicates, while some members continued to believe that open-source innovation was the quickest road to change, others came to see benefits in commercialization for wider reach. A third group was agnostic when it came to these innovation paths but highly concerned with keeping the community moving forward and amplifying its message to the outside world. Our data revealed that over time the community fell into a palpable division of work across three different pathways of change - 'breaching', 'bridging', and 'bonding'.

### **The 'breaching' pathway**

The 'breaching' pathway involved work to disrupt established device makers and regulators by hacking into and manually linking up T1D devices – or, in the community's parlance, 'closing the loop'. Those engaged in this work were mainly patients with prior programming or engineering skills, though some inexperienced members simply had a strong desire to learn how to build T1D technology:

We're working to demonstrate the need of the community to have closed-loop systems; demonstrate the safety of basic closed-loop systems and efficacy compared to "standard of care" without closed loops. Many of us are not waiting by building and running our own DIY APS implementations. (archival material,

community member, 2019).

With its unregulated and highly disruptive technological work happening “under a black flag”, as one interviewee described it, we interpret the ‘breaching’ pathway as representing the radical flank of the #WeAreNotWaiting community. Members engaged in the ‘breaching’ pathway saw their activities not simply as open-source innovation, but also as a way to regain agency for patients; material breach work was thus accompanied by discursive breach work to precipitate change, as we will outline.

***Material breach work.*** While individual DIY efforts stood at the origin of the #WeAreNotWaiting community, when members joined forces and started distributing code on the platform GitHub, these efforts turned into a more concerted attempt at technological disruption through material breach work. In early 2014, sharing this illegal code was a “very dangerous decision”, and members were aware that they took high personal risks when doing so, as their instructions could be modified, misused, and potentially harm users:

I have no problem with technically savvy people doing these things. Where I get concerned is with people who do not understand the limitations. They might go to bed thinking their phone will wake them if their kid’s glucose level goes low, but then their Internet connection goes down, the phone doesn’t ring, and the kid dies. ... (archival material, community member, 2014)

The FDA as the main regulator in this area was clear that those engaging in this work were potentially liable (interview P6, 2019), and early on, hackers used complicated programming language when sharing code on GitHub to avoid the risk of less tech-savvy people misusing it. Some also protected their identities online to thwart any legal repercussions. This was particularly important given the exposed profile of some of the patient hackers of the first hour:

We made it to the front page of the Wallstreet journal - and think about the powerful story of ‘chief engineer at [medical device firm] hacks competitor device to serve the need that his own company doesn’t serve’. This was a very dangerous time for me (interview P1, 2019)

Toward the end of 2014, these material breaching efforts resulted in one patient ‘closing the loop’ between their T1D devices, to the delight of the budding community. Their work attracted a steady flow of new patients committed to building their own DIY APS. At this point, community members started organizing hackathons to share and co-develop code and proselytized others to join their efforts:

Show that you're a rebel: #wearenotwaiting. Folks there will help you set it up. (tweet, 2015).

With the help of ‘administrators’ - members who translated the programming language and created manuals - new members with no prior programming knowledge learned how to ‘loop’. The growing number of patients engaging in material breach work led to rapid advances in T1D technology, with new features and new ways to make this technology available to other T1D patients soon significantly outpacing commercial device makers:

[referring to an innovative step in the DIY technology] This is pretty HUGE since there are currently no commercial tools that help people fine-tune their pump settings in this way (tweet, 2018).

Our analysis revealed that this ‘radical’ commitment to material breach work despite high personal risks created substantial momentum for change. The purity of intention in taking personal risks for the common good cemented the change project’s mission of ‘not waiting’, and the literal prizing open of commercial devices and data siloes through material breach work gave a clear signal to industry and regulators that the technological status quo was irrevocably breached.

***Discursive breach work.*** The radical approach of developing unregulated T1D technology resulted in early public attention to the #WeAreNotWaiting community, which opened the door to discursive breach work. News media quickly picked up on these ‘Citizen health hackers’ (The Guardian, 2015). Coverage veered between intrigue and admiration:

Third-grader Andrew Calabrese carries his backpack everywhere he goes at his San Diego-area school. His backpack isn’t just filled with books, it is carrying his robotic pancreas. The device, long considered the Holy Grail of Type 1

diabetes technology, wasn't constructed by a medical device company. It hasn't been approved by regulators. It was put together by his father Jason Calabrese, a software engineer, following instructions that had been shared online to hack an old insulin pump so it could automatically dose the hormone in response to his son's blood-sugar levels. .... (archival data, The Wall Street Journal, 2016)

This media attention was quickly seized by some in the emergent #WeAreNotWaiting community to frame the material breaches in the broader context of patient-centric innovation, for instance in this widely circulated blog post:

So why would home programmers want to hack into their CGMS and pumps? As patients, our relationship to diabetes devices is both special and frustrating. Picture a sci-fi movie of a dystopian future where we have devices attached to us that must be refilled, serviced, and touched all the time if they are to keep us alive. The manufacturer's instruction manual and guidance represent very real political controls on how we spend our time. Hacking on open-source software allows us to have a sense of control in the process of insulin delivery that can't be found within the pages of the traditional user manual. I believe it allows us to stay safer, too, and establish a greater sense of trust in our devices. (archival data, 2015)

Some members began to actively seek engagement with news media, even utilizing war metaphors to describe the David-versus-Goliath battle between patients and industry:

Are you a journalist looking at #diabetes and #tech stories? Let us connect you with the front line. #WeAreNotWaiting (tweet, 2015).

Members also started recruiting allies in academia to conduct research on the potential of patient-driven technology, thus launching what would become a growing field of academic research: while in 2014 10 papers were published on the topic, by 2020 this had increased to more than 200 articles, some of these co-authored by community members (archival data). By engaging academic and media discourses, community members carved a public space to discuss the reasons why innovation was needed and how it linked to the ethos of patient-centric healthcare. This debate eventually caught the attention of institutional incumbents: at a large diabetes conference, an FDA official revealed that the agency was closely monitoring the growth of the movement (archival material, MDedge, 2016).



Overall, where material breach work “created facts”, as one community member put it, and significant momentum for change, discursive breach work framed this radical material work as necessary and urgent in the public debate. By challenging industry and regulators both discursively and at a material level, this pathway threw down a bright-red gauntlet to incumbents to fundamentally re-think T1D healthcare.

### **The ‘bridging’ pathway**

At the point where the ‘breaching’ work became visible in the public realm, it would have been relatively easy for industry incumbents to show their muscle and shut the patient hackers down through legal proceedings. Somewhat surprisingly, this did not happen, and our analysis indicates that this was largely due to another set of community practices, which made up the ‘bridging’ pathway. This more moderate pathway developed throughout 2014 and quickly built on the ongoing material and discursive breach work by seeking ways to “mainstream” the emerging DIY technology. In contrast to the radical flank activities, the strategy here was to take “the proper path, the correct path, the legal path to commercialization” (interview P1, 2019), which was seen as fundamental to both broaden and sustain the technological change:

You know, the DIY movement has got really amazing attraction... but you can’t get huge. Our goal has always been to support, in the US, 1.7 million people with diabetes... so that doctors are comfortable prescribing or recommending something. And it shouldn’t have to be a DIY product and I love that the community has shown how you can innovate using open-source community projects. But part of our mission has always been let’s do it the right way (interview P3, 2019).

Our data showed that the ‘bridging’ pathway consisted predominantly of material bridge work and relational bridge work and that both tapped into the momentum and resources built in the breaching pathway.

**Material bridge work.** In the ‘bridging’ pathway, to eventually reach a large percentage of the world’s T1D patients with open T1D technology, co-innovating with established device makers was seen as unavoidable:

Our commitment is to you, the diabetes community, to take the incredible work of the #WeAreNotWaiting giants and bring this incredible technology to the masses. (archival material, community member, 2019).

To fulfill this promise, some community members turned to entrepreneurship, but they needed to forge technology partnerships that would facilitate interoperability and integration of existing hardware and software components. They also needed to convince device makers to release their proprietary data protocols - something that evoked considerable concern in an industry not used to ‘open’ technology innovation. Material bridge work was thus required to “help industry see the value in liberating device data”. On the basis that material breach work had already “created facts”, entrepreneurial community members started to reach out to device makers for co-development opportunities. Material bridge work was envisaged as an effort to build a technological “win-win ecosystem”, as explained by this patient entrepreneur:

We are experts in innovative software and partnering with software experts will allow the device companies to use their financial resources to invest in their devices instead of software, which isn’t their strength. ‘A rising tide raises all boats.’ (archival material, community member, 2014)

In late 2014, just as the first hackers had “closed the loop”, one such member managed to secure an agreement with the insulin pump maker Asante to use their data protocols - the first device maker on the market to do so in a move that surprised many of its competitors (archival material, 2014). Further data-sharing agreements and integration protocols with device makers including Dexcom and Abbott and other forms of joint development work followed this initial success:

Excited to hear about the @FreeStyleDiabet Libre and @mysugr integration announcement! #wearenotwaiting @onedroptoday” (tweet, 2016)

These were essential steps in bringing commercial APS technology to a broader target population and “provide people with T1D an accessible, affordable, automated, connected solution”(archival material, community member, 2015). A major milestone for this material bridge work was reached in 2019 when industry stalwart Medtronic agreed to co-innovate with a patient entrepreneur to finetune the development of their technology. Its Vice President of Research and Development for the Diabetes Group explained:

We have been listening and engaging with the diabetes community to understand what is important to them- we recognize that collaboration with [P3] is a way to further drive industry innovation. Working with [P3] and supporting interoperability, we can increase the options available to people with diabetes (archival material, 2019).

Through material bridge work, community members thus secured vital technology agreements and co-innovation opportunities, which enabled access to data and opened up the technological infrastructure for T1D care – a crucial material basis to tackle the regulatory approval process and to scale up closed-loop technology.

***Relational bridge work.*** Beyond the technological co-development efforts of material bridge work, relational work in the ‘bridging’ pathway involved reaching out to regulators and other key institutional stakeholders whose support was vital for technology innovation. Relational bridge work was first and foremost needed to eliminate regulatory barriers, which had been a consistent threat to those involved in material bridge work. Given that the FDA had the community’s activities on its radar already but had yet to decide on how to approach them, the community’s offer to engage in dialogue was readily taken up:

[S]o we went into the FDA early. My first meeting with the FDA was early 2014 and I bluntly said that here is what I am doing and the current guidelines don’t support this and to my wonderful pleasant surprise, the FDA said why don’t you come and talk to us. Come and have a meeting with us and tell us what you are thinking about doing and we figure it out. (interview P3, 2019).

Informal meetings and conversations culminated in an invitation, in 2017, to one patient entrepreneur to be part of a revolutionary Digital Health Software Pre-certification Pilot

Program, a major initiative that would inform a new regulatory model for software-based medical devices (archival material, 2017). This was seen as clear proof that the FDA was responsive to relational bridging efforts. It also lessened the threat to those still pursuing DIY technology development and encouraged commercial firms to join the collective innovative efforts. Dexcom's Vice President of Strategy for instance acknowledged that the efforts made in the #WeAreNotWaiting community had "likely played a role in tipping the scales of FDA approval" for its mobile app to support closed-loop technology (archival material, 2018).

Relational bridge work also included efforts to establish relationships with central diabetes research funders. In 2017, one such funder announced an initiative encouraging insulin pump companies to make their codes and documentation freely available to patient entrepreneurs, thus facilitating material bridge work:

We are not working on this Open Protocol initiative alone. We are working with the FDA, groups in the #WeAreNotWaiting community, leadership of device manufacturers and legal counsel to understand how this dream can be a reality (observation notes, JDRF representative, 2020).

Though clearly divergent from the activities in the 'breaching' pathway, these bridging efforts had a positive spillover effect on the more radical breaching activities.

Technologically, the opening up of data protocols allowed the DIY efforts to advance more quickly; discursively, they "helped the entire movement stay legitimate" (interview, P4, 2019). For example, prior to 2016, the #WeAreNotWaiting community was shunned by the American Diabetes Association (ADA) – an institutional stalwart - as the community was seen as potentially too disruptive. Through continuous relational bridge work, the community eventually secured participation at the ADA's highly prestigious annual conferences:

The interesting thing now is that we are a normal part of that [ADA] conference now. It was heresy in 2014. In 2015 we were considered disrupters and as years go by finally last year at ADA, they embraced it. There was a whole series of classes on #WeAreNotWaiting. We had community members speaking at various panels presenting their work (interview P5, 2019).

Beyond immediate technology development, bridging efforts helped device makers perceive the benefits of integrating patient voices into their innovation practices more broadly:

There is a hashtag used on social media by many in the type 1 diabetes community - #WeAreNotWaiting. It is a call to action to take innovation and ideas into the public domain (...) I love this. It is a reminder to the industry as a whole that the time is now. It is why we are one of the first pharmaceutical companies to systematically engage disease experience experts in R&D” (archival material, NovoNordisk spokesperson, 2016)

In sum, building on the momentum created by the ‘breaching’ pathway, material and relational bridge work drew central stakeholders into the community’s cause and prepared the ecosystem to leverage the technological disruption created in the breaching pathway.

### **The ‘bonding’ pathway**

With two such disparate approaches to change in one community, there was a constant danger that conflict would drive members apart, for instance when open-source code was integrated into commercial T1D technology. Our data indicate one focal reason why this did not occur: concerted and ongoing work in pulling the community together through a ‘bonding’ pathway. This pathway involved values and amplification work (Bertels et al., 2014; Gehman et al., 2013); it sustained the community’s core values and promulgated these to external stakeholders. Twitter became an essential platform for this pathway:

[asked about their heavy Twitter engagement] We are not necessarily providing those [innovative] actions but we are looking for the most exciting and most important pragmatic actions and trying to explain and funnel people into whatever course of action those are (interview P9, 2019).

Our analysis showed that the ‘bonding’ pathway played a fundamental role in establishing and maintaining an overarching context for the community’s ambitions.

**Values work.** Throughout 2015 and 2016 the #WeAreNotWaiting community grew quickly. In 2015 the number of unique users was 785, and the hashtag was retweeted 7,354 times; by 2016, these numbers grew to 964 users and 10,534 retweets. This steady increase could have easily led to a dilution of the community and a potential weakening of its change

mandate. When, in their first meeting back in 2013, the community had drawn up the manifesto depicted in Table 3, they had created what Fan and Zietsma (2017) called a ‘values platform’, which centered around the community’s core value of ‘paying it forward’:

The notion of paying it forward is a massive part of the #WeAreNotWaiting community. If you have benefited from it well you don’t hold that tight, you don’t do a complete Gollum with the Ring. You share it with everybody else so they can benefit from what you have learned. (interview P28, 2020).

This core value became an important umbrella that spanned the other two pathways, encouraging all community members to help share useful information on technology innovation and enable open-source development wherever possible, even in commercial projects. Twitter was heavily used to impress this core value upon newcomers:

When you are done building your system, your responsibility is to pay it forward #WeAreNotWaiting @[commercial startup] #diyhealthtech15 (tweet, 2015).

Related to such values work, we noted a certain level of value ‘policing’ (Crawford and Dacin, 2021). Reprimands would be made if individuals used the hashtag for commercial purposes, not in line with the community’s objectives and values, or to downplay the struggles of living with T1D:

Glad you have an easy time with it. Many do not. Congrats on 9 easy years with T1. Our son has 5 major medical issues (including T1D), not easy at all (tweet, 2015).

Values work created a strong sense of the collective and its goals and thus reduced the risk of mission drift between the more radical and the more moderate flank activities (Mitzinneck and Besharov, 2019). By continuously corralling members around the community’s core values, this work functioned as an important social glue, giving members the freedom to engage in very different types of work yet ‘stay true’ to the community’s objectives.

***Amplification work.*** Beyond the discursive work to frame material breaching and the highly targeted relational work with industry and regulators, members also amplified the

community's values and goals to external stakeholders. Sharing personal stories about the struggles of living with T1D was a powerful tool to promulgate the community's 'why':

Personal stories amplify the purpose of the movement ...just like amplifying the voices of patients and parents who were worried for their children while their children were in school (interview P23, 2020).

Amplification work involved organizing outreach events and members talking at conferences or panel discussions about how open-source technology had challenged the status quo in T1D healthcare, thus broadcasting the successes of the 'breaching' and 'bridging' work.

Amplification work further entailed tweets addressed to specific stakeholders to draw their attention to the community's cause:

Yo @[commercial device manufacturer] I have to say I'm deeply disappointed that there is NO PATIENT on your "patient impact" panel. As in, steam from ears disappointed. (tweet, 2018).

Much of the amplification work was aimed at healthcare providers (HCPs) as important institutional gatekeepers. Initially, HCPs had raised significant concerns about potential risks and their limited understanding of DIY technology (observation notes, conference, 2019). However, over time many HCPs began to support patients who used DIY APS technology. Our analysis indicates that amplification work contributed considerably to this change in mindset. For example, research results demonstrating improved blood glucose control through the DIY APS technology were widely circulated on Twitter and presented by members at medical conferences. Blogposts described ways in which "healthcare professionals can support users" (archival material, 2020). A community member who works as an endocrinologist explained:

I think three years ago many healthcare professionals had more of a negative feeling about it and there was a lot of skepticism. Now that we have more and more data and more people have been using it [...] most stories that you hear are success stories, the data that you see outperform anything that the commercial market has to offer, and I think that has led to a shift in healthcare professionals' mindsets over the years (interview P20, 2020).

In sum, values and amplification work in the ‘bonding’ pathway created critical alignment between pathways and amplified its successes in the broader healthcare ecosystem, thus continuously reinforcing the communal ‘why’.

### **A process model of interweaving pathways of change**

In this section, we present a process model that builds on our analysis above to theorize how pathways of change interweave over time, illustrated in Figure 3. As the three pathways unfolded, they developed interesting temporal dynamics, which our longitudinal design allows us to examine more closely - an issue that Lawrence and Philips (2019) highlighted as virtually absent from the social-symbolic work literature. We use Lawrence and Philips’ terms to map the temporal sequencing, aligning, and integrating that we observed between different dimensions of work in and across the three different pathways. While this process model is situated in the context of challenges to T1D technology and regulation, we believe that some of its dynamics may also be transferable to other collective action cases, in particular those revolving around open-source technology development, patient entrepreneurship, and other forms of patient activism (Geiger, 2021).

===FIGURE 3 HERE===

Our framework starts with a community’s suffering and their quest to change the institutional status quo, and it culminates in institutional accommodation, via a dynamic process involving six types of social-symbolic work in three pathways, which cross-fertilize each other. In our framework, the radical breaching pathway serves to catalyze and trigger the institutional change process. Through direct action situated in a legal grey zone, the breaching pathway demonstrates to institutional incumbents that change is unavoidable. In our case, ‘material breach work’ acted as a crucial catalyst triggering a momentum for change: for one, the personal risks that early community members take in breaching the technological status quo may inspire others to share the burden of these activities and accelerate the pace of



technology development. Two, material breaching ‘creates facts’ and signals to institutional incumbents that the tide of technology innovation cannot be turned back. And three, because of its radical nature, material breaching draws attention from news media and academia, which opens up a discursive space to challenge the institutional status quo. In our analysis, community members were quick to seize on this opening and *integrate* discursive with material breach work. ‘Discursive breach work’ thus accelerates the initial momentum by publicly calling out institutional incumbents’ failures and highlighting the need for change, lessening the immediate risk taken by those engaging in material breach work. Brought together, the material and discursive work undertaken in the breaching pathway establishes a figurative and literal ‘breached’ space, creates bottom-up pressure, and sets a pace for change.

With the breach work gathering grassroots support and media attention, activities that we associate with the ‘bridging’ pathway soon started to emerge in our case. In our model, the moderate bridging pathway utilizes the ‘breached’ space to seek out collaborations with institutional incumbents, in our case through ‘material bridge work’ and ‘relational bridge work’. While the public discourse is likely to continue to focus on the more sensational radical challenges realized in the breaching pathway, the bridging pathway can seize on this ‘opening’ through more targeted and less public material and relational bridge work: in our case, community members initiated technology co-innovation partnerships with industry incumbents and engaged with regulators about ways to support the technology innovation momentum. Importantly, by reaching out to institutional incumbents all while material and discursive breach work continue to exert pressure, ‘bridge work’ is crucial to thwart incumbent threats to those pursuing work in the radical breaching pathway. It also offers incumbents an important means to deal with the radical challenge without losing face. In our case, rather than suppressing the activities of desperate patients, the hand reached out by the

community through relational bridging allowed regulators to control the spread of DIY innovation, and the technological co-development partnerships outlined helped accelerate the overall pace of innovation. As in other cases of institutional disruption (e.g. Reinecke and Ansari, 2021), if the community had continued to pursue a radical strategy only, it would have likely risked running dry of its disruptive energy and/or fallen victim to institutional reprisals or a media backlash (Ellefsen, 2018).

Thus, we propose that the *sequencing* of radical and moderate work can enable the breaching and bridging pathways to successively build resources for each other. The work conducted in the bridging pathway gives the community credibility and legitimates its activities among institutional actors, which in turn enables accommodation of the community's change initiative into the existing institutional ecosystem. For example, our analysis shows how open data protocols achieved through the bridging pathway accelerated innovation efforts in the breaching pathway, as data could now be compiled to provide evidence of the DIY APS technology's effects on patients' quality of life. Thus, careful sequencing of the two pathways may result in increasing the scope of change while simultaneously sustaining the pace and pressure on the institutional change process.

Moving beyond other studies of collective action displaying radical flank activities, our model in Figure 3 depicts a medial 'bonding' pathway. In researching our case, we puzzled time and again over the apparent lack of tension between the radical and moderate pathway efforts, which we probed in our interviews and data analysis. From the literature, we expected, for instance, conflict around the continued use of unregulated technology once commercially developed devices came onto the market, or accusations of 'betraying' the community's strong open-source ethos when device makers made intellectual property claims to technology that integrated open-sourced code. In line with Bertels et al. (2014), we

propose that the lack of such tensions in our case might be due to the continuous *alignment* of pathways through the bonding pathway. Aligning was achieved via a combination of ‘values work’ and ‘amplification work’. We found that particularly when the community started to grow beyond its initial core, values work became a vital means to ensure cohesion and rally the community together (Gehman et al., 2013). Underpinning this, ‘amplification work’ tied the community’s diverse activities into the broader discursive space of patient-centric innovation. We thus propose that as work in the breaching and bridging pathways gains momentum, ‘amplification work’ helps energize this work by broadcasting it inside and outside the community, feeding its growth and maintaining its vitality and voice. ‘Values work’ in turn preserves the community’s initial core values throughout the process and unites those pursuing radical and moderate pathway strategies, respectively, onto a common values platform (Fan and Zietsma, 2017). Hence, for ‘flanked’ collective action, a bonding pathway is essential in pulling diverse community activities and directing progress toward an overarching goal.

Our analysis above and Figures 1a and 1b showed the community’s institutional change efforts to have considerable cumulative effects that were characterized by many ‘small wins’ (Reay, Golden-Biggle, and Germann, 2006). In Micelotta et al.’s (2017) categorization, our case would likely fall into the ‘institutional accommodation’ quadrant, which describes change dynamics that are revolutionary in pace but developmental in scope by being reinserted into institutional givens. While other factors undoubtedly played into the changes achieved, one research participant summed up the movement’s contributions as follows:

It really pushed the industry to think harder and to be more involved in real-life design ...[it] has had a huge impact on the fact that industry and regulators and medical technology providers are waking up and that they really do need to innovate alongside patients and they really need to understand what it is like to wear a system in real life for people and they should not create this machinery for people to get some clinical outcomes but really looking at can people live

with this thing and how will it impact our lives. (interview P2, 2019)

We propose that this success in paving the way for patient-centric technology innovation in T1D care is due to the reflective sequencing, aligning, and integrating of moderate, radical, and medial pathways, which allowed the community to maintain its revolutionary pace and focus on its goals all while exerting integrative institutional efforts that broadened its scope. We will discuss the broader consequences of these insights next.

## **DISCUSSION**

This paper combines the radical flank and social-symbolic work perspectives with a longitudinal research design to conceptualize a collective effort to change the technological and regulatory standards of T1D healthcare. By theorizing the sequencing, aligning, and integrating (Lawrence and Philips, 2019) across three pathways of change, we draw focal awareness to the fact that institutional change projects require multifaceted types of collective material, discursive, and relational work, which may often emerge organically, but which needs to be reflectively aligned to effect change.

### **Contributions to Radical Flank Theory**

Our study answers calls for research on the micro-dynamics in the interactions between radical and moderate flanks (Ellefsen, 2018). Prior studies tended to focus either on structural shifts in the organizational field due to radical flanks (Schifeling and Hoffman, 2019) or on role conflict among radical and moderate organizations in large social movement collectives (Downey and Rohlinger, 2008). Perhaps more surprisingly, in those cases where interactions and synergies between groups arose, they tended to be treated as ‘externalities’ (Baron et al., 2016). Addressing this gap, our framework suggests that in some institutional change processes the work carried out by different flanks can in fact fruitfully build on each other. We observed positive flank effects: rather than shutting down the T1D ‘hackers’, regulators and medical device manufacturers over time started to collaborate with the movement and

accommodated its demands. However, unlike in many other cases, these collaborations with incumbents did not turn radicals away from moderate ‘sellouts’ (Downey and Rohlinger, 2008; Snow and Cross, 2011). As highlighted, the lack of substantive tension between the two flanks in our case is remarkable. We acknowledge that this may be partly caused by the fact that our community was much less divided by ideological questions than some prior radical flank accounts (Haines, 1984; Schifeling and Hoffman, 2019), which greatly facilitated the alignment of radical and moderate work. Community members were also relatively demographically homogeneous, which may not have been the case in other types of collectives (though see Truelove and Kellogg, 2016).

We offer two conceptual explanations for the synergistic relationships we observed: first, our practice-based research design allowed us to study the radical and moderate flanks not as separate oppositional organizational positions but rather as relatively fluid pathways of action, which can develop in parallel and which, crucially, allow for members crossing pathways or engaging in two pathways simultaneously. While the notion of pathways has crept up in Ellefsen’s (2018) account of a flanked but well-integrated animal rights campaign, his analysis remained largely structural. By contrast, we highlighted that while there was a certain division of labor between the pathways relative to individuals’ backgrounds, skills levels, and resources (as per Table 2), we also observed fluidity. Members initially engaged in the ‘bonding’ pathway, for instance, moved toward material breaching work, and some early hackers adopted more moderate bridging practices over time. We further observed a relatively strong continuity of activities in each pathway even when core members left, which did not threaten the movement as a whole – unlike, for instance, in Ellefsen’s (2018) case. From a practice-based perspective, it is clearly less important who carries out certain forms of work and more important that types of work are combined and mutually reinforcing to support institutional change (Lawrence, 2017). This important shift from a role-based to a

practice- or more specifically work-based perspective of radical flanks opens up a much more granular analysis of distributed and interweaving collective action repertoires.

Our second explanation for the lack of friction, as discussed above, is the existence of the medial ‘bonding’ pathway. Our study thus adds evidence and nuance to early insights by Bertels et al. (2014), who suggest that ‘direct work’ – actions aimed directly at changing a field’s practices – needs to be complemented by what they called ‘indirect work’ – practices fostering social cohesion and effectiveness of direct actions. Where Bertels et al. (2014) saw this work relegated to support organizations, in our case the bonding pathway was a central part of the movement and crucial in keeping all community members focused on the overarching goals, despite differences in tactics. This stands in contrast to McInerney’s (2008) study of circuit riders and Truelove and Kellogg’s (2016) occupational groups, where this intermediate bonding work was absent and where ‘radicals’ and ‘moderates’ turned their differences into a question of power – and eventually into all-out conflict.

### **Contributions to social-symbolic work**

Our study holds significant insights for management research combining social-symbolic work and institutional change perspectives. To our knowledge, ours is the first study that draws Lawrence and Philips’ (2019) social-symbolic work and Micelotta et al.’s (2017) pathways of change frameworks together into a process model by considering the former’s three dimensions of social-symbolic work in conjunction with the scope and pace of change conceptualized in the latter.

We were able to examine the dynamic relationships between six types of work in the change project we studied: institutionally disruptive material and discursive work, institutionally accommodating material and relational work, and a medial set of values and amplification work. We find the temporal stacking, integrating, and aligning of these pathways of work crucial for synergies between types of work to arise. The pathways each

contributed to an overall change pattern of institutional accommodation, in Micelotta et al.'s (2017) categorization: change that is revolutionary in pace but developmental in scope. We suggest that this particular outcome may be related to how the pathways of action intertwined in our case: where the radical flank pathway (and particularly material breach work) precipitated the change and kept propelling its momentum, forcing incumbents to stay apace, the efforts within the moderate and bonding pathways continually translated these radical efforts into the existing institutional context. Though the change was significant for patients, it was not the “dramatic and frame-bending experience” of institutional displacement (Micelotta et al., 2017, p. 1886), and neither had such displacement seriously been envisaged by the movement. For the change efforts to affect the lives of the largest number of T1D patients, it was clear even to the most radical early hackers that incumbent support was eventually needed. On the other hand, institutional alignment and accretion, slower in pace, might have been achieved by following a more standard innovation trajectory without continued grassroots pressure, but this would have left patients suffering for even longer. As in so many other cases of great societal importance, urgency and need were substantial, and the pace of change directly impacted many patients' quality of life.

Extrapolating from our findings, we hypothesize that the reflective sequencing, integration, and alignment of radical and moderate pathways of work will more likely lead to institutional accommodation than to other types of change. This should not be seen as a settlement or compromise of a movement's more transformational efforts, but rather as a constructive combination of a recurrent radical impetus, accelerating and maintaining a rapid pace of change, with efforts to translate this impetus to incumbents. Our research thus adds significant detail to the micro-dynamics of change of Micelotta et al.'s (2017) pathway notion, but further research is required to corroborate our proposition. Such research may also

examine other and perhaps more strongly diverging combinations of moderate and radical collective action pathways, which may lead to different institutional change dynamics.

Our case highlights the significant role of radical material breach work as a major catalyst for institutional change, which allows us to help rebalance the over-emphasis on discursive work in the management literature (Hampel et al., 2017). Material breaching, defined as the illicit altering of material artifacts that are central to an organization's practices, invariably triggers shifts in the discursive landscape and in actor configurations, which need to reorient around a changed material topology. In our case, material breach work rendered institutional change literally irreversible: the opening up of the T1D devices was synonymous with prizing open the tight grip this industry had on patients' lives. Material breaching of the central device in this case – the T1D pump - was both a crucial challenger symbol, of patients no longer accepting the industry's dominance over patients' bodies, and a very concrete act of 'fact-making' that shifted the entire innovation ecosystem into a new technological era. Materiality, thus, is not just a contextual factor; actors work in, through, and with materiality to shape and alter institutions (Lawrence and Dover, 2015). We thus urgently encourage researchers who 'turn to work' to also 'turn to materiality' – including the body and bodily technologies such as our T1D devices as contemporary sites of material work (Michel, 2023).

### **Limitations and boundary conditions**

The central argument of our paper is that 'radical' and 'moderate' approaches in a flanked movement may in fact be bundles of dynamic and at times overlapping practices rather than fixed actor positions, and we demonstrated how such practices interact in the case of a patient movement seeking technological and institutional change. Because our theorization is based on a single case study, we acknowledge several boundary conditions to this claim, which also open up opportunities for future research. We studied an institutional change project in the



field of healthcare, which is characterized by high institutional inertia and regulatory complexity (Bartram et al., 2020; Reay, Goodrick and D'Aunno, 2021). The fact that the change project we studied was 'successful' in such a context may have had causes that were external to the movement's actions. The 2010s were a period of time where patient empowerment was often discursively framed through technological empowerment (Geiger and Kjellberg, 2021; Geiger and Gross, 2021). Thus, there may have been a particularly promising 'window of opportunity' resulting from work done elsewhere and by other actors that may have affected the observed change (Castro and Ansari, 2017). Further, healthcare is a field where collective action is typically bound up with high personal and emotional stakes and considerable dependencies on institutional and commercial gatekeepers (Geiger, 2021; Vidolov et al., in press). 'Muscle' tactics and radical ideologies, which may be observed in movements that display more distinct radical flanks (Ellefsen, 2018), are thus less likely in this arena, which may partly explain the lack of a stronger actor division in our case. We urge future studies to explore the extent to which our findings can be transferred to other types of collectives and research settings including those with greater ideological differences between radical and moderate pathways and those with less institutionally accommodating stances. In addition, we see further opportunities for process research approaches that consider other divisions and variations of social-symbolic work in social movements. With Wickert et al. (2021), we finally encourage management researchers to explore the policy and practical implications of such work in order to support societal transformation and "grand challenges large and small" (p. 307). In this light, we hope that our case may assist small-scale challenger movements to distribute their efforts and combine repertoires of action more effectively to help them in their David-versus Goliath fights against institutional inertia.

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**Table 1: Data sources and their use in the analysis**

| <b>Source of data</b>      | <b>Type and quantity of data</b>  | <b>Use in the analysis</b>  |
|----------------------------|---|---|
| Twitter posts              | Followed prominent hashtag users (n=200)<br><br>Content analysis of 18,600 tweets.  | Identify hashtag key users<br>Understand activity pattern over time<br>Identify topics and actions related to topics.<br>Understand community interactions.   |
| Semi-structured interviews | 31 interviews with community members.<br>1351 minutes transcribed, 390 pages of transcription (single-spaced).                          | Community history (actors, activities, events).<br>Detailed understanding of different forms of social-symbolic work in the community; actors' intent, activities, actions, and outcomes.<br>Understand relations between forms of social-symbolic work |
| Observations               | 7 diabetes conferences and innovation workshops.<br>78 hours of participant observations.<br>50 pages of field notes (single-spaced).   | Key actors, main activities, key events, outcomes.<br>Community interactions.<br>Interactions with industry, regulatory bodies and healthcare professionals.<br>Triangulation of interview data.  |
| Archival material          | 90 documents, including newsletters, presentations, blog posts, magazines, mission statements, business plans and regulatory guidelines | Characterization of the community.<br>Track events, actions, and outcomes over time.<br>Deeper understanding of the forms of social-symbolic work.<br>Triangulation of interview data.  |



Figure 1a: Timeline of Main Events (2013-2016)

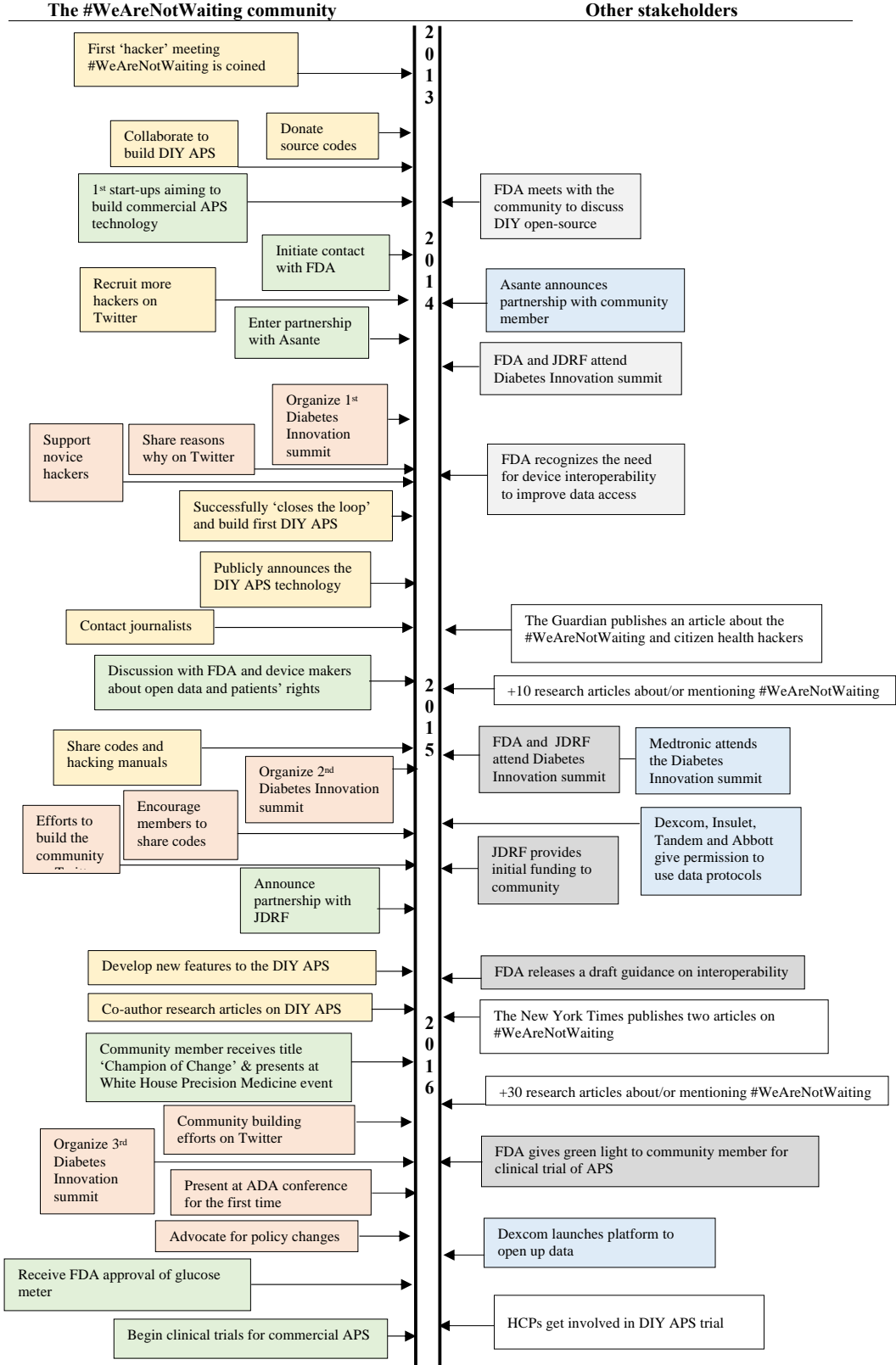
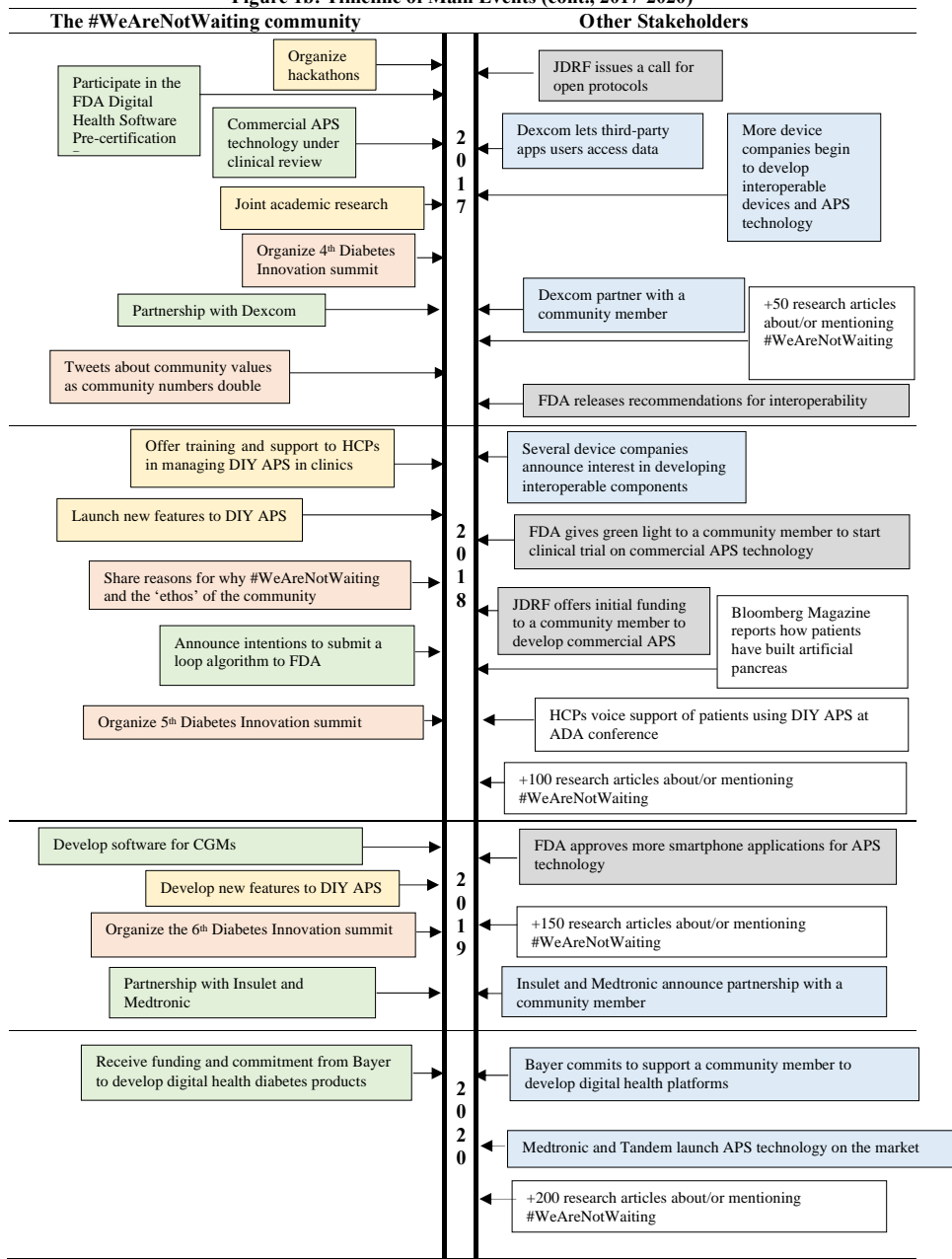


Figure 1b: Timeline of Main Events (cont., 2017-2020)



Legend: Light green = bridging pathway; light yellow = breaching pathway; light pink = bonding pathway; light blue = medical device manufacturers; grey = FDA and funders; dark yellow = academics; dark pink = newspapers and magazines

**Table 2: Pathways of Social-Symbolic work**

|                   | <b>Community skills</b>  | <b>Pathway Rationale</b>  | <b>Actions and Activities</b>   | <b>Types of work</b>   | <b>Illustrative data excerpts</b>  |
|-------------------|--|---|---|------------------------|--|
| Breaching pathway | <ul style="list-style-type: none"> <li>• Programmers</li> <li>• Developers</li> <li>• Engineers</li> <li>• Other</li> </ul>                                    | <ul style="list-style-type: none"> <li>• “We take action now”</li> <li>• Do not comply with FDA regulations</li> <li>• DIY APS technology is safe and effective</li> <li>• DIY APS technology is opensource and free for all to use</li> <li>• DIY APS technology is not for the commercial market</li> </ul> | <ul style="list-style-type: none"> <li>• Collectively develop DIY APS technology</li> <li>• Collectively create and test codes and algorithms</li> <li>• Write books and co-author academic articles</li> </ul>   | Material breach work   | We agreed to collaborate using several modern development practices. We started sharing our work and branches and updated the documentation to suit. We also started recruiting community members and within a few weeks made several critical changes to the DIY APS technology (archival material, 2018).  |
|                   |  |   |   | Discursive breach work | Rolling up his sleeve, he reveals a small box, about half the size of a cigarette packet, taped to his upper arm. From the box, a sensor runs under his skin, delivering a readout of his blood glucose level to his mobile phone (...). He is a citizen hacker. Tired of waiting for the pharmaceutical and medical device companies to come up with new, affordable ways to improve the lives of diabetic patients, he has taken matters into his own hands.” (archival material, The Guardian, 2015). |
| Bridging pathway  | <ul style="list-style-type: none"> <li>• Entrepreneurs</li> <li>• Business developers</li> <li>• Venture capitalists</li> <li>• Software developers</li> </ul> | <ul style="list-style-type: none"> <li>• “We do it the right way”</li> <li>• Comply with FDA regulations for innovation and dissemination</li> <li>• Collaborate with industry and regulators is necessary</li> <li>• Develop commercially available T1D technology</li> </ul>                                | <ul style="list-style-type: none"> <li>• Build networks with industry and regulators</li> <li>• Develop a commercial, open-source APS, digital apps and platforms for integrated digital diabetes management,</li> <li>• Use traditional commercial channels</li> </ul> | Material bridge work   | We said to them [device makers] if you deliver the data and allow users to have full control over it, and you allow app developers have access to that data, magical things will happen. (archival material, 2015).  |
|                   |  |   |   | Relational bridge work | Excited be at Roche HQ in Basel for Partnering for Innovation Summit talking #WeAreNotWaiting patient movement. hear some techs in the room! (tweet, 2017).  |
| Bonding pathway   | <ul style="list-style-type: none"> <li>• Diabetes advocates</li> <li>• Podcasters</li> <li>• Bloggers</li> <li>• Other</li> </ul>                              | <ul style="list-style-type: none"> <li>• “We activate the community”</li> <li>• Spread the message</li> <li>• Encourage action</li> <li>• Put pressure on industry and regulators</li> </ul>  | <ul style="list-style-type: none"> <li>• Encourage, support and engage with community members</li> <li>• Organize conferences, workshops and networking events</li> <li>• Public speaking, podcasts, blog series</li> </ul>   | Values work            | Yeah, the hashtag ringfences the whole thing. We have got lots of groups of people that have got different communities. (interview P25, 2020)  |
|                   |  |   |   | Amplification work     | My ‘job’ in the #WeAreNotWaiting community is to help share stories. I’m sharing the stories, I let the smart people do what they do when they say it is done I tell everybody about it” (interview P19, 2020).  |

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**Table 3. The objectives of the #WeAreNotWaiting community**

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**#WeAreNotWaiting to bridge disconnected data islands.**

**#WeAreNotWaiting while our endocrinologist tries to assemble the disjointed pieces of the data puzzle.**

**#WeAreNotWaiting for competitors to cooperate.**

**#WeAreNotWaiting for regulators to regulate.**

**#WeAreNotWaiting for device manufacturers to innovate.**

**#WeAreNotWaiting for payers to pay.**

**#WeAreNotWaiting for peace of mind that our children with type 1 diabetes are safe.**

**#WeAreNotWaiting to get some decent sleep for the first time in years.**

**#WeAreNotWaiting for our child to be able to safely have a sleepover at friend's house.**

**#WeAreNotWaiting to give our child a better chance to succeed at school.**

**#WeAreNotWaiting for others to decide if, when, and how we access and use data from our own bodies.**

**#WeAreNotWaiting to build applications that focus on design and usability.**

**#WeAreNotWaiting to compel device makers to publish their data protocols.**

**#WeAreNotWaiting to insist that patients have access to their own diabetes data.**

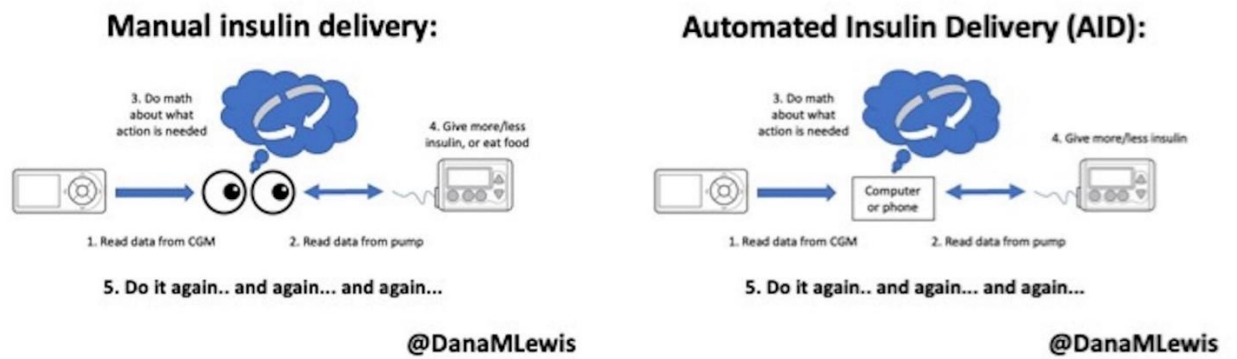
**#WeAreNotWaiting to allow PWDs to have a choice in how they see their own diabetes data, and not be forced to use substandard software that comes with their device.**

**#WeAreNotWaiting to make it easier to get data off of devices.**

**#WeAreNotWaiting to bring together the best and brightest minds from around the world to help make things better for PWDs.**

**#WeAreNotWaiting for the cure.**

**Figure 2: Illustration of Closing the Loop** Source: Dana M. Lewis



**Figure 3: Process Model of Interweaving Pathways**

