ABSTRACT
With colleagues and collaborators I work on a range of technology projects involving participatory design, many in the health space, and many involving marginalized communities. At the OzCHI 2016 workshop on “Digital Participation: Engaging Diverse and Marginalised Communities” I will discuss a selection of these projects, argue the case for participatory methods, and describe experiences and issues that have arisen.

Author Keywords
participatory design; sensitive HCI

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION
Participatory design (PD) techniques are used by HCI researchers to help ensure that the voices of disadvantaged people are heard when technologies are being built for them. Arguably, PD can be seen as advancing the digital inclusion of marginalized groups beyond technology use to technology design.

At OzCHI 2015, Waycott et al. (2015) discussed technology research in sensitive settings, calling for HCI researchers to reflect on common challenges and discuss possible responses in order to contribute to a discourse on “sensitive HCI”. We used this term to highlight two concerns: the sensitive and complex nature of the research setting, and the need for researchers to work in a careful, empathetic, sensitive manner in such settings.

The paper contributed a small body of case studies of sensitive HCI, aiming to promote a wider understanding of issues that arise in sensitive settings and to generate dialogue, foster shared learning, and promote reflexive practice.

My goal in attending the Digital Participation workshop is to expand the contribution of the OzCHI 2015 paper by discussing a selection of projects I am involved in. My aim is to enrich the sensitive HCI discourse by sharing interesting and challenging experiences and issues that have arisen in these projects. I also want to argue the case for participatory methods in projects of this kind.

Participatory Design typically involves close encounters between design participants and prospective end users

who are members of marginalized groups, and researchers and developers who often are not members of marginalized groups. This suggests that efforts to promote digital inclusion should extend beyond “access to technology” to include inclusion in the research and development of technology; that is, a goal of HCI research with marginalized groups should be to enable members of such groups to join the community of researchers and developers. Some existing academic programs aim to do this; for example UTS’s Jumbunna and the University of Melbourne’s Murrup Barak and Indigenous Engineers programs. Clinical research programs such as the Youth Research Council based at Orygen, the Centre of Excellence in Youth Mental Health have a related goal of including (potential) consumers in the design of health programs, many of which involve technology.

But participatory design in sensitive settings does not necessarily translate straightforwardly into inclusiveness, regardless of how earnestly researchers wish for it. PD encounters, when they bridge an intercultural gulf, can involve problems of mutual misunderstanding which may require translation and education, and these encounters can be difficult for researchers and participants.

EXPERIENCES
Online therapy for youth mental health
This project involves collaboration with a youth mental health clinic (Wadley et al., 2013). Sensitivity arises because mental illness is debilitating (which diminishes the ability of participants to take part in design activities) and stigmatizing (making anonymous participation important), and because participants are young. Clinical research has been extended to include a larger group of representatives who do not necessarily have lived experience of mental illness and may be located anywhere. Thus the clinic is at the leading edge of inclusiveness in mental health program design.

We are fortunate in that our partner clinic strongly promotes the participation of its clients in research, and has formal mechanisms in place to facilitate this while protecting the wellbeing of clients and researchers. For example, the clinic maintains a group of current and former clients, supported by a dedicated staff member, who act as patient advocates and are called upon to comment on proposed clinical and research projects. This youth participation program has recently been extended to include a larger group of representatives who do not necessarily have lived experience of mental illness and may be located anywhere. Thus the clinic is at the leading edge of inclusiveness in mental health program design.

Nevertheless issues arise and great care must continually be taken both in face-to-face design workshops and in online interactions. For example, there must be staff
present at workshops who can provide mental health first aid, and such aid is sometimes required. At the same time researchers need to be aware that some workshop activities that seem relatively benign to them may be emotionally challenging to some participants; an example is creative tasks that may seem to involve or imply competition with other participants or criticism by researchers. Also, technology-mediated interventions that extend the reach of clinical communication with clients must acknowledge the possibility that a client may use the technology to signal an emergency situation, at any time or place, which must be detected and responded to quickly.

Social connection for hospitalized children
This project involved collaboration with patients and staff at a children’s hospital as well as the patients’ families, school teachers and school friends. We designed and trialled a tablet app that supported social connection between hospitalized children and their schools and families (Wadley et al., 2014a).

While all stakeholders wanted to improve patient social connection, they did not agree on how a technology ought to do this. The different contexts of hospital, school and home created different constraints on what the technology could do. For example, parents were excited by the idea of audiovisual connection between hospital ward and school. But school and hospital staff felt this would disrupt important activities and put children’s privacy at risk.

Climate change adaptation on Pacific islands
This project involved conducting design of mobile technology to help Pacific Islanders respond effectively to climate change (Wadley et al., 2014b). We felt it was essential to include prospective end-users in design, so we conducted a series of workshops in Fijian villages.

A number of factors meant we could not straightforwardly translate a standard workshop approach to the traditional village setting. Yet by carefully following ceremonial and political protocols and the instructions of an experienced guide, and taking the time to establish trust before getting to work, we were able to conduct a modified form of PD.

Wellbeing app for taxi drivers
This project involves conducting research and design with a highly-mobile, mostly male, low-paid workforce, many of whom are recent arrivals to Australia and who face a number of physical and mental health risks including a sedentary work style and exposure to physical danger and mental trauma.

A salient feature of driver experience is needing to work very long hours, a large proportion of which paradoxically is spent waiting for periods of varying length. We are currently designing an app to encourage drivers to exploit work breaks to carry out activities that promote physical and mental health. We plan to trial it in 2017 after co-designing prototypes this summer.

Assistive apps for people living with HIV/AIDS
With the implementation of effective treatments, long term management of HIV/AIDS now shares many of the same features as management of chronic diseases such as type 2 diabetes or heart disease. Yet many people living with HIV/AIDS (PLWHA) continue to live in fear of being marginalised, and are afraid to disclose their status for fear of discrimination. Many still experience compromised quality of life and significant mental health distress.

Like people living with other chronic conditions, PLWHA need to self-manage complex treatment regimens and improve their lifestyle in order to maximize their health and wellbeing and reduce their risk of other common chronic conditions.

This project is designing a digital health program to improve the self-management of HIV and enhance the long term mental health and social wellbeing of PLWHA. Privacy and sensitivity are critical during this research; yet we don’t want to inadvertently reinforce existing stigma.

Co-designing with Indigenous Australians
A group based at Melbourne is conducting a project to co-design health and wellbeing technology with Indigenous Australians. Indigenous Australians are not a homogenous group but represent a range of distinct cultures in a variety of environments. This raises challenges for inclusion and participatory design. Researchers must follow a protocol that is culturally respectful. Furthermore we believe inclusion should not stop at design but should occur at all stages of the technology lifecycle, including implementation and maintenance. We are guided by an Indigenous lead researcher and by the Postcolonial Computing framework (Irani et al., 2010) which proposes that ICT4D projects be framed within an understanding of the global and historical dynamics of power, wealth, and political influence that shape contemporary cultural encounters.

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REFERENCES


