PDFi: Participatory Design Fiction with Vulnerable Users

Larissa Vivian Nägele  
University of Southern Denmark  
Kolding, Denmark  
LarissaVNaegle@gmail.com

Merja Ryöppy  
University of Southern Denmark  
Kolding, Denmark  
merja@sdu.dk

Danielle Wilde  
University of Southern Denmark  
Kolding, Denmark  
d@daniellewilde.com

Abstract
Traditional user-centred design processes frequently marginalize vulnerable users. Their perspectives are thus not well represented in discussions of the future of the medicines and technologies on which they rely. We present PDFi, a method that responds to this issue in the context of Urinary Tract Infections (UTIs). PDFi was developed through a collaboration with a medical device development company. The method marries Participatory Design (PD) strategies with Design Fictions (DFi) to personally ground, inspire and reveal values and imaginaries of vulnerable individuals who rely on medical technologies for their health and wellbeing. By more fully including these vulnerable users in shaping their medical technology futures, PDFi gives voice to those most impacted by such futures; it elicits emotions, discussion and debate, and powerfully reshapes current approaches to user-centred design.

Author Keywords  
Design Fiction; Participatory Design; Participatory Design Fiction; User Centered Design; Vulnerable Users; Urinary Tract Infection.

ACM Classification Keywords  
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;
Introduction

This paper recounts a study undertaken in collaboration with a multinational company that develops medical devices for vulnerable individuals. The company’s design teams follow a user-centred design approach to product development, typically working five years into the future. Always on the lookout for new tools and techniques to better serve their client base, for this project they requested the first author design 10-25 years into the future, with people with chronic or recurrent Urinary Tract Infections (UTIs). This request called for a careful application of speculative design strategies [26].

A UTI is a common bacterial infection that occurs in any part of the urethra. UTIs affect around 150 million people a year worldwide and are considered a severe public health problem [12]. They can be categorized as Complicated or Uncomplicated. Complicated indicates a structural or neurological abnormality in the urinary tract (UT) and other factors that compromise the UT or immune system [12]. Uncomplicated UTIs affect people with otherwise healthy UTs. In both cases, when chronic or recurrent, the experience can be emotionally challenging, and the accumulation of associated doctor’s visits and hospitalizations, costly. The condition is thus a complex personal and societal issue (cf. [16]).

Speculative Design is an approach to futuring [2], which has been criticized for disseminating to select social groups, and concentrating on ‘first-world’ problems [4,35,36]. The stated intention is to prompt a generalised ‘us’ to collectively imagine, discuss and debate what a preferable future might be [9]. However, questions remain about who ‘us’ refers to [19,35]. To ensure that our approach to speculation is inclusive, this study is founded on the democratic principle that those who are most impacted by a future outcome should have a say in shaping that outcome [35]. Diverse people have different stakes in futures and different ideas about what a preferable future might look like. It is therefore critical to take divergent perspectives into account when speculating [40].

Speculating futures of people with UTI’s demands a rethinking of traditional user-centred processes and speculative design strategies. To this end, we merge Participatory Design and Design Fiction. We use storytelling, sketching and design, as well as theatre methods to surface and shape preferable futures with our vulnerable stakeholders. Theatre methods have proven useful to negotiate vulnerable encounters between chronic pain patients and health care professionals [21]. These methods combine to support our participants to take distance from their current situation and explore alternative ‘coping strategies’.

We present our study and the resulting Participatory Design Fiction (PDFi) method: a 4-stage process that assists a research team to derive design values and insights by working with marginalized and vulnerable individuals (figure 1). We examine the merits of the method from the perspectives of the medical device design company, the researchers and the participants to uncover shortcomings, as well as potential for the method beyond the case of UTI’s. To assist the reader to immerse themselves in the challenges of UTI’s and the potential of the method, we first provide an example PDFi developed with Charlotte, a Columbian communications analyst based in Washington D.C. who suffers from chronic kidneys stones, which result in painful, complicated and recurrent UTIs.

Figure 1: The four stages of the PDFi method
**Prologue:** Washington DC, 2050: Charlotte is working late again. She mostly works from home as a communication analyst, and lives in a modular home similar to her friends and most others in Washington D.C. The city is extremely overcrowded so highly functional and modular homes have been created to accommodate suitable living conditions. Insurance companies fight for better and healthier clients in this world to strike better deals. Charlotte pays a reasonable fee, like most others, for her medical insurance but because of her unique medical condition her home is installed with special features to accommodate her condition. For instance, her home includes a more comfortable bathroom and special remote linkage to Doctors and specialists.

**C: Charlotte, D1: First Doctor, D2: Second Doctor**

Charlotte falls asleep at 4:00 am just to be woken up by her alarm-pillow vibrations 2 hours later.

She gets up before it automatically deflates and the sound alarm begins. She stumbles on her shoes - her house is like a shoe landfill, and the light is still to dawn to find a shoeless path.

She enters the bathroom; the light turns on as she walks in. She sits down on the toilet and pees. After two drops, the lights change to red. Still peeing, she turns her hand, and on her right wrist she sees a message on her skin:

```
Alert: Urinary Incontinence
Possible cause: Lower Urinary Tract Infection
Expected recovery in 24 hours
```

She shakes her hand and the message changes:

```
Drug prescription requested. Expected at home delivery in 20 mins.
```

She grabs toilet paper and cleans herself carefully. She then gets up and without fully standing upright, tries to reach a box underneath the cabinet in front of her. She can’t reach it, so reluctantly, stands up and with her underwear still wrapped below her knees, makes two jumps forward, grabs the box, and makes two jumps backward and her ass lands perfectly back on top of the toilet. Inside the box, she grabs two objects that look like mini magnets and places one on her back and the other on her stomach. They immediately start moving up and down her body, still attached to her skin, until they stop moving.

She snaps her fingers, and the lights return to normal. Then she looks at her wrist again:

```
Kidney stone located. No laser treatment required.
```

*UTI symptoms may occur.*
She joins her index finger and thumb and starts dictating: “Cancel sex with what's his name... send sick leave to office...”

She opens a lower compartment of the box. And grabs a metallic-spider looking object. She places it in her belly button, and the object melts into her skin like mercury, then hardens filling up her belly button hole.

Meanwhile, messages pop on her wrist, but she only glances at some: Antispasmodic in place. Medicine release every 5hrs. Linking to Doctor Robert Muriel McKibben for monitoring. Dosages may change... calibrating.

She grabs a silicon tube inside the box and takes it out of the plastic wrap. It looks like a transparent lipstick. She grabs it and leans back, opens her legs and looks at the ceiling while holding the tube:

C: I hate this part. - She mumbles while taking a breath.

She rubs the silicon tube at the tip of her urethra and it sort of melts. She immediately feels an icy-knife pain going inside of her and into her lower back. Although she is looking at the ceiling, she can still catch the glow of messages on her wrist.

C: I swear the cure is just as bad as the disease.

She lays there for what felt like half an hour, with her knees wide open, eyes shut and occasional tears running down. She put her fingertips together again and said in a shuttered voice through the pain.

C: Turn on v-butt.

Vapors started coming out of the toilet, and she felt some relief. After five minutes, she finally stood up, cleaned her vagina again and took a shower. After she got dressed in her most comfortable pajamas, she sat down on her chair and looked at her wrist. And she saw a countdown. Her mail chute (a cylinder coming out of the wall) made a sound, and she walked towards it and got her prescription. It had arrived an hour earlier. It was a round shaped box with a note on the top. She decided to go back to sleep.

Her belly button device woke her up. It felt like injections in her stomach. She looked at the watch, and in about two hours she would be in horrible pain. She put the tips of her fingers together and said:

C: Set alarm 15 minutes before pain begins.

She then stood up and cleaned her kitchen, rearranged her apartment, and picked up a pair of shoes. She was about to make some pop-meat when suddenly the house lights turned to intermittent red. She immediately got on her knees and put the palms of her hands on the floor and waited like a dog staring into a void.

Ten minutes later she was in excruciating pain, and the shaking began. She didn't know which was worse, the injections in her belly or the back pains. She crawled to the bathroom and opened the toilet seat, she puked inside and then curled up next to the toilet putting her head on the floor and clutching her knees. With shaky hands, she pulled the round medicine box out of her pocket and squished it. A small porcupine-disco-ball popped out and rolled to her back where the magnet device was placed. It pinched her skin a couple of times.
The pain went away, and she passed out on the bathroom floor. She woke up hours later sweating. She wished she hadn’t taken the numbing device; it will leave a mark for days and blood will come out of her back for at least a week. That would be an inconvenience for sure. She looked at her wrist and read: “Check for UTI status and insert new lubricant.”

She peed first, then took another silicon stick and repeated the process from this morning. When she managed to stand up, she noticed her wrist turned red. She turned to her arm and saw an important message:

UTI detected. Administer Antibiotics

She went to her kitchen put her fingertips on a metal plated case next to the refrigerator. There was an unlock sound and the boxed opened. Inside was a chip. She took it and her wall-screen opposite her turned on. She turned around and found the face of a very old man behind her.

Why do all urologists look old? - She thought.
Designing Fictions

Design Fiction (DF) is a relatively new research and design practice. The term was coined by Bruce Sterling in *Shaping Things* [33] where he describes how DF reads similarly to science fiction, but 'sacrifice[s] the miraculous' to be practical. DF works in the space between rigid scientific facts and the 'playful imaginary' of Science Fiction [3]. Like Science Fiction, it involves society, as well as technology to speculate toward futures [10]. Science Fiction plays a strong role in how people envision and even enact the future. DF intends towards a similar role, not to predict the future, but to speculate on how things could be, in order to critique and discuss possibilities [11]. It uses a range of media to open up a problem space and is fundamentally anti-solutionist, building on the recognition that a search for solutions can close down problems [4,9]. While interest in participatory DF practices is rising (cf. [4,37]), we contend that the participatory approach needs to be reconsidered when working with individuals with a sustained medical condition.

Participation in Design

Sanders and Stappers [29] describe participation as methods and tools that revolve around making, involving non-designers through an iterative design process. When 'making' a co-designer can construct and transform meaning that inspires views on future experiences and future ways of living [29]. The making can take various forms, from tangible probes and prototypes to enacted scenarios and fictive narratives. In this study, the participants are acknowledged as the experts of their body, future dreams, fears, and condition [28]. The resulting method is designed to ensure researchers attend to how radically participant views may differ from their own, and the familiar.

Designing for Medical Disability

Many well-meaning technology experts seek to "solve" the "problem of disability" through tech fixes by (re)making disabled bodies [7,31]. The resulting technologies may conform well to medical needs, but they often neglect complex aesthetic and social needs of the individual. PDFi attends to this problematic by giving voice—first and foremost—to the individuals who need the medical devices. Rather than seeing their UTI as a problem to be solved, the method recognises that the challenge of having chronic or recurrent UTI’s is a complex, situated challenge that is in part medically constructed, and in part socially constructed. The economy between social representations and the ill body is not unidirectional or non-existent, but reciprocal and thus complexly embodied [31]. Knowledge is socially situated and adheres in embodiment, identities are socially emergent (and thus embodied). Some bodies—in particular disabled bodies—are excluded by dominant social ideologies [15,31]. As a result, people in marginal social positions, enjoy an epistemological privilege that allows them to theorise society differently from those in dominant social locations [14,15,31]. Designers must therefore consider disability as a source of valuable perspectives that needs to be extensively explored to relate to the phenomenon and from which to design—not only for the disabled individual, but for everyone. The PDFi method therefore pays careful attention to unravel the complex embodied expertise of our participants.

The PDFi Method

In this section we detail the four stages of the PDFi method: (1) Probe, (2) Sci-fi narratives, (3) World-building journey, and (4) PDFi Showroom.
**PART ONE: PROBE**

- Craft a science fiction writing prompt
- Send to volunteers via an online platform

To begin the study, a probe in the form of a writing prompt (Figure 2) was posted to Facebook. We hoped to recruit UTI sufferers and medical personnel who handle patients with UTI issues. We also wanted to include individuals from different geographic and cultural locations. Facebook thus was useful. It afforded easy sharing and distribution among concerned individuals, without being location-specific. We recruited 12 women, aged 23–33, from: Panama, Colombia, The U.S., Croatia and Denmark. One participant was a female occupational therapist writing about a male spinal cord injury patient who uses catheters. The other 11 were women who suffer from varying degrees and cases of UTIs.

**PROBES**

Probes have been successful in sensitive settings where a researcher may find it hard to gain insight [5]. The information a participant chooses to share can surprise the researcher and be useful. In our probe we ask participants to write a science fiction story that involves them personally. We thus lean on a particular strength of written narrative. As Stewart explains [34] (citing Southern et al. [32]), writing a fictional narrative, as opposed to speaking it, allows a participant to creatively imagine, and express their experience without having to disclose personal circumstances. Further, research with chronic pain patients demonstrates that a fiction needs to resonate with participants’ experience, but not be too imaginary or they may not find it interesting to work with [17,21]. Written narratives attend to both of these concerns.

They enable us to elicit personally meaningful, possibly intimate information relating to the UTI condition, without compromising participants’ need for privacy. Our UTI experts could protect their vulnerabilities by portraying fictitious characters and situations. At the same time the design team could learn from the experts’ personal experiences, as reflected in the stories. The intention of Part One was to foster positive, cathartic participation: imaginative, investigative, emotional, discursive, reflective and playful participation [13,24]. The resulting narratives serve as discursive material, for Part Two.

**PART TWO: SCI-FI NARRATIVES**

- Collect the sci-fi narratives, analyse and organise them into themes to broaden the problem scope.
- Scaffold a story board to be used as a discursive and world-building tool in a co-creative workshop.

In this stage, the narratives collected in Part One act as preliminary or partial, design fictions. We received 12 science fiction narratives. Drawing on Brinkmann [6], we viewed the narratives not as data, but as “instances”; situations that we broke down based on our understanding of the events that took place; and heightened ‘matters of concern’ that ‘surprised’ us, which we tried to make sense of [6]. Our abductive analysis extended the problem scope to include themes to be considered by a design team later in the process. Charlotte’s sci-fi narrative, for example, brought focus to the relationship struggle between her and her doctor(s). Similar struggles were evident in other participant narratives. Additional themes included: problems obtaining medicine because of poorly designed services, the need for privacy when struggling with a UTI and transhumanist concerns. Mary, for
example, writes about a future world where many people augment their bodies to be more talented or more efficient at work. She writes: "Those AUGs are so cheap! But people forget that some of us actually need our AUGs to feel normal. And honestly during my catheter days all I wanted to be was normal."

Critically, PDFi frames the narratives that result form Part One as future artefacts. They form continuous personal narratives that connect the present with future, in the same way that postcards connect the present with the past [34]. These narratives are lively accounts that the designer sketches into preliminary storyboards for use in a shared world building activity in Part Three (cf. figure 5).

PART THREE: WORLD BUILDING JOURNEY

- Upload narratives and preliminary storyboards to a co-working platform.
- Conduct a one-on-one workshop via the platform

In Part Three a 1-2 hour one-on-one workshop is conducted with each participant using video chat (f.x. Google Hangouts, FaceTime, or Facebook Video) and CoSketch.com, a collaborative online workspace. We conducted the workshops with 5 out of the 12 participants. The sessions were documented using audio and screen recording, following participant preferences. To prepare, the facilitator uploaded the participant’s Sci-Fi narrative and the preliminary storyboard to CoSketch.com. The participant was to bring simple making materials to build diegetic artefacts—designs or objects from their ‘fictional worlds’ [3,18,22]—and accessories to help them take on the character of their fictional future self. However, many did not do this.

THE WORKSHOP

The aim of the workshop is to understand the participant’s view of their future world based on their personal circumstances. It strengthens the storyworld through three world building activities:

1. **Storyboard & Narrative:** The facilitator explains how to use CoSketch.com, and introduces the partially completed storyboard and the sci-fi narrative to propel the world-building journey.

2. **In-Character Interview & Making:** The participant is asked to respond to world building questions from the first-person perspective of their future self, then to construct a diegetic artefact (cf. Figure 3).

3. **Discussion:** The facilitator uses a diagram showing multiple presents and futures (Figure 4) [11,36,38] to investigate how the participant views their world and why they created certain aspects. An unstructured conversation is conducted to enhance the quality of the resulting design considerations.

Role-playing within an interview is a proven method to immerse a participant in a fiction and experience an issue at hand from another perspective [20]. In PDFi, the role-playing provides insight into the challenges of the UTI condition and enables the facilitator and participant to unwrap the broader fictional world together. To construct their diegetic artefact, the participant uses found objects, low-fi materials, sketching, and gestures, and the facilitator sketches their emerging understanding of the artefact within the storyboard and storyworld (cf. Figure 5 & 8). This process is further supported by the facilitator using strictly operational questions to clarify and appropriately value emerging concepts [39]. Through this process, Part Three deepens the fiction. It identifies
personal motives behind the author’s narrative and uncovers socio-political elements to perceptually scaffold and craft the final Design Fiction [1]. It thus ensures that the sci-fi narrative is appropriately represented in Part Four.

PART FOUR: PDFi SHOWROOM

- Synthesis: complete the storyboard and construct a finely crafted diegetic artefact
- Present the completed PDFi to the design team

Part Four synthesizes the findings from the previous three stages of the PDFi. The facilitator completes the storyboard, verifying changes with the participant and develops conceptually resolved diegetic artefacts (Figure 6). A prologue is added to the narrative to give further context. The original narrative, the newly created storyboard, diegetic artefacts, and the participant’s profile, along with values and design considerations uncovered in Part Three, are then presented to the initial design team.

Discussion

In this section, we discuss the potential and the shortcomings of the PDFi method from the medical device company’s, the participants’, and the researchers’ perspectives. Charlotte’s completed PDFi was presented to the company. The aim was to enable discussion about preferable futures from participant perspectives, and validate the method.

THE COMPANY PERSPECTIVE

At the presentation, the company claimed valuable insights into participant challenges, fears and desires of the future of their condition. The presented PDFi’s inspired future concepts and ideals, and opened up the problem space about the company’s end users by highlighting more personal future design considerations in a speculative, yet personal way. The company expressed some doubts about how they would recruit participants. Nonetheless, they appreciated participant reactions throughout the process, in particular how PDFi made the participants feel less vulnerable and foremost act creatively. They noted that the method also eliminates ‘the wearisome task of trying to predicting the future’ (personal correspondence), and voiced the intention to test out the method, stating it would enable them—for the first time—to unite future users of their products with the user insights team and the design team in an early front end scoping phase that would not disrupt either patents or bureaucracy.

PARTICIPANT RESPONSES

“I would say that this is the first time I have ever been even asked about UTIs by anyone other than like my parents and my doctors, and I definitely think my story reflects how I really want there to be a focus on women’s health problems in the future […] And it’s not like they don’t take me seriously… I mean I think they know I am in pain, but like Doctors are so withdrawn and I feel so judged sometimes. […] This was really fun actually, I really enjoyed doing this. I can write another one if you want” (Sofia)

Participants’ articulated various devices in their sci-fi narratives. We use Charlotte’s example PDFi to discuss the underlying mechanisms. During the Part Three discussion, Charlotte explained how the devices in her fiction are based on the medicine she routinely receives from the doctor except these are preferred versions. The “Localized Morphine medicine” (Figure 7) is a response to her fear about the strength of medicines in
the U.S., while the ability for her medicine to be delivered to her home and self-administered is part of her yearning for privacy and comfort in these situations. She speaks about how she values control, comfort and transparency about her kidney stones and UTIs because otherwise she lives in fear of a painful and embarrassing unexpected attack. Charlotte’s PDFi countdown timer highlights the design value of control over unexpected situations. Her desire for privacy and balanced relationships with doctors is highlighted by the design of her future home, which linked to doctors remotely (Figure 8) and the many wearables that she can administer and monitor herself.

RESEARCHER REFLECTIONS
PDFi enables participants to voice their thoughts through fiction and willing professionals to sense the different voicing. The method thus can unsettle conventional practices and be a starting point for reflexive transformation [21,27]. The process of generating and reflecting the fiction based on lived experiences enabled Charlotte, for example, to reveal themes that might otherwise stay hidden. Researchers working with theatre methods have reported similar insights by unfolding: "feelings of insecurity, fear, depression and loneliness when the attempt (is) to express or ‘manage’ the unmanageable fails." [20].

The need for self-efficacy in management of a chronic condition is widely recognized in the medical field [23]. However, people struggling with chronic conditions are rarely encouraged to imagine far-out technologies and medical concepts for self-care. Charlotte’s narrative brought critical aspects to self-care devices, demonstrating how many particularly unpleasant aspects of her care remain unresolved.

Crafting a sci-fi narrative—an unknown future world based on the known present—allows a participant to observe their familiar, taken-for-granted situation, from an unfamiliar angle. The five participants who went through the entire process were excited about their contributions and felt empowered about their situations. Sofia, in particular, highlighted the feeling of being heard and having fun through the process. Many who withdrew from the process after Part Two also reported cathartic and empowering effects.

Despite this positive feedback, there were times when participants felt silly and stepped out of character. Participants who struggle with role-playing their future selves might be encouraged to take a less personal role, and write the narrative from the perspective of a doctor, relative or imaginary character. Facilitation techniques based on improvised theatre can be used to strengthen the world building process and in-role interview [17,20,21].

The PDFi method evoked empathy from the facilitators. When attempting to design sustainable or preferable futures with someone with UTIs, the context is intimate. It is important to understand personal feelings and connect with the potential user emotionally [25,30]. Researchers using the method also need to be responsible for maintaining promises and relationships with participants, as we found that empowerment and motivation increases when narratives are valued in each step of the method. Furthermore, some participants in highly vulnerable situations may not feel comfortable thinking about their future, and thus the term ‘alternative realities’ may be more appropriate.
Although effectiveness of a DF is difficult to quantify [35] there is promise that the PDFi method can surface insights that effect and inspire developers of medical device technologies and rightfully give voice to people in vulnerable positions. The PDFi method notably uses the fictional strategy of 'science fiction', as a mobilizing medium to enable participants to craft a personally related design fiction. This helps to make the DF more relatable, personal and thus, plausible, assisting a company to engage intellectually and emotionally with the DF. Furthermore, drawing from DF examples that use Storyboards or comic strips, Coulton et al., 2017 [8, p.8], argue that a benefit of communicating a DF with a comic strip "cajoles readers into properly considering the content of each panel", while video reduces viewer criticality. Thus, DF directly benefits from participatory approaches as a crafting quality to help create more relatable and ‘perceptually bridged’ speculations [1,19].

CONCLUSION
As technologies increasingly imbed themselves in our lives, it is important to question who the visionary behind such concepts is and what justifies their vision. By opening future visionary quests to people who are most impacted by those futures, researchers, designers, organizations and others with large influence over the future, can help in shaping preferable futures. The Participatory Design Fiction method gives voice to those who are vulnerable and who are otherwise not normally included in a design process. By concentrating on participatory principles within Design Fiction, the method pushes the idea that those who are most impacted by technological futures should be part of crafting those outcomes. Furthermore, the process strives to observe the current reality in an unusual way, so that vulnerable participants can cathartically enjoy speaking about their unspoken concerns and futures.

The example PDFi was undertaken within the context of people who suffer with Urinary Tract Infections. We envision future iterations of the method in other contexts where intimate care and medical device development collide. Representations of futures in Speculative Design, Design Fictions and even Science Fiction can steer present directions, thus it is important to involve those who are most vulnerable to help steer the present and shape the future by developing their own fictions.

REFERENCES


