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EXTENDED-ABSTRACT

How To Train Your Stakeholders: Skill Training In Participatory Health Research

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ABSTRACT
Currently, health research increasingly involves diverse groups of stakeholders. Such collaborations occur on various levels, where in some cases, stakeholders become co-researchers. However, these stakeholders (e.g. patients) are not always trained in the necessary research skills. On the other hand, researchers are not trained to collaborate with stakeholders. While there is agreement that skill training should be offered as an integral part of participatory health, so far knowledge is lacking on what such a training should look like. This workshop aims to collect experiences from those who have either previously implemented stakeholder skill training or have experiences where stakeholder skill training was lacking but would have been beneficial, and facilitate the exchange of ideas between participants who are interested in the topic. The outcomes will be communicated in ways that are accessible for academic and non-academic stakeholders and will provide them with guidance for conducting stakeholder skill training.

1 BACKGROUND

In health research, stakeholders are actively involved in a variety of research approaches, for instance participatory design [1], action research [2] or citizen science [3]. All of these approaches aim to democratize science and empower people to have their voice heard, for example in order to co-create actionable knowledge that might improve practice or actively shape new innovations. Such participatory approaches have a long tradition in Scandinavia [4, 5], which makes NordiCHI a very suitable setting for this workshop.
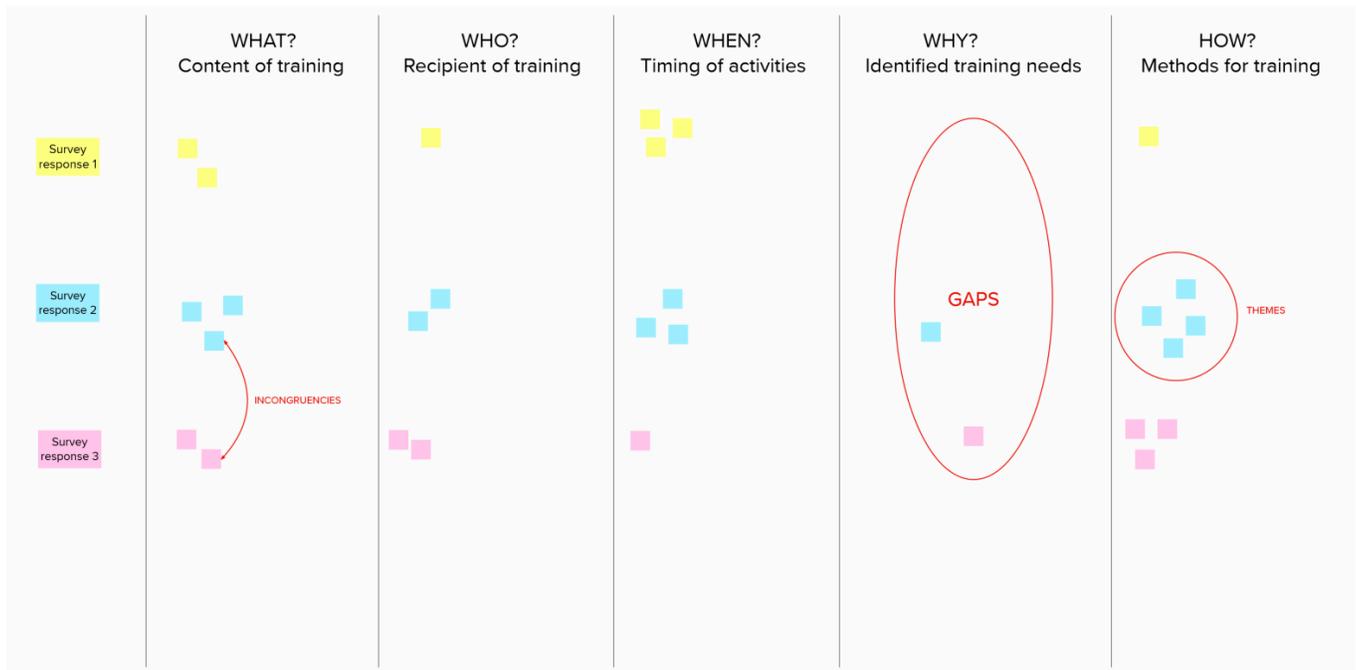
Figure 1: Example of the matrix that will be used to synthesize results and identify gaps and/or incongruencies.

In participatory health research the involved stakeholders, like patients or healthcare professionals bring their own experience and expertise to the table (e.g., lived experience of living with a chronic condition, contextual knowledge about work practices). When participating in research projects, they are then often asked which roles they would want to take on. However, being able to make that decision necessitates knowledge on what research and the different roles in it entail. Furthermore, stakeholders need to be confident enough to make such a decision for themselves. Lastly, they might need skills that are new to them. On the other hand, professional researchers have been trained in the scientific process but lack contextual knowledge from practice and might need to learn new ways of working with the public. Additionally, working with other, sometimes vulnerable groups, requires more interpersonal and social skills, as well as experiences on how to avoid epistemic injustice in the co-creational processes – to ensure that every voice is heard and listened to. Therefore, training and learning in participatory health research concerns all involved parties.

As pointed out in a recent literature review on eHealth action research [6], limited research has been done on how, when, and who should be the recipient of training and which topics should be covered, so to be able to fully engage as and with co-researchers.

The aim of this workshop is to learn about best practices and lessons learned when engaging in training activities within participatory health research, as well as barriers and facilitators. The outcomes of this workshop can guide those who wish to implement stakeholder training in their projects.

2 DRAFT OF THE CALL FOR WORKSHOP PARTICIPATION

The initial idea is to ask participants to complete a survey stating their previous experience (if any) with stakeholder skill training activities in participatory health research. The survey will contain questions regarding important characteristics of stakeholder training (content, recipients, timing, reasoning and methods). Participants are asked to describe these characteristics based on their previous experience or explain what they were missing in previous projects. There will also be room for participants to reflect on these activities (or lack thereof) and make suggestions for improvement. All applicants are free to emphasize topics that they find particularly important, for example power relations or confidence training.

3 OVERVIEW OF PLANNED ACTIVITIES

In preparation of the workshop, the participants' responses will be read and synthesized by the workshop organizers in a matrix that is similar to the example in Figure 1. From this synthesis, topics for discussion in the workshop will be drawn, for example by identifying gaps, or pointing out incongruencies between contributions.

Preliminary agenda for the workshop:

1. Introduction & outline of the day: (1-1.5 hrs)

Participant will introduce themselves to each other including presenting a summary of their expertise/experience with stakeholder training (e.g., by sharing some use cases or lessons learned) and their motivation for joining the workshop. The organizers will then present the results of the survey including the matrix that was created based on the responses. The participants can ask questions

or add comments on the highlights presented, before splitting into groups.

2. Morning break (30 min)

3. **Group work 1**: "gaps and incongruencies" (1 h)

Participants will be divided into groups to discuss the survey results and the identified gaps and incongruencies in the synthesis. Participants can share their personal experience related to the topics and add further points to the matrix.

4. **Plenary**: all groups present a short summary of their discussions (30 min)

5. Lunch break (1-1.5 hrs)

6. **Group work 2**: "facilitators and barriers" (1 h)

Participants are asked to identify barriers of and facilitators for stakeholder training activities in participatory health research. They are asked to take the results from the survey, the synthesis, and the earlier discussions in the workshop into account.

7. **Plenary presentation**: all groups present the results of their group work, (30 min)

8. Afternoon break (30)

9. Discussion & training strategies & next steps (1 h)

Discussion for taking steps to reduce the identified barriers and strengthen the facilitators as well as developing training strategies.

10. Closing of workshop

4   INTENDED OUTCOME

Our aim is to collect experiences from those who have previously either (1) implemented stakeholder skill training in their projects, or (2) have previous experiences where no training was performed but would have been beneficial. During the workshop we want to learn from each other and through discussions identify facilitators and barriers for stakeholder training. After the workshop, we aim to communicate the outcomes both in a scientific paper and in a more approachable format that is accessible to non-academic stakeholders who are conducting training activities in their projects (e.g. blog posts).

5   PROMOTIONAL STRATEGY

The workshop will be promoted through the broad and diverse network of the organizers and their institutions (e.g., ECSA working group Citizen Science for Health; Design Research Society; HCI, CSCW, Participatory Design community; local UX and Citizen Science meetups). This can be through general communication, like newsletters, mailing lists or social media posts, but also through direct personal contact with others who might have experiences that contribute to this workshop. We will not only reach out to researchers, but also non-academic parties (e.g., healthcare professionals, patient organizations).

6   FLEXIBILITY IN TERMS OF HYBRID PARTICIPATION

Participants are free to join in person or online. For the group work, online participants will form groups in breakout rooms and in person attendants will form groups in the room. The decision to not mix groups between in person and online participants is made because in our experience it is difficult to include online participants in hybrid group work. However, online participants will be able

to take part in all activities of the workshop, and will be able to present and discuss their findings with the other participants in the plenary parts of the workshop. There will also be designated online moderators who support the online participants with any content related questions or technical issues.

7   ORGANIZERS' BACKGROUND

Kira Oberschmidt is a PhD student at Roessingh Research and Development. Her research focuses on action research in eHealth. Specifically, Kira is interested in the active involvement of various stakeholders in the design, evaluation and implementation processes. She studied Psychology (BSc and MSc) and Health Sciences (MSc) at the University of Twente. During her studies she participated in different research projects related to the use of eHealth in (mental) healthcare. At Roessingh Research and Development Kira is involved in several international and national projects on the use of technology in healthcare.

Christiane Grünloh, PhD is a senior researcher at Roessingh Research and Development with a research interest in value sensitive eHealth design. Christiane has a medical background with several years of experience working as a medical assistant (GP, Urology) and holds degrees in Media Informatics (BSc, MSc) obtained from TH Köln University of Applied Sciences, Germany. From 2008 to 2018 she worked as research assistant and lecturer in Media Informatics and Web Science as well as the program coordinator of the master program Web Science at TH Köln. Christiane obtained her PhD degree in Human-Computer interaction at KTH Royal Institute of Technology, Stockholm on opportunities and challenges of patients accessing their electronic health records, especially in relation to patient participation and the doctor-patient relationship. In her role as senior researcher, Christiane works in several international and national research projects adopting participatory health research approaches (e.g., action research, citizen science, human-centered design).

Kevin Doherty, PhD is a postdoctoral researcher at the Technical University of Denmark (DTU HealthTech), where his current research focuses on the design of mobile technologies to support mental healthcare through primary care clinics across Denmark. His research interests include interdisciplinary design research, mental health and psychotherapy, user engagement and self-report methods, care ethics, and mobile interaction design. He holds a PhD in Human-Computer Interaction from Trinity College Dublin, an MAI in Electronic & Computer Systems from the Grenoble Institute of Technology and an MSc in Medical Device Design from the National College of Art and Design, Dublin.| web

Ria Wolkorte, PhD is a postdoctoral researcher at the Department of Health Technology and Services Research of the University of Twente (UT). She has a PhD in medical sciences from the University of Groningen (The Netherlands), and an MSc on clinical movement sciences from the Radboud University Nijmegen. Her research focuses on citizen science for health and wellbeing. Her interests are inclusive research, ethics of citizen science, monitoring and evaluation of citizen science, and movement science. She is currently involved in the TOPFIT Citizenlab, which is a regional and national fieldlab. In the fieldlab she focuses on collaboration

between different stakeholders on an equal footing in projects focusing on health and wellbeing supported by technology. Ria is involved in multiple national and international research projects that use a citizen science approach. Ria Wolkorte is member of the European Citizen Science Association working group Citizen science for health.

Sheree May Saßmannshausen is a PhD student and Research Assistant at the chair of CSCW and Social Media at the University of Siegen. She studied Media Informatics (BSc, MSc) at TH Köln University of Applied Sciences, Germany. During and after her studies she used to work as a research assistant in the Media Informatics Lab at TH Köln. In parallel, she also worked in Cologne as an UX designer in a research project related to healthcare. Her current research interests include the field of Human-Computer-Interaction and Human-Centered-AI. In her research, she explores human-centered design approaches for technologies like Augmented Reality or Artificial Intelligence in the context of healthcare as well as citizen participation.

Lara Siering is a PhD student in the Interaction Design Group at the Department of Design, Production and Management of the University of Twente. She studied Industrial Design Engineering (BSc, MSc) with a specialization in Human Technology Relations at the University of Twente. During her studies, she worked as a research assistant and applied co-design methods to design digital health for children. In her doctoral research, Lara is combining participatory design with speculative design in the context of health. Working as PhD in the national MOCIA (Maintaining Cognitive function In Ageing) research program, she will look at the design of meaningful digital health and methods for a better involvement of older adults in the design of digital health tools.

Åsa Cajander is a Professor of Human Computer Interaction at the Department of Information Technology at Uppsala University. She has more than 20 years of experience from participatory Action research with different stakeholders. Professor Åsa Cajander leads the multidisciplinary research unit Human Machine Interaction with around 30 members. Her research spans digitalization, gender, work engagement and professional competencies. Her research interests are related to eServices for patients and implementation of eHealth systems generally.

Michal Dolezel, Ph.D. is an Assistant Professor of Business Informatics and Information Systems Development at the Department of Information Technologies of the Prague University of Economics and Business. He obtained his doctoral degree in Information Systems from the same university. He holds master's degrees in Electrical and Biomedical Engineering (from Brno University of Technology) and Engineering Management (from Czech Technical University in Prague). Before fully joining academia in 2017, he spent more than ten years in the industry (telecom, finance, pharma) in various IT roles. During that time, he carried out several action research projects in the role of practitioner-academic. His current research interests revolve around consumer health informatics and the social aspects of software development.

Svante Lifvergren, M.D. PhD, works fulltime as a development director at the Skaraborg Hospital Group (SkaS) in Sweden. He is a specialist in internal and pulmonary medicine and has worked as a senior physician at SkaS since 1997. He has a PhD in Quality Sciences from Chalmers University of Technology in Sweden. He

has been connected to the Centre for Healthcare Improvement (CHI) at Chalmers since 2006 in various roles. Currently, he is an affiliated lecturer at CHI/the Service Management and Logistics Department at Chalmers, primarily supervising master and PhD students. His main research interests entail participative action research to design new mobile care models as well as to improve care quality and safety in a healthcare context. He has served as an associate editor for the Sage Action Research Journal since 2011.

Karin van den Driesche is a design researcher at the DesignLab for the Faculty of Electrical Engineering, Mathematics and Computer Science of the University of Twente (UT). She studied Fine arts (BA) at the St.Joost School of the Arts at the University of Applied Sciences of Breda (The Netherlands), and she has a MA in Philosophy. During her career she has been working in academia and in the creative industries as an UX designer and had her own company in User Centred Design. Her interests are design methodologies, transdisciplinary working, Human Centred Design, co-design, digital art, visual research, philosophy, and biomimicry. She is currently doing research in design methodologies for an inclusive citizen science approach for health and technology at the TOPFIT Citizenlab, which is a regional and national field lab.

ACKNOWLEDGMENTS

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