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Valuing users of Needle Syringe Exchange programs: Design approaches within the healthcare sector

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Keywords

Human-Centered Design, Co-Creation Design, Design Research, Healthcare Design, Empathic Design

Abstract

Injecting drug users are among the most marginalised and stigmatised groups in society. This is a wicked problem exacerbated by multifaceted assumptions, misconceptions, and stereotypes surrounding injecting drug users. Stigmatisation results in injecting drug users being frequently denied basic human rights and subjected to severe social isolation (AIVL, 2003). Human-centered research approaches are particularly pertinent when conducting research in healthcare. The application of design approaches to define and address the perceived issues can result in more empathic and relevant designed outcomes (see Clarkson et al., 2010; Lamb, Zimring, Chuzi, & Dutcher, 2010; Loscin & Nagji, 2009; Razzouk & Shutre, 2012; Santos et al., 2014; Shraiky, 2010).

This paper discusses a design project that seeks to explore the value of empathic co-creation methods to reframe complex perceptions surrounding the use of Needle and Syringe Programs (NSPs) and Needle and Syringe Exchange Programs (NSEPs). Co-funded by the Public Health Division within the WA Department of Health, this project is a collaborative initiative, guided by a steering committee representing three NSP/NSEP service provider organisations. It seeks to investigate the impact stigmatisation and other access barriers have on the utilisation of Needle and Syringe related services, and how these barriers are perceived and defined by the experiences of injecting drug users that are clients to these services.

The paper reports on data collection methods that were developed to respect and value participants' input, empowering them through the acknowledgment of their voices. Bottom-up methods that could be used synchronously and asynchronously maximised the opportunities for injecting drug users to express their point of view. This paper proposes that the value of empathic design methods in complex healthcare challenges is to preserve the interest of the intended end-user. The process of co-creating with the end-user is as important as the design outcome itself.

Samantha Pekaar was the successful applicant of Edith Cowan University's first Industry linkage scholarship in the former School of Communications and Arts. Her PhD research focuses on the application of design processes and methods to address complex problems that exist within public healthcare services. This collaboration project has been guided by a steering committee comprised of several key health organisations.

Dr Hanadi Haddad works extensively with external clients for undergraduate and supervises postgraduate design projects, including a current Industry Collaboration PhD project with the Executive Director of the Public Health Division of the WA Health Department. This involves the application of ethically designed co-creation methods with several health based organizations and their clients, classified as vulnerable.

Background

Needle and Syringe Programs in Western Australia

In an effort to reduce the transmission instances of blood-borne viruses (BBVs) such as HIV, hepatitis B and hepatitis C between injecting drug users, harm prevention has remained a key point of conversation between both government and non-government agencies across Australia (Australian Government Department of Health, 2010; Kirwan, Carrotte, & Dietze, 2015). Harm prevention programs and strategies focus on decreasing the risks and associated health consequences related to the unsafe use of intravenous drugs. Needle and Syringe Programs (NSPs) and Needle and Syringe Exchange Programs (NSEPs) are a fundamental aspect of currently integrated harm-minimisation and intervention approaches undertaken in Western Australia (Hepatitis WA, 2014; WA Department of Health, 2015; WAAC, 2015; WASUA, 2012).

Despite a robust body of research and evidence attesting the validity of NSP and NSEP programs in Western Australia, they are frequently subjected to societal disapproval. Many misconceptions appear to exist regarding the operations, values and benefits of these services. For example, NSP and NSEPs are often viewed as condoning drug usage and increasing the unsafe disposal of injecting equipment. Contrary to this view, research has shown that harm-minimisation efforts such as NSP and NSEPs do not enable drug use and such practices occur despite efforts to reduce the supply and demand of illicit drugs (MacDonald, Silins and Topp, 2005). These programs seek to reduce the harm associated with injecting drug usage and to provide resources for those who wish to cease injecting drug usage. Furthermore in contrast to collectively held public views, harm prevention initiatives also benefit the communities in which they function. These initiatives help reduce the amount of used injecting equipment being discarded in public spaces through the provision of safe disposal facilities. The cogency of NSP and NSEP service providers rely in their ability to engage marginalised and stigmatised individuals, connecting them to healthcare and welfare facilities, without forcing them to change against their will.

Design for Healthcare

Proficient communication and the provision of healthcare services are firmly interlaced in complex ways. A discernible aspect of this connection supports the creation of purposeful relationships with patients (end-users) firmly routed in trust. As

such, design and user-centered approaches is generating interest amongst other fields of practice, particularly healthcare. Previously employed strategic design strategies to healthcare required patients to fit to a service or product that is typically mass-produced. End-users held little to no value having previously been predicted and shaped by producers (Leavy, 2009). The adaption of holistic and integrated user-centered approaches allows for innovation and idea generation to occur as a process of collaborative discovery. End-user experience centered interactions are considered essential to creative solutions, through harnessing collaborative problem solving (Razzouk & Shutre, 2012; Santos et al., 2014). Such techniques become particularly relevant to the healthcare sector when a push for patient centered approaches to operation has been identified (Santos et al., 2014). Innovative solutions to complex healthcare problems hold promise when they are firmly grounded in meeting the needs and wants of the intended end-users. To provide improvements to health related services, the end-users' motivations and emotions must be acknowledged and clearly understood (Innovation Hub, 2014).

The value of design methods and approaches to the healthcare sector and more specifically health care delivery, is gaining in interest and application. However, meeting the needs of a myriad of stakeholders with differing opinions and perspectives as to the most suitable resolution to a problem is fraught with difficulty. In the healthcare problems are frequently interrelated and addressing one particular aspect can result in unpredicted impacts for another (Stitchler, 2009). Such problems are often referred to as 'wicked' due to their complexity and the difficulties faced when attempting to understand, solve or resolve them (Stichler, 2009; Wagman, 2006). Such problems are resistant to solutions that assume traditional, conventional and linear approaches (Buchanan, 1992).

In addition to the increasing interest in design applied to healthcare, there has been a notable shift from the once widely accepted traditional role of designers; creating tactical artifacts from an already developed idea in an effort to make it more appealing (Brown, 2011). The employment of design processes allows for a unique collaboration between diverse stakeholders, increasing the likelihood that developed solutions meet the requirements of each whilst simultaneously preserving the interests of the intended end-users. This participative approach enables stakeholders in collaboration with end-users to propagate value and meaning and ownership of meaning, therefore becoming dialogic in nature (Ind & Coastes, 2013; Razzouk & Shutre, 2012; Santos et al., 2014). These approaches transform a typically static and

flaccid relationship between the producer and user to one that is dynamic, fluid and active (Leavy, 2009). This defies typical power provisions by reassigning the control from producers and placing the end-user in a position of power (Sanders & Stappers, 2008). Jones and VanPatter (2009) suggest that the different levels of thinking required to address design problems be categorised into several keys modes, each with increasing levels of complexity (Jones & VanPatter, 2009: Fig. 1).

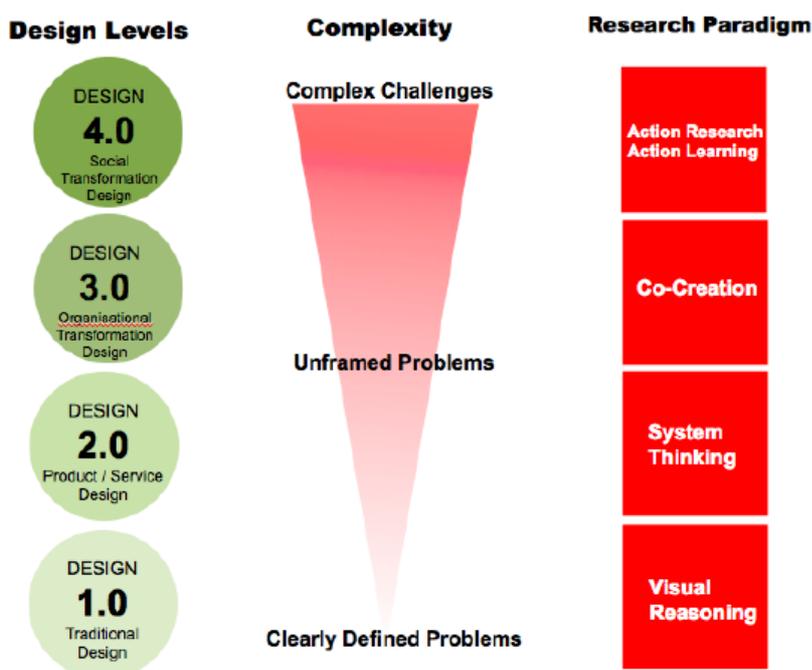


Figure 1: Design Levels, Jones & VanPatter (2009)

As the complexity expands, the higher modes are inclusive of aspects of the lower modes. Focus is shifted from the development of 'design artefacts' towards human behavior/interaction and social change (Fig 1). These high order approaches are ideally suited to tackling problems in healthcare settings.

Application of Design to the Stigmatisation of Needle and Syringe Program Users

In response to the stigmatisation inflicted on end-users of harm prevention strategies such as NSP and NSEP service providers, this project was erected in a collaborative fashion with three NSP/NSEP organisations and the Public Health Division within the WA Department of Health. Together representatives of these organisations formed a steering committee to guide the project, which aimed to explore the complex problem of stigmatisation of injecting drug users through alternative means, utilising design approaches. Specifically, it sought to explore the barriers preventing the utilisation

and further development of such valuable services.

The purpose of this paper is to report on the process developed to investigate the impact barriers currently faced by injecting drug users when accessing NSP and NSEPs. The iterative and user-centered approaches employed attempted to break down these barriers whilst improving both client (user of NSP/ NSEP) and public perceptions of these programs. Furthermore, it will consider the importance design processes play in facilitating a multidisciplinary collaboration amongst a variety of stakeholders.

While the main project is still underway, this paper reports on some of the methods developed through the duration of this project. It will consider the value of empathic co-creation methods in a design project that seeks to reframe complex perceptions surrounding needle usage. Additionally, it proposes that to penetrate such multifaceted problems, deeper levels of thinking and sense making are required.

Methodology

As discussed, design can provide malleable frameworks to address some of the multidimensional problems that currently exist within the healthcare sector, of which the stigmatisation of NSP/ NSEP clients is just one. The design methodology for this project was to adapt a fusion of two methods; Participatory Action Research (PAR) and the design based approach developed by the British Design Council (2005), the Double Diamond Design process (Fig. 2). This fusion endeavored to facilitate the deeper exploration of the problem through an exploratory process of developing, testing and refining ideas. The project was therefore catalogued into four distinct stages; Observing, Reflecting, Planning, Acting. These stages aligned with the convergent and divergent nature of the Double Diamond approach. Two cycles of this process were introduced to ensure a more effective communication system was achieved, and any discrepancies identified in the initial reflection were addressed.

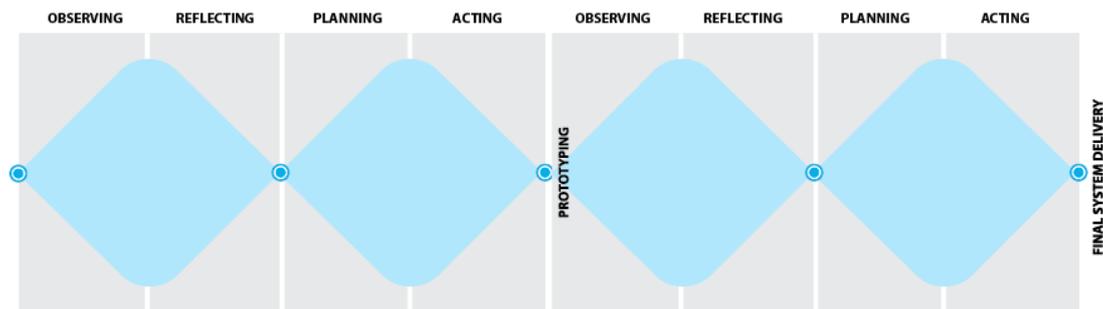


Figure 2: British Design Council's (2005) Double Diamond Methodology.

Development of New Research Methods

The overarching Double Diamond design of the project involved discrete research methods in different phases including in depth interviews, focus groups and interaction workshops. The initial phase of the project involved the in-depth interviewing of NSP/ NSEP service providers from the three organisations to glean their insights into the issues surrounding the stigmatisation of clients. The next phase was focus groups conducted with clients on site at each organisation in turn. These sessions aimed to gather insights about stigmatisation and other barriers faced from clients' perspectives, experiences and more importantly in their language. At this phase of the research several challenges to active involvement of clients in the research project were identified, including:

- Difficulty of recruitment
- Unreliable attendance
- Inability to turn up on time
- Non-completion of session
- Organisation operating hours
- Access to transport
- Being unable to contribute effectively due to substance use
- Communication difficulties
- Behavior not conducive to effective interaction
- Accommodation within busy schedule of organisations

Initially it was proposed that the co-creation workshop stage to follow would be conducted at one of the 3 NSP/ NSEP organisations. This workshop would be comprised of 1-2 participants recruited by members of the steering committee from each organisation who would be invited to the one location. This phase required clients to be further involved in identifying and organising perceived access barriers

based upon their importance. Additionally, it would require the generation and voting of ideas and solutions to removing/reducing these barriers proposed by clients.

However, due to the difficulties faced during the previous focus group stage, it appeared that recruitment and participation would be challenging and result in an extended data collection schedule. Upon reflection a more efficient collection method was needed, whilst still maintaining a co-creation methodology and yielding valuable data. It was also evident upon preliminary analysis of the data that the clientele differed between each organisation, with the importance placed on each impact barrier varying between the focus groups. This meant that by only conducting the one unified focus group, the richness of data would be significantly limited and thus impacted.

In order to complete the next phase of the research it was necessary to develop a tool, which was asynchronous but still centred on the clients' perspective. Falling back on a traditional data collection tool such as a questionnaire would alleviate many of the challenges to client involvement. However the contention remained that it was critical to preserve the co-creation participation element as much as possible, along with the bottom up informal approach valued within this research project. Additionally to truly explore such a complex problem, a deeper level of thinking and engagement was still required to ensure the acquisition of rich and in-depth data. Questionnaires are already heavily utilised within these organisations and the healthcare sector overall and could have been perceived as "another one we have to do" by clients.

The solution arrived at was the "Idea Matrix" which allowed an assortment of ideas to be presented to clients on an A1 sheet, giving them the opportunity to respond and interact (Fig 3). The identified impact barriers from the interviews and focus groups were listed in the first column and suggested platforms/approaches to alleviate the barriers, seeded by the researcher along the top row to start the interaction process. These were written in a language familiar to NSP/NSEP clients and these ideas were presented visually with hand drawn, informal sketches to encourage them to also use drawing to express themselves.

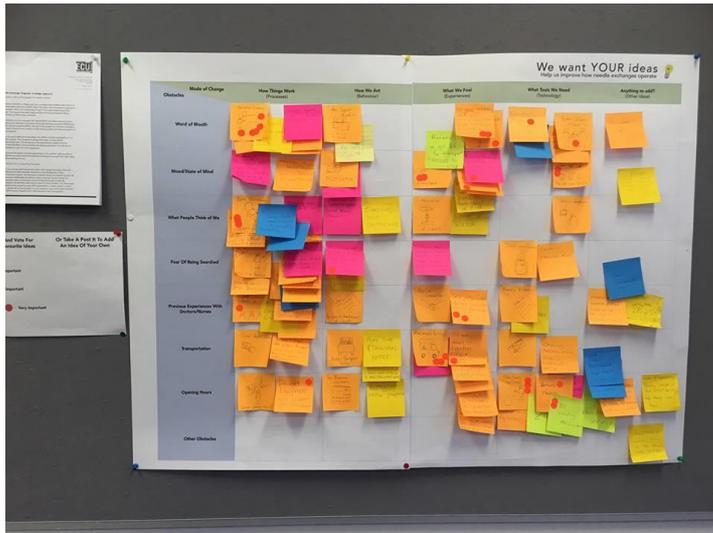


Figure 3: Idea Matrix

At each intersection there was a space for input by the client, such as generation of ideas towards resolving the identified barriers. The clients were asked to score the barriers according to importance, rate ideas using numbers and submit their own. Post-it notes and voting sticker dots were provided to allow interactions to build upon each other and resolve space issues.

This process was more fluid in nature than traditionally employed approaches and the clients were treated in a more holistic manner (Irving & Dickson, 2004). It allowed for the encapsulation of sensitivity to both the informational and emotional facets of communication (Irving & Dickson, 2004). The Idea Matrix was utilised on site at each organisation over the period of a few days, with recruitment taking place by the researcher as clients entered the facility. The procedure was approved by both the university ethics and steering committee members. Each walk-in client was a potential participant and was provided with a brief explanation about project, its purpose, and potential outcomes. An invitation was then extended to engage with the Idea Matrix and the benefits of their contribution discussed. Interaction with the Idea Matrix by the client after this, indicated consent to participate. This relaxed and spontaneous method of recruitment allowed clients to engage with the Idea Matrix at their leisure, often whilst waiting to be served at the exchange counter. The informal judgment-free environment meant that clients felt comfortable to contribute in their own unique way with their differing experiences and approaches to problems. With no prerequisites for the amount or type of contributions required, clients could contribute as much or little as they liked in their own time. Each interaction was visible to the next contributor and then added to, giving valuable insights into

similarities and differences between client experiences. Therefore, a greater volume of data was obtained with clients solidifying and building upon previously submitted ideas and thoughts. The post-it note system facilitated idea building, allowing clients to quickly view previously submitted entries, and stimulating responses and new ideas. Clients were able to evaluate, categorise and prioritise options by numbering, highlighting, circling, writing or simply voting by use of sticker dots. The sticker dot system was mostly preferred for voting and allowed meaningful patterns/idea clusters to be identified quickly.

The adaption of this empathic method resulted in three full A1 sheets of client input. The asynchronous, yet still co-creative interactions, allowed for the thoughts, feelings and opinions of clients to be contextualised, establishing an understanding of how things related to one another both literally and figuratively (Battarbee, Suri & Howard, 2015). Furthermore, it allowed the empathetic consideration of the many processes and subsequent barriers faced by clients on a daily basis when attempting to access harm prevention services such as NSP/NSEP's. The engagement of clients through this process allowed for the recognition of constraints and prior history that lead to the problems' existence (Lam & Suen, 2015). Initial analysis of the data across organisations identified seven client perceived themes. A request to genuinely listen to clients and seeing their input in action, as well as the wish to be involved in any future solutions, including peer lead initiatives was prominent. This emphasis highlighted the value of the co-creative process itself applied to this research. Any future initiatives could indeed employ co-creative methods such as this in their design.

Conclusion

Whilst there were many challenges faced throughout the duration of this project, methods were adapted to help accommodate these difficulties whilst also maintaining the user-centred Participatory Action Research/Double Diamond methodology. The development and utilisation of empathic approaches proved particularly valuable with conducting research and obtaining data from such a vulnerable group within the healthcare sector. Unlike top-down methods typically employed with research in this area, bottom-up methods empowered clients by encouraging contributions to occur in a collaborative manner. Furthermore, it provided clients the opportunity to explore, share and discuss the barriers faced when accessing NSEP and NSP services as well as generate ideas, create concepts and explore meaningful possibilities to

address these issues. The inclusion of these methods allowed those who are typically disdained, marginalised and discriminated against to voice their experiences.

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