Participatory Action Research and Open Source Hardware Appropriation for Large Scale In-The-Wild Studies

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ABSTRACT

With the rise of ubiquitous computing, the use of research in-the-wild approach in both Ubicomp and HCI context has become more viable, but not without its challenges. End-users and communities can be great beneficiaries of such an approach if actively involved in the process from an early stage and throughout the whole process. We start by presenting a future case study, the Cue Band study, which revolves around the creation of a wristband cueing device for people with Parkinson's that experience drooling. We present an approach for research in-the-wild, which draws on participatory action research theory, that places the end-user at the centre of the process, aiming to first and for most to create a workable product for the end-user, before engaging in a formal study. In the last section, we explore the appropriation of existing open-source hardware for in-the-wild research, by describing problems and solutions associated with developing Ubicomp technologies for large-scale studies.

CCS CONCEPTS

• **Human-centered computing → Ubiquitous and mobile computing**; **Participatory design**.

KEYWORDS

Participatory Action Research; Open Source; Hardware; Large Scale Studies; Wearable; Parkinson's Disease

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1 INTRODUCTION

With the increasingly pervasive nature of ubiquitous computing and the decreasing cost of ubiquitous technologies[4], the use of in-the-wild methodologies in large scale ubicomp studies has become more viable, but this is not without its challenges [2] – namely consolidating the development of ubiquitous technology (both hardware and software) with large scales studies. Ubicomp studies typically tend to be smaller scale and use bespoke technology to conform to the end-user needs in more controlled environments. When it is time to transition to a final product that is reliable and monetarily feasible, new challenges can arise. If we also consider the additional difficulties of scaling up to cope with larger populations, navigating this transition into the wild successfully becomes increasingly complex. Common strategies adopted by ubicomp researchers are to 1) use off-the-shelf hardware[9] – allowing for a quicker prototyping stage, but might have compliance issues with the study and the user needs; or 2) develop bespoke technologies which require a longer prototype development process but more easily allows the users to be involved in the design of the device and to shape it to their specific needs.[3, 8] With the rise of the open-source movement and the democratisation of hardware/software access, there is an opportunity to re-appropriate open source technologies as the foundation of our ubicomp studies for rapidly creating and customising technologies to support large scale in-the-wild studies. We can curtail the initial hardware barriers as there is an off-the-shelf near-ready product to start with; and thanks to the open-source community development ethos, we can re-imagine and re-configure the existing soft aspects of those technologies to better meet the needs of our end-users and research studies. Moreover, the malleable nature of the open-source software and device firmware enables us to engage the end-users in co-design and co-production at much earlier stages to reduce further the risks and costs associated with ubicomp in-the-wild. By bringing on the end-users as co-designers and working with them to create solutions that are of immediate benefit to them, we are effectively engaging them as invested contributors to our open source technology. Ultimately, by growing our community of interested parties around the technology before deployment, we hope to mitigate the typical teething issues impacting research study compliance and feasibility. Similarly, this approach of fostering a strong community upfront could offer potential insights into more sustainable routes for ubicomp technology roll-out and scaling up as researchers seek to transition into a practical application of their work.

In this paper, we posit our existing ubicomp study and the development of Cue Band, a digital health device for people living with Parkinson's Disease, as a case study for doing large scale research in-the-wild. We draw inspiration from participatory action research theory [1, 5] to shape our approach and prioritise direct engagement with the Parkinson's community to co-create a solution to a fundamental and immediate problem faced by that community. Through this work, we hope to stimulate meaningful discussion around the opportunities and challenges of co-opting and re-appropriating existing open-source technologies to support large-scale ubicomp research in-the-wild.

2 WEARABLE TECHNOLOGIES FOR PEOPLE WITH PARKINSON'S DISEASE

McNaney et al. [6, 7] piloted the cueing approach using a wrist-worn device to provide haptic cues for automatic swallowing for PwP experiencing drooling. Despite the limitations of the pilot study, it demonstrated that wearable haptic cueing was an effective treatment method and a socially acceptable solution for PwP. This new study will deploy a new wristband wearable, the Cue Band, and a companion mobile application. The individual will define a 7-day cueing schedule through the mobile app, modify intervals and intensity of the cues. Once a schedule is defined, the user might decide to receive the cueing through the mobile phone or the Cue Band as a standalone.

We propose a wild by design approach that focuses on disempowering ourselves, the researchers and academics, and empowering the end-users and their communities. We advocate that before starting a research project, we should first consider the immediate needs of a community and how, as researchers, we can best support them. Before formulating research questions, undertake research activities such as workshops and interviews with the community to find their needs and challenges and gain a deeper understanding of the community and the surrounding stakeholders. The main objective of this initial engagement should not solely be focused on knowledge acquisition and understanding but also on creating deeper relationships with the community, between individuals and researchers. In the case of our study, we will start by establishing contact with local and national Parkinson's associations.

Taking inspiration from PAR, community engagement should be iterative. Every step of the way, the community is involved in giving input around designing a possible solution and making the decisions on the next steps. This engagement is essential since the answer for the challenge should be bespoke and fit seamlessly into their lives, aiming to remove or diminish any barriers to entry. In this iterative stage of the research, workshops and interviews will be held initially to find the needs and challenges of people living with drooling, followed by sessions where prototypes of the wristband and the mobile application will be demonstrated and given to the participants to try.

During this process, it will be essential to ensure that any shared understating established and any created protocols are understood and easily accessible by all stakeholders. We advocate for the creation of platforms that enable the displaying of research objectives and roadmaps of future stages of the research. At the same time, allow the creation of a digital community place, where members of the community, researchers, and anyone who then wishes to contribute can directly deliberate and take action around the research. As open-source platforms and technologies have shown, there needs to be a community for these solutions to continue to exist and evolve. We will develop an online platform where individuals can access the study information, protocols and development roadmaps. Through this platform, PwP experiencing drooling will be able to register their interest in participating in the study.

When it comes to technology, the solution should meet where the community is or aim to be an easily understandable technology by the participants and seen as obviously beneficial. The researchers should explain the technology and the perceived benefits for the community while giving space for participants to decide the technology corresponds to their needs. This process is necessary as they need to feel a sense of ownership over the technology itself, as it is something they are bringing into their world, and therefore needs to be compliant and complicit with their rules and how they behave.

At the end of this process, there should be a complete infrastructure rolled out that provides the solution to the challenge faced by the community, to which the community itself has complete understanding and ownership. Throughout this process of developing a solution, the community needs are kept central to the work rather than the research objectives. Only once a solution has been achieved and infrastructure is operational should researchers and the community engage in search of a formal study using the existing connections with the community and the deployed infrastructure. This implies that not all the work, development and features created to achieve the solution will be used in the formal study. The study should still follow the conduct and interests of the community and preserve their identity.

In our specific study, once the technology has been fully developed and the infrastructure rolled out, all participants will receive a Cue Band to keep and continue to use beyond the study if they choose to. With a smaller sample group of 300 participants, we will conduct a comparison study to explore the potential effects of the cueing methods using different devices (Cue Band vs mobile app only). During an eight-week cueing method intervention study, participants will experience both interventions and be asked to maintain a daily diary using the tools provided through our mobile app.

3 UBICOMP TECHNOLOGY FOR IN-THE-WILD RESEARCH AT SCALE

Research that relies on bespoke hardware can find the technology becomes a severely limiting factor on the scale of effective in-the-wild studies. The development and distribution of consumer-grade devices are difficult and expensive, and in particular, wearable/IoT devices pose many challenges. Bespoke devices can work well as a prototype for lab-based studies or small trials, where participants tend to be tolerant of systems' fragility at an early stage of development. However, specific skilled engineering is required to make designs practical for mass production at larger scales – and academic research organisations are typically ill-suited to undertake such work. These issues can be avoided when some existing hardware meets the minimum requirements, and instead, an existing device could be reprogrammed with bespoke firmware. Many commercial off-the-shelf devices have received the attention of "hacker" communities keen to "open up" their hardware, to customise or re-purpose as they see fit. The hardware and existing firmware are reverse-engineered and documented to allow modifications to be made. However, there are issues with this approach: external design/markings may misrepresent the device/manufacturer or its compliance/certification; or the firmware may be responsible for a safety-critical aspect; or that circumventing protection mechanisms may not be permissible in some jurisdictions. Moreover, such an approach would present uncertainties in the long run: consistency would not be guaranteed as the device's internal specification could be subject to incompatible changes without warning, and availability would not be controllable, but challenging to forecast, and a device may even be withdrawn entirely without notice.

One solution would be to use a more generic hardware design, likely to suit a wide range of applications, which would have a broader user base and bring greater economies of scale, where some of the overheads of the design, testing, and firmware/software development can be shared with a larger community. Some commercial platforms are designed to be extensible and interchangeable, such as user-installable apps on an Android Wear device. However, complex smart devices tend to have a high unit cost, suffer from a short battery life, pose limitations on app behaviour, and have complex setup requirements (e.g. required pairing to a phone).

Open designs from the open-source movement typically also offer this wider community. Many open hardware projects exist, but a significant proportion is only suited to a low-yield maker/DIY approach and suffer the same limitations as bespoke hardware and are generally not ready for commercial manufacture.

However, some open hardware projects have already reached the mass manufacture stage, with suppliers willing to produce devices in significant quantity, and have developed a wide user base from a community of people. This brings several economies of scale: any new development (hardware/firmware) does not have to start from scratch; there are resources and a community to support the work; a supply of ready-to-use devices that the manufacturer will handle the testing, logistics and support for. An open project will bring some reassurance in future-proofing hardware decisions: there could potentially be multiple manufactures in the future (better availability, lower cost); there will be a skill base of experts; the community will be motivated to work around obstacles (e.g. a component shortage can be replaced and the firmware made compatible); and the design can be iterated on and is likely to have backwards-compatibility as a consideration. An open design also reduces doubts about consistency and, as a fall-back, if production was not continued in the future, it could be offset by having the tried-and-tested, ready-to-manufacture design at hand to get quotes for bulk purchasing from a manufacturer.

For the Cue Band hardware, we chose PINE64's open-source *PineTime* wearable device. It is a versatile wrist-worn device with a touch screen, hardware button, Bluetooth wireless radio, accelerometer, multi-day battery life, vibration motor, *over the air* updatable firmware. There is a significant community around the device, and several firmware options to build upon. The most popular is currently *InfiniTime* (GPL license), which provides a good base feature set for a wearable device. The intention is that our Cue Band mobile app (iOS/Android) will be able to *bootload* the device with our own firmware from the initial condition that the device arrives. At the time of writing, the PineTime costs $26.99, plus shipping. At this price level, and that it can be delivered directly to the purchaser and have its firmware replaced using the app, means that there will be no distribution costs/overheads, and the overall price to the user will be kept to a minimum. These factors combine to maximise the scalability of a deployment.

4 CONCLUSION

We have described an approach for research in-the-wild which draws on participatory action research theory, placing the end-user at the centre of the process, and discussed why adapting existing open-source hardware is an appropriate method for developing Ubicomp technologies in such large-scale studies.

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