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# Integrating empathy and lived experience through co-creation in service design

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## Abstract

While empathy is often hailed as a central aspect of service design, there is a growing acknowledgement of the risks associated with an over-reliance on empathy in design processes. As such, there is increasing recognition of the need to integrate lived experience—the direct, first-hand perception of a relevant situation, condition, or identity in an everyday context. This paper reviews existing literature related to empathy and lived experience in co-creation, with particular attention to the associated risks of amplifying one over the other. From this literature, we highlight two different manifestations of the relationship between empathy and lived experience: “I—It” and “I—Thou”. We build an understanding of the interdependence of empathy and lived experience and argue for an integration of both to enable reciprocal co-creation. To advance the existing discussion, we highlight a number of important directions for future research in this area.

**KEYWORDS:** empathy, lived experience, co-creation, service design

## Introduction

Empathy is repeatedly stressed as a central and distinguishing factor in design, especially in service design (Koskinen et al., 2003; New & Kimbell, 2013). It is typically described as understanding what it feels like to be another person or to walk in someone else’s shoes (Kouprie & Sleswijk Visser, 2009; Wright & McCarthy, 2008). Over the years, a variety of design methods have been developed and employed to elicit empathy including: bodystorming (Burns et al., 1994), observation (Leonard & Rayport, 1997), experience prototyping (Buchenau & Suri, 2000), design probes (Mattelmäki, 2006), role playing games (Kaario et al., 2009), and service walkthroughs (Blomkvist & Bode, 2012). While empathy in the service design process has commonly been perceived as having positive effects, such as

supporting a creative understanding (Postma et al., 2012), critics have recently highlighted its dark side by suggesting that an over-reliance on empathy can promote single-mindedness, a present-day orientation, reinforce otherness, enhance exclusion, and ironically support designers to design for people like themselves (Abbott, 2017; Holt, 2011; Meill, 2015; Staffer, 2015; Wendt, 2017). As such, too much emphasis on empathy can contribute to controlling and disciplining the interpretation of human experiences, further reinforcing the practices of colonization in design (Glostanova, 2017).

One response to the over-emphasis on empathy is to leverage lived experience in service design processes through co-design, participatory design, or user-led design (Couvreur et al., 2013; Holmlid, 2009; Sanders & Stappers, 2008; Steen et al., 2011; Trischler & Scott, 2014; Trischler et al., 2017). We define lived experience as direct, first-hand perception of a relevant situation, condition, or identity in an everyday context. While there has been significant attention paid to empathy within design literature, there has been little research on the nuances of lived experience or how to effectively integrate empathy and lived experience in co-creation (Cipolla & Bartholo, 2014). As highlighted by Smeenk and colleagues (2016, p.31): “the specific utility, and legitimacy, validity of this first-person perspective in design is currently not sufficiently understood and recognized [...] a better understanding of the relative value of the first-person perspective compared to—and combined with—other fundamental perspectives [...] can contribute to enrich and develop design methodologies.”

This paper focuses on integrating empathy and lived experience for co-creation in service design. For the purpose of this paper, we define co-creation as collaborative activities between two or more actors. Traditionally, most research in service design has accentuated the beneficial nature of co-creation: it fosters the fit between services and its users (Holliday et al., 2014; Hussain et al., 2012); leverages a mutual understanding between involved actors (Akama, 2014; Fjuk et al., 2016; Følstad et al., 2014); and supports the development of new and existing services (Aro et al., 2012; Holliday et al., 2014; Kronqvist and Korhonen, 2009). However, a growing body of literature suggests that co-creation can actually be a ‘double-edged sword’ (Chan et al., 2010; Dong et al., 2015; Piller et al., 2011; Xu et al., 2014) due to several associated risks, such as participants not having an equal voice in co-creation efforts (Näkki, 2012) and concerns about the sustainability of ideas (Akama, 2014). Extant research insinuates that a pressing risk in many co-creation efforts is that the scope and value of innovations may be biased towards the designer, as the designer often takes on the dominant role in the co-creation process (Takeyama et al., 2012). Although there is some acknowledgement of the risks inherent in co-creation, more research is needed on these pitfalls as current literature predominantly focuses only on the positive aspects (Dong et al., 2015; Mustak et al., 2013, 2016).

In this vein, the current paper specifically reviews existing literature related to empathy and lived experience for co-creation in service design, with particular attention to the associated risks of amplifying one over the other. A focused literature review was conducted by manually scanning abstracts for relevance to empathy, lived experience, and co-creation in previous *ServDes proceedings* and the *International Journal of Design* as well as through a general search of design and service research outlets. In addition, opinion pieces from popular discourse, such as blog posts, were added to capture the evolving public sentiment regarding empathy and lived experience. To illustrate issues brought forward through the literature, we draw on short examples of activities within service design processes supported by Experio Lab, a group that uses a service design approach to foster co-creation within the healthcare system in Sweden. The examples presented here were gathered through ethnographic research, which involved observation, interviews, and a review of archival data related to Experio Lab’s work. In doing so, this paper contributes to service design literature by: 1) synthesizing the documented risks of co-creation caused by a dominant focus on empathy or lived experience; 2) detailing the different manifestations of the relationship between empathy and lived experience in service design; and 3) highlighting the interdependence of these processes for reciprocal co-creation.

## The Over-Emphasis on Empathy

Within design literature, and more specifically service design studies, there has been a growing body of research on empathic design focusing on how designers attempt to get closer to the lives and experiences of users (Koskinen et al., 2003; Leonard & Rayport, 1997; Mattelmäki et al., 2014; Postma et al., 2012). Empathic design aims to move beyond a consideration of rational and practical issues to the experiences and contexts of users, typically to inform new product and service development (Mattelmäki & Battarbee, 2002; Postma et al., 2012). The conceptualization of empathy in design has been informed by a variety of perspectives. Drawing on social theory, Wright and McCarthy (2008) highlight that empathy involves both perceiving the emotion of another as well as articulating the other's context within one's own. Similarly, inspired by psychology, Kouprie and Sleeswijk Visser (2009) highlight two common dimensions of empathy: 1) the affective dimension associated with emotions and feelings and 2) the cognitive dimension focused on understanding and perspective.

In service design, a variety of methods have been introduced to help facilitate empathic engagement with a user's experience of a service (Stickdorn & Schneider, 2011). One such example are service walkthroughs, which aid actors in understanding service in a holistic way, focused on the experience of customers and other stakeholders, by enacting and walking through the process of a service (Blomkvist & Bode, 2012). Other common approaches include the use of empathy tools (Hoss & Roopani, n.d.), which involve working with physical objects or social techniques to get a sense of what users feel in their everyday life, and empathy maps, which help to visualize the multi-sensual experience of actors (Gray et al., 2010). However, when actors simulate the experience of others, without having lived experience themselves, their experience remains one of novelty and they cannot fully understand what it feels like for someone who lives this experience (Abbott, 2017). Through the use of these empathic methods, actors can end up projecting their own assumptions on to the experiences of others and falsely rationalizing design directions (Meill, 2015; Staffer, 2015; Wendt, 2017).

To put this in context, Figure 1 illustrates examples of the use of empathy tools and empathy maps at Experio Lab. Within the context of Experio Lab's work, empathy tools are often used to help healthcare staff take on the role of the patient and build their understanding of different perspectives. In the photograph on the left, a healthcare leader is putting on an 'aging suit' to simulate what it feels like being 30 years older while moving around the hospital. Here the actor wearing the suit makes assumptions based a short-term simulated experience about what it might feel like to move through the hospital for seniors. Furthermore, empathy maps are often used to detail the experience of patients and stimulate a dialogue about their underlying emotions and motivations. In the photo on the right, designers are working with healthcare staff to brainstorm about what their patients might be thinking, feeling, saying, and doing in relation to their service. However, completing empathy maps without intentional interaction and input from patients may simply reflect staff's own interpretations of the patient experience, clouded by their own role, identity, and experiences.

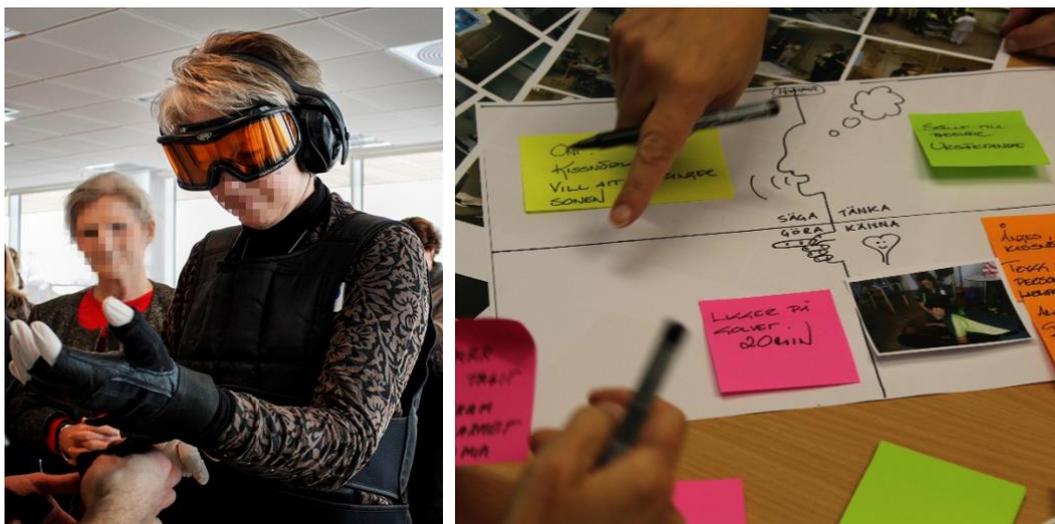


Figure 1: The use of empathy tools and empathy maps at Experio Lab

When these empathic methods are employed without the participation of those with lived experience or a critical dialogue with them to unpack the limitations, these methods can contribute to replicating colonial practices in service design. By colonial, we refer to the process of European political domination that involves ‘othering’ and undermining the self-definition of people (Tunstall, 2013). Decolonizing service design practice and research requires an understanding of the locations and bodies related amid complex power dynamics (Schultz et al., 2018). As such, we must acknowledge that empathic methods can often create a semblance of participation and end up becoming tools for the coloniality of design (Tlostanova, 2017). When actors objectify those that they are designing for by assuming that they know them and can understand them through their own actions, they engage in what Cipolla and Bartholo (2014, drawing on Buber, 1921/1996) refer to as “I—It” relationships. The authors highlight the need to move toward reciprocity in co-creation for more socially responsible service design practices. One way to do this is by leveraging lived experiences in co-creation.

## Leveraging Lived Experience

Although there has been some recognition of the need to engage users to cross-validate insights (Buchenau & Suri, 2000) or provide expertise throughout the design process (Wetter-Edman, 2012), the role of lived experience in co-creation has not received much attention within the service design literature to date. There are, however, some methods associated with engaging actors with lived experience, such as: auto-ethnography (Curedale, 2013), co-creation workshops (Stickdorn & Schneider, 2011; Westerlund et al., 2003), and prototyping with users (Sanders & Stappers, 2014). While the body of knowledge on lived experience remains in its infancy, there has been a growing movement in service design to appreciate users as partners in the design process through co-design (Sanders & Stappers, 2008). This movement is peripherally connected with the maturing field of participatory design, which was built on the premise that users should be involved in the process of designing systems that affect them (Halskov & Hansen, 2015; Holmlid, 2009; Kensing & Blomberg, 1998). This evolving ecosystem of collaborative design processes also shares certain links with discussions on user innovation, where users with lived experience actively take on the role of designers in the development of specific products and services (Essén and Östlund, 2011; Oliveira et al., 2015; Trischler and Scott, 2014).

Within these converging bodies of literature, a variety of benefits of user involvement have been discussed, such as: service providers gaining a better understanding of users' needs (Steen et al., 2011), supporting user empowerment (Holmlid, 2009; Hussain et al., 2012; Taffe, 2015; Wetter-Edman, 2012), and combining different knowledge sources for enhanced novelty (Trischler et al., 2017). However, there is also some evidence suggesting that user-generated ideas are less feasible, producible, and sustainable (Akama, 2014; Magnusson et al., 2003; Trischler et al., 2017). Additionally, there is discussion that a more user-driven approach can cause a greater reliance on users' own knowledge (Oliveira and von Hippel, 2011) and may create difficulty in integrating traditional forms of expertise (Carr et al., 2009). On most occasions, the user is still entering the designer's sphere and the designer takes on a dominant and guiding role (Takeyama et al., 2012), which results in participants often not having an equal voice in the process (Näkki, 2012). As such, there is recognition of the need for role renegotiation (Donetto et al., 2014). Further research suggests that the involvement of end-users in the design process may actually shift their role away from designing for their own needs toward designing for a hypothetical 'other' (Taffe, 2015).

While the potential negative outcomes or risks associated with these collaborative design approaches remain under-researched (Vink et al., 2016), early work suggests that the integration of lived experience in co-creation on its own is not a panacea. While lived experience has immense value in deepening the understanding of needs and context, it is also critical to integrate different knowledge sources (Trischler et al., 2017) and work with multiple 'truth regimes' (Sellen, 2017) to enable the full benefits of co-creation. As such, both empathy and lived experience are required to bring together the relevant skills and knowledge within a service design process. Furthermore, research suggests the importance of designers leveraging their own lived experience in local contexts to connect with other actors in a more reciprocal exchange (Cipolla & Bartholo, 2014). In this way, lived experience is not necessarily only held by end users, but designers and other participating actors may also have direct and first-hand perceptions that are relevant within a design process. However, little is said within service design literature to date about how diverse actors can tap into their own lived, not just simulated, experience. Based on this notion, it is important to discuss empathy and lived experience among diverse constellations of actors, not simply the designer-user dyad that has been the dominant focus of existing literature in this area.

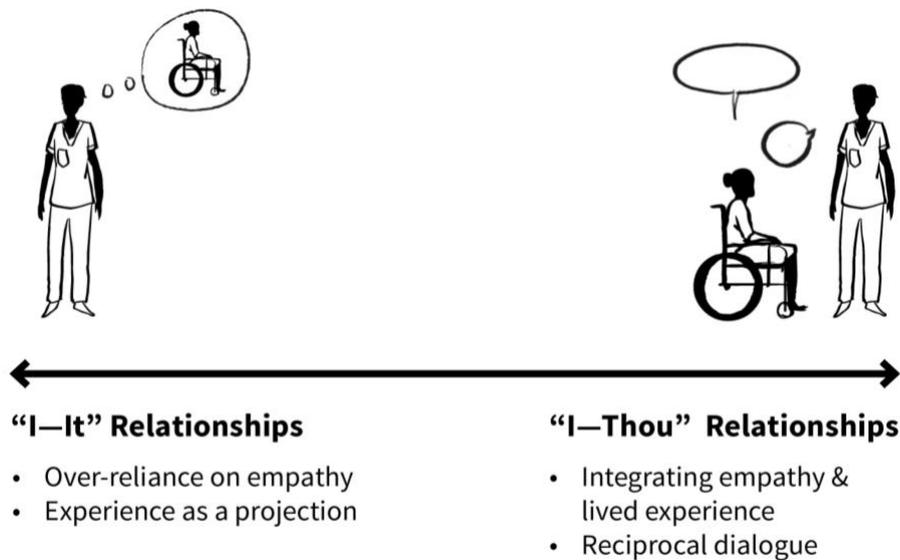
To contextualize this discussion, an example of the involvement of actors with lived experience in the service design process is shown in Figure 2. The image captures a co-creation workshop with youth in the development of a digital mental health service for young people supported by Experio Lab. During this project, one youth was hired as an advisor for this two-year project. While the designers and staff members supporting the project were once youth themselves, they acknowledged the value of having youth who are living and breathing this experience every day to contribute to moving the project forward. Throughout the entire service design process, the voices and experiences of youth themselves drove design decisions and influenced the perspectives of the healthcare staff and designers supporting the project. Driven by youth's own experiences, a new digital service was developed to support youth with monitoring their own mental health and to connect them with support more easily. Within this interactive service design process, staff built empathy for the youth by hearing their stories and visions for the future, which sparked them to make shifts in their own clinical roles in a way that recognized youth as the experts of their own experiences. This example from Experio Lab moves closer to what Cipolla and Bartholo (2014) call "I—Thou" relationships where an actor relates to another actor by recognizing that they do not know them entirely and can only know more by engaging with them in reciprocal dialogue.



Figure 2: A co-creation workshop during the design of a digital mental health service supported by Experio Lab

## Integrating Empathy and Lived Experience

As highlighted in the literature review above, there are different manifestations of the relationship between empathy and lived experience in co-creation. We draw on existing literature, particularly the work of Cipolla and Bartholo (2014), to highlight two critical manifestations as show in Figure 3. The first manifestation is co-creation based on “I—It” relationships, where there is an over-reliance on actors’ empathy. Here actors use methods to project their own assumptions, negating the value of others’ lived experiences and undermining their self-determination. The “I—It” relationship reflects a situation where actors objectify the ‘other’, assuming they know and understand them. The second manifestation is co-creation based on “I—Thou” relationships, where actors’ empathy is not recognized as sufficient on its own, but must draw on and be seen in service to others’ lived experience to enable reciprocal benefit. Co-creation based on “I—Thou” relationships acknowledges that all actors can tap into their own lived experience while recognizing others’ unique experiences within a dialogic process, rather than constructing a false ‘us vs. them’ divide within service design.



**Figure 3: The spectrum of different manifestations of empathy and lived experience in co-creation**

From the literature review on empathy and lived experience in co-creation, it may seem that empathy and lived experience in design are somewhat opposing forces: empathic design approaches are about designing for others, while the use of lived experience in design is more about designing for one’s self. However, when viewed systemically, it becomes clear that empathy relies heavily on lived experience and that lived experience can benefit significantly from empathy within reciprocal co-creation. In this way, we can see the mutual benefits of integrating both empathy and lived experience in service design. While designers, for example, are able to develop valuable offerings through their technical expertise and empathizing with other actors, they often cannot experience certain situations first-hand and thus, lack contextual and situated knowledge. On the other hand, actors with lived experience embody this situated knowledge, yet in some cases they may miss the particular technical knowledge to fully develop valuable innovations for themselves and others. In this way, co-creation based on “I—Thou” relationships through integrating empathy and lived experience can offer reciprocal benefits.

Figure 4 highlights the complementary nature of some of the risks and benefits of empathy and lived experience. For example, while one risk of empathy is that designers or other actors only gain a superficial understanding of a person’s needs and experiences, the benefit of leveraging lived experience is that actors offer specific, situated understanding informed by their inherent contexts. Similarly, while the integration of lived experience in co-creation has sparked the need for role renegotiation between actors, it is through empathy that others experience disruption and conflict, which can facilitate role shifts. The application of either empathy or lived experience within co-creation relies on the existence of the other. One cannot truly have empathy unless it is informed by lived experience, and the use of lived experience in co-creation requires the integration of particular skills and knowledge from an empathic other to realize valuable innovations that are of mutual benefit.

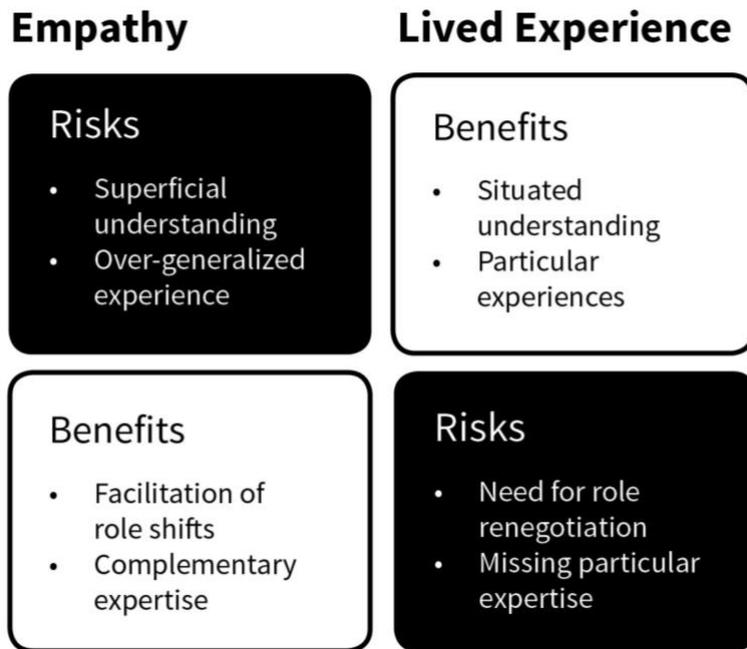


Figure 4: Illustrations of the complementary nature of empathy and lived experience in co-creation

## Moving Toward Reciprocal Co-Creation

Through an examination of the literature, supported by empirical examples from Experio Lab, we have highlighted the pressing issues related to the over-emphasis on empathy in service design. We argue that while empathy is a key building block for an actor's ability to design valuable offerings for others, lived experience is just as important and functions as a necessary complement to empathy in co-creation. Yet, while there is increasing recognition of the value of integrating actors with lived experience into service design processes, there is little discussion within this discourse about how actors can and do leverage their own lived experience while co-creating with other actors. Existing research details a one-sided process of empathy in co-creation that, we argue, has the possibility to manifest itself as an "I—It" relationship. To move beyond "I—It" relationships, we, aligned with the work of Cipolla and Bartholo (2014), suggest the need for reciprocal co-creation. The foundational work of Bohm (1996) on the principles of dialogue may offer further insights for reciprocal co-creation, including working with no pre-set agenda, nurturing sensitivity, and suspending assumptions.

While the principles of dialogue offer a starting place, in-depth empirical research on the practices of lived experience and the inter-related processes of empathy and lived experience amid reciprocal co-creation is necessary. To continue the journey towards "I—Thou" relationships in service design, there is a need to deepen the understanding of the potential risks associated with empathy that have been touched upon in popular discourse (Abbott, 2017; Meill, 2015; Staffer, 2015; Wendt, 2017) and to better understand the important and intertwined role of lived experience in service design. More work needs to be done to apprehend how actors can leverage their lived experience to support reciprocal co-creation; for instance, how do actors become aware of and interpret their own experiences and contribute to envisioning desirable alternatives to their own situation? Furthermore, more research is needed to understand if and how the open-ended process of dialogue and leveraging lived experience may support the process of decolonizing service design practices. How can we move from "I—It" to "I—Thou" relationships in co-creation? What are the

practices of lived experience and how do these practices relate to the practices of empathy in “I—Thou” relationships? What are the enablers and barriers of integrating the lived experiences of actors in service design?

While this research highlights connections between empathy and lived experience, it is important to reinforce that these two processes are not mutually exclusive. More work is needed to better understand how we can move from seeing these as separate processes by distinct people, to eliciting empathy and leveraging lived experience from all actors. For example, at this intersection we see the role of caregivers in healthcare service design processes that have a particular lived experience and often deep empathy for those they are caring for. We also believe it is important to better understand how designers themselves can be encouraged to tap into, rather than ignore, their own lived experience in service design. In this vein, there is a need for examining the representation among actors in service design processes, including designers, end-users, and other actors. Are the actors involved reflective of the spectrum of lived experiences of the populations they are designing with and for?

Healthcare is an interesting context in which to investigate this phenomenon because of the difficulty in fully understanding the experiences of actors who have conditions that can never be experienced by others. In addition to the investigation of co-creation activities with actors with lived experience in healthcare, user-led design activities, such as activities of the “Patient Innovation” platform in Portugal, could also be fruitful settings for advancing the understanding of the role of lived experience in the design process. Here patients with rare diseases who are often underserved by pharmaceutical firms and other medical suppliers, due to the small market size, innovate themselves and with some support from others to develop valuable and novel offerings (Oliveira et al., 2015). By examining the processes of these patients, insights may be gathered on how actors perceive their own situations and leverage their insider knowledge to develop solutions that are beneficial for themselves and others.

## Conclusion

This research highlights several issues following an over-emphasis on empathy in service design, including that it can result in actors projecting their assumptions onto the experiences of others. We argue that while empathy is a key building block for actors’ ability to design valuable offerings for others, lived experience is just as important and functions as a necessary complement in co-creation. By building on the work of Cipolla and Bartholo (2014), we have highlighted two different manifestations of the relationship between empathy and lived experience: “I—It” and “I—Thou”. Furthermore, we have shown the interdependent nature of empathy and lived experience within co-creation, and the importance of working toward “I—Thou” relationships by integrating both in reciprocal co-creation. In calling for more research on lived experience and reciprocal co-creation, we have highlighted a number of lingering questions that will be important for service design research and practice to address moving forward.

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