Untangling multi-stakeholder perspectives in digital mental healthcare

Elvira Perez Vallejos
NIHR Nottingham BRC for Mental Health and Tech, University of Nottingham, UK
elvira.perez@nottingham.ac.uk

Tommy Nilsson
School of Computer Science, University of Nottingham, UK
tommy.nilsson@nottingham.ac.uk

Peer-Olaf Siebers
School of Computer Science, University of Nottingham, UK
peer-olaf.siebers@nottingham.ac.uk

Penelope Siebert
School of Social Sciences, Nottingham Trent University, UK
penelope.siebert@ntu.ac.uk

Michael Craven
NIHR Nottingham BRC for Mental Health and Tech, University of Nottingham, UK
michael.craven@nottingham.ac.uk

Carolina Fuentes
School of Computer Science, University of Nottingham, UK
carolina.fuentes@nottingham.ac.uk

ABSTRACT

Digital mental healthcare constitutes a complex area for development of novel technological solutions. Designers are frequently forced to deal with requirements posed by a range of different stakeholders with particular needs, goals and interests which may either align or conflict. In search of an inclusive approach for assessing the needs and requirements of this diverse socio-technical landscape, we have developed a novel user research framework heavily drawing on elements from the fields of Software Engineering and Agent-Based Social Simulations. Relying on this framework allowed us to scaffold

and stimulate constructive focus group discussions between multiple key stakeholders and in turn elicited and shed light on important areas of friction.

CCS CONCEPTS

• **Computer systems organization → technology policy**.

KEYWORDS

Healthcare and medical systems; Human-Computer Interaction; Research methods; Software engineering; User experience.

ACM Reference Format:
Elvira Perez Vallejos, Tommy Nilsson, Peer-Olaf Siebers, Penelope Siebert, Michael Craven, and Carolina Fuentes. 2019. Untangling multi-stakeholder perspectives in digital mental healthcare. In *Proceedings of* . ACM, New York, NY, USA, 6 pages. https://doi.org/10.475/123_4

INTRODUCTION

The World Health Organization has recently flagged that mental illnesses are on track to becoming the leading global disease burden by 2030 [16]. In the UK alone, mental health problems already represent the largest single cause of disability, with one in four adults experiencing at least one diagnosable mental health issue in any given year [2]. Meanwhile, progress in the field of information technology, including the proliferation of the world wide web, artificial intelligence, machine learning and ubiquitous computing, is paving the way for a range of novel systems capable of diagnostics and treatment. Such emerging technologies are naturally sparking optimism for their potential to transform and revolutionise mental healthcare by making relevant services more accessible than ever before [15]. It is important, however, to treat such visions with a degree of caution. Recent studies show that the introduction of digital services may carry the risk of changing relationships between the key stakeholders (such as service users, healthcare practitioners and managers) in ways that may be judged by some or all of the stakeholder groups, or individuals within them, to be detrimental [11]. Breach of privacy and security [3], marginalization or exclusion of various user groups [8], limited compatibility between emerging services [23] and inefficient use of resources [10, 19] are but a few of the problems stemming from stakeholder misalignments caused by mental health technologies.

If the full potential offered by these technologies is to be successfully harnessed and help us combat the rising tide of mental illnesses, it is imperative to adopt a highly inclusive approach to design of relevant solutions so that the experience and accessibility of mental healthcare is improved for all users, including those most vulnerable or marginalised, while also satisfying healthcare professionals and managers.

Our use of the EABSS framework

1. Analyse the problem: Focus group participants are asked to formulate key problem areas and perceived issue that they deem to be in need of attention. This results in a list of hypotheses to be tested and a definition or relevant experimental factors and model outputs.

2. Define scope: This step requires participants to list key actors (i.e. the specific roles of individual agents), relevant elements of the physical environment and the social as well as psychological aspects implicit in the problems defined in the previous step.

3. Define key activities: Participants are required to list all the potentially relevant activities (use cases) and interactions that might occur between the actors (under consideration of their roles in the system modelled) included in the scope.

4. Define archetype stencils: In order to represent a relevant population, participants are tasked to come up with a categorisation schema that will allow to separate a simulated population into behaviourally different groups.

5. Define agent stencils: The purpose of this step is to develop agent templates by listing the different states that the actors identified in the *defining scope* step can take on. The transitions between these states, and what triggers them (i.e. decision-making processes of individual agents) must also be made clear.

6. Define objects stencils: This is the same as *defining agent stencils* but for objects that have been identified in the scope table as part of the physical environment. This step might not be required for all object categories.

7. Define interactions: In this step the key focus is placed on defining sequences of interactions that take place between individual agents and between agents and objects. Participants are asked to depict agents and objects involved in specific use case realisations. This includes the sequence of interactions that needs to take place to carry out the functionality of every given use case.

8. Define artificial lab: Finally, participants are asked to look at their model as a whole and try to define its global functionalities (macro level view). This includes the variables that ought to be tracked in order to gain insight about the issues defined during the problem analysis step of the framework. Once done, participants will end up with a rich model of a complex social setting.

Existing human-centered design frameworks usually focus on the development of solutions that would please a well-defined group of end users [5], while showing little concern for the broader implications, including other individuals that might get inadvertently affected as a result of said solutions [13]. It comes as no surprise then that the guidances set out by the UK government [21] and Design Council [20] emphasizes the need to explore better human-centred design strategies in order to more effectively anticipate human needs pertaining to the use of mental health technologies.

Following this call, we propose an alternative approach which borrows elements from a range of existing fields, including *Software Engineering* and *Agent Based Social Simulations* and combines them with methods traditionally found in qualitative user studies. To test its viability, we have organized a set of four focus groups featuring a total number of 17 participants representing multiple major stakeholders in mental healthcare, including service users, clinicians, managers and researchers. Our findings highlight the capacity of our approach to facilitate structured dialogue and gain a better understanding of key differences between individual stakeholder groups as well as within them.

AGENTS TO THE RESCUE

Agent-Based Social Simulations represent a powerful paradigm that can be used for conducting "what-if" analysis of human centric systems by modelling them as a collection of autonomous decision-making entities called *agents* [17]. Each agent individually assesses its situation and makes decisions based on a set of predetermined rules [4]. The individual agents then interact with each other and their environment to produce complex collective behaviour patterns, which in turn allows us to make conclusions based on the system's emergent properties. Such simulations are commonly used to explore the interaction of different groups of stakeholders, where the latter are often people in a specific context. This in turn enables relatively accurate predictions regarding the outcomes of complex social events as well as provide valuable information on the society. A key challenge in this process is the appropriate specification of agents in order for them to behave similarly to humans.

EABSS: The underlying framework of our user research approach

The Engineering Agent-Based Social Simulation framework (or EABSS for short) was developed as a model development framework intended to provide modellers from the social simulation community with all the agent specifications required to build realistic simulations of human-centric systems [18]. The EABSS is - metaphorically speaking - a "checklist" used to probe relevant human stakeholders for the information needed to build an accurate agent-based social simulation model.

In our study we took this approach further by combining design philosophies with the EABSS framework and using these to drive focus group communications. This is accomplished through a set of predefined table templates in combination with UML diagrams (a graphical notation used in software engineering to conduct system analysis and design [9]) as a means to guide focus group

members through the individual EABSS steps (as detailed in the sidebar). Each step sees focus group members brainstorm and argument their case, while focus group moderators document the activity.

This process is grounded in the concept of co-creation [14], while drawing on elements of Kankainen's [12] focus group approach to service design.

Argumentation and knowledge sharing

The Maltese philosopher Edward de Bono has famously distinguished between two approaches to argumentation [7]. The "Socrates" approach sees individuals engage in a dialectic discussion until a consensus is reached. On the other hand, the "Confucius" approach shifts the focus to information gathering and thus accepts all views, regardless of whether they are mutually conflicting.

Given the inclusive nature of agent-based simulations, distinguishing between these two approaches represents a crucial aspect of our study. Unlike in standard focus group discussions, a key role of the moderators during our study was therefore to direct and intervene to ensure that information gathering and discussion happen at the correct times, and that everyone has equal opportunities to contribute. Furthermore, we relied on an iterative approach based on the agile concept from Software Engineering [1]. Information needed to get started with each step can be found by looking at the information gathered during previous steps, ensuring a fluent progression through the framework.

RESULTS AND DISCUSSION

To assess our approach, we carried out a focus group study with 17 participants representing 4 relevant stakeholders in the manner described above. Given our area of interest, we constrained the workshop topic to mental healthcare tehcnology. This in turn allowed us to expose some of the intricate reasoning provoked by digital mental healthcare solutions.

Our inclusive approach surfaced a myriad of perspectives; some of which were overlapping, while others appeared to be irreconcilable. Indeed, each participant partaking in our focus group study constituted a unique individual with a singular set of experiences and values. And yet, as the study progressed, a number of common themes begun to materialize among the participants from each stakeholder category. Service users emphasizing the need for human accountability. Clinicians desiring to remain in control of patient treatment. Managers concerned by the reshuffling of social power structures and researchers putting the spotlight on looming ethical dilemmas. All of these themes share some common denominators, but are ultimately being approached from different perspectives, making any universally acceptable solution problematic. In the remainder of this section we reflect on these findings and discuss the implications of our approach in more detail.

Embracing complexity

A key contribution of our study is to show that borrowing elements from the field of agent based social simulations can provide us with an inclusive lens for qualitative enquiry into complex social settings. We were able to demonstrate this by drawing on the EABSS, a novel framework for generating input data for agent-based social simulations, designed to inclusively cover all the important variables that generally shape the dynamics of complex settings. Whereas the field of agent-based simulations is principally interested in the emergent properties of a social setting as a whole, rather than its individual constituencies, we have reversed this focus by instead analyzing the reasoning of focus group participants as they progressed through the individual EABSS steps.

Frameworks involving diverse stakeholders are per se not novel. As highlighted by Voinov and Bousquet [22], they are however traditionally employed to find an answer to a predefined problem and as such seek to stimulate a debate, rather than information gathering. Our method thus differs from many of the traditional human-centered design frameworks by not focussing on a limited set of system properties [6] nor on a relatively homogenous group of end users [24], but by instead embracing the complexity found in interactions between diverse stakeholders.

CONCLUSIONS

At a time where mental health technologies are on the rise, predicting and understanding their impacts on a growing spectrum of stakeholders is of considerable importance. We have proposed and evaluated a novel approach for facilitating constructive dialogues between individuals who might hold radically different views. We hope our work will provoke and inspire future research into exploring new cross disciplinary approaches to better sensitize and inform developers about the need for inclusive design of mental health technologies.

ACKNOWLEDGMENTS

This work was made possible through financial support from the NIHR Nottingham Biomedical Research Centre.

REFERENCES

[1] Agile Alliance 2018. *Agile Alliance.* Agile Alliance.

[2] American Mathematical Society 2015. *Using the amsthm Package.* American Mathematical Society. http://www.ctan.org/pkg/amsthm.

[3] Michael Bauer, Tasha Glenn, Scott Monteith, Rita Bauer, Peter C Whybrow, and John Geddes. 2017. Ethical perspectives on recommending digital technology for patients with mental illness. *International journal of bipolar disorders* 5, 1 (2017), 6.

[4] Eric Bonabeau. 2002. Agent-based modeling: Methods and techniques for simulating human systems. *Proceedings of the National Academy of Sciences* 99, suppl 3 (2002), 7280–7287.

[5] Fred D Davis. 1985. *A technology acceptance model for empirically testing new end-user information systems: Theory and results*. Ph.D. Dissertation. Massachusetts Institute of Technology.

[6] Fred D Davis, Richard P Bagozzi, and Paul R Warshaw. 1989. User acceptance of computer technology: a comparison of two theoretical models. *Management science* 35, 8 (1989), 982–1003.

[7] Edward De Bono. 1985. Six Thinking Hats: An Essential Approach to Business Management from the Creator of Lateral Thinking. *Little, Brown and Co* (1985).

[8] Liam Ennis, Diana Rose, Mike Denis, Ninjeri Pandit, and Til Wykes. 2012. Can't surf, won't surf: the digital divide in mental health. *Journal of Mental Health* 21, 4 (2012), 395–403.

[9] Martin Fowler. 2004. *UML distilled: a brief guide to the standard object modeling language*. Addison-Wesley Professional.

[10] Sue Hignett, Alexandra Lang, Laura Pickup, Christine Ives, Mike Fray, Celine McKeown, Sarah Tapley, Matthew Woodward, and Paul Bowie. 2018. More holes than cheese. What prevents the delivery of effective, high quality and safe health care in England? *Ergonomics* 61, 1 (2018), 5–14.

[11] Chris Hollis, Richard Morriss, Jennifer Martin, Sarah Amani, Rebecca Cotton, Mike Denis, and Shon Lewis. 2015. Technological innovations in mental healthcare: harnessing the digital revolution. *The British Journal of Psychiatry* 206, 4 (2015), 263–265.

[12] Anu Kankainen, Kirsikka Vaajakallio, Vesa Kantola, and Tuuli Mattelmäki. 2012. Storytelling Group–a co-design method for service design. *Behaviour & Information Technology* 31, 3 (2012), 221–230.

[13] Joseph Lindley, Paul Coulton, and Miriam Sturdee. 2017. Implications for adoption. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 265–277.

[14] Eve Mitleton-Kelly. 2003. Complexity research-approaches and methods: The LSE Complexity Group integrated methodology. (2003).

[15] JA Naslund, KA Aschbrenner, LA Marsch, and SJ Bartels. 2016. The future of mental health care: peer-to-peer support and social media. *Epidemiology and psychiatric sciences* 25, 2 (2016), 113–122.

[16] World Health Organization et al. 2012. Depression: A Global Crisis. World Mental Health Day, October 10 2012. *World Federation for Mental Health, Occoquan, Va, USA* (2012).

[17] Peer-Olaf Siebers and Uwe Aickelin. 2008. Introduction to multi-agent simulation. In *Encyclopedia of decision making and decision support technologies*. IGI Global, 554–564.

[18] Peer-Olaf Siebers and Franziska Klügl. 2017. What software engineering has to offer to agent-based social simulation. In *Simulating Social Complexity*. Springer, 81–117.

[19] Ellen Taylor, Sue Hignett, and Anjali Joseph. 2014. The environment of safe care: considering building design as one facet of safety. In *Proceedings of the International Symposium on Human Factors and Ergonomics in Health Care*, Vol. 3. SAGE Publications Sage India: New Delhi, India, 123–127.

[20] The United Kingdom Government 2018. *Design Council (2014) Inclusive Environments*. The United Kingdom Government.

[21] The United Kingdom Government 2018. *UK Gov (2012). Government design principles. The United Kingdom Government*. The United Kingdom Government.

[22] Alexey Voinov and Francois Bousquet. 2010. Modelling with stakeholders. *Environmental Modelling & Software* 25, 11 (2010), 1268–1281.

[23] Jen-Her Wu, Shu-Ching Wang, and Li-Min Lin. 2007. Mobile computing acceptance factors in the healthcare industry: A structural equation model. *International journal of medical informatics* 76, 1 (2007), 66–77.

[24] Lucy Yardley, Leanne Morrison, Katherine Bradbury, and Ingrid Muller. 2015. The person-based approach to intervention development: application to digital health-related behavior change interventions. *Journal of medical Internet research* 17, 1 (2015).