

THE PISHI CONCEPT: A TECHNIQUE FOR
INCREASING INCLUSION IN THE DESIGN OF OPEN-
SOURCE ASSISTIVE TECHNOLOGIES

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Abstract

This thesis addresses how to make Open-Source (OS) Assistive Technology (AT) more inclusive. The thesis employs a Research Through Design (RtD) methodology on a particular case study: the Switch Activated Writing System (SAWS) that is in transition to an Open-Source project (OSSAWS). Analysis of the literature reveals the potential to leverage persona representations into OS AT. This thesis includes three RtD iterations which focus on successive modifications of persona representations and markdown templating, converging on a final design concept called **Persona Inclusion for open Source assistive tecHnology Innovation (PISHI)**. The PISHI concept centers on the representation of family-level dynamics, crucial in the AT domain and design innovation. The thesis develops persona representations for the users of OSSAWS following the PISHI Concept. This thesis presents a rationale for the generalizability of the PISHI concept, which will provide a crucial means for increasing inclusion in Open-Source (OS) Assistive Technology (AT).

Dedication

Dedicated to the loving memory of my beloved grandparents, Mamani & Baba Akhavan,
who loved and believed in their Pishi.

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I would like to express my sincere gratitude to my supervisor Professor Melanie Baljko, for her continued support and guidance throughout my studies at York University. I learned a lot from her and I cannot imagine this work being possible without her brilliance and immense knowledge.

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1 Introduction

1.1 Designing For vs. Designing With

There is an on-going issue in UX Design of power and inclusion: the main users of a design are often the ones who have the least effect on the design process (Iskander, 2018; Rajapakse et al., 2015). Human-centered design, participatory design, and other co-design approaches and techniques have been developed to address this issue. The situation is particularly noted in the design domain of Assistive Technologies (AT), as people with disabilities are typically marginalized in the design process (Rajapakse et al., 2015). An Assistive Technology can be defined as a piece of technology that helps with tasks that an individual would otherwise find difficult and, as a result, may not be able to perform (Cowan et al., 1999). Most commercially-available ATs tend to overlook individual differences and individual uniqueness (Rajapakse et al., 2015). However, it is often the case that each individual needs a tailored piece of technology to fit their specific needs (Hurst & Tobias, 2011; Phillips & Zhao, 1993b). Currently, most AT technologies are being designed *for* disabled people, not *with* them (Rogers & Marsden, 2013). Oftentimes, the voices of people with disabilities are not heard, and decisions are made for them. This is an issue of inclusion in the design process. The design process of AT should move towards designing *with* the people who want to use them rather than being designed *for* them. Open-source development offers this possibility.

1.2 SAWS (2009-present)

The Switch Activated Writing System (aka “SAWS”) is a tailor-made non-commercial AT that was designed and developed by a university-based project team to assist M¹, a person with vision, hearing, and motor impairments (CanAssist, 2009). M approached CanAssist², a center based in the University of Victoria, BC that develops customized ATs, to request a tailor-made device that could assist them in writing. The SAWS system was developed in response, led by the efforts of members of the Practices in Enabling Technologies (PiET) Research Lab of York University (who were visiting scholars at the University of Victoria at that time). Even though M is the direct user of the system, M’s family and intervener are also involved in the process of M using the system. M and the people with whom M is in close contact form the user circle of SAWS.

People with severe vision and hearing impairments are considered as deaf-blind (Caporusso, 2008). Deaf-blindness can mean some sense of hearing and sight can be present, but not to an extent that it can be used to communicate or to access information. Different people in this community might experience different levels of both impairments and this makes their situation unique to themselves (DeafBlind Ontario Services, n.d.). Deaf-blindness can have different causes and types. Regardless of the origin of the conditions, communication — whether through speech, writing, or other communication

¹ To anonymize the actual participant in the study, I wrote under the pseudonym M.

² <https://www.canassist.ca>

systems — is an imperative human activity. In describing deaf-blindness, we make use of the term *impairment*, which refers to the problems in form of a significant deviation or loss in organs, body structure, or function (World Health Organization, 2001). Impairments can have different types, levels, and combinations. We will refrain from using the term *disability*, which is a contested social construct (Kafer, 2013). According to advocates of the social model of disability, disability is the result of people with impairments interacting in disabling environments.

The SAWS system was designed based on a specialized input technique called scanning and a large font display for presenting the sets of options. This design capitalized on M’s minimal residual visual sense and M’s ability to iterate over successive input choices using a single push-button input device (also called a ‘switch’). M’s vision allowed them to see a few characters at a time, provided each character is at least 10 cm tall and could be viewed within 25 cm of the screen (figure 1-1). The system was customized for M in 2009, who has been using it since then for personal communication, doing schoolwork, and writing in general. The fact that the system fit M’s needs for over ten years is astonishing as most ATs are abandoned within the first five years (Phillips & Zhao, 1993b).



Figure 1-1 A snapshot of the current Switch Activated Writing System (SAWS).

The current SAWS system has over ten configuration parameters. For example, there is the *dwell time* configuration parameter, which specified the amount of time (msec) for the highlighting to linger on each option. The shorter the dwell time, the faster the reaction time needed. A longer dwell time allows for slower selection actions, but the overall time required for text entry is extended. There are configuration parameters for font face selection, colour and size, background colour, as well as many different parameters that stipulate which selection options are offered and in which order of presentation.

Contact was recently made regarding SAWS. M's needs and priorities have changed in life, and the SAWS system needed to be modified. Thus, SAWS needs software

maintenance and revision, thereby creating the premise of the thesis research project described in this document.

1.3 SAWS, The Open-Source Future

The request for SAWS software revision also activated the long-standing but dormant goal to deploy SAWS more widely and through an open-source distribution.

There are conventional, commercially available ATs helping people with deaf-blindness that make use of their sense of touch. However, these ATs are not suitable for users who also have motor impairments. When deaf-blindness combines with other conditions such as motor impairment, conventional ATs are often not usable. SAWS has the potential to be used by other deafblind users with motor impairment. This would provide an enabling technology for communication and writing.

The SAWS codebase, at present, offers the possibility to instantiate an app that has an extremely high degree of configurability. The configuration of SAWS to each particular direct user is an essential step in its installation and set-up. The people who are in close contact with the direct user (e.g., the family members and interveners) have a prominent role in the configuration step. For example, a possible scenario could be that a family member, after starting the software, tweaks the configuration for longer dwells on each character.

The SAWS codebase, alongside its support resources, has the potential to be shared as an open-source project. The support resources currently consist of software documentation and a draft of a user guide. These support resources could be augmented

in many ways. This has become a question for this project: which support resources should be developed and included?

1.4 SAWS, The Open-Source Challenges

Being shared as an open-source software, people in the open-source community will be provided with the chance to contribute to SAWS enhancement, development, and longevity. It is anticipated that even further additional configuration parameters may be needed, as well as other design modifications. For instance, for the AT to be usable by people with different levels of impairments, the configuration step of the SAWS installation and set-up needs to be made usable for end users in different scenarios of use. The configuration step of SAWS suffers from usability issues, which need to be addressed in upcoming revisions, potentially through design modification. As well, additional configuration parameters are needed, such as having an easy to reach option to change the order of characters shown to the user.

But we wish for this design process to be inclusive. There should be a way for this particular AT technology to be designed *with* the users, not *for* them. An infrastructure is needed to be provided through which SAWS and its support resources can be shared, to facilitate the possibility of the enhancement and tailoring of the design according to the needs of different users. The infrastructure needs to allow for co-designing with and for the users. There are non-trivial access barriers to participation in open-source development, so the question becomes: how to accommodate a larger diversity of participants in the

open-source development process. Thus, the sharing of the SAWS code base in the open-source community presents some design challenges.

1.5 Design and Open-Source Development

Open-source AT represents a legitimate path for improved AT delivery. The skills and abilities of the decision makers within the process of open-source AT has a dominant role on how open-source projects move forward and get designed. We can identify two aspects of inclusion in open-source AT: (i) content inclusion (who gets represented within the design process and how?) and (ii) process inclusion (who gets to be part of the open-source community?).

The open-source community tends to be dominantly focused on software development with a focus on the sharing of source code (and test cases), as opposed to the sharing of the design process. Sharing the design is typically limited to the sharing of design artefacts (e.g., schematic diagrams, CAD files, and other design representations) (Hurst & Tobias, 2011), which often does not include the design process, the intermediary design outcomes, and insights elicited through the process. Sharing provides the conditions for innovation, as different design directions can be pursued by different community members (e.g., via forking). This model of innovation means that design decisions are being made during the open-source development process: the design decisions are made for people initially by the open-source contributors (Rajanen & Iivari, 2015).

People, when involved in a design process, make use of conceptions of the stakeholders and of the envisioned scenarios of use when making design decisions. These conceptions

can be made explicit — as *design representations* — or can be left implicit — as *mental models*, which make use of both unconscious and conscious assumptions. These conceptions, especially when made explicit as design representations, can aide the cognitive process of the designer, help them to better keep track of and communicate design ideas, and therefore support the design process (Cooper et al., 2014). The persona is the most powerful design representation method available that explicitly models and documents the mental models of the people involved in the process of design (Cooper, 1999). When these mental models are incomplete or incorrect, there will be a negative impact on the design outcome. Many mental models of assistive technology use and users tend to incorporate ableist assumptions (Crippledscholar, 2015; Mankoff et al., 2010). Thus, the failure to use explicit *persona design representations* in open-source AT software development is problematic: at a minimum, it fails to foreground assumptions that need to be examined, and, at worst, it reproduces ableism. Because this is an issue of representation, we associate this with content within the design process and identify this as a form of **content inclusion**.

A second issue concerns who gets to be part of the open-source community. There are many barriers to entry into the Open-Source AT community. The projects often follow the trend of technological advances and its capabilities, rather than needs of the people for which the software is being designed (Norman, 2021). In other words, the design is technology-centered as opposed to human-centered. One of the issues with this focus on technology is that a certain degree of software knowledge and expertise is needed as a

condition of participation. This way of open-source software development reproduces the same design issues, especially the marginalization of people with impairments in the AT field. This is an issue of **process inclusion**.

1.6 Line of Inquiry

The goal of this thesis project is to investigate **open-source AT** from a critical perspective. Open-source AT represents a legitimate path for improved AT design and delivery. Rather than considering solely the outputs (pieces of specific open-source AT), we consider the AT delivery ecosystem as a whole. We have identified two mechanisms of inclusion in open-source AT: (i) content inclusion (who gets represented and how?) and (ii) process inclusion (who gets to be part of the open-source community).

At present, open-source software has a focus on the sharing of source code, as opposed to the sharing of the design process. Current open-source practices tend to focus on technological aspects of the code base, rather than needs of the people for which the software is being designed (Norman, 2021), and current open-source practices tend to not make use of explicit design representations, especially personas, which are design representations of the stakeholders. By failing to use explicit design representation of stakeholders, the conditions are created whereby open-source contributors fall back onto conceptions. This creates issues with **content inclusion**. As well, the focus on technology as opposed to a more human-centered design process creates the situation in which others, who have relevant expertise, are not able to contribute because there is a lack of ways in which to do so. This creates issues with **process inclusion**.

The focus of this thesis project is to provide means of inclusion in open-source AT in both aspects of content and process, through undertaking the design challenge: how can we create more inclusion in open-source AT?

Since there are many potential design directions that could be considered as a response to this question, it will be important to make use of a suitable methodology for this research project.

1.7 Note about COVID-19

This research project was originally designed around a series of in-person data collection and observation sessions. Unfortunately, due to the situation caused by COVID-19, a redesign of the research project was needed, since these forms of data collection were no longer possible. The situation dictated a redesign of the research project.

1.8 Thesis Overview

In Chapter 2, I study the literature to identify the main challenges in designing open-source software and tools. As well, I provide a summary of some of the representation tools available in design, their shortcomings, and the field's suggestions for their evolution. At the conclusion of chapter two, once I have established the necessary terms and concepts, I will restate the path of investigation for this project in a more detailed manner.

To follow the thesis impetus, I have designed a research project that makes use of the Research through Design methodology. I describe this methodology, its tools and process, and the rationale for employing it further in Chapter 3.

In Chapter 4, I summarize the process I went through that led me to develop a new design representation to be used within the persona technique and an approach for incorporating the persona technique into open-source development. I will show how the new design representation addresses the shortcomings of the currently-used persona representations and how the incorporation of the persona method addresses the need to increase inclusion in open-source AT. I propose and describe the OSSAWS project (Open-Source SAWS), which is the open-source deployment of SAWS and serves as a case study to demonstrate the shortcomings of currently-used personas and to demonstrate how the proposed persona representations can be used in practice. I argue that this approach can be used more broadly for design in the AT domain and open-source community.

In the conclusion (5), I provide a summary of the project, conclusions, and future work. I will review the design method developed for the enhancement of SAWS and its support resources, and the process I went through to develop that. I will discuss the possibilities for future work on the proposed design method, explore its potentials, and suggest other ways to improve inclusion and knowledge mobilization in the open-source AT. I will also point out the need for further investigation of the potential of RtD as a design methodology.

2 Related work

2.1 Deaf-Blindness and Assistive Technologies Supporting Communication and Writing

2.1.1 *Deaf-Blindness*

People with severe vision and hearing impairments are considered to be deaf-blind (Caporusso, 2008). Deaf-blindness usually means some sense of hearing and sight is present, but not to the extent that the senses can be used to communicate fully and/or to access information fully. Deafblind individuals may experience visual and hearing impairments to different extents and, thus, deaf-blindness can be a situation unique to each individual (DeafBlind Ontario Services, n.d.).

Deaf-blindness can have different causes and types, but the two main types are *acquired* deaf-blindness (which is a kind that one experiences in their later life) and *congenital* deaf-blindness (which is a kind that happens before the development of language skills (DeafBlind Ontario Services, n.d.).

Deaf-blindness may be combined with other types of impairment, such as motor impairment.

Many different types of assistive technologies (ATs) are used to support communication and writing for deafblind individuals. These ATs typically need to be tailored to fit the unique situation of the individuals using them.

2.1.2 Configuration, Customization, and Personalization

Before discussing the different types of assistive technologies (ATs) that are used to support communication and writing for deafblind individuals, I will first clarify the terms *configuration*, *customization*, and *personalization*.

The term *configuration* refers to tailoring an instance of software through changing pre-defined parameters (Sun et al., 2008). Examples of this kind of change can include modification of GUI elements, such as: changing the name of the fields, changing button labels, and modifying the items that appear in lists. The term *customization*, however, refers to tailoring that happens through making changes to the source code of software, in order to add functionalities beyond the configurable limit (Sun et al., 2008). The term *tailoring* is a more general term. It can refer to either configuration or customization or even to the choices made during the software design process.

The term *personalization* is used to refer to a situation in which a software system is designed so that it employs users' data to provide each user with a tailored experience. For example, personalization may mean that the software system suggests a list of options to a user by predicting their needs based on their previous data (Sundar & Marathe, 2010).

In software engineering, a *variable artefact* is a software artefact that can be adapted for different product use contexts (Bachmann & Clements, 2005). Therefore, a variant is a specific instantiation of the software artefact. Each software artefact has a set of configurable parameters that may be set differently across different instantiations, but these parameters are common to all variants (Liang et al, 2009).

In the Open Design community, makers often demonstrate a high degree of creativity and deviation from the ‘original’ version of a design that is offered for community use. Open Designs may refer to hardware-based components (e.g., Arduino), software apps (e.g., Mozilla Firefox), or assemblages that include both hardware and software components (e.g., the RepRap Open-Source 3D printer). Although makers may choose to instantiate a design exactly as specified, they often do not. Makers may deviate from the ‘original’ version of the design for many different reasons, including changes at the ‘source’ level (software source and/or hardware schematics) that customize for the specific needs of certain users and for certain use cases. Thus, a design that is offered often represents not only a specific system, but also can latently represent just one concrete instance of a more abstract “conceptual design” that serves as a starting point from which several variants may emerge. We define ‘design phenotype’ as a “conceptual design” that has many latent variations, that is, a conceptual design instantiation that can be customized for different users and use cases. A piece of AT evolved from a design phenotype includes the same set of parameters of the original phenotype (with or without the additional customized features) that can be configured to fit a unique scenario of use.

2.1.3 Assistive Technologies Supporting Communication and Writing for Deaf-Blind Individuals

People with deaf-blindness typically communicate through their sense of touch. There are many ways with which people with acquired or congenital deaf-blindness can communicate, such as tactile fingerspelling, print to palm, adapted sign language, Tadoma

(speechreading using fingers), and braille, to name a few. Because these systems require advanced training to master, they are not commonly known in the general community. As well, these forms of communication require a “helper” — usually known as an intervenor —to be present and to serve as an interpreter. This kind of dependency on the interpreter may lead to social isolation for deafblind individuals (Caporusso, 2008; Gollner et al., 2012). Empowering people with deaf-blindness to communicate without the help of an intervenor is expected to lead to more engagements in society, in social activities and in relationships, and to lead to an enhanced overall quality of life. Many researchers have talked about and analysed the efforts to empower at the community-level, such as makers movement and Do-It-Yourself Assistive Technology (Hurst & Kane, 2013; Meissner et al., 2017; O’Kane et al., 2016; Okerlund & Wilson, 2019; Rajapakse et al., 2015).

2.1.3.1 *Synchronous Co-located Communication*

Advances have led to some useful assistive technologies for people with deaf-blindness to empower them to communicate independently from the presence of an intervenor as much as possible. For instance, Caporusso (2008) introduced Malossi gloves that people with deaf-blindness can use to feel the alphabet on their hands using the Malossi technique (Figure 2-1). Similarly, Gollner et al. (2012) introduced Lorm gloves for people with deaf-blindness. To use Lorm gloves, both the person with deaf-blindness and the interlocutor should know the German Lorm alphabet. Both Malossi and Lorm gloves can interpret the message into tactile stimuli and vice versa.

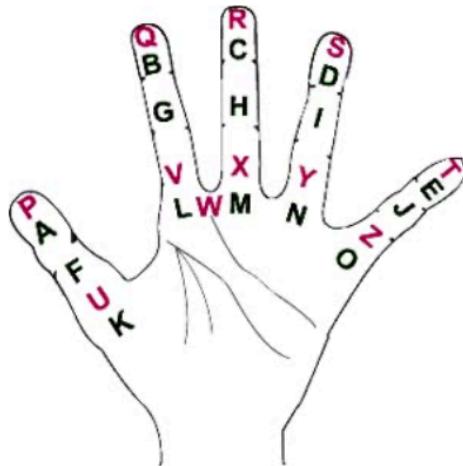


Figure 2-1 Location of characters in Malossi alphabet

2.1.3.2 *Synchronous Communication, Writing*

VBraille, introduced by Jayant et al. (2010), uses vibrations as a means to “display” braille on touchscreens for people who are blind or deafblind and who use braille as their main method of communication.

TeslaTouch (Xu et al., 2011) is also another touchscreen based solution developed to help people with visual impairments communicate.

2.1.3.3 *Scanning Methods*

As mentioned earlier, deaf-blindness can refer to a very diverse set of impairments. Some deaf-blind individuals have at least some vision which can help them see large font text or large scale pictures (DeafBlind Ontario Services, 2019). Large font demonstration has been in use for a long time to assist people with low vision in their activities (DeafBlind Ontario Services, 2019; Glinert, 1984). If deaf-blindness exists in combination with motor impairment, the ATs described above might not be usable.

Scanning is a very common way of affording a means of selection to users with motor impairments. In this method, a screen display shows a set of options and highlights a set of options one at a time, one group after the other. If the user's target selection is among those options, the user performs an action (typically presses a button, usually a switch) to select that option or group of options and if not, they let the scanning move on to the next group of options.

According to Roark (2010), Augmentative and Alternative Communication (AAC) systems are particular Assistive Technologies that help persons with motor impairment for whom conventional text entry systems are hard to work with. Such users scan through a grid of characters row-by-row, with the user selecting the row in which their intended character is. After that, they scan on every column on that row until the user presses the button again meaning the target character is in that row and column.

Using scanning method to step through large scale options on the screen is a combination that can assist people with low vision in writing.

2.2 Non-Commercial Assistive Technologies

As explained in 1.2, SAWS is a piece of tailored assistive technology originally made through a collaborative approach to suit the unique needs of an individual with deaf-blindness and motor impairments. This system has been in use for over 10 years by its user circle, which proves that this system has been successful in addressing and suiting the writing needs of its user.

As established in section 1.3, in the future, SAWS is envisioned to be shared with the open-source community. Open-source and commons-based peer production invite helper community members to engage in the process of enhancement of assistive technologies or instantiating them for the use of a particular member of the community. Publishing this product as an open-source AT can prolong the longevity of the system alongside affording writing to more people in the community. In the following sections, we will review the current state of AT devices, the importance of usability in the domain of AT, and its place in open-source projects.

2.2.1 Commercial Assistive Technology, Usability, and Abandonment of AT

As reported in many research projects in the field of assistive technology, mass production of assistive devices can lead to high abandonment rates of the products (Hook et al., 2014; Hurst & Kane, 2013; Meissner et al., 2017; Phillips & Zhao, 1993b). People with impairments often encounter accessibility barriers (Theil, Buchweitz, Gay, et al., 2020), and circumventing these barriers require unique physical, cognitive, and sensory adaptations. These needs are most often not fully considered in mass-produced market solutions which often focus on the commonality among impairments rather than the uniqueness of their differences (Hook et al., 2014; Hsieh et al., 2008; Rajapakse et al., 2015). And despite recent and growing attention to inclusive design, resulting systems and services either often exclude people with impairments or get abandoned by them, since a design that tries to ‘fit all’ inevitably neglects individual differences and uniqueness, and thus becomes unusable or unused (Harris, 2010; Marcus et al., 1999; Rajapakse et al., 2015;

Ravneberg, 2012). Therefore, AT often must be tailored to a high degree to a particular individual, either through customization or configuration.

While designing and producing these devices is very costly, they usually are not adaptive to the needs of the users, the fact that makes them more prone to be abandoned in the future (Meissner et al., 2017; Rajapakse et al., 2015). Also as mentioned by Deafblind Ontario Services (DeafBlind Ontario Services, n.d.), every individual's experience of disability and impairments is unique, so it only makes sense if a system is uniquely designed for their needs or can be configured to fit their needs the best way possible.

Current research mostly focuses on the use of AT in an individual context of use (Theil, Buchweitz, Fuentes, et al., 2020). The cognitive psychology literature argues that when tasks become too challenging for a person, one can experience anxiety (Csikszentmihalyi, 2008). A person can only accomplish a set of tasks with a certain level of difficulty, beyond which an anxiety response is triggered. Therefore, in order to have an optimal experience, it is important to help lower the anxiety caused by the tasks (Csikszentmihalyi, 2008). Fischer (2008) argued that a tool-rich, socio-technical environment can help a person with impairments to accomplish certain tasks (such as higher difficulty tasks) when the demands are distributed across one's close circle and the tools available. Therefore, one approach for AT design could be to move towards designs that distributes some aspects of the tasks among members of the family group, rather than placing task completely solely on the individual with impairments.

According to a survey conducted by Philips and Zhao (1993) most assistive technologies get abandoned within their first year of use, and they almost completely become obsolete after five years. Based on their results, one of the main reasons for abandonment of assistive technology was the AT's inability to be configured to the changing needs/priorities of the user. Other reasons for abandonment include ease of obtaining the device, device performance, and lack of user involvement in device selection.

Hurst and Kane (2013) showed that involving the users in the process of design and development of assistive technologies, and empowering them to modify it, can help their engagement with the technology, as well as giving them a sense of control in managing the technology they are using.

Rajapakse et al. (2015) emphasized on the need for individualized technologies designed for and with people with disabilities that suit unique needs of the people. They argue that technologies designed in this way can improve the quality of life for people with disabilities. According to them, one of the key tensions in the creation of more sustainable assistive technologies is the need to accurately identify and manage the needs and expectations of people in design.

2.2.2 Usability in Open-Source Communities

According to Nielsen, *usability* is “a quality attribute that assesses how easy user interfaces are to use” (2012). A system that is usable is a system that enables the user to accomplish their goals in a “pleasurable, simple, effective manner” (Interaction Design Foundation, 2020).

A problem in many Open-Source Software (OSS) projects is that the (software) outcome has poor usability, particularly for non-technical users. Multiple factors contribute to this problem, such as the lack of design knowledge of people contributing to the development of open-source technologies; the lack of contribution of usability experts; the lack of suitable means of documentation and representation of data, design ideas, and decisions; and the lack of proper channels for usability experts and end users to access the decision makers with their concerns (Cheng & Guo, 2018; Nichols & Twidale, 2006; Rajanen & Iivari, 2015). These can lead to design decisions being made by decision-makers who are not usability experts (Nichols & Twidale, 2006; Rajanen & Iivari, 2015).

In discussing the UX design process for OSS projects, Rajanen and Iivari (2015) explain that OSS projects typically follow the *onion model*. In this model (Table 1), a person (or a few people) in the core of the onion is (are) the ultimate decision-makers. On the next outer layer, there are the committers who contribute to the project with the approval of the core, and on the next outer layer to that are the end users of the software. In this model, the usability experts, if included at all, are usually included in the outer layer, alongside the end users, and these experts have very little to no power in the process of decision making. Rajanen and Iivari (2015) suggest that for achieving better usability in OSS projects, the usability experts should be included and influence the core of the decision-makers.

Layer	Description
Core	a person (or a few people) who is (are) the ultimate decision makers

Middle	committers who contribute to the project with the approval of the core
Outer	usability experts alongside the end users, who have very little to no power in the process of decision making

Table 1: Rajanen and Iivari (2015) Onion model of Open-Source Software Community

2.2.2.1 Usability and SAWS

Usability, as a qualitative attribute, measures the degree to which user interfaces are easy to use (Nielsen, 2012). Therefore, usability of a system can refer to the quality of a user's experience when interacting with the system (usability.gov, 2013). A system that is usable is a system that enables the user to accomplish their goals in a “pleasurable, simple, effective manner” (Interaction Design Foundation, 2020).

In the design domain of Do-It-Yourself AT (DIY-AT), one can make use of two senses of usability. In the first sense, there is the usability of the instance of the AT itself. For instance, in the case of SAWS, this sense of usability means that the SAWS app is usable by the users of the system (a circle of users, a concept that is further developed in Chapter 4). The term *usability* in this sense means that, through the instantiation of the system, **writing** is afforded to the user in an effective manner. The term *effective* in this context means that the ability to configure the AT to the direct user of AT based on their abilities and knowledge is afforded. In the following sections, a short review of how (current) AT devices afford writing is provided.

In the second sense of the term *usability*, there is usability as it pertains to open-source development: for example, the SAWS codebase, alongside its support resources, is

to be shared as an open-source project. As explained in section 2.1.2, we identify a ‘design phenotype’ as a “conceptual design” that has many latent variations; that is, it is a conceptual design that has the potential to be customized for different users and use cases. Because of the high degree of customizability, SAWS also functions as a design phenotype. Thus, we want to ensure that the SAWS phenotype will be usable in both senses. Not only should the SAWS app be usable, but it should be able to be instantiated by the target users, and the open-source infrastructure provides the means and support resources to do so.

2.2.3 *Do-It-Yourself Assistive Technology (DIY-AT) and Open-Source (OS) AT*

There are several DIY/OS communities for Assistive Technologies. The ‘Open-Source Assistive Technology Software’ (OATS) repository, launched in 2006, was the first source code repository dedicated to AT software (S. Judge & Lysley, 2005; Nutter, 2006; “OATS,” 2016). This repository is currently defunct, and all the access points to it are broken. However, there are many communities existing and emerging, with a focus on co-creation and simplicity in open-source AT. Makey Access (*Makey Makey – Joylabz Official Makey Store*, n.d.), Thingiverse (*Thingiverse - Digital Designs for Physical Objects*, n.d.), and Makers Making Change (*Makers Making Change*, n.d.) are the most notable ones. These communities, alongside Github and other tools providing Git, share the characteristics of having a facility to collect feedback (e.g., regarding usability, customization process, etc.), and providing a means to keep track of issues, to maintain the systems, and to empower the community to redesign and to redeploy the systems.

However, there are knowledge barriers to entry to the open-source community. Some of these barriers to open-source adaptation, as reported by Nagy et al. (2010), are the “lack of awareness of software availability or relevance” and “technical knowledge needed to implement and use” open-source software. Therefore, not everyone can easily contribute to open-source projects, and a lot of newcomers give up contributing to open-source software projects (Steinmacher et al., 2014). If the direct users of ATs were to have the means to contribute, this would constitute a form of grassroots participatory design.

The need to share the process of AT design with UX experts and AT direct users in the DIY OS community was flagged as an important issue early on (Andreasen et al., 2006; Fitzgerald, 2004; Nichols & Twidale, 2006; Sack et al., 2006). And according to recent reports in the literature, there has not been much subsequent focus on the platforms for prototyping DIY-AT (Hamidi & Marcu, 2019).

2.2.3.1 *Enabling infrastructure for Open-Source Development*

Groupware is an umbrella term that, according to George (2003), refers to a class of computer software that facilitates the collective work of a group. The open-source software platforms (e.g., Github) function as a type of groupware, as they provide the grounds for collaboration of the contributors through offering version control, code management, and other functionalities. Therefore, the open-source infrastructure platforms can be considered a type of groupware, in which the users use the infrastructure as a group and the infrastructure facilitates the use by the group.

2.3 The Persona Method and the Design Process

Since this research project focuses on building the means for inclusion in the design of OS ATs, it is important to describe and discuss the persona method, which is the primary design method used to address this aspect.

A persona is a crucial design representation in the ideation and validation of design concepts (Cooper et al., 2014). In this section, I summarize the research literature: what persona representations are, how they are used, and why they are important in the process of design.

2.3.1 *Users and Stakeholders*

A *user* is a person “who uses a product, machine, or a service” (Cambridge University Press, n.d.). An end user is a person who is an actual user of the software system and defines the details of the software system (Pressman & Maxim, 2020).

A *stakeholder* is defined by Pressman & Maxim (2020) as anyone who benefits from the successful outcome of the project. Therefore, users of a project outcome are counted as part of the stakeholder constituency. However, the users may be excluded from the stakeholder constituency, which results in the focus of design being wrongly put on the needs of the stakeholders who are not the users of a system.

We use the term *direct user* to refer to an end user who directly uses the system, as opposed to other stakeholders who may not directly use the system, but participate in the process of use, support, and maintenance of the system.

2.3.2 Human Centered Design (HCD)

Although creativity can lead to breakthroughs in design, it is not always the case that a design process solely based on creativity will produce a satisfactory outcome. That is why it is very important to know the user, to see how they deal with their real-life situations and problems, and to capture this information in order to design for a more human-centered experience (Cooper et al., 2014). There is a need to bridge between designers' conceptual model of the users and the actual prospective users. *Scenarios* and *personas* are some of the representations used in UX design. The design processes necessarily need to make use of abstraction and archetypes when considering the population of potential users and the potential situations in which the system will be used. These archetypes — whether of users or situations — are developed to be these abstracted representations.

Not using these representations can mean not capturing insights that are based in the reality of the potential users and making design decisions that are not based on real user data. Not using these representations can lead to design pitfalls, which Cooper (2014) has enumerated as the elastic user, self-referential design, and edge case design.

2.3.2.1 The Elastic User

The concept of *the elastic user* is used to characterize the situation in which the idea of the users' needs and goals changes to adapt to what a design team member uses as reasons for decisions being made about the system. When there are no clear points of reference of who the users are (e.g., what they want and how they may behave or think), design team members have the power to bend the needs of the *imagined* user as needed (e.g., to back

up their ideas). For instance, this imagined user might be an expert sometimes, and a novice at other times. When this happens, the project could lead to a product outcome that is not based on real users of the system and therefore does not fit their needs. Cooper suggests that to avoid this, it is necessary to be specific about our users. The persona method is used to represent prospective users and to establish a common ground of understanding among the team members (Cooper, 1999; Cooper et al., 2014).

2.3.2.2 Self-Referential Design

Developers and designers tend to build products that they think will be right and will work according to their own perception of the user. But these perceptions can be inaccurate. Sometimes, the decision-makers tend to imagine themselves as the prospective users, and that these prospective users are like themselves. This can lead to a poor outcome (e.g., users not having a good experience using the product, such as not understanding how the system works or finding the system unfitting to their needs), all because the user's point of view was overshadowed by the decision makers' inaccurate assumptions (Cooper, 1999; Cooper et al., 2014).

2.3.2.3 Edge Cases

Inevitably, there will be some use cases that, while possible, are not likely to happen to most users of a system, the so-called *edge cases*. Although these situations should be considered and planned for, they should not be the focus of the design. It is easy to misplace the relative priority of the use cases on which the designers work. Not having a clear

understanding of the main goals and needs of the users, the team can be distracted by situations that might not be commonly happening (Cooper et al., 2014).

2.3.3 *The Persona Design Representation*

As described above, the design process necessarily needs to make use of abstraction and archetypes when considering the population of potential users. Many potential users will be similar to one another, at least with respect to some attributes. A design representation called a *persona* is a particular type of archetypical, abstracted representation of a group of similar users. A persona, in principle, can represent any stakeholder constituency (that is, any group of individuals who would be in some way affected by the system and should be considered in the process of design). However, personas are most often used to represent the group being targeted as the main users of the system.

The persona design representation is not meant to represent a specific real user. Rather, it represents an amalgamation of users, all with similar attributes. These attributes are commonly attributes such as goals, behaviors, and thoughts.

The concept of personas was first introduced in 1995, following the efforts of Alan Cooper and Wayne Greenwood, in response to the need for a tool to communicate design decisions to clients and to convey the user needs (Goodwin, 2009). Prior to this, Alan Cooper used a similar method known as proto persona, starting in 1983. In his proto-persona method, he tried to explain why he, as a user, would perform a certain task, what

he would know in the beginning of the task, and what he would find out as he goes on (Goodwin, 2009; Pruitt & Adlin, 2006).

In current practice, personas tend to be developed and employed in certain ways. Their development typically happens during the ‘discovery’ phase of the Double Diamond design process model (see Chapter 3 for a description of the 4 phases: Discover, Define, Develop, Deliver).

For the initial creation of personas, data is collected from various sources (e.g., from user observations, field research, other products and projects, user logs, etc.). Subsequently, the data is synthesized and analyzed, and commonalities and patterns in the data are extracted. The users are then grouped, mainly based on similar attributes, such as goals, behaviors, and thoughts, although these attributes also can include other attributes such as needs, stories, and basic demographics. Thus, personas are developed as representations of the attributes of empirically observed users, drawing upon the patterns found in the data collected from them during the research process. Through this process, the persona representation develops on real users’ lives, what they go through, and what they are doing or trying to do. Thus, personas are not ‘made up’ by the designers’ minds. Aggregating behavior patterns with the data collected from personas, a model demonstrating how “groups of users behave, how they think, what they want to accomplish, and why,” according to Cooper (2014).

The data analysis process potentially yields several clusters of users, for any of which a representative persona can be developed. From among these, one archetype is

identified by the design team to be considered as the primary focus, often referred to as the *primary* persona. Other personas are still important in the design process, with their needs and goals also being captured, but they are identified as *secondary* to the primary persona.

In current practice, the persona representation typically consists of the attributes that are the main characteristic of the group of users being represented (consisting of key goals, behaviors, and thoughts alongside some background information). As well, a pseudonym is chosen for the representation, which is a fictitious name that serves to personalize and identify the persona (Figure 2-2). Some representative quotes are usually included as well, as gathered from user data from the preceding research phases. The user quotes are thought to make the persona representation more relatable. The information within the persona representation is thought to help the team to understand the users and their points of view more deeply, alongside what they desire, what they want to accomplish, how they behave, and how they think (Cooper et al., 2014; Goodwin, 2009). A short story — usually called a *scenario* — is typically developed to accompany personas, to make them even more real and relatable. These stories include the human activities that allow “exploration and discussion of contexts, needs, and requirements” (Sharp et al., 2019).

Flora "Family Chef"



Housewife
Flora is 36 years old, mother of two kids (ages 8 and 10), fairly skilled, cooks most weekdays and occasional weekends. She is dedicated to her family and puts her children first. Needs to know an array of different dishes to keep kids interested. Flora has a small to midsize kitchen with enough appliances to cook most of the 'basics' and has about two or three general recipe books and a specialist one on healthy meals. She likes to provide healthy, nutritious and tasty meals for her family.

Goals
Flora wants to be appreciated by her family and have more variety in her cooking. In doing so she would like to make her regular meals look more interesting. She wants her family to eat together so they can bond better and in general she would like to be more social.

Where we can help

- Help her to more easily know about and access cooking related content on TV.
- Help her remember ideas and ingredients needed from TV cooking shows.
- Help her know she has bought everything she needs whilst shopping.
- Help her be aware of promotions and new grocery items (especially ones the kids will like) in store.
- Assist with planning meals around kid's schedule (possibly husbands as well).
- Help her be aware of kid's favourites, likes, dislikes etc, and reminders of these when cooking.
- Allow easy referral of recipe whilst cooking.
- Help her modify recipe based on friends comments or contact them for help whilst they are cooking.
- Monitor the cooking process if she is distracted by her kids, remind her what she was doing before being distracted.
- Allow her to share recipes and ideas with friends through quick uploading of pictures online.
- Help her remember what worked and what didn't in a meal.

Figure 2-2 A primary persona in Singapore for the design domain of cooking support.

2.3.3.1 Persona Template

Here we provide a template in form of a table of attribute-value pairs that can be used to model a persona (Table 2). The attributes used to define a persona may vary, depending on the needs of the field and templates used.

Attribute	Value
Persona Name	Moniker to identify the archetype and distinguish the archetype from other archetypes
Persona Picture	A picture representing the archetype, makes the archetype more memorable
Key Characteristics	Includes assembled background information for the archetype; type of information varies according to design domain
Story & Quotes	representative quotes, and stories
Key Goals	Goals that are relevant to the archetype and the design domain

Needs	The needs of the archetype to be able to achieve their goals
Other Tools	Other tools the archetype uses for similar needs

Table 2: Attribute-Value Pair Template for an Individual Persona

2.3.4 Benefits of Personas

Personas provide many benefits: avoiding design pitfalls, creating empathy, and supporting iteration within the design process.

2.3.4.1 Avoiding design pitfalls

The use of personas in the design process prevents the injection of designers' or developers' own goals and motivations into the process. As discussed in the subsection 2.3.1.1, when there are no fixed points of reference of how the real users of the system are, the expected needs of the user bends to what the team desires (the so-called 'elastic user'). The use of persona design representations also prevents misplacing the focus on edge scenarios. Relating and empathizing with users, and therefore understanding their goals and needs better helps to prevent the team from applying their assumptions to the design. The team uses personas instead as their point of reference for what will be the actual scenario of use, and therefore what needs to be done to achieve it.

2.3.4.2 Creating empathy

Personas are employed to create empathy. As opposed to raw data collected from users, a model like persona provides the grounds for better designers' understanding of the users

and empathizing with the way they behave in specific circumstances (Goodwin, 2009). Personas remind the people involved in the process of design and development of an artefact, that real users will be using the product. Being based on real user data and presenting it in the form of a hypothetical character, expressing their goals, acting in a particular pattern, and having their own thoughts, personas become personifications and can act as a powerful *part of the team* in the design process that the team can *relate* to and *empathize* with (Cooper et al., 2014). This is especially important in cases where the users cannot be directly involved in the process of design (Hamidi et al., 2017; Matthews et al., 2011). Storytelling is afforded through using personas as a data representation model. This engages the emotional and social aspects of our brains, making this tool more relatable. As a result, it becomes easier to understand and incorporate users' goals in the design, in comparison to other forms of delivering information (Goodwin, 2009). A persona provides a summary of the research data, in a form that makes users memorable (Nielsen Norman Group, n.d.; Pruitt & Adlin, 2006), and provides the grounds for relatable communication in a common language that all the team members can understand.

Personas have been shown to facilitate and improve communication (Cooper et al., 2014). Through the narration of a scenario that is happening to a persona, design decisions can be communicated, discussed, analyzed, and made. Thus, personas can be considered as a means of communication for people included in the process of design and development of an artefact (Cooper et al., 2014).

2.3.4.3 *Supporting iteration within the design process*

Personas have been shown to support iteration with the design process (Colquhoun et al., 2014). Personas allow the possibility of “test driving” ideas. Through the use of personas and scenarios, team members can see if the design concepts are valid and assess the degree to which the decisions being made address the goals of the users. The team uses personas as their point of reference for what will be the actual scenario of use, and therefore what needs to be done to achieve it. This has been described by Alan Cooper as the “predictive powers” of personas (Cooper et al., 2014; Goodwin, 2009). The use of personas certainly cannot replace the need for testing the system with real users, but they are regarded as a useful and effective measure for decisions made in the process of design, in a quick and inexpensive way (Cooper et al., 2014).

2.3.5 *Critiques and Shortcomings of (Individual) Personas*

Several critiques have been made about the use of persona design representations in the Interaction Design research literature.

One issue in critique concerns the validity of individualization. The principle is that a persona is an archetypical individual representative or prototypical of a group of similar individuals, and as such, a persona should resonate with all individuals within the group. However, in many domains, technological artefacts are used not on an individual basis, but rather on a group basis. An example would be a learning management system used in a group-based course, where students must form small groups to work on their projects. In this example, the student groups can be seen as one entity that works with the system, logs

in, views course material, communicates with the teaching team, and submits work as a group. Therefore, the design should consider the group's interactions and collaboration style to be able to support them in achieving their group goals. There are cases in which the goals, behaviors, and thoughts of a group, using the system together, are so related and intertwined that they can be considered as one entity to design and build products for. In fact, looking at the people as individuals and trying to focus on their individual goals, behaviors, and thoughts without considering their emergent attributes (e.g., their goals as a group, how they interact with each other and work together, etc.) can obscure really valuable data and lead to an outcome not quite fitting the needs of people for whom they are targeted.

Matthews et al. (2011), in focusing on groups of people working together in organizational settings (medium to large companies), argued that individual personas fail to reflect the collaborative aspects of the members of a group. In designing for organizational settings, they argue for the importance of understanding a number of relational aspects: the interactions among the users (e.g., as contributors to a project), their collective goals, the tools they use to collaborate, their management style, and more generally, their methods of collaboration. These aspects cannot be fully captured in individual personas, in which the focus is on the goals, behaviors, and thoughts of individuals and in which there is little attention to the interactions these individuals have with other contributors and their position in groups (Matthews et al., 2011).

Matthews et al. (2011) also argue that the task of choosing a representative persona as the primary persona among the individual personas is problematic, as none of the individual personas can truly reflect the group characteristics.

Cooper et al. (2014) also identified the need to consider social relationships between personas and the difficulties in representing these relationships. They claimed that representing social relationships between sets of personas can be easier than representing such relationships between individual personas.

2.4 Group Personas

In many scenarios, a goal is held and achieved collectively by a group of people rather than on an individual basis. For example, an organization working on an outsourced part of a system uses a panel to communicate the project requirements with the outsourcing company. The design of interventions (e.g., supports, solutions, aids, tools and so) in these domains is different than the design of interventions for individual use. When designing in these domains, the focus needs to move away from individual-oriented interventions towards group-oriented interventions. Thus, instead of focusing solely on the attributes of the individuals in the group, there is the need to capture the attributes of the group working together. Moreover, analogously to the individual personas, we seek to develop archetypes at the group level.

The research literature contains several proposals for personas that represent group-level attributes, such as the collective goals, behaviors, and thoughts of groups of people working together using a product or interactive system.

2.4.1 Early Work

Pruitt & Adlin (2006) reported on the unpublished work of Tammy Snow and her team as early efforts in this direction, who used ‘organizational archetypes’ to describe the needs and goals of IT teams in big organizations working with Windows Servers. They created the organizational archetypes to describe the needs, and goals of the IT teams in organizations using the Windows Server, rather than the individuals on the teams. Individuals from different companies might not have a say in choosing and using the systems, and sometimes are not even stable members of the team. Therefore, focusing on the individual characteristics of the people on the teams would have brought irrelevant information to the design. Whereas by portraying them as groups, the design can focus on more important information (e.g., the group interactions between the IT teams from organizations and the Windows Server).

The early Interaction Design ‘grey’ literature³ contains anecdotal accounts mentioning the need for group personas, for instance, Kuniavsky (2004) narrates the process his team went through in a workshop to design a piece of personal technology in a European amusement park. They noticed that all their scenarios consisted of a group of people (e.g., a family or a group of friends coming to the amusement park) making

³ Literature that is not published or distributed through traditional channels is considered as grey literature. Examples include reports, documents, etc. on the websites of organizations or the government (McKenzie, 2022).

decisions and acting as one entity. As a result, they grouped the users with the same group goals into a group persona. They found out that aggregating individual personas into group personas can prevent the distraction of the design team members to irrelevant individual details.

2.4.2 Collaboration Personas

Perhaps the most notable model of group personas suggested is “Collaboration Personas” by Matthews et al (2011). They proposed an approach to group personas as an alternative to conventional individual personas, focusing on the collaboration dynamics between the members of the group. They argue that the collaboration persona method is necessary to guide the design of workplace collaboration tools, to think through the ‘pain points’ of the group’s joint activities, and to think through and to anticipate issues of adoption and use.

The new design representation tool proposed by Matthews et al. (2011)— called *collaboration personas* — captures four key attributes: goals and three characteristics additional to goals in order to characterize the interactions and dynamics in a group: working style, type of leadership within the group, and stability of the group membership.

As stated earlier, the main attribute in forming personas is user’s goal(s). Matthews et al. (2011) recognized that there will be overlaps or commonalities among all the goals of the individuals within groups in certain organizational settings (they focused specifically on the organization settings of medium to large companies). They identify the goals that are common to the group members to be the group’s *archetypical* goals.

They elaborated that although the group's archetypical goals are important, some of the individual goals that are in alignment with the collective goals of the group can also be considered in building collaboration personas (Matthews et al., 2011). For example, when people on a group formed to win a customer sale (group goal) are personally motivated to do a good job so that they can establish their reputation and enhance their future sales opportunities (individual goals).

Matthews et al. (2011) argue that in order to preserve the power of the persona representation, the representations cannot solely be based on goals. They introduce three characteristics additional to goals to characterize the interactions and dynamics in a group: working style, type of leadership within the group, and stability of the group membership.

Matthews et al. (2011) argue that people working in collaborative groups have one of these different working styles: the 'pooling work' style (members work independently then merge their work); the 'co-creating' style (members collectively deliver the deliverables by working closely together); and the 'communication-focused' style (where members' work delivery is not dependent on others' and they only collaborate to share information or maintain relationships).

The type of leadership in collaborative groups refers to how and by whom the decisions are made. Two styles were identified: these groups can be run democratically or have designated leader(s) for making the decisions (Matthews et al., 2011).

With respect to the attribute of the stability of the group membership, Matthews et al. (2011) point out that the members of a group may not be stable overtime and thus, the

group membership may be dynamic. Despite this, they argue that the group's goals are almost always stable over time and through group changes. This assumption of stability is helpful to the design process. For instance, if individual personas were to be used, then the goals and behaviors of each member of a team as an individual might be swapped out at any time by a new member, leading to the need to revisit the individual persona. In fact, in their model, the stability/dynamicity of the members is one of the important characteristics of a group that should be considered in the process of design and therefore when building personas (Matthews et al., 2011).

2.4.2.1 Primary and Secondary Personas in Collaboration Personas

As Matthews et al. (2011) point out, the goal of personas is to guide design. And with collaboration personas, the possibility remains (just as with individual personas), that there can be a primary collaboration persona (i.e., the groups that are envisioned as the primary users of the groupware being developed), as well as secondary collaboration personas. Matthews et al. argue that the use of collaboration personas can bring into focus the neglected user groups like communities as secondary collaboration personas.

2.4.3 Organizational Personas

Cooper (2014) suggests a model of aggregated personas he calls *organizational personas*. They are an aggregation of the individual personas of the members of an organization, considered alongside the goals and behaviors of the organization. Cooper claimed these aggregated personas to be representative of organizations and social units, and he also

mentions the possibility of aggregated personas to be representative of other social units, such as families as well (although detail is lacking).

2.4.4 Discussion: Offerings of Group Personas

The research literature indicates that group personas offers several benefits over conventional individual personas. Judge et al. (2012) conducted a comparative study reporting that Collaboration Personas are preferred to Individual Personas by design and user experience practitioners.

In cases where users work in groups towards certain goals (e.g., in companies and organizations), the entity being studied, modeled, and designed for should be a group. If we were to model user data using individual personas in such cases, numerous different personas would need to be created, to adequately reflect the team members (since there are different goals, personalities, needs, concerns). In addition to this, the use of individual personas for group-based systems raises other problems. The first is choosing the primary persona that is representative of all different group members. Since the primary persona will be the focus of the design, other people in the group with their goals which might be just as important will be marginalized or overlooked in the design process. Basing the focus of design on one primary individual persona can also lead to the misrepresentation of group goals, as the design is solely focused on one persona's goals, not the group's collective goals (Matthews et al., 2011).

Another issue would be the potential for the design to be misfocused on non-relevant information about each member of the team, as opposed to the group's collective goals. This could potentially lead to edge scenarios (as described in 2.3.2.3).

Additionally, as pointed out earlier, some of the characteristics at the group level (e.g., the interactions between the group members, collaboration style, etc.) may get underrepresented or overlooked completely when using the conventional persona tool. This is unsurprising, considering that the conventional persona tool is originally designed to represent individuals. Analyzing users in groups provides the chance to focus on group interactions between the group members and their way of collaboration (Matthews et al., 2011).

Through thinking about these issues, the use of the individual persona representations may not be well suited in design processes for groupware. Modeling the user data as a group rather than modeling it on an individual basis helps to focus the design process appropriately.

Using group personas to model the groups also helps to mitigate the challenges of groups that are not the primary focus of design (like communities) by making room for them as secondary group personas (Matthews et al., 2011).

2.5 Research Question, Restatement

The central question of this research project, as articulated initially in Chapter 1, is “How can we create more inclusion in open-source AT?”

After completing the literature review, we see that there is an important dimension in open-source AT that concerns representation and inclusion: (i) content inclusion (who gets represented and how?) and (ii) process inclusion (who gets to be part of the open-source community). The literature review discusses issues with the design process, barriers to entry in the design process, and barriers to entry into open-source development projects (section 2.2.1, 2.2.2, 2.2.32.2.1).

The literature review shows that, when adopted for AT, the conventional design processes fail to incorporate and consider the needs and wants of people with impairments (section 2.2.1). Part of this is due to how people with impairments get involved and represented in the design process (subsection 2.2.1). As a result, the commercial AT produced through these design processes often fails to adapt to the unique and changing needs of people with impairments and thus gets abandoned (subsection 2.2.1). Open-source community makes use of the collective talents of the community to co-create and can help to reduce the costs of adaptation of AT (section 2.2). However, design and usability in open-source communities are gravely neglected (subsection 2.2.2).

The literature review has demonstrated the importance of personas as a design representation. The literature review demonstrates that personas are the primary design representation in current common practices for capturing and reflecting user needs (subsections 2.2.3, 2.2.4, and 2.3.4). The literature review also demonstrates that individual personas often fail to represent group-level dynamics and group needs adequately when the users are operating in group scenarios of use (sections 2.3 and 2.4).

Design representations are the means to aid the cognitive processes of people involved in the design process, and, thus, they play an essential role in how design tasks get carried out. They also carry much information about the design process, which, if made explicit and documented as part of the design outcomes, can be helpful to future designers to maintain and enhance the design.

Design representations can also pave the way for more inclusion of people in the design process. Engagement of people in creating design representations has a lower barrier than engaging people in crafting source code. By creating the means that allows for including people in making design representations and applying their feedback, needs and concerns iteratively, we can move towards a more inclusive human-centered design process.

Thus, with the information gathered from the literature review, we see the importance not only of the content of persona representations, but also how personas are constructed and revised.

Thus, the central question of this research project can be refined as follows “How can persona representations be leveraged into open-source AT in order to build inclusion?”

3 Methodology/Approach

As established in Chapter 2, we seek to answer this question: “How do we bring persona representations (as one particular component of a HCD approach) to open-source AT and how do we build inclusion in open-source AT through persona representations?”

If we were to conduct the SAWS case study according to the current practice, the same faulty results would have been reproduced. Therefore, the shortcomings and challenges of the current tools and techniques regarding how people are presented in the design process need to be investigated.

As a result of this acknowledgement, we needed to employ an approach that allows us to explore novel ways of representing people and increasing their involvement in the design process. Therefore, Research through Design was chosen as the leading approach in this research project.

3.1 Research Through Design

Research through Design (RtD) is “an approach to conducting scholarly research that employs the methods, practices, and processes of design practice with the intention of generating new knowledge” (Olson & Kellogg, 2014). RtD is the practice of conducting research through a design project. This means it employs a design process as its primary approach to framing and conducting experimental work as a means of researching the problem space. RtD takes advantage of the design process to investigate and answer the research question. Most successful design processes consist of a common pattern of four

to five main activities that can guide how to investigate the problem space and explore solutions. No process is established as best practice by consensus (Design Council, 2007). As well, the RtD approach includes a reflection piece.

Knowledge in the process of RtD is generated and then disseminated to other knowledge users, who consist primarily of other investigators (design and other researchers) who are engaged in the same design domain. This knowledge is mainly communicated through two means. The first is through the creation and sharing of prototypes (Stappers, 2007; Stappers & Giaccardi, n.d.). These are direct outputs from the design process. The second means is through other forms of design knowledge outcomes, such as the field data collected, observations and insights, records of how the project found its way (process, challenges, breakthroughs), and discussions of the chosen and dismissed alternatives. These other forms of design knowledge outcomes are potentially helpful to future researchers and designers in their investigations of design possibilities and thus should be recorded and documented. In section 3.3, we will explain the method used to document the design knowledge outcomes in this project, but first the Double Diamond Design Process Model will be discussed in more detail.

3.2 Double Diamond Design Process Model

We will employ the Double Diamond Design Process Model as our base process model to be followed for the process of design in RtD.

The Double Diamond Design Process Model was first articulated by the Design Council of the United Kingdom, alongside principles and methods as their framework for

innovation (Design Council, 2015). The process model consists of four phases, which are in alignment with the philosophy of user-centered (and by extension, human-centered⁴) design (Sharp et al., 2019): a focus on people in each phase of the design process, basing design decisions on empirical evidence, and iteration as a means to improve the design as it receives more understanding of people.

The four phases are organized into two diamonds, where each diamond involves both a phase of divergence, in which the options are explored, and a phase of convergence towards a focused decision (Design Council, 2015). These diamonds are illustrated in Figure 3-1.

The four phases (Design Council, 2015) over which the Double Diamond iterates are:

Discover: Designers research the problem space; try to understand the people by observing them, taking insights from them, finding out about their needs and goals; and possible opportunities. Subsequently, designers use design representations (among them personas and user scenarios) as a tool to model user data (subsection 2.3.2).

Define: The designers define the challenge through the design brief using the insights gathered in the discovery phase.

⁴ The field is starting to recognize that the term user is discursively constructed and is focusing on the abilities of the people regarding the “use” of a specific piece of technology, whereas people can go beyond that by “building, modifying, maintaining, repairing, reusing, and repurposing” (Roedl et al., 2015).

Develop: In search for answers that work, designers collaborate with people or use the design representations such as personas as advocates for people to explore possible solutions and co-create prototypes.

Deliver: Design team members test and analyze the solutions at small-scale with the help of the design representations like personas (section 2.3.4.3). Eventually, the design outcomes get tested with people. Through this process, the designers find out which solutions work and refine the final solution (what fits the needs of people the best) in response to the design brief.

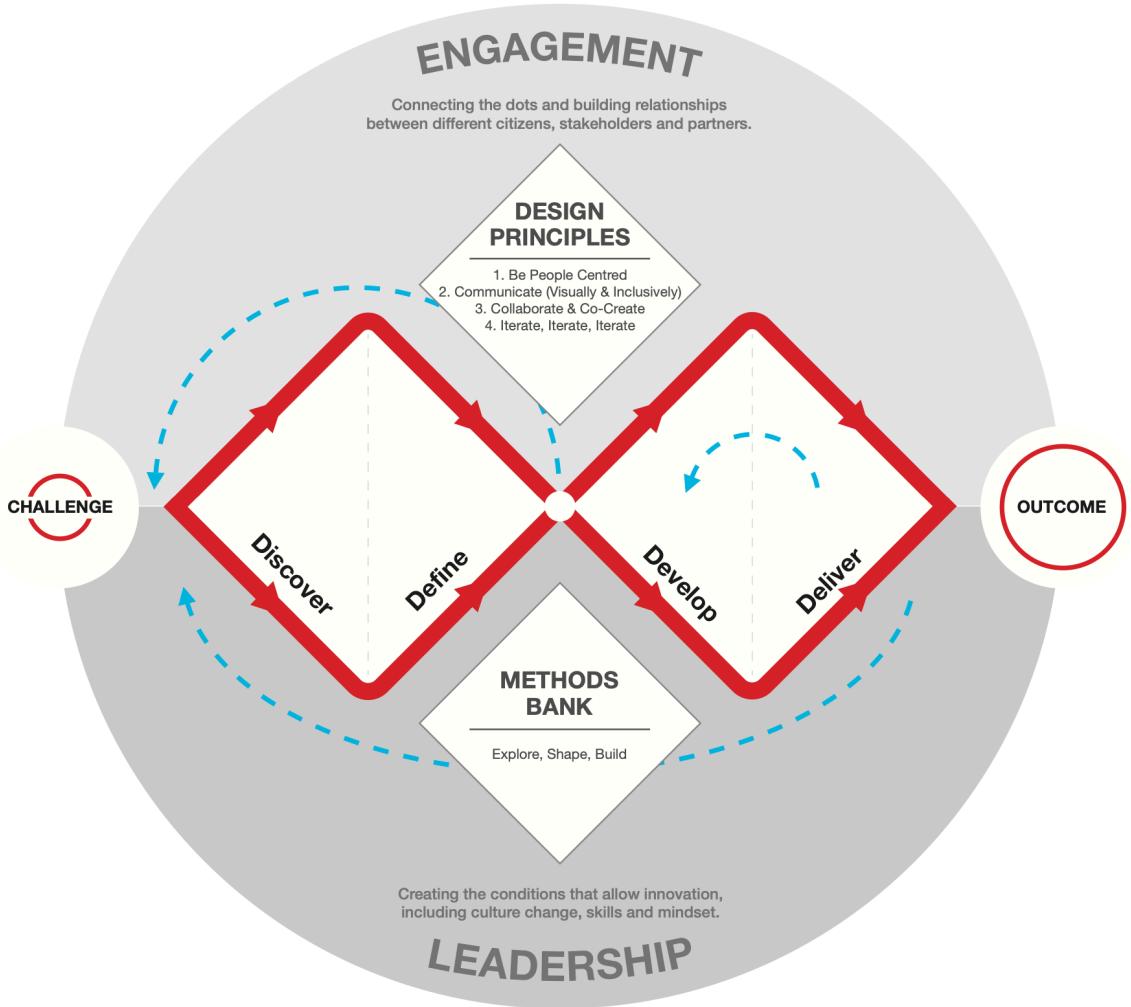


Figure 3-1 Overview of the Double Diamond Design Process Model, demonstrated phases of divergence and convergence.

3.3 RtD Documentation: The Workbook Technique

Several methods for documenting the design process have been described in the design literature, including workbooks, journals, project management systems, papers, and annotated portfolios (Bardzell et al., 2016; B. Gaver & Bowers, 2012; W. Gaver, 2011).

In fact, any means of documenting the design process can also serve a role in RtD, but these means are not attuned to RtD specifically.

One of the main methods of documentation specifically used to document the process of RtD and its knowledge outcomes is the workbook technique, first introduced by Gaver (Bardzell et al., 2016; W. Gaver, 2011). According to Gaver (2011), workbooks are “collections of design proposals and other materials drawn together during projects to investigate options for design.” He considers workbooks to be an excellent technique for recording the design process as the design ideas and artefacts develop over time, since the technique requires the inclusion of proposed ideas, obstacles encountered, the decisions made, the alternatives taken, and the design artefacts created. Since workbooks develop over the perspectives of the people involved in the design and their reflections and elaborations on the design ideas, they “can support a quasi-participatory design approach”. Therefore, they are an appropriate tool to be used to document the knowledge outputs of the RtD process. We have elected to use the workbook technique in this project.

3.4 Rationale for Using RtD

To select the approach to conduct our research, we considered as important factors the following: the methodology’s capability to investigate design opportunities, to engage the people who will be using the system, and to support broad knowledge production. In this section, I will explain why RtD addresses these factors.

As stated earlier, in this research project, we are seeking appropriate design tools and methods in the field to increase inclusivity and move towards a more Human-Centred

Approach for open-source AT. Hence, the nature of the problem requires an open inquiry in the design space for better solutions. The process of design and its outcomes, including prototypes and their iterative production, the observations of people interacting with them, and the insights elicited during the process, pave the way to the discovery of new challenges, breakthroughs, and design possibilities. RtD uses design process to frame the research experiments exploring the design possibilities, and thus supports research and knowledge production.

Moreover, RtD provides the means to include stakeholders' perspectives, by incorporating and reflecting their feedback and insights in the process of the development of prototypes. Their involvement can result in a more human-centered design outcome.

Finally, as stated earlier (sections 1.4, 2.2.1, 2.2.2), we aim to share the design ideas, process, and prototypes to the open-source community to be used and enhanced by designers and usability experts. The insights, breakthroughs, and difficulties faced on the way of design, recorded in the workbook, will help the open-source community to get a better understanding of the situation of the project, the decisions made, and the possibilities for alterations and enhancement of the system. Therefore, a methodology like RtD is needed that documents the path taken as part of its knowledge outcome.

In addition to these factors, previous research in the domain of assistive technology has been conducted using the RtD methodology (Hamidi, 2015; Hamidi et al., 2017). Therefore, for these reasons, RtD is a suitable methodology to conduct this research project.

4 Iterative Design; Discover, Define, Develop, Analysis

In this chapter, we will recap the iterations we went through in our project for prototyping the personas. As established in 2.3, personas are an important tool in the process of design that model the user data better to be used to evaluate and validate the design ideas.

As described in Chapter 3 Methodology, we are employing RtD, which entails the practice of conducting research through a design project, which is the primary approach to frame and investigate the problem space. Chapter 3 also described the Double Diamond approach. In this chapter, we describe several iterations of this design process.

The detailed process, alongside personas, are provided in the workbook. The workbook of our design process can be reached at SAWS website⁵. However, we will review the iterative steps taken in this chapter; the research conducted, the prototypes created, and the analysis and evaluations done on the outcome.

The anticipated outcome of this design process is a design intervention that will consist of concrete steps and tools for bringing persona representations into the open-source AT community and building inclusion in open-source AT through these representations (section 2.5). We envision Open-Source SAWS (OSSAWS) and the anticipated emergent open-source AT community that will arise around it as a case study for the design intervention that is developed in this RtD approach.

⁵ <http://saws.eecs.yorku.ca>

4.1 First Iteration

4.1.1 *Discover/Define*

As described in section 3.2, the purpose of Discover/Define steps is to research the problem space and to define the challenge (typically through the design brief). The content presented in the introductory chapter of this thesis captures the fuzzy-front end of the design process, which formed around the question of how to build inclusion in open-source AT.

The fuzzy-front end transitioned into a discover phase, which we carried out via the literature review discussed in Chapter 2. There are many facets to the lack of inclusion in open-source AT, such as knowledge and attitudinal barriers for those who are not part of the open-source AT community. As well, there are subtle and unconscious knowledge and attitudinal barriers for those who are part of the open-source AT community, in connection to the conceptions that are being held about the target users of ATs and the design domain. At the conclusion of the first iteration of the Discover phase, we assembled strong evidence that the representations used throughout the design process, and the persona design representation, in particular, plays a key role in the conception and subsequent representation of the target users of ATs. As well, we assembled strong evidence that transition from individual to group persona rectified some of the representational shortcomings of individual personas in complex design domains, but representation remains an on-going issue.

Therefore, we define the key challenge as one of representation:

4.1.1.1 *Challenge Brief (v.1)*

How can persona representations be leveraged into open-source AT in order to build inclusion?

4.1.2 *Develop, first iteration*

As a starting place to developing a response to the challenge brief, we undertook several steps, summarized here and each described in more detail below in sub-sections.

- First, we sought to establish the ‘groupware’ aspects of open-source AT design and development (section 4.1.2.1). We show below that the open-source software infrastructure and the social infrastructure for Open-Source SAWS (OSSAWS) functions as a de facto groupware interactive system and, as such, has users.
- Given that we want to develop a design intervention into this ‘groupware’ context, and given that particular target mode of intervention is through design representation (and specifically the persona representations), we will begin by analyzing the current and/or target potential users of this ‘groupware’ and by deciding on which modelling approach to use: first, we will model the OSSAWS users using the conventional individual persona technique that was first described in section 2.3.2 (section 4.1.2.2).
- Before populating the personas with content, we first consider the issue of assessing the adequacy of persona representations, with an initial focus on these individual persona representations. We anticipate the shortcoming of individual personas for groupware design domains, but we follow this approach to use the assessment as the

basis for reflecting upon and developing revisions to the individual persona representation (section 4.1.2.3).

- We then populate the archetypes with content from the OSSAWS domain (section 4.1.4.1)

The Develop phase is wrapped up with a discussion (section 4.1.4.2) and a summary overview (section 4.1.4.3).

4.1.2.1 *Open-Source AT Infrastructure for OSSAWS*

I am using the term Open-Source SAWS (OSSAWS) to refer to the open-source infrastructure for innovating SAWS. This infrastructure shares the SAWS code-base alongside its support resources (including the design outputs of the RtD process), to provide the grounds for connection and collaboration of contributors with different expertise and experiences. The open-source infrastructure for OSSAWS operates as a de facto groupware (section 2.2.3.1) for innovation.

As the most popular open-source software platform (2020), Github will be the main platform for sharing the code-base for OSSAWS. Furthermore, a supporting website is being created through which the design outputs of the RtD process (e.g., workbook) will be shared. This website will also perform as a hub for the users and the open-source contributors to connect, ideate, share their experiences, and/or provide feedback. When necessary, other online groupware platforms will be used, such as Figma, the links to which can be accessed through the supporting website.

Different instances of SAWS get designed and instantiated from the phenotype SAWS on the OSSAWS infrastructure. Eventually, there may be several OS AT infrastructures that become active if the initial repository of OSSAWS gets forked by different communities. These OS AT infrastructures potentially can function as groupware for innovation of other types of AT, through which the AT phenotypes are shared, and specific instances of AT get designed and developed from the shared phenotype.

As indicated in section 2.2.2, the decisions in the open-source software community are dominantly made by people with software skills. This has been depicted earlier through the onion model (Table 3) introduced by Rajanen and Iivari (2015).

Layer	Description
Core	a person (or a few people) who is (are) the ultimate decision makers
Middle	committers who contribute to the project with the approval of the core
Outer	usability experts alongside the end users, who have very little to no power in the process of decision making

Table 3: Onion model by Rajanen and Iivari (2015) representing levels of involvement with an Open-Source Software Community.

As explained in section 2.2.2, this way of decision-making results in poor usability of the open-source software outcomes. The process of design of OS AT needs to be more inclusive. And thus, there should be a way for people in addition to those with software skills to participate. To combat the barriers to entry to OS AT (section 2.2.3), it will be important that points of inclusion must be created. I intend to model the users of OSSAWS as a way to identify these potential points of inclusion.

4.1.2.2 Modeling of the potential users of OSSAWS

In this step, we focused on gathering and using data about the potential users of OSSAWS, with the goal of following the persona development techniques described in section 2.3.3.

In this step, we paid particular attention to goals.

First, we focus on investigating the users of **specific instances of AT**. We adopted a broad perspective of ‘use’ (section 2.2.2.1, 2.2.2.1). Specific instances of AT resemble groupware in some respects, and especially so for SAWS, which has the complex configuration step. We observed that people who ‘use’ specific instances of AT fall into these main categories:

- **Direct user:** those who use particular instances of the ‘SAWS phenotype’ for writing (SAWS users),
- **Close circle user:** those who are in close contact with the direct user and who participate in the process of acquiring, learning, configuring, and maintaining the system

We observed that all of these ‘users’ can be envisioned as a *community of use*. The direct user can be thought of as being at the heart of the community of use: the person with deaf-blindness and motor impairments whose main goal is to use the OSSAWS instance for writing. We define the ‘close circle’ of direct user as an assemblage of ‘helpers’: people who are close to the direct user and who participate in the process of acquiring the system (as well as learning, maintaining, etc.). The close circle can include the direct

user's intervenor, close family members, friends, and/or other people close to the direct user who are involved in the process of use of the OSSAWS instance.

Regarding the discussion of process inclusion, it is important to notice that the direct users of OSSAWS and their close circle, and more generally the users of specific instances of AT have important experience and expertise in use of AT that their ideas can be helpful in coming up with grassroot solutions to the everyday issues, a kind of expertise and experience that others might not have. Therefore, they have a lot to contribute to the design process of AT and should be included in the process.

Next, we turn our attention to investigating the users of OSSAWS, which is the groupware that functions as a ‘groupware for innovation’. Also, we could focus on modelling the status quo (e.g., current users of open-source infrastructure), we instead focus on building the aspirational model --- that is, the model of the users who we hope will become the users of the groupware for innovation. In this way, we adopt a broad perspective of the potential use of this groupware. We feel that people who will constitute the future users of OSSAWS will fall into these main categories:

- **Category A: Direct users:** those with lived experience and expertise as direct users of Assistive Technologies, who are motivated to engage in co-design
- **Category B: Close circle users:** those with lived experience and expertise gained from being in close contact with direct users and from acquiring,

learning, configuring, and maintaining the system, who are motivated to engage in co-design

- **Category C: Helpers ‘users’:** those with other forms of expertise (software and UX design), who are motivated to engage in co-design. They are users of the Open-Source Infrastructure more generally, and thus are OSSAWS users.

In our analysis of user data (the origin of the data is explained in 4.1.2.2.1) we see two main trends in the adoption of SAWS or similar assistive technologies by the families. First trend will be the families that collectively and together can manage to download, install, and set up the system by themselves. Another would be the families that might need help in acquiring the system; downloading it, installing it, setting it up, and later learning how to use it.

As established in section 2.2.1, there is a need for a higher focus on the design of the Assistive Technologies to be tailored to the needs of the users. This focus on design requires expertise in the design and its processes and techniques from the product team. And as explained in 2.2.2 a common problem with the design in the open-source community is the lack of people with expertise in usability and user experience design. The current state of the open-source communities overlooks design and excludes usability experts and UX designers as decision-makers. Therefore, it is necessary to include the UX designers and usability experts as decision-makers in the open-source AT design domain to both complement the contributors with software expertise and to

advocate for the users. We envision that all three types of OSSAWS users will work together, to help to maintain and to improve the OSSAWS and to provide support and resources.

We next will build one or more archetypes (individual persona representations) for these three categories of OSSAWS users, as per the persona method described in section 2.3. In the subsequent design iteration, we will expand out the persona representation with further modelling of the group dynamics.

We expect that these categories to be generalizable in the domain of open-source AT. Additionally, we envision the need for persona representations of direct users and their close circle in the AT design domain, and the need for persona representations of direct users, close circles, and the helpers in the open-source AT design domain.

4.1.2.2.1 Data Gathering and Observations

According to Cooper (2014), personas are primarily created through qualitative research, especially observations from a product's users. Cooper (2014) suggests obtaining additional data and research from subject matter experts, stakeholders, and the literature available to fill in the gaps in data.

The data used in this project is diffuse and includes observations, field notes, videos, anecdotes for gray literature sources (e.g., sources which contain discussions about disabilities), and primary data as reported in scientific journals.

The most important component of this set of data are the observations drawn from M's case study. Her family sent several videos. Some videos showed M and her intervenor

working with the SAWS system. Other videos showed M and her intervenor talking about her concerns, problems, and needs. Qualitative field notes were taken from these videos. A series of in-person data collection and observations sessions were planned, but unfortunately, due to the situation caused by COVID-19, a redesign of the research project was needed to move away from these forms of data collection. During the outbreak of COVID-19 in Canada, contact was lost with M's family, for unknown but probably completely understandable reasons. The situation dictated a redesign of the research project.

Other research projects focused on the design of ATs in general and designing for and with people with deaf-blindness were also examined and used as the basis for analysis of the data in this field (Caporusso, 2008; DeafBlind Ontario Services, 2019; Hamidi & Marcu, 2019; Korn et al., 2018; Meissner et al., 2017; Okerlund & Wilson, 2019; Plaisier & Kappers, 2021; Theil, Buchweitz, Fuentes, et al., 2020).

4.1.2.2 Persona Creation Process

We created personas mainly following the current practice discussed in section 2.3.3. This process is shown in Figure 4-1 which in summary involves phases of research, finding trends and patterns in the data collected, identifying the main goals and characteristics of users belonging to different trends, and creating personas based on the trends found in data.

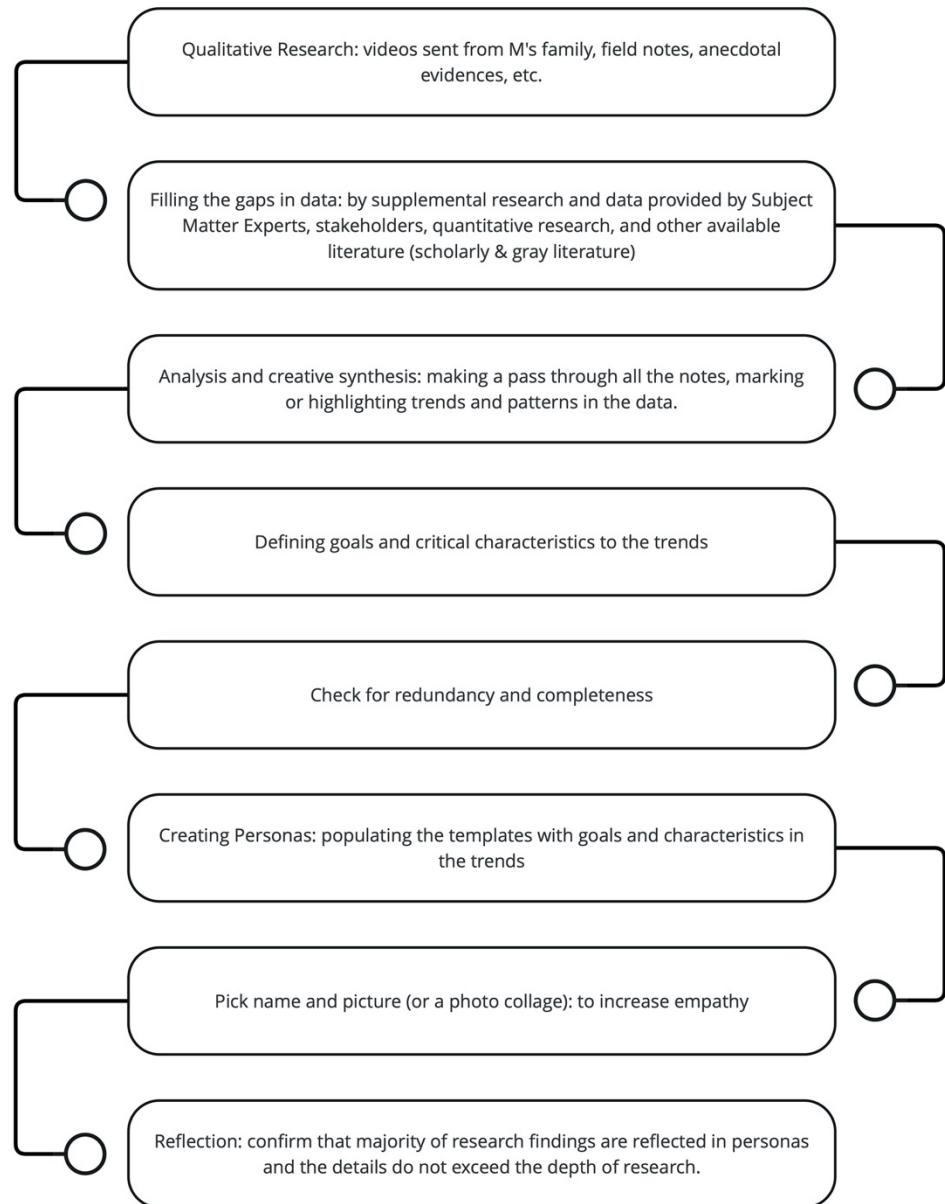


Figure 4-1 Persona Creation Process

4.1.2.3 Design Concept Evaluation Criteria: Assessing the Adequacy of a Persona Representation

Before constructing the individual persona representations, we asked ourselves: to what extent can this type of design representation capture the needs of the users of OSSAWS? To operationalize the concept of the adequacy of a particular design representation, we decided to employ a criteria-based approach. We understood that the development of the criteria was likely to be iterative, as the RtD process is designed to generate insights through the reflection components. The initial set of criteria that we developed includes:

Criteria for Evaluation of Response to Challenge Brief (v.1)		
Identifier	Criterion	Description
C1.1	Granularity	The representation has a suitable level of granularity. The archetype is not constructed too broadly, meaning important distinctions are not being captured (the archetype could be sub-divided into different archetypes). The archetype is not constructed too narrowly, meaning the distinctions between different archetypes are not salient (two or more archetypes could be collapsed and merged).
C1.2	Goal Capture	The representation captures all the goals that are important to the archetype, as they pertain to the design domain.
C1.3	Salient Characteristics Capture	The representation captures all the characteristics that are important to the archetype, as they pertain to the design domain.
C1.4	Inclusion	The representation serves to increase inclusion. There are two aspects: content inclusion (who gets represented within the design process and how?) and (ii) process inclusion (who gets to be part of the open-source community?). For content inclusion, this criterion assesses the degree to which the persona representation can capture the barriers to inclusion and/or the particular characteristics of the archetype upon which inclusion is based. For process inclusion,

		this criterion assesses the persona representation itself is a vehicle for inclusion.
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A persona, as described in chapter 2, is a hypothesized archetype. An archetype can represent a group of similar individuals --- direct users of a system or any other entity affected by the system. A key element of a persona is the persona goals. To establish the personas, one must look for patterns in the data collected and try to group the individuals based on the patterns found, with a particular focus on goals.

The personas in this step are built according to the template provided in section 2.3.3.1.

4.1.3 Design Concept

The Challenge Brief (v.1) identified at the end of Section 4.1.1 was as follows: How can persona representations be leveraged into open-source AT in order to build inclusion?

To respond to this challenge, I first investigate the utility of using individual personas as the design concept. To address the aspect of open-source AT, I extended the design concept to include the use of markdown and the use of a standard persona template to structure the markdown content. This template has been termed the “OS AT Persona Template”. I used the design concept to instantiate a set of 10 personas. This set serves as the representation of the archetypes of potential future contributors to OSSAWS.

The Open-Source *persona representation* template is next described. The template is meant to be shareable and suitable for inclusion in any code repository. The template instances, once populated with content, would be included in the same repository as the code base. In the case of OSSAWS, the populated templates would be included, under the

category of support resources, in the same repository as the SAWS codebase. The template must afford the ability to be easily altered and to have their changes track over time (e.g., via a “Git diff”). This is important because the persona representations for a software app are expected to persist throughout the life cycle of the project (even if aspects of the representations get revised, which is the case for OSSAWS). Therefore, I decided to make a template that provides said affordances.

For the SAWS domain, in particular, the persona representations need to carry important information, both for the direct user and for the close circle users. This information can inform the design of SAWS to afford better usability, particularly on the configuration parameters that are needed and the configuration steps that are required. Therefore, it is pivotal to capture the characteristics of the direct user and the close circle users in form of personas and share them in the support resources.

The characteristics represented in the persona representation at this iteration are as shown in Table 4. The attributes are taken directly from 2.3.3.1.

OS Persona Template (v.1)

- Persona Name
- Persona Picture
- Demographics
- Key Characteristics
- Story
- Key Goals
- Needs
- Other Tools in Use

Table 4: OS AT Persona Template (v.1), consisting of 8 attributes.

4.1.4 Application of Design Concept

4.1.4.1 Development of Personas – Individual Technique

We have established that persona representations would be beneficial to think through potential design interventions to increase inclusion in the domain of OSSAWS. We will develop persona representations for the direct users (archetypical direct users), for close circle users (archetypical close circle users), and for ‘helpers’ (archetypical helpers). From this exercise, a set of 10 archetypes emerged:

4.1.4.1.1 Direct Users Archetypes

These archetypes are representing the users of SAWS. The users of SAWS by extension, need to be represented and included in OSSAWS as well. Therefore, these archetypes are useful both for SAWS and OSSAWS.

4.1.4.1.1.1 Archetype 1: Filanges (Direct User)

Name of the Persona

Filanges



Demographics

- 13 years old
- Student
- Located in Vancouver

Key Characteristics

- Deaf-blindness and motor impairments
- Little to no technical knowledge
- Life-time first-hand experience of dealing with impairments and the disabling environment

Story

Filanges is a student who has been dealing with acute vision and hearing impairments. Even though he loves his intervener, he likes to find a way to be able to do his homeworks without her being there all the time. He is tired of having to have her around when he wants to ask questions about his homeworks from his teacher or friends. Things become extremely difficult when his intervener is on leave.

Key Goals

- To be able to write without much effort
- To be able to do activities related to or using writing, such as:
 - communication
 - doing schoolwork which includes writing among other things
 - making an influence (e.g. through publishing their work in writing)
- To be able to access and use the support resources for learning, maintenance, reconfiguration due to change in needs

Needs

- A way to integrate SAWS with other ATs
- Support (for future configuration, customization, etc.)

Other Tools In Use

- Kurzweil
- VoiceOver

Figure 4-2 Archetype 1: Filanges (Direct User)

4.1.4.1.1.2 Archetype 2: Mina (Direct User)

Name of the Persona

Mina



Demographics

- 17 years old
- Student
- Located in Saskatoon

Key Characteristics

- Deaf-blindness and motor impairments
- Enough knowledge to be able to use the system with little to no help from their close circle
- Life-time first-hand experience of dealing with impairments and the disabling environment

Story

Mina is a student who has been dealing with acute vision and hearing impairments. Despite that, she has been progressing with her school work with the help of a few assistive technologies. She has been using SAWS for 10 years now for writing and communicating. Her needs have changed a lot during the course of these years and recently, Mina seems to have some problems with her SAWS. She needs her system to be adjusted to her current needs.

Key Goals

- To be able to configure SAWS to their needs
- To be able to write without much effort
- To be able to do activities related to or using writing, such as:
 - communication
 - doing schoolwork which includes writing among other things
 - making an influence (e.g. through publishing their work in writing)
- To be able to access and use the support resources for learning, maintenance, reconfiguration due to change in needs

Needs

- A way to integrate SAWS with other ATs
- Support (for future configuration, customization, etc.)

Other Tools In Use

- Kurzweil
- VoiceOver

Figure 4-3: Archetype 2: Mina (Direct User)

Figure 4-4 shows the persona above (Figure 4-3) in form of a visual presentation. This form of presentation can be easily created by adding CSS to the markdown version of the personas.



Mina

"Mina is a student who has been dealing with acute vision and hearing impairments. Despite that, she has been progressing with her school work with the help of a few assistive technologies. She has been using SAWS for 10 years now for writing and communicating. Her needs have changed a lot during the course of these years and recently, Mina seem to have some problems with her SAWS. She needs her system to be adjusted to her current needs."

Age	17
Occupation	Student
Degree	High School
Location	Vancouver

OTHER TOOLS SHE USE

Kurzweil
VoiceOver

NEEDS

- A way to integrate SAWS with other ATs she's using, or share the documents generated more easily with other programs or other computers
- Some form of support for the system, for future configurations and customizations

GOALS

- To be able to configure SAWS to their needs
- To be able to write without much effort
- To be able to do activities related to or using writing, such as:
 - o communicate
 - o do schoolwork which includes writing among other things
 - o make an influence (e.g. through publishing their work in writing)
- To be able to access and use the support resources for learning, maintenance, reconfiguration due to change in needs, etc.

KEY CHARACTERISTICS

- Deaf-blindness and motor impairments
- Enough knowledge to be able to use the system with little to no help from their close circle
- Life-time first-hand experience of dealing with impairments and the disabling environment

Figure 4-4 One of the personas made, persona for Mina (archetype 2)

4.1.4.1.2 Close Circle Archetypes

4.1.4.1.2.1 Archetype 3: Farah (Close Circle)

Name of the Persona

Farah



Demographics

- 35 years old
- House wife
- Located in Vancouver

Key Characteristics

- No assumptions are being made that the person does or does not have impairments
- A member of the close circle of a person belonging to archetype 1
- Little to no technical knowledge
- Long-term close contact with someone dealing with impairments and experiencing disabling environments

Story

Farah is Filanges' mom. She is a house wife and prior to having Filanges, she did not use computers very much. However, recently she realized there are some softwares available that can help her son. So, she started to learn more about computers by going to computer training classes.

Key Goals

- To be able to acquire the system (SAWS instance) through the support resources
- To be able to access and use the support resources for learning, maintenance, customization/reconfiguration due to change in the needs of the deafblind with motor impairments

Needs

- Support (for learning, future configuration, customization, etc.)

Other Tools In Use

N/A

Figure 4-5: Archetype 3: Farah (Close Circle)

4.1.4.1.2.2 Archetype 4: Foad (Close Circle)

Name of the Persona

Foad



Demographics

- 26 years old
- Care Taker
- Located in Vancouver

Key Characteristics

- No assumptions are being made that the person does or does not have impairments
- A member of the close circle of archetype 1
- Enough knowledge to be able to use the system with little to no help from the helper community or other members of the close circle
- Close contact with people dealing with impairments and experiencing disabling environments

Story

Foad is a professional care taker. He has been helping many families over the years. He has some experience with some Assistive Technologies and he is very much interested in how they work, so he tries to keep himself up to date with the advances in technologies available. However, it is his first time to hear about SAWS.

Key Goals

- To be able to acquire the system with the help of the support resources
- To be able to customize and/or configure the system with the help of the support resources
- To be able to access and use the support resources for learning, maintenance, customization/reconfiguration due to change in the needs of the deafblind with motor impairments

Needs

Other Tools In Use

N/A

Figure 4-6: Archetype 4: Foad (Close Circle)

4.1.4.1.2.3 Archetype 5: Mahan (Close Circle)

Name of the Persona

Mahan



Demographics

- 41 years old
- Farmer
- Located in Saskatoon

Key Characteristics

- No assumptions are being made that the person does or does not have impairments
- A member of the close circle of a person belonging to archetype 2
- Little to no technical knowledge
- Long-term close contact with someone dealing with impairments and experiencing disabling environments

Story

Mahan is Mina's dad. He is a farmer and most of the technologies he uses are heavy agriculture equipment. He has to spend a lot of time on the ranch every day, so despite his desire to help his daughter, he never had much time to learn more about the technology so he can help her better.

Key Goals

- To be able to acquire the system (SAWS instance) through the support resources
- To be able to access and use the support resources for learning, maintenance, customization/reconfiguration due to change in the needs of the deafblind with motor impairments

Needs

- Support (for Learning, future configuration, customization, etc.)

Other Tools In Use

N/A

Figure 4-7: Archetype 5: Mahan (Close Circle)

4.1.4.1.2.4 Archetype 6: Mana (Close Circle)

Name of the Persona

Mana

**Demographics**

- 20 years old
- Student
- Located in Saskatoon

Key Characteristics

- No assumptions are being made that the person does or does not have impairments
- A member of the close circle of archetype 2
- Enough knowledge to be able to use the system with little to no help from the helper community or other members of the close circle
- Long-term close contact with someone dealing with impairments and experiencing disabling environments

Story

Mana is Mina's older sister. She is very smart and always eager to learn about new technologies. She loves programming and dreams to be working in PIET lab so that she can contribute to the creation of Assistive Technologies. She always tries to find new technologies that can assist Mina in her everyday life.

Key Goals

- To be able to acquire the system with the help of the support resources
- To be able to configure the system with the help of the support resources
- To be able to access and use the support resources for learning, maintenance, customization/reconfiguration due to change in the needs of the deafblind with motor impairments

Needs**Other Tools In Use**

N/A

Figure 4-8: Archetype 6: Mana (Close Circle)

4.1.4.1.3 Helper Archetypes

The important attributes of these set of personas were different, because these personas are representing the users of OSSAWS other than the SAWS users.

4.1.4.1.3.1 Archetype 7: Adam (Helper)

Name of the Persona

Adam



Key Characteristics

- Designer/ Usability expert
- Expertise and years of experience in Human-Computer Interaction and User Experience Design

Story

Adam has years of experience in the industry in designing interactive systems. In his quest to give his life more meaning, he's been trying recently to contribute to design for accessibility. He's searching for a way to use his experience in the field to make the design of everyday things more accessible.

Key Goals

- To be able to contribute in the process of design enhancement of the OSSAWS phenotype
- To be able to contribute in the process of design configuration of OSSAWS for a specific scenario of use
- To be able to contribute in the process of maintenance and reconfiguration of OSSAWS for a previously configured instance
- To be able to document and share the design process and outcomes with the community (Developers, other (or prospective) designers/usability experts)

Figure 4-9 : Archetype 7: Adam (Helper)

4.1.4.1.3.2 Archetype 8: Moss (Helper)

Name of the Persona

Moss



Key Characteristics

- Developer of the OSS community
- Technical knowledge, software background

Story

Moss is part of the IT team in a big company. He is very hardworking and the most knowledgeable person in their team. He always tries to keep his skills and knowledge sharp by contributing to the open-source projects. He likes the challenge to learn more about new things and find new ways to solve the problems. However sometimes his solutions are hard to understand for other people, even other programmers.

Key Goals

- To be able to contribute in the process of enhancement and maintenance of OSSAWS phenotype
- To be able to access the design prototypes outlined by the designers/usability experts

Figure 4-10 : Archetype 8: Moss (Helper)

4.1.4.1.3.3 Archetype 9: Beth (Helper)

Name of the Persona

Beth



Key Characteristics

- part of other helper communities, organizations, or groups

Story

Beth is a representative at a non-profit organization for people with disabilities. Beth is always on the watch to find ways to help people.

Key Goals

- To be able to provide feedback on the design
- To be able to send bug reports and minor fixes for errors in the code.

Figure 4-11 : Archetype 9: Beth (Helper)

4.1.4.1.3.4 Archetype 10: Frankie (Helper)

Name of the Persona

Frankie



Key Characteristics

- A person willing to help the community of helpers with little to no expertise in Design of Assistive technologies or development with the platforms used to develop SAWS.

Story

Frankie's life is all about helping to make everyone else's life easier. Despite her advanced age, she always is intrigued about new technology and tries to keep herself up to date with things.

Key Goals

- To provide feedbacks, insights, etc.

Figure 4-12: Archetype 10: Frankie (Helper)

4.1.4.2 Discussion of Pattern and Archetypes

Initially, Farah (Close Circle, #3) and Foad (Close Circle, #4) were clustered with Mahan (Close Circle, #5) and Mana (Close Circle, #6) respectively, due to goals being similar in the duos (Figure 4-13). However, these archetypes react differently in similar scenarios. An example can be a scenario in which Mina (Direct User, #2), having enough technical knowledge, can guide Mahan to operate a specific task, but Farah needs more support resources to accomplish the same task, alone or in collaboration with Filanges (Direct User, #1). Therefore, Mahan is different from user Farah, because the direct users (person with deaf-blindness and motor impairments) of the system around which these

archetypes are formed, are different in terms of their level of technical knowledge which affects their needs. And thus, merging Mahan and Farah leads to misrepresentation of the users. Same reasoning can be applied for Mana and Foad. Yet, this connection is not reflected well when the direct user is studied separately from their close circle.

4.1.4.3 Schematic of User Archetypes

Figure 4-14 demonstrates the ten user groups affected by OSSAWS. We made a persona representing an individual from each of the user groups. A conventional persona representation of archetype 2 is illustrated in Figure 4-4.



Figure 4-13 The hierarchy of archetypes using OSSAWS - version 1



Figure 4-14 The hierarchy of archetypes using OSSAWS - version 2

4.1.5 Analysis/Reflection

As discussed in 2.3.3, the next step in the persona method is to choose the primary persona as the focus of the design process. Unsurprisingly, we experienced some difficulties in accomplishing this task, as we will discuss in this subsection. In this section, I will provide the analysis of this iteration according to the criteria established in subsection 4.1.1.

4.1.5.1 C1.1 Level of Granularity

Extracted Criterion for Evaluation of Response to Challenge Brief (v.1)		
Identifier	Criterion	Description

C1.1	Granularity	The representation has a suitable level of granularity. The archetype is not constructed too broadly, meaning important distinctions are not being captured (the archetype could be sub-divided into different archetypes). The archetype is not constructed too narrowly, meaning the distinctions between different archetypes are not salient (two or more archetypes could be collapsed and merged).
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As per discussed in 4.1.4.2, we went through several rounds of archetype development, with the goal of achieving the best level of granularity. We finally came down to the 10 different user profiles which were stated earlier, in section 4.1.4.1. If we were to create the archetypes solely based on goals and merge the personas with similar goals, this would eliminate information that could potentially impact OSSAWS design decisions. Therefore, following the technique at hand, the persona representations thus developed have a suitable level of granularity.

4.1.5.2 C1.2 (*Individual*) Persona Goals

Extracted Criterion for Evaluation of Response to Challenge Brief (v.1)		
Identifier	Criterion	Description
C1.2	Goal Capture	The representation captures all the goals that are important to the archetype, as they pertain to the design domain.

Looking across the different persona representations, we observe that many of the roles the personas have in our model are complementary. Unlike the conventional uses for personas (in which different goals vary across personas), in our case, the personas are dependent on each other, and their goals either overlap or are in line with each other. In

the OSSAWS domain, the personas have converging (not distinct) goals with one another, and in the groupware domain, we don't want to choose one of the persona's goals as the main goal of the design intervention. This reflection aligns with the same issue raised in Matthews et al.'s study, in the context of the use of individual personas for groupware design (Matthews et al., 2011).

4.1.5.3 C1.3 (*Individual*) Persona Characteristics

Extracted Criterion for Evaluation of Response to Challenge Brief (v.1)		
Identifier	Criterion	Description
C1.3	Salient Characteristics Capture	The representation captures all the characteristics that are important to the archetype, as they pertain to the design domain.

As stated in 4.1.5.2, personas in this groupware design domain are complementary and aligned with one another. There are group dynamics that arise from having shared and complementary goals. Having these types of personas means that there are interactions between the personas, based on this complementarity. Individual personas do not capture the interactions and collaboration between the family members and thus fail to properly represent the characteristics of the users they were based on. In different design domains, the interactions and collaborations between the users of a system vary in importance. Oftentimes, these interpersonal interactions are not important, as the tasks carried out in the design domain are individualist. Consequently, mostly the systems are designed to be used mainly by one individual. Therefore, the focus of the conventional design practices, such as the persona method, is often on individualist domains of use. However, as

mentioned in chapter 2, how the data is modelled in a system designed to be used by a group of people should reflect the users' group nature and their group characteristics (interactions, collaboration). Considering the interactions between the users, we will be able to design, analyze, and evaluate the “use by the group.”

Based on what has been discussed, the conventional model for personas, aka individual persona, fails to properly represent users of our system since it overlooks important factors, like complementary goals and collaboration of the family members in learning and using the system and the interactions between them.

4.1.5.4 C1.4 Inclusion

Extracted Criterion for Evaluation of Response to Challenge Brief (v.1)		
Identifier	Criterion	Description
C1.4	Inclusion	The representation serves to increase inclusion. There are two aspects: content inclusion (who gets represented within the design process and how?) and (ii) process inclusion (who gets to be part of the open-source community?). For content inclusion, this criterion assesses the degree to which the persona representation can capture the barriers to inclusion and/or the particular characteristics of the archetype upon which inclusion is based. For process inclusion, this criterion assesses the persona representation itself is a vehicle for inclusion.

Some of the users' important characteristics are captured and explicitly represented in the representations. However, as pointed out earlier, the representations do not capture the interactions and collaboration between the family members very well. Therefore, while being a step forward towards more content inclusion, they need to be improved.

The “key characteristics” in the representations include aspects that pertain to the ability to participate in the design process of OS AT. These personas bring aspects like the experience and expertise of the users into notice. This is helpful in increasing the process inclusion.

4.2 Second Iteration

4.2.1 *Discover/Define*

In the first iteration, we responded to the following:

Challenge Brief (v.1): How can persona representations be leveraged into open-source AT in order to build inclusion?

We developed a response consisting of a design concept to use an Open-Source Persona template and populated the template in a set of 10 archetypes. However, in our analysis and reflection phase, we showed that the individual persona technique (used within the Open-Source Persona template) did not capture key aspects of the group dynamics among co-design contributors, and that to do so would require us to revise the challenge brief as follows:

4.2.1.1 *Challenge Brief (v.2)*

How can Open-Source persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group and decision-making dynamics of this open-source AT?

4.2.1.2 Design Concept Evaluation Criteria (v.2)

In anticipation of the assessment of the response to the Challenge Brief, we recognized that the success criteria (first described in section 4.1.1) would require adjustment to assess the group characteristics being sought in the Challenge Brief. We expect the ideal Open-Source persona template should satisfy the following:

Criteria for Evaluation of Response to Challenge Brief (v.2)			
Identifier	Criterion	Description	Change from v.1 to v.2
C2.1	Granularity	The representation has a suitable level of granularity. The archetype is not constructed too broadly, meaning important distinctions are not being captured (the archetype could be sub-divided into different archetypes). The archetype is not constructed too narrowly, meaning the distinctions between different archetypes are not salient (two or more archetypes could be collapsed and merged).	Same as C1.1
C2.2	Goal Capture	The representation captures all the important representative goals of all groups using the system.	Similar to C1.2, “The representation captures all of the important representative goals of a group of individuals.”
C2.3	Salient Characteristics Capture	The representation captures all the important and relevant characteristics common to all groups. More specifically, collaboration and interactions of the members in using the system needs to be captured.	Similar to C1.3, “The representation captures all the important and relevant characteristics common to a group of individuals.”
C2.4	Inclusion	The representation serves to increase inclusion.	Same as C1.4

		<p>There are two aspects: content inclusion (who gets represented within the design process and how?) and (ii) process inclusion (who gets to be part of the open-source community?). For content inclusion, this criterion assesses the degree to which the persona representation can capture the barriers to inclusion and/or the particular characteristics of the archetype upon which inclusion is based. For process inclusion, this criterion assesses the persona representation itself is a vehicle for inclusion.</p>	
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4.2.2 *Develop, Second Iteration*

We decided to retain the design concept of an Open-Source persona template, and to revise the particular persona technique employed within the template. As explained in section 2.4 ‘Related Work’, several sources in the literature have suggested the use of group-based persona models when the design is intended to be used by a group of people. Most notable among these sources is Matthews et al. (2011) who, alongside outlining ways in which individual personas fail to capture some of the key characteristics of a group, proposed a model for group personas, called *collaboration personas*. We also considered the models for group personas suggested by Kuniavsky (2004) and Cooper (Cooper et al., 2014). We concluded that among the extant group persona approaches, Matthew’s

collaboration personas are by far the most complete model at hand that addresses the interactions and collaboration of the members. Thus, to respond to Challenge Brief (v.2), we will start by building and populating an Open-Source persona template based on collaboration rather than individual personas.

In collaboration personas, we seek to consider and represent the interactions between the members in terms of the four dimensions of work style, goals, leadership, and the stability of the personnel. (This model is explained in more detail in section 2.4.2).:

1. **Group goals:** the goals of the group persona are identified as the collection of objectives, interests, and relationships. The goals of a group can be a core or a secondary responsibility of a group. According to Matthews et al. (2011), some group goals can be similar to individual persona goals.
2. **Work style:** specifies “who will do the major group tasks and how they will work together.” According to them, pooling work, co-creating, sharing information, and communicating around relationships are different work styles of a group.
3. **Leadership:** indicates whether a group makes decisions by consensus (democratic), or a leader is appointed to make the decisions (designated leader) (also referred to as management style).
4. **Stability of the members:** the degree to which the group members remain in the group through its entire life span (stable) or if their membership in the group is temporary, meaning they leave the group when their expertise is no longer needed (dynamic).

I undertook the development of OS Persona template instances, drawing on the 10 individual personas (Figure 4-14) from the first iteration.

4.2.3 Design Concept

In this iteration, the Challenge Brief (v.2) (see section 4.2.1.1) was as follows: How can Open-Source persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group decision-making and dynamics of this open-source AT?

To respond to the challenge, I refined the previous design concept by altering the composition of the persona template. In the refined design concept, an altered and extended version of the Collaboration persona model, which was first introduced by Matthews et al. (2011) was chosen to be employed as the best option available. I used this refined design concept to instantiate a set of five collaboration personas to represent the potential users of OSSAWS.

The design concept developed in this iteration was very similar to the first iteration, with the modification of the persona modelling technique. The template was modified (OS Persona Template v2), as summarized in Table 4 below.

OS Persona Template (v.2)

- Archetype Name, *altered to unchanged, now referring to a group archetype*
- Archetype Picture, *altered to unchanged, now referring represent an archetypical to group archetype*
- Description (summarizing the attribute ‘Key Characteristics’)
- Key Goals, *altered to unchanged, now referring to goals of the group, as per the archetype, existent in the Matthews technique*
- Addition of Workstyle, *added to the template, as per the Matthews technique*

- Leadership, *added to the template, as per the Matthews technique*
- Stability of Members, *added to the template, as per the Matthews technique.*
- Story, Needs, Other tools in use, and Demographics were removed as per the Matthews technique

Table 5: OS AT Persona Template (v.2), consisting of 7 attributes. . The differences with respect to OS Persona Template v.1 are indicated.

The template is mainly following the Collaboration persona template suggested by Matthews (2011). Collaboration persona template originally did not have archetypal name, archetypal picture, and description. Adding an archetypal name, archetypal picture, and description to the collaboration personas representing families promotes empathy. This makes the personas more relatable for the product team (section 2.3.4.2). Therefore, these attributes were added to the suggested set of attributes by Matthews.

The characteristics attributes are added to the template attributes by including additional lines and otherwise do not involve any other markdown codes. Thus, the incorporation of by the collaboration persona technique will not affect the affordability of Git Diff in the Open-Source setting.

4.2.4 Application of Design Concept

The revised persona template led to the creation of five group personas (described in more detail below) in this iteration. I regrouped the users of OSSAWS with a focus on the group characteristics outlined in the collaboration persona model. The following persona groups emerged from this exercise:

4.2.4.1 Group Archetype #1: The Mavericks (Direct Users + Close Circle)

Since the characteristics defining a collaboration persona mainly focus on the type of collaboration, all the direct user and close circle personas consolidate into one group dynamic.

Name of the Persona

The Mavericks



Description

A group consisting of a person with deaf-blindness and motor impairments and their close circle.

Key Goals

Core deliverable

- To be able to configure SAWs to the needs of the person with deaf-blindness and motor impairments
- To be able to write without much effort
- To be able to do activities related to or using writing, such as:
 - communication
 - doing schoolwork which includes writing among other things
 - making an influence (e.g. through publishing their work in writing)
- To be able to access and use the support resources for learning, maintenance, reconfiguration due to change in needs of the person with deaf-blindness and motor impairments.

Workstyle

Co-creating

- The close circle assists the person with deaf-blindness and motor impairments in their activities.
- The person with deaf-blindness and motor impairments communicates with their close circle (often) through the sense of touch.

Leadership

Democratic

- The members make decisions together, there is no main leader for this group

Figure 4-15: Group Archetype 1: The Mavericks (Direct Users + Close Circle)

Figure 4-16 shows one of the collaboration personas I made in this exercise based on group 1 in form of a schematic. The collaboration persona model introduced by Matthews (2011) does not provide guidelines on how to create a schematic representation. However, we saw it necessary to provide the schematics to create more empathy during the design process. This also helps to ease the comparison between different personas made in different iterations.

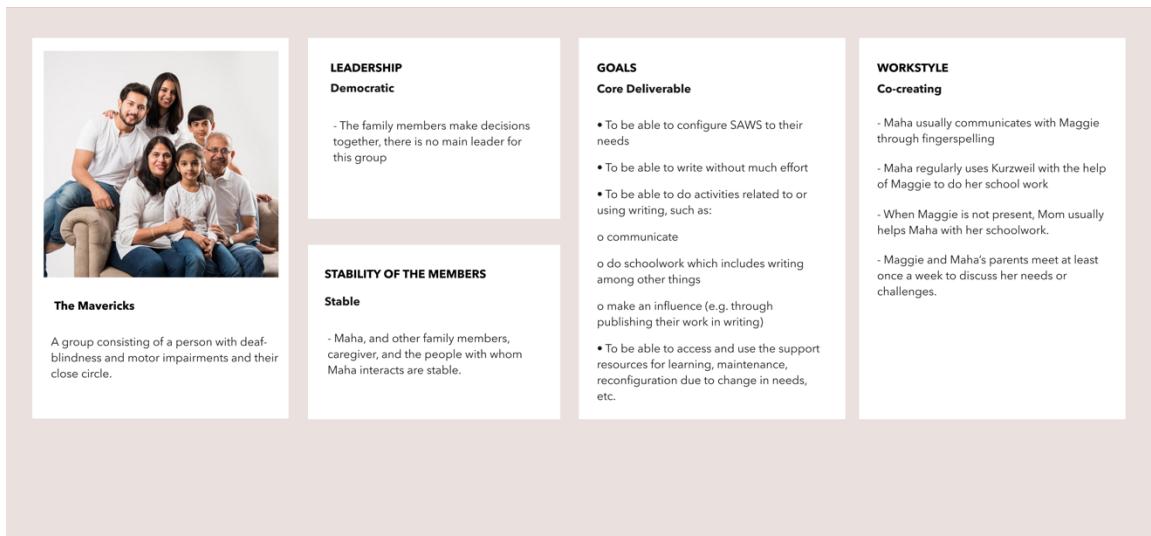


Figure 4-16 A Collaboration Persona, which was developed to represent User Group 1. This schematic is more detailed compared to the original collaboration persona model, to create empathy (using a picture, bio, etc.).

Group Archetype #2: The Designers/Usability Experts (Helpers)

Name of the Persona

UX Designers



Description

The Designers/Usability Experts

Key Goals

Core deliverable

- To be able to contribute in the process of design enhancement of the OSSAWS phenotype
- To be able to contribute in the process of design configuration of OSSAWS for a specific scenario of use
- To be able to contribute in the process of maintenance and reconfiguration of OSSAWS for a previously configured instance
- To be able to document and share the design process and outcomes with the community (Developers, other (or prospective) designers/usability experts)

Workstyle

Pooling & co-creating

Leadership

Designated leaders lab members and/or lead usability expert assigned to their project

Stability of the members

Stable and/or dynamic

Figure 4-17: Group Archetype 2: The Designers/Usability Experts (Helpers)

4.2.4.2 Group Archetype #3: OSS Developers (Helpers)

Name of the Persona

OSS Developers



Description

The Developers of the OSS community

Key Goals

Core deliverable

- To be able to contribute in the process of enhancement and maintenance of OSSAWS phenotype
- To be able to access the design prototypes outlined by the designers/usability experts

Workstyle

Pooling & co-creating

Leadership

Democratic

Stability of the members

Stable and/or dynamic

Figure 4-18 : Group Archetype 3: OSS Developers (Helpers)

4.2.4.3 Group Archetype #4: Other helper communities, organizations, or groups (Helpers)

Name of the Persona

Helper Organizations



Description

Other helper communities, organizations, or groups

Key Goals

Secondary interest

- To be able to provide feedback on the design
- To be able to send bug reports and minor fixes for errors in the code.

Workstyle

Mostly communication-focused

Leadership

Democratic

Stability of the members

Stable and/or dynamic

Figure 4-19: Group Archetype 4: Other helper communities, organizations, or groups (Helpers)

4.2.4.4 Group Archetype #5: The Non-Technical Philanthropists (Helpers)

Name of the Persona

The Philantropists



Description

Other people willing to help the community of helpers with little to no expertise in Design of Assistive technologies or development with the platforms used to develop SAWS

Key Goals

Secondary interest

- To provide feedbacks, insights, etc.

Workstyle

Communication-focused

Leadership

N/A

Stability of the members

Dynamic

Figure 4-20: Group Archetype 5: The Non-Technical Philanthropists (Helpers)

4.2.4.5 Discussion of the Group Archetypes

Group Archetype #1 addresses the issues raised in 4.1.4. If we created persona representations with a higher focus on goals rather than interactions, different personas could have emerged. In this scenario, the persona group #1 would have been broken down to two main personas:

Persona 1: An individual persona representing the deaf-blind person with motor impairments.

Goals:

- To be able to configure SAWS to their needs
- To be able to write without much effort
- To be able to communicate with the world without the constant need of an intervener to be present
- To be able to do activities related to or using writing, such as:
 - do schoolwork which includes writing among other things
 - make an influence (e.g., through publishing their work in writing)
- To be able to access and use the support resources for learning, maintenance, reconfiguration due to change in needs, etc.

Persona 2: A group (collaboration) persona representing the close circle of the deaf-blind person with motor impairments.

Group goals: Core deliverable

- To be able to acquire the system with the help of the support resources
- To be able to access and use the support resources for learning, maintenance, re-customization/reconfiguration due to changes in needs, etc.

Workstyle: Co-creating

Leadership: Democratic

Stability of the members: Stable

However, in this representation, the issues mentioned in 4.1.4 persist since the interactions and collaborations between the person with deaf-blindness and motor impairments (direct user) with their close circle is still overlooked. Therefore, these two personas were grouped together to resolve the original problem in the previous iteration.

4.2.5 Analysis/Reflection

The design concept that was developed as a response to Challenge Brief (v.2) is now analyzed with respect to the criteria that were developed in section 4.2.1.2.

4.2.5.1 C2.1 Level of Granularity

Criterion for Evaluation of Response to Challenge Brief (v.2)			
Identifier	Criterion	Description	Change from v.1 to v.2
C2.1	Granularity	The representation has a suitable level of granularity. The archetype is not constructed too broadly, meaning important distinctions are not being captured (the archetype could be sub-divided into different archetypes). The archetype is not constructed too narrowly, meaning the distinctions between different archetypes are not salient (two or more archetypes could be collapsed and merged).	Same as C1.1

The Open-Source persona template (v.2) lacks the expressive affordance needed to make the necessary distinctions between groups of users. This template affords a certain degree of detail through its attributes. As a result, all families are represented by one group

persona: a group consisting of a person with deaf-blindness and motor impairments and their close circle. This way of grouping inevitably happens because all the family groups acquire the same value in accordance with the attributes of this persona model. This representation is a very broad assumption, as the template does not reflect the differences between different family groups. These differences (explained in more detail in section 4.2.3.5.) could potentially lead to different needs and wants and subsequently different designs. Therefore, these differences are important and should be captured, but this template is lacking the attributes needed to reflect the distinction.

4.2.5.2 C2.2 (Group) Persona Goals

Criterion for Evaluation of Response to Challenge Brief (v.2)			
Identifier	Criterion	Description	Change from v.1 to v.2
C2.2	Goal Capture	The representation captures all the important representative goals of all groups using the system.	Similar to C1.2, “The representation captures all of the important representative goals of a group of individuals.”

The OS Persona template (v.2) provisions for the representation of goals at the group level, now that the collaboration persona technique has replaced the individual persona technique. The personas emerging from the use of the template (the five user groups described in section 4.2.2) demonstrate this, as they all have clear goals that are representative of the user groups.

4.2.5.3 C2.3 (Group) Persona Characteristics

Criterion for Evaluation of Response to Challenge Brief (v.2)			
Identifier	Criterion	Description	Change from v.1 to v.2

C2.3	Salient Characteristics Capture	The representation captures all the important and relevant characteristics common to all groups. More specifically, collaboration and interactions of the members in using the system needs to be captured.	similar to C1.3, “The representation captures all the important and relevant characteristics common to a group of individuals.”
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The OS Persona template (v.2) provisions for the representation of the interaction between the group members, thanks to the use of the collaboration persona technique. However, the template does not yet capture all the important characteristics of the groups of relevance in the Open AT domain.

4.2.5.3.1 Organization-based vs Family-based groups

There are important differences between a family-based social group and a group of individuals/employees in a workplace setting. These characteristics pertain to how the family is structured and the different ways their interactions can be modeled. Members of an organization-based group are usually the product of a hiring process (one that will embed the requirement for the skills required by the company and the team). Group members become members only once they have successfully completed an interview process, which will ensure that they satisfy the needs of the team in terms of their level of knowledge, experience, and expertise. Families are not constructed like this. In a family, people are not hired or chosen based on their skills. They come together from different backgrounds with different levels of knowledge, abilities, skills, and motivations. This highlights an important difference between an organization-based group construct and a family-based group construct. Collaboration personas are predicated on the assumption of

organization-based groups and embed assumptions about group composition and inclusion.

The collaboration persona technique treats all members of a group as if they have all the same characteristics and thus, overlooks the heterogeneity of the members, which is particularly relevant for the social groups being considered here.

The heterogeneity of the group members is important in this design domain. Even though all the users across different direct users and close circles will share some similarities (e.g., they might have the same goals), they will also have different needs due to their differences in their embodiment, their differences in their knowledge, experience, expertise, and set of skills. Collaboration persona assumes uniformity between the members of a group. This assumption, in the domain of AT, is problematic as it is likely to lead to the reproduction of the same faulty results of approaches like Inclusive Design, due to overlooking the individual differences in embodiment and uniqueness of people with impairments (as discussed in section 1.1, section 2.2). The use of collaboration personas in a group setting like a family may not be effective. There will be a much greater diversity of knowledge, skills, and experience of the members and no explicit provision to represent this diversity. Thus, this lack of representational power for heterogeneity is a shortcoming of the OS Persona template (v.2) design concept. We will return to this issue in the next design iteration (the distributed cognitive framework in section 4.3.6.1).

4.2.5.3.2 Organization-Based Collaboration Software vs Assistive Technology

The characteristics of collaboration personas make them useful in domains that involve the use and/or development of collaboration software, but the benefits may not generalize to domain of assistive technology (AT) software. Collaboration personas were created for modelling the users of certain workplace-based collaboration software tools. The nature of the use cases and the nature of the groups for these workplace-based collaboration software tools differs from those of AT. This leads to a mismatch between the characteristics that are represented in the Collaboration personas and the characteristics that need to be captured in the domain of AT (but are not captured in the Collaboration persona model).

For instance, in the realm of assistive technology and the family setting of use, the issue of group stability is quite different than the workplace. For example, family membership is typically more stable than workplaces over time. Thus, representing the stability of the group membership is not likely to bring useful information to the design process of AT. This aspect of the template is likely to only add clutter to the design representations and therefore may confuse or hinder the process.

Moreover, collaboration personas do not capture some of the important characteristics of people involved in the process of maintenance and use of assistive technologies. After all, they were introduced to assist the process of design in a different domain. Therefore, even though collaboration personas provide a good baseline guideline on how the group personas should be created and they do bring into attention critical aspects of groups that have been overlooked in conventional personas targeted for individuals, they fall short

when representing social constructs like families or close circle of a person with impairments. This mismatch is better depicted in the Venn diagram in Figure 4-21.

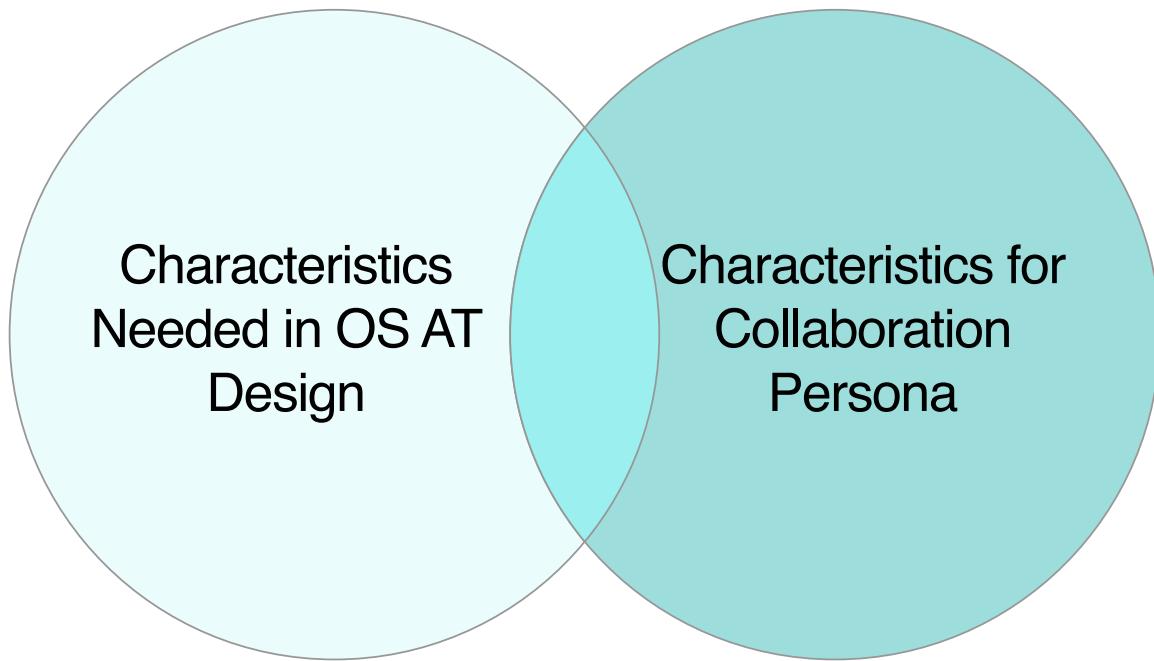


Figure 4-21 This figure shows that some of the characteristics needed in the design of OS AT is not captured in Collaboration personas, and some of the characteristics in collaboration personas are not applicable in the domain of OS AT.

4.2.5.4 C2.4 Inclusion

Criterion for Evaluation of Response to Challenge Brief (v.2)			
Identifier	Criterion	Description	Change from v.1 to v.2
C2.4	Inclusion	The representation serves to increase inclusion. There are two aspects: content inclusion (who gets represented within the design process and how?) and (ii) process inclusion (who gets	Same as C1.4

		<p>to be part of the open-source community?). For content inclusion, this criterion assesses the degree to which the persona representation can capture the barriers to inclusion and/or the particular characteristics of the archetype upon which inclusion is based. For process inclusion, this criterion assesses the persona representation itself is a vehicle for inclusion.</p>	
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The Open-Source persona template (v.2), through the use of collaboration personas, increases the possibility of content and process inclusivity.

Using collaboration personas to represent the users of OSSAWS has improved the inclusion of content in the design process because the content represented reflects the group nature of the users and that they are collaborating and interacting.

Yet, it requires further improvement when it comes to the assemblage of users who belong to categories A and B due to the failure in capturing the differences (such as differences in their knowledge and experience) across user circles.

In terms of inclusion for the helpers (category C), the Open-Source persona template (v.2) provisions better than the v.1 template for capturing the characteristics of the helpers because instead of representing the helpers as having solely individualistic goals, the v.2 template allows helpers to be represented as having group interactions and group-

based goals. This is an important characteristic of the helper communities and needs to be adequately captured (section 2.4.2.1).

4.3 Third Iteration

4.3.1 *Discover/Define*

The Challenge Brief (v.2) from the second iteration (see Section 4.2.1.1) is as follows:

Challenge Brief (v.2): How can persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group and decision-making dynamics of this open-source AT?

To recap the second iteration, we utilized collaboration personas as a model to represent the group nature of users and helpers. Analysis shows that the collaboration personas is likely to help to increase inclusion, especially when it comes to representing the helper communities. However, these design representations fail to represent some of the key characteristics of users, notably the heterogeneity of the members of the user circles in terms of their knowledge, experience, and expertise. Therefore, we needed to tweak the challenge brief. Therefore, we take the opportunity needed to revise the challenge brief as follows:

4.3.1.1 *Challenge Brief (v.3)*

How can persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group and decision-making dynamics

of this open-source AT? How to do so in a way that considers the heterogeneity of the users in terms of their knowledge, experience, and expertise?

4.3.1.2 Design Concept Evaluation Criteria (v.3)

The criteria for a successful Persona representation tool from 4.2.2 needed to be adjusted to reflect the changes in the challenge brief.

Criteria for Evaluation of Response to Challenge Brief (v.3)			
Identifier	Criterion	Description	Change from v.2 to v.3
C3.1	Granularity	The representation has a suitable level of granularity. The archetype is not constructed too broadly, meaning important distinctions are not being captured (the archetype could be sub-divided into different archetypes). The archetype is not constructed too narrowly, meaning the distinctions between different archetypes are not salient (two or more archetypes could be collapsed and merged).	Same as C1.1 & C2.1
C3.2	Goal Capture	The representation captures all the important representative goals of all groups using the system.	Same as C2.2
C3.3	Salient Characteristics Capture	The representation captures all the important and relevant characteristics common to all groups. More specifically, the heterogeneity of the members in terms of knowledge, experience, and expertise, alongside realizing their collaboration and	similar to C2.3, “The representation captures all the important and relevant characteristics common to all groups. More specifically, collaboration and interactions of the members in using the system needs to be

		decision-making process within their group.	captured.” With more focus on the knowledge, experience, and expertise.
C3.4	Inclusion	<p>The representation serves to increase inclusion.</p> <p>There are two aspects: content inclusion (who gets represented within the design process and how?) and (ii) process inclusion (who gets to be part of the open-source community?). For content inclusion, this criterion assesses the degree to which the persona representation can capture the barriers to inclusion and/or the particular characteristics of the archetype upon which inclusion is based. For process inclusion, this criterion assesses the persona representation itself is a vehicle for inclusion.</p>	Same as C1.4 & C2.4

4.3.2 Develop, Third Iteration

As discussed in 4.2.5, Matthews et al.’s collaboration persona model for group personas has some limitations in the domain of OS AT. In the context of designing for OS AT, collaboration is more about how knowledge, experience, and expertise are shared through the interactions of the members and how this reduces the load of work for each individual. Therefore, we felt the need to create a new archetypal description that can be representative of social constructs like families in the context of designing AT. In 4.3.3, I will introduce the PISHI concept, an empirically derived description of archetypal social groups

(representing families in the context of Assistive Technologies), including details that inform the design of the group members' collaboration and interactions based on sharing knowledge. This new archetypal description is explained through the distributed cognitive framework in 4.3.6.1. In this subsection, I will explain how we employed the PISHI concept to model the users.

PISHI concept describes a family construct. A person with impairments is in the center of this construct (direct user). Individual details of this person, as the main focus of the design, are important and should be captured. The members of the close circle are represented through the group characteristics of the persona template of the PISHI concept. Therefore, PISHI concept consists of two sets of attributes, individual attributes related to the direct user (person with impairments), and the group attributes describing the group interactions and characteristics.

The individual attributes are as below:

- Individual Archetypal name
- Individual Archetypal picture
- Demographic information
- Impairment(s) (Access Barriers)
- Goals
- A bio/explanation of their experience can be added to the persona to increase relatability

The group attributes are as the following:

- Group Archetypal name
- Group Archetypal picture
- Group Goals
- Knowledge, experience, expertise

4.3.3 Design Concept

The revised Challenge Brief (v.3) (section 4.3.1.1) was as follows: How can persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group decision-making and dynamics of this open-source AT? How to do so in a way that considers the heterogeneity of the users in terms of their knowledge, experience, and expertise?

To respond to the challenge, I refined the previous design concept (OS AT Persona Template v.2) by altering the template even further, to better capture the family nature and the family setting of the users using an instance of an AT.

This third iteration of the design process converged on my final design concept that responds to the challenge brief, a concept that I am calling **Persona Inclusion for open Source assistive tecHnology Innovation (PISHI)**. The PISHI concept has three components:

- i. the use of a structured template for persona modelling within the design domain,
- ii. the use of a particular kind of template (described below), and
- iii. the instantiation of the template with content in a diff-friendly representation format (markdown).

To reflect the group nature of the family setting while focusing on the individual differences of the direct users of the system, the design concept consists of two components, as shown in Table 6.

The revisions in the design concept included embedding an individual persona to represent the direct user within a group persona representing the whole circle of use. Therefore, in this template, the first component reflects the central goals and characteristics of the direct user of the system, and the second component reflects the combined goals and characteristics of the close circle and direct user in collaboration.

OS Persona Template (v.3)

Individual Attributes (direct user):

- Individual Archetypal Name, *altered, now referring to the archetypal name of the direct user*
- Individual Archetypal Picture, *altered, now referring to the archetypal picture of the direct user*
- Demographic Information, *added*
- Impairment(s) (Access Barriers), *added*
- Goals, *altered, now referring to the goals of the direct user*
- A bio/explanation of their experience can be added to the persona to increase relatability, *added*

Group Attributes (direct user + close circle):

- Group Archetypal Name, *altered, now referring to the archetypal name of the family (direct user + close circle)*
- Group Archetypal Picture, *altered, now referring to the archetypal picture of the family*

<ul style="list-style-type: none"> • Group Goals, <i>altered, now referring to the goals of the family</i> • Knowledge, experience, expertise, <i>added</i>

Table 6: OS AT Persona Template (v.3), consisting of 10 attributes divided into 2 components.

4.3.4 Application of Design Concept

To address the points raised in the analysis in section 4.2.5, the persona model used to represent the direct users and their close circle (categories A & B) were revised. In this revision, we make use of PISHI Concept as our revised template and populate the templates as per our observations of the trends in the data mentioned in section 4.1.2.2.

4.3.4.1 Family Archetype #1: The Smiths (Direct Users + Close Circle)

The Smiths

Person with Impairments: Filanges



Demographic information:

- 13 years old
- Student
- Located in Vancouver

Impairment (Access Barriers): Deafblindness and Motor Impairment

Goals:

- To be able to write without much effort
- To be able to do activities related to or using writing, such as:
 - communication
 - doing schoolwork which includes writing among other things
 - making an influence (e.g. through publishing their work in writing)

Bio

Filanges is a student who has been dealing with acute vision and hearing impairments. Even though he loves his intervener, he likes to find a way to be able to do his homeworks without her being there all the time. He is tired of having to have her around when he wants to ask questions about his homeworks from his teacher or friends. Things become extremely difficult when his intervener is on leave.



Knowledge, Experience, Expertise:

- Little to no technical knowledge, experience, or expertise to acquire and use the system with little to no help
- Life-time first-hand experience of dealing with impairments and the disabling environment for at least one of the family members

Goals:

- To be able to acquire the system with the help of the support resources
- To be able to configure SAWS to the needs of the direct user
- To be able to access and use the support resources for learning, maintenance, reconfiguration due to change in needs of the person with deaf-blindness and motor impairments.

Figure 4-22: Family Archetype #1 (the Smiths), created using PISHI template (persona template v.3).

4.3.4.2 Family Archetype #2: The Mavericks (Direct Users + Close Circle)

The Mavericks

Person with Impairments: Mina



Demographic information:

- 17 years old
- Student
- Located in Saskatoon

Impairment (Access Barriers): Deafblindness and Motor Impairment

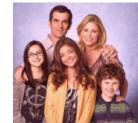
Goals:

- To be able to configure SAWS to their needs
- To be able to write without much effort
- To be able to do activities related to or using writing, such as:
 - communication
 - doing schoolwork which includes writing among other things
 - making an influence (e.g. through publishing their work in writing)

Bio

Despite her acute vision and hearing impairments, Mina has been progressing with her school work with the help of a few assistive technologies. She has been using SAWS for 10 years now for writing and communicating. Her needs have changed a lot during the course of these years and recently, Mina seems to have some problems with her SAWS. She needs her system to be adjusted to her current needs.

Knowledge, Experience, Expertise:



- Enough knowledge, experience, expertise to acquire and use the system with little to no help
- Life-time first-hand experience of dealing with impairments and the disabling environment for at least one of the family members
- Adequate experience using this system

Goals:

- To be able to acquire the system with the help of the support resources
- To be able to configure SAWS to the needs of the direct user
- To be able to access and use the support resources for learning, maintenance, reconfiguration due to change in needs of the person with deaf-blindness and motor impairments.

Figure 4-23: Family Archetype #2 (the Mavericks), created using PISHI template (persona template v.3).

Figure 4-24 shows the persona above in form of a visual presentation. This form of presentation can be easily created by adding CSS to the markdown version of the personas.

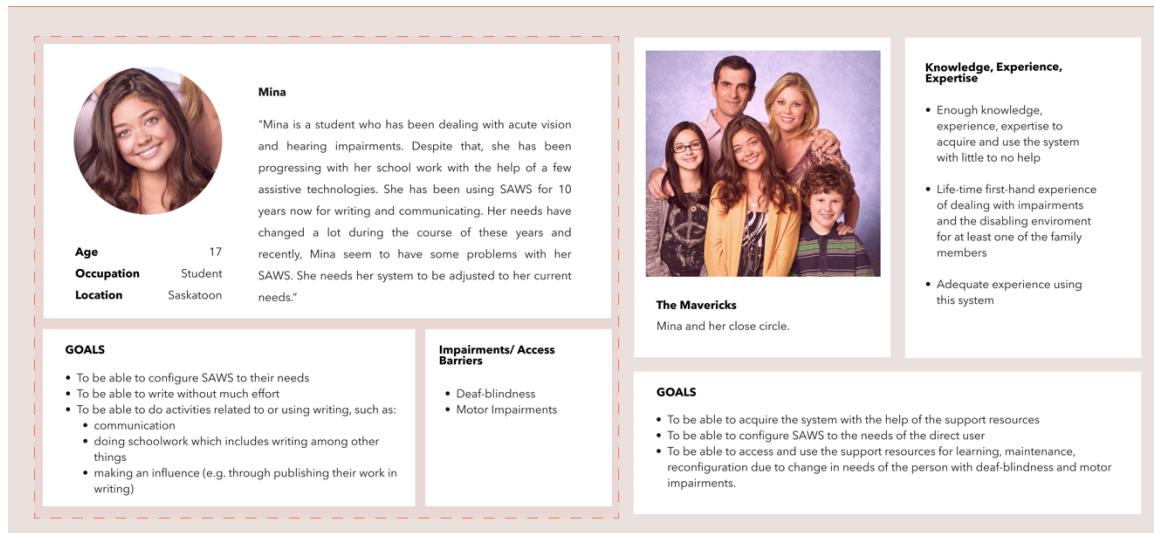


Figure 4-24 Visual Representation of the Family persona, Archetype #2 (the Mavericks), based on the PISHI concept template

4.3.5 Analysis

In this section I analyze the design concept that was developed as a response to Challenge Brief (v.3) with respect to the criteria that were developed in section 4.3.1.2.

4.3.5.1 C3.1 Level of Granularity

Criterion for Evaluation of Response to Challenge Brief (v.3)			
Identifier	Criterion	Description	Change from v.2 to v.3
C3.1	Granularity	The representation has a suitable level of granularity. The archetype is not constructed too broadly, meaning important	Same as C1.1 & C2.1

		distinctions are not being captured (the archetype could be sub-divided into different archetypes). The archetype is not constructed too narrowly, meaning the distinctions between different archetypes are not salient (two or more archetypes could be collapsed and merged).	
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The revised persona template in the revised design concept has several additional attributes, and thus have a finer level of granularity. This template represents the direct user at the core and expresses their goals and characteristics in more detail. Other information — about the close circle of the direct user, their collaboration as a group, their collective characteristics and goals — is also bundled in template. As a result, the archetypes created using this template will be at a finer level of granularity than those created using the v.2 template. This finer level of granularity is necessary. For instance, we created two archetypes using the v.2 template, each of which representing the two different major trends in how families (direct users and their close circle) use SAWS (as an instance of AT). These archetypes provide the basis for their inclusion in the decision-making process, as each represent the users of OSSAWS.

The level of granularity is appropriate. There is no basis to believe that archetypes will become constructed too narrowly. Distinctions between different archetypes have not been identified salient in the analysis. There does not seem to be need that the archetypes be broken into smaller or more specific archetypes beyond this. One risk of doing so

would be to create representations that are likely to overfit on edge cases. Another risk is to underemphasize or neglect some important aspects of the (group) nature of use (as happens in the case of the individual personas). Therefore, we believe that the archetypes created for the direct users and the family members in this iteration are at a suitable level of granularity.

4.3.5.2 C3.2 Persona Goals

Criterion for Evaluation of Response to Challenge Brief (v.3)			
Identifier	Criterion	Description	Change from v.2 to v.3
C3.2	Goal Capture	The representation captures all the important representative goals of all groups using the system.	Same as C2.2

The revised persona template in the revised design concept captures both the individual goals of the direct users and the group goals of the close circle and thus performs well in capturing all the important goals. The individual goals of the direct user of the AT are central in defining the relevant needs. As well, the group goals that the (family) group wants to achieve together should also be captured. The archetypes shown in Figure 4-22 and Figure 4-23 (Archetypes #1 and #2) were created using this template and capture both individual goals and the group goals. Furthermore, the goals of the close circle members that are relevant to the design are reflected and included through group goals of the persona. This change of capability of representations in capturing goals is due to the new structure of personas in PISHI concept, in which two attributes are capturing the individual and group goals in this technique.

4.3.5.3 C3.3 Persona Characteristics

Criterion for Evaluation of Response to Challenge Brief (v.3)			
Identifier	Criterion	Description	Change from v.2 to v.3
C3.3	Salient Characteristics Capture	The representation captures all the important and relevant characteristics common to all groups. More specifically, the heterogeneity of the members in terms of knowledge, experience, and expertise, alongside realizing their collaboration and decision-making process within their group.	similar to C2.3, “The representation captures all the important and relevant characteristics common to all groups. More specifically, collaboration and interactions of the members in using the system needs to be captured.” With more focus on the knowledge, experience, and expertise.

The persona templates in the PISHI concept have been refined to better represent the heterogeneity of the members through the explicit representation of the “Knowledge, Experience, and Expertise” attribute that is now embedded in the persona template. Such characteristics were not well represented in the persona template (v.2), as they were only captured on an individual level in the conventional individual personas. In PISHI concept however, the collective knowledge, experience, and expertise of the users is explicitly represented in through a template attribute. The persona template (v.3) in the PISHI concept recognizes the importance of focusing on the direct users in the context of the group they are working with and also accounts for the group collaboration towards the group goals, through the use of a group persona representation template. Therefore, the archetypes created based on the PISHI concept are expected to capture all the important and relevant characteristics.

4.3.5.4 C3.4 Inclusion

Criterion for Evaluation of Response to Challenge Brief (v.3)			
Identifier	Criterion	Description	Change from v.2 to v.3
C3.4	Inclusion	The representation serves to increase inclusion. There are two aspects: content inclusion (who gets represented within the design process and how?) and (ii) process inclusion (who gets to be part of the open-source community?). For content inclusion, this criterion assesses the degree to which the persona representation can capture the barriers to inclusion and/or the particular characteristics of the archetype upon which inclusion is based. For process inclusion, this criterion assesses the persona representation itself is a vehicle for inclusion.	Same as C1.4 & C2.4

The revised persona templates provision for increased inclusion in several important ways. As mentioned earlier in section 4.1.2.2, the direct users and the close circle users have a lifetime experience and expertise in dealing with their own disability and in developing their own approaches and hacks in response. The goal set in the Challenge Brief (v.3) (section 4.3.1.1) was to increase inclusion in OS AT by using persona representations. Two important aspects of this inclusion were: (i) process inclusion which is achieved through the representation of the users in a way that draws upon their decision making dynamics and group work and (ii) the content inclusion which is

achieved through the inclusion of the diversity of their knowledge, experience, and expertise.

The process inclusion is increased through using the personas and emphasizing the collaboration of the members, their group dynamics, and interactions. These characteristics are reflected through the realization of direct users and their close circle as the users of the system and their group collaboration. Personas in PISHI concept put the direct user in the center, representing them as the core in the decision making process and the primary goal for design, while recognizing that all the members are in collaboration and interacting with each other (Figure 4-25). Therefore, the direct user and the close circle of use are included in the design process of the system through using personas that reflect upon their group nature of decision making and dynamics.

The content inclusion is increased through one of the main characteristics captured in the PISHI concept: the knowledge level, experience, and expertise of the direct users and their close circle. This characteristic also informs the design of the differences in needs arising from differences in these characteristics. Through this characteristic, the lifetime experience and expertise of the users of the system are included in the design, enriching the content.

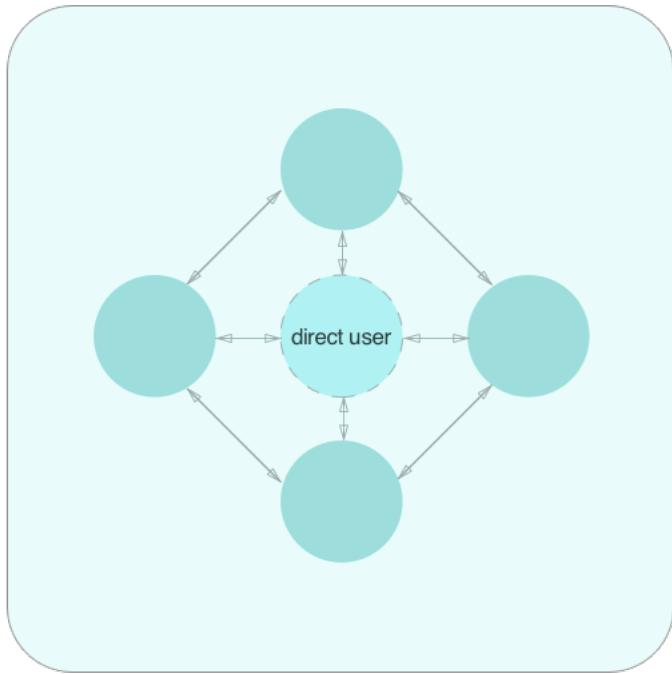


Figure 4-25 PISHI persona concept puts the direct user in center, while recognizing that all the members are in collaboration and interacting with each other.

4.3.6 *Reflection and Discussion*

4.3.6.1 *Shared knowledge and experience, collaboration, and interactions, introduced through distributed cognitive framework*

As explained earlier in section 4.2.5.3.1, one of the issues with individual personas that was also overlooked in Matthews et al.'s model of collaboration personas and other mentions of group personas in the literature is the notion of shared knowledge, experience, and expertise in a group. We claim the knowledge, experience, and expertise to be a collective power of a group of people working towards a goal.

This can be better explained using the distributed cognition framework. As described in section 2.2.1, when the demands of a task (of high difficulty) are divided across individuals and artifacts, the same tasks can be accomplished more efficiently, triggering less anxiety in people. Similarly, distributed cognition provides a framework that can describe how the cognitive cost of computational tasks is distributed among people and artifacts, putting less load on each individual. Through interactions and a series of artefacts people use, the information gets represented and re-represented and propagates through the system (Sharp et al., 2019). Thus, each individual is only doing a part of a big complicated task, bringing their knowledge, abilities, experience, and expertise to the team. The load of the work and materials to be learnt is divided and the group benefits from the collective expertise and experience of the members. Thus, the task can be accomplished more efficiently demanding less effort from each individual.

Members of a family, alongside caretakers and helpers, may have different levels of knowledge or different experiences with technology or ways of learning regarding people with impairments. They might as well have different levels of motivation to learn or use a specific piece of assistive technology, and/or different abilities in learning about, dealing with, and adapting to new technologies, situations, or methods of doing things. The whole process of acquiring, learning to work with a piece of assistive technology, using it, and contributing to its enhancement can be a difficult goal for a person with impairments to accomplish by themselves alone, causing them anxiety and lead them to the abandonment of the assistive technology. However, when distributed among the

members of the close circle, the load of work resulting from the things that must be learnt and used, can be reduced. In any scenario, each member can take a part of the job to be done based on their powers or help others in doing their part. This way, the load of work is being distributed among the members, and the total cost of learning (to work with the new technologies, etc.) will be reduced. Thus, a task that might seem impossible to accomplish for an individual, can be achieved with the collective powers of the members of the close circle.

As an example of how the distributed cognition framework can help to describe the use of Assistive Technologies like SAWS, we will discuss the steps the members of the user circle take to accomplish the task of fixing the font size on SAWS.

- Mina, the person with the impairments has difficulty in seeing the letters on her SAWS program.
- She tells her caretaker about the problem.
- The caretaker goes online, finds the supporting material related to changing the font size, and realizes this problem can be managed through the SAWS configuration panel.
- She then shares the instructions with Mana, the older sister of Mina, who is a tech-savvy person and set up the system in the first place, to change the font setting.

- Mana goes over the different font sizes and asks Mina which font size is more perceivable to her.
- Mina chooses the font size she likes.
- Mana saves the setting and exists the configuration panel.

So collectively, they are able to achieve the goal of fixing the font size on their SAWS program. Similarly, more complicated tasks can be broken down to smaller tasks and achieved through the collaboration and shared knowledge of the users. It is possible that not everyone in the user circle has the knowledge or confidence to do all the tasks by themselves. However, their collective knowledge and expertise can help them get through the tasks.

Downloading, installing, setting up, learning, using the system, customization, giving feedback and probably contributing to the project later are examples of tasks with high cognitive loads that can be achieved way easier through collaboration and sharing knowledge and experience of the members of the user circle.

4.4 Reflection: The Four Evaluation Criteria for a Research through Design Project

Zimmerman et al. (2007) provide a set of four criteria that can be used for evaluating a Research through Design project: process, invention, relevance, and extensibility. In this section I describe the contribution of this research project with respect to each of the criteria.

4.4.1 *Process*

The first criterion, *process*, captures the degree of rigor and detail involved in the development and implementation of the design rationale. In chapter 3, I explained how the design process is being documented through the use of workbook. In chapter 4, I explained my rationale for the creation of each of the templates, the techniques I employed, and finally in the last iteration, the technique I developed. I also provided analysis, after each iteration, of the performance of the templates and the instances created. I have also included the details and templates for replicating the design prototypes in workbook.

4.4.2 *Invention*

The second criterion, *invention*, measures the contributions of the design and the potential for future advancements resulted by the novelty of the contributions. As discussed earlier, the PISHI concept includes the representation of social groups through a template that includes structure and characteristics that have not previously been included in any other persona modelling techniques. Although other persona representations exist and are in use prior to this study, they were not specialized to be used in the domain of Assistive Technologies and not specialized to model social groups such as the families of people who use AT. This project described how these other representations did not adequately capture critical aspects of use in these scenarios. The model for personas within the PISHI concept is suitable for OSSAWS and also can be generalizable to be used in the design domain of OS AT. The PISHI concept, with its focus on creating better design tools for the domain of assistive technology and the approach to documenting the design process to

be shared with the helper community are examples of other innovative aspects that resulted from this research project that can inspire future designs.

4.4.2.1 *The PISHI Concept: Generalizability*

The PISHI concept was shown to have utility in the case of OSSAWS, and now we will describe how it has utility to the domain of Open-Source (OS) Assistive Technology (AT) more generally.

As explained earlier, the PISHI concept was a response to the questions raised in Challenge Brief (v.3) (section 4.3.1.1): How can persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group and decision-making dynamics of the open-source AT? How to do so in a way that considers the heterogeneity of the users in terms of their knowledge, experience, and expertise? The goal was for the technique to capture the two aspects of inclusion that were posed in the questions in this iteration: the process inclusion and content inclusion.

For process inclusion, not only should the users be represented in the design process through the use of personas, but also these personas, in the context of AT, should be capable of representing the dynamics of how decisions are made in a social construct like a family.

As explained in section 2.2.2, open-source software projects typically follow the onion model (e.g., see Table 1 in section 2.2.2). This model has features which are at odds with the goal that the design of AT be inclusive in its process and content. The model reinforces the model that AT is designed *for* the users, rather than *with* them (see section

1.1). We envision that the design decisions made in the course of Open-Source AT software development should have a root in the experiences and needs of the direct users and their close circles, rather than the decisions of the OSS developers. We envision that, by increasing the inclusion of direct users and their close circle in the design process of OS AT, an enhanced onion model, such as the one depicted in Table 7 below can be achieved.

Layer	Description
Inner Core	A person with impairments and their close circle
Outer Core	Usability experts and designers who make the design decisions based on the needs and expectations of the inner core
Middle	Developers and committers who contribute to the project with the approval of the core
Outer	Other helper communities, organizations, interested people with little technical knowledge or experience in AT and disability

Table 7 : Model of improved levels of involvement with an Open-Source Software Community for Open-Source Assistive Technology

In this model shown in Table 7, the direct user (i.e., the person with impairments who is the direct user of the AT) is placed at the center of the process. The members of the close circle (family members, care takers, friends, helpers, and anyone who can be contributing to the process of acquisition, installment, and use of the assistive technology) are shown as interacting with the person at the center. The helper communities in this model are

embracing the circle of users. The model in Table 7 can also be illustrated visually, as shown in Figure 4-26.

Thus, the PISHI concept serves to provide the means for improved levels of involvement with an Open-Source Software Community for Open-Source Assistive Technology.

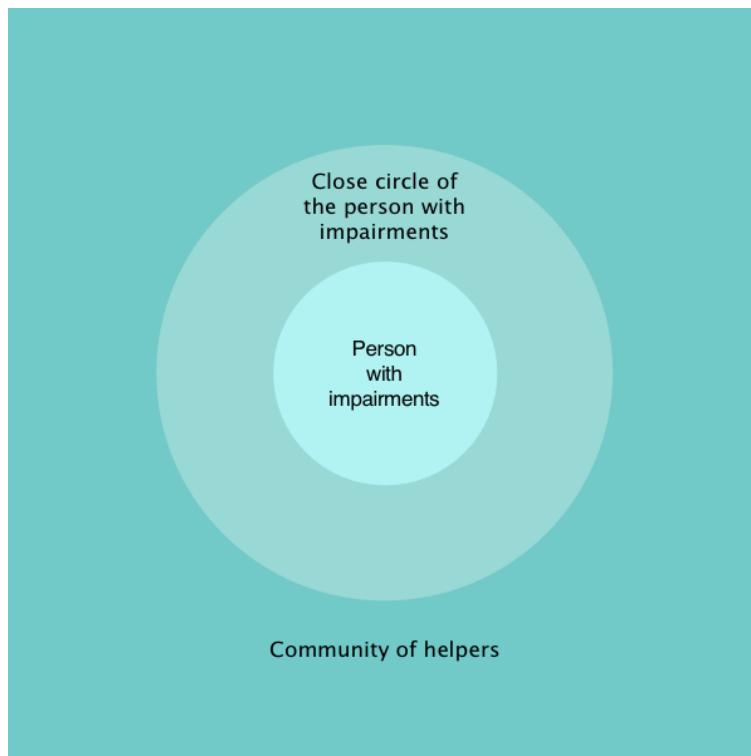


Figure 4-26 The person with impairments is at the center, at the center of circle of use, and embraced by the members of the helper communities.

The PISHI concept generalizes to other instances of OS AT in a way that other persona techniques are not able to. Existing models for personas represent to a small degree or not at all the group dynamics and characteristics of a social construct such as a family in the context of AT. In the case of individual personas, the technique considers each family

member as an individual entity. This kind of perspective overlooks the interactions between the members. This perspective is illustrated in Figure 4-27(a). Also, representing every individual with their goals and characteristics adds redundancy and clutter to the personas represented, as some of their characteristics might be irrelevant to the design or repeated in different representations. Matthews et al. (2011) acknowledged the failure of individual personas to capture collaboration and interactions in the context of use by the group. However, as discussed in section 4.2.5, their proposed alternative — collaboration Personas — is applicable primarily in the design domain of organizational groupware. The collaboration persona approach assumes homogeneity among the members of a group. This perspective is illustrated in Figure 4-27(b). The persona template developed with the PISHI concept does not make this homogenizing assumption. In the PISHI concept, the persona template structure represents the direct user in center of their close support circle. The goals, needs, and characteristics of the direct user as the focus of the circle has more weight. This perspective is illustrated in Figure 4-27(c).

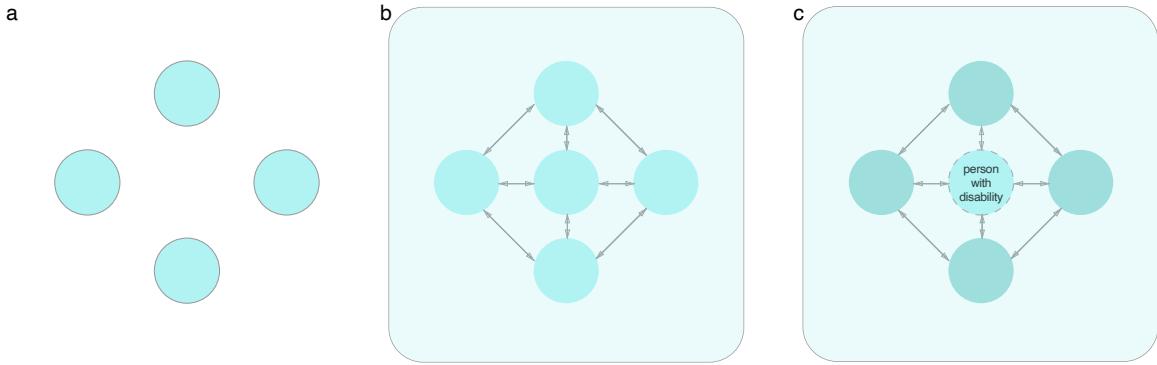


Figure 4-27 shows how SAWs users (direct user and their close circle) are perceived and represented in a) individual personas, b) collaboration personas, c) PISHI concept

With respect to the goal of content inclusion, any persona representation should recognize the heterogeneity of the members within the family group who is using the AT (i.e., the expanded concept of ‘use’, see section 2.2.2.1). It is important to represent the differences in knowledge, experience, and expertise of the members of the family group within the design process. This can be valuable in two ways: (i) it informs the design in terms of making visible the differences in needs that arise due to heterogeneity, and (ii) it informs the design by providing a path for inclusion for the otherwise disregarded or invisibilized non-technical experiences and expertises of people with impairments and their close circle in dealing with disability. Both of these aspects are critical to finding effective AT solutions.

4.4.3 *Relevance*

The third criterion, *relevance*, captures the preferred state of the design intervention and the positive change it can bring to the real world. Surely, it will take time for the impact

of the PISHI concept to become apparent within OS development. Nevertheless, the concept performed well in capturing the characteristics, dynamics, and heterogeneity of the targeted people in the SAWS case study. The PISHI concept was effective when other persona models failed. As established in section 2.3.4.2, using personas increases empathy and inclusivity in design, which results in better usability of the design outcome. A persona representation that describes in a better way the construct it is representing is preferred. I believe that the PISHI concept is a step toward a better understanding, increased inclusion, and a more complete representation of the people with impairments in the process of designing Assistive Technologies.

4.4.3.1 Design Implications – the PISHI Concept and Participatory Design

As was pointed out in section 2.2.3, if the direct users of ATs were to have the means to contribute to OS AT development, this would constitute a form of grass-roots participatory design. This represents process inclusion. The PISHI concept provisions for this. Through their contribution to populating and refining the personas created using the PISHI persona template, direct users and family members are provided with a means to participate in OS AT development, since those personas form a component of software development materials (code base and other materials). Users participating in the participatory design process may not be a permanent part of the team throughout the lifetime of the OS AT system development, but their participation even in this limited form is still a valuable form of participation. The PISHI concept provides the means for their data, goals, and behavioral

patterns to be captured and for them to participate via the personas creations that are being made on the basis of their own data.

The personas developed using the PISHI concept can grow or change over time, based on the changing nature of the user circle's needs and circumstances. The ongoing need to refine the persona provides the rationale for direct users and family members to remain ongoing members of the OS AT team throughout the process of design and development. This will potentially provide stability to the OS AT project, since no matter how often the other SW-focused contributors are involved in the process of design change (e.g., through attrition and through new members joining), the PISHI concept provides the means so that the direct users and close circle can always have a presence through their advocacy to ensure the persona representations are apt. They can remain part of the ongoing process, advocating for their needs, illustrating their goals explicitly through the persona representation, and participating in the design process.

4.4.4 Extensibility

The fourth criterion, *extensibility*, evaluates the extent of impact and future contribution of the project outcomes. The further contribution of the PISHI concept to the OS AT domain will be revealed through time. Considering the demand in the field for ways to improve the inclusion, I believe that the PISHI concept and the PISHI Persona template can be beneficiary to the field of AT and can be used as a starting point for exploring means to inclusion.

4.5 Summary

In this chapter, the RtD methodology was followed through three iterations to respond to the line of inquiry (1.6) for this project: “how can we create more inclusion in open-source AT?” As established in 2.5, Personas are a critical part of the design process and crucial to increase inclusion in the open-source AT. In the first iteration, I investigated the use of individual personas as a means to represent the users of OSSAWS and as a means to increase their inclusion in the design process. I established a set of criteria (section 4.1.2.3) to measure the success of individual personas in responding to the challenge brief (v.1). In the analysis component of the first iteration (section 4.1.4), I demonstrated that individual personas failed to capture important group characteristics of the users in the domain of designing for AT.

Therefore, in the second iteration, I made use of a group persona method — namely collaboration persona (Matthews et al., 2011) — as a technique to respond to the design challenge (v.2). Collaboration personas were introduced to model the organizational groups. Therefore, they are good for modeling the helper communities (category C). However, as per the analysis of the second iteration (section 4.2.5), they misrepresent the direct users and their close circle (Categories A & B) who do not have the same characteristics of an organizational group. Therefore, I argue that another form of representation is needed to represent the social groups like families in the context of AT.

In the third iteration, I invented and used a persona technique, called the PISHI Concept. This persona technique is mainly capturing the overlooked characteristics of the

social groups in the context of AT. In the analysis of the third iteration (section 4.3.5), I showed how personas created using the PISHI Concept overcome the failures of previously used persona techniques in representing the users of OSSAWS and help to provide the means to increase process and content inclusion in the design process.

At the end of Chapter 4, I evaluate the RtD process and argue that the use of the PISHI Concept can be generalized to the domain of AT to increase inclusion in this domain. I also envisioned a model for inclusion/decision-making in the OS AT and argued that the PISHI Concept can be an important aid towards achieving that model.

5 Conclusions and Future Work

5.1 Summary of Research

At the start of this thesis project, I pointed out the issues with process and content inclusion in the design of Open-Source (OS) Assistive Technology (AT) and posed the question “How can persona representations be leveraged into open-source AT in order to build inclusion?”, both in terms of process and content. To answer this question, I established the importance of the persona design representation tool as a component of human-centered design (HCD) approaches. I used the SAWS project as a case study to analyze the role and function of persona representations in OS AT and investigated the available persona modelling techniques. Through this process, I identified several shortcomings of these techniques when used for designing ATs. In response, I iteratively developed the PISHI Concept to provide the means to leverage persona representations into open-source AT, with a focus on providing the means to model social groups like families.

In chapter 2, I presented a summary of the literature review exploring the issue of inclusion in the design of ATs. The literature review indicated the failure to incorporate and consider the needs of people with impairments to be one of the main issues with the adoption of conventional design processes and their tools and techniques in the domain of AT design. The literature review also demonstrated that personas are considered the primary design technique used for the representation of the users in the design process. However, this technique has shortcomings in representing the characteristics of groups in

groupware domains (e.g., when the nature of use of the system is by a group). I also showed how AT can seem both as a single-user system (i.e., the conventional perspective), as well as a group-ware system (i.e., an alternative perspective that recognizes many aspects of use, such as configuration and reconfiguration). Later in Chapter 4, I elaborate the group-ware perspective to identify direct users of ATs, the close circle users, and the helper communities. Considering the importance of personas and their role in the design process, the central question of this research project was refined to “How can persona representations be leveraged into open-source AT in order to build inclusion?” The question is explored through a particular case study: the Switch Activated Writing System (SAWS) system, a system that is in transition to an Open-Source project (OSSAWS).

I employed a Research through Design (RtD) methodology (Chapter 3) since this methodology allows for research to be conducted through the iterative exploration of different design solutions to a given design challenge. Also, the knowledge outcomes of the RtD methodology inform future researchers and designers of the possibilities in the design investigation. In order to make use of RtD, a design process was followed and for that, I used the Double Diamond of Design process model, which entails the phases of Discovery, Define, Develop, and Delivery (which was reshaped into an analysis/reflection phase).

In chapter 4, I describe how I undertook a sequence of design iterations. I went through three iterations of this process model, each time refining the research questions and presenting my results and findings from the research conducted in each iteration. In the

first iteration, I articulated the design challenge, which was “How can persona representations be leveraged into open-source AT in order to build inclusion?” I investigated the use of markdown-based persona template, to be included in the software repository. The template was based on the individual persona technique. In the analysis component of this iteration, my analysis of this design concept showed how the use of a markdown-based template within the codebase addressed the design challenge, but that basing the template on individual personas is insufficient, since doing so fails to capture important group characteristics of the users in the AT design domain. As a result, the challenge brief was revised to add the requirement that the solution needs to build upon group and decision-making dynamics in open-source AT. Subsequently, in the second iteration, I investigated refinement of the design concept through refinement of the persona template, which instead should make use of a group persona method — namely collaboration persona (Matthews et al., 2011) — as the technique to be reflected in the persona template. The analysis of this design concept revealed mixed results. Collaboration personas, which were initially introduced to model organizational groups (e.g., in workplaces), worked well for the helper communities, but do not adequately represent the users, namely both the direct users and the close circle users. The representation does not account for the heterogeneity of the users, in terms of knowledge, experience, and expertise.This analysis revealed the need to reformulate the design challenge to draw upon the heterogeneity of the users as one important component of the response.

In the third and final iteration, I proposed a design concept called **Persona Inclusion** for open Source assistive tecHnology Innovation (PISHI). The PISHI concept provisions for a markdown-based persona template to be included in the software repository, where the persona template is one that has been further developed beyond (Matthews et al., 2011) collaboration personas to more thoroughly model the use of OS ATs by social groups (like families). This PISHI concept is instantiated in the third iteration of this project, producing a set of archetypes to represent the users of OSSAWS (in the expanded sense of user). The PISHI concept was developed to increase the process and content inclusion in the design of OS AT, which is demonstrated through a prospective model for inclusion and decision-making in the OS AT and through a rationale that argues that the PISHI concept can be generalized. My evaluation of the RtD outcomes — in terms of the process undertaken, the novelty of the invention, the relevance, and the extent of the impact — is provided at the conclusion of Chapter 4 and shows that the outcomes of this thesis project are not only useful for its case study (OSSAWS), but also will inform and inspire future research and design in this area.

5.2 Future Directions

As Goodwin (2009) puts it fittingly, “any good method is a living thing that continues to evolve and grow.” Our aspiration is to increase inclusion in the design process of AT, and we believe the introduction of PISHI concept is an important first step. Below, some directions for future extensions are described.

5.2.1 Extending the Use of Markdown for Persona Representation to Other Design Domains

The use of markdown as a markup language was incorporated into the PISHI concept as a modelling technique. As part of the PISHI concept, the use of markdown provides for an explicit representation of user groups (consisting of the direct user, the close circle users, and the expanded helper community) for OS AT in general, as demonstrated for the specific case of OSSAWS. The conjecture is that these markdown representations will provision for the expanded participation in OS development by providing an external representation of what otherwise may be internalized concepts of the users. An external representation, even if not fully accurate, can be revised by others. The use of the markdown format to represent the personas provides the possibility for versioning: representations can be revised, expanded, or forked via open-source approaches. Markdown personas are of potential utility in user-facing open-source projects more generally than the domain of AT, for both groupware and for single-user software. This potential represents many different lines of further investigation.

5.2.2 Empirical Validation

We identified Personas as a crucial means for modelling and representing users, and we developed the means for including users in the design process. The PISHI concept was developed to address the need for a representation technique in the domain of OS AT that is capable of modeling social groups such as families in which a member uses a piece of AT. Although this project included a synthesis of compelling evidence from the research

literature, it did not include an empirical study to investigate the degree to which this social intervention has the desired impact on the OS development process. Thus, this represents a future extension of this project. An empirical study can be conducted investigating the extent to which the open-source community make use of persona technique in open-source projects. And subsequently, the diffusion of uptake of PISHI concept and its persona templates in open-source communities, after the introduction of this technique to the AT development community can be explored. Empirical study can also be conducted in terms of generalizability to other design domains, such as groupware domains other than AT and single-user application domains.

5.2.3 Devise Additional Touchpoints for UX Designers in OS Development

Through using PISHI concept and including users in the design process, we envision that the model for decision-making in OS AT will evolve towards putting the direct users and their close circle more in focus (in the core of the decision-making process model), supported by UX designers and usability experts (in the next outer layer of the decision-making process model). By building more bridging between platforms using Git (e.g., GitHub) and design groupware platforms (e.g., Zeplin and Figma), and by improving the communication between the open-source SW developer community and UX designers and Usability experts, two important steps will be taken to achieve more outreach to the design community. Therefore, future work can also focus on ways to invite more UX designers and usability experts to collaborate on open-source projects.

5.2.4 Expanding the Points of Inclusion in the Design of OS AT

Another concern is the issue of barriers to entry in the design of OS AT. We argued that PISHI concept, and incorporation of persona techniques in the design process of OS AT more generally, will lead to an increase in the points of inclusion in OS AT for UX designers and provides the grounds for more inclusion of the direct user and their close circle with their experience regarding the need and use of AT. Yet, more points of inclusion need to be created for an even larger group of contributors. Some potential contributors with software skills lack critical disability studies knowledge, which can be addressed through initiatives such as to develop explainers and other educational materials on topics such as AT devices, inclusion in design and development of AT, and the notion of ableism for contributors to the software in the open-source communities. Similarly, people with lived experiences in needing and in using ATs, and those who have expertise in the AT domain may not have software skills and could be provided with educational material to learn more about how the open-source communities work and evolve. As well, interventions can be built to encourage these people to contribute to open-source projects that use PISHI concept as a means for inclusion. These educational materials alongside the interventions can provide the grounds for a mutual understanding between different contributors through using the communities' potential for knowledge mobilization and therefore lead to more inclusion and evolvement of the open-source communities.

5.2.5 RtD Methodology for Assistive Technology Development More Generally

One of the reasons that we employed RtD methodology in this thesis project is that the approach provisions for documentation of its knowledge outcomes, which will be helpful for paving the way for future designs and for avoiding the issues raised in the past. Future lines of research could investigate the extent of RtD's potential as a methodology with regards to technology and anti-ableism more generally.

5.2.6 Open-Source Innovation for Personalization and Customization

And finally, the SAWS case study started with the goal of modifying SAWS and its design process to adapt to the changing needs of its users. Regarding this case study, a possibility that can be explored and tested is the personalization of SAWS settings. There has been a debate about whether personalization is preferred by the users of a system. While in personalization, the system changes automatically to tailor to the needs of different users, customization gives them a sense of control and thus is preferred by some users (Sundar & Marathe, 2010). This, however, must be investigated thoroughly in the AT domain, where the systems are intended to be used for a relatively long period of time and the needs of the users gradually changes during the time frame of use.

Bibliography

- Andreasen, M. S., Nielsen, H. V., Schrøder, S. O., & Stage, J. (2006). *USABILITY IN OPEN SOURCE SOFTWARE DEVELOPMENT: OPINIONS AND PRACTICE.* 10.
- Bachmann, F., & Clements, P. C. (2005). *Variability in Software Product Lines:* Fort Belvoir, VA. Defense Technical Information Center.
<https://doi.org/10.21236/ADA450337>
- Bardzell, J., Bardzell, S., Dalsgaard, P., Gross, S., & Halskov, K. (2016). Documenting the Research Through Design Process. *Critical Practice*, 12.
- Cambridge University Press. (n.d.). *User*. Retrieved December 27, 2021, from
<https://dictionary.cambridge.org/dictionary/english/user>
- CanAssist. (2009). *Switch-Activated Writing System*. <Https://Www.Canassist.Ca>.
<https://www.canassist.ca/EN/main/programs/technologies-and-devices/education/writing-system-education.html>
- Caporusso, N. (2008). A wearable Malossi alphabet interface for deafblind people. *Proceedings of the Working Conference on Advanced Visual Interfaces - AVI '08*, 445. <https://doi.org/10.1145/1385569.1385655>
- Cheng, J., & Guo, J. L. C. (2018). How Do the Open Source Communities Address Usability and UX Issues?: An Exploratory Study. *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, 1–6.
<https://doi.org/10.1145/3170427.3188467>

- Colquhoun, H. L., Levac, D., O'Brien, K. K., Straus, S., Tricco, A. C., Perrier, L., Kastner, M., & Moher, D. (2014). Scoping reviews: Time for clarity in definition, methods, and reporting. *Journal of Clinical Epidemiology*, 67(12), 1291–1294. <https://doi.org/10.1016/j.jclinepi.2014.03.013>
- Cooper, A. (1999). *The Inmates are Running the Asylum* (U. Arend, E. Eberleh, & K. Pitschke, Eds.; Vol. 53). Vieweg+Teubner Verlag. https://doi.org/10.1007/978-3-322-99786-9_1
- Cooper, A., Reimann, R., Cronin, D., & Cooper, A. (2014). *About face: The essentials of interaction design* (Fourth edition). Indianapolis, IN. John Wiley and Sons.
- Cowan, Dr. D., Turner-smith, Dr. A., & Centre Of Rehabilitation Engineering. (1999). *The role of assistive technology in alternative models of care for older people, in [26]*.
- Crippledscholar, ~. (2015, July 4). When Celebrating Accessible Technology is Just Reinforcing Ableism. *Crippledscholar*. <https://crippledscholar.com/2015/07/04/when-celebrating-accessible-technology-is-just-reinforcing-ableism/>
- Csikszentmihalyi, M. (2008). *Flow: The Psychology of Optimal Experience*. HarperCollins e-books.
- DeafBlind Ontario Services. (n.d.). *DeafBlind Ontario Services: A Canadian Perspective to the World Federation of the Deafblind report, At Risk of Exclusion from CRPD and SDG's implementation: Inequality and Persons with Deafblindness*. 58.

DeafBlind Ontario Services. (2019, May 14). *Technology's Impact on Communication and Social Connection for the Deafblind*. DeafBlind Ontario Services.

<https://deafblindontario.com/technologys-impact-on-communication-and-social-connection-for-the-deafblind/>

Design Council. (2007). *Eleven lessons: Managing design in eleven global companies* (p. 18) [Desk research report]. Design Council.

Design Council. (2015, March 17). *What is the framework for innovation? Design Council's evolved Double Diamond*. Design Council.

<https://www.designcouncil.org.uk/news-opinion/what-framework-innovation-design-councils-evolved-double-diamond>

Dokumacı, A. (2014). *Disability and “Affordances” of the Everyday*. 08(01), 4.

Fitzgerald, B. (2004). A critical look at open source. *Computer*, 37(7), 92–94.

<https://doi.org/10.1109/MC.2004.38>

Gaver, B., & Bowers, J. (2012). Annotated portfolios. *Interactions*, 19(4), 40–49.

<https://doi.org/10.1145/2212877.2212889>

Gaver, W. (2011). Making spaces: How design workbooks work. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 1551–1560.

<https://doi.org/10.1145/1978942.1979169>

George, J. F. (2003). Groupware. In *Encyclopedia of Information Systems* (pp. 509–518). Elsevier. <https://doi.org/10.1016/B0-12-227240-4/00084-8>

Github Language Stats. (2020, January).

https://madnight.github.io/githut/#/pull_requests/2021/4

Glinert, E. P. (1984). A large font virtual terminal interface: A software prosthesis for the visually impaired. *Communications of the ACM*, 27(6), 567–572.

<https://doi.org/10.1145/358080.358099>

Gollner, U., Bieling, T., & Joost, G. (2012). Mobile Lorm Glove: Introducing a communication device for deaf-blind people. *Proceedings of the Sixth International Conference on Tangible, Embedded and Embodied Interaction - TEI '12*, 127. <https://doi.org/10.1145/2148131.2148159>

Goodwin, K. (2009). *Designing for the digital age: How to create human-centered products and services*. Indianapolis, IN. Wiley Pub.

Hamidi, F. (2015). *RAFIGH: A LIVING MEDIA SYSTEM FOR MOTIVATING TARGET APPLICATION USE FOR CHILDREN*. 361.

Hamidi, F., Baljko, M., & Gómez, I. (2017). Using Participatory Design with Proxies with Children with Limited Communication. *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*, 250–259. <https://doi.org/10.1145/3132525.3132527>

Hamidi, F., & Marcu, G. (2019). DIY Assistive Technology Prototyping Platforms: An International Perspective. *IEEE Pervasive Computing*, 18(4), 12–16.

<https://doi.org/10.1109/MPRV.2019.2947749>

- Harris, J. (2010). The use, role and application of advanced technology in the lives of disabled people in the UK. *Disability & Society*, 25(4), 427–439.
<https://doi.org/10.1080/09687591003755815>
- Hook, J., Verbaan, S., Durrant, A., Olivier, P., & Wright, P. (2014). A study of the challenges related to DIY assistive technology in the context of children with disabilities. *Proceedings of the 2014 Conference on Designing Interactive Systems - DIS '14*, 597–606. <https://doi.org/10.1145/2598510.2598530>
- Hsieh, A., Hausman, T., Titus, N., & Miller, J. (2008). If you build it, they will come ... if they can: Pitfalls of releasing the same product globally. *Proceeding of the Twenty-Sixth Annual CHI Conference Extended Abstracts on Human Factors in Computing Systems - CHI '08*, 2591. <https://doi.org/10.1145/1358628.1358719>
- Hurst, A., & Kane, S. (2013, June 24). Making “making” accessible. *12th International Conference on Interaction Design and Children*.
- Hurst, A., & Tobias, J. (2011). Empowering individuals with do-it-yourself assistive technology. *The Proceedings of the 13th International ACM SIGACCESS Conference on Computers and Accessibility - ASSETS '11*, 11.
<https://doi.org/10.1145/2049536.2049541>
- Interaction Design Foundation. (2020). *Useful, Usable, and Used: Why They Matter to Designers*. The Interaction Design Foundation. <https://www.interaction-design.org/literature/article/useful-usable-and-used-why-they-matter-to-designers>

Iskander, N. (2018, September 5). Design Thinking Is Fundamentally Conservative and Preserves the Status Quo. *Harvard Business Review*.

<https://hbr.org/2018/09/design-thinking-is-fundamentally-conservative-and-preserves-the-status-quo>

Jayant, C., Acuario, C., Johnson, W., Hollier, J., & Ladner, R. (2010). V-braille: Haptic braille perception using a touch-screen and vibration on mobile phones.

Proceedings of the 12th International ACM SIGACCESS Conference on Computers and Accessibility - ASSETS '10, 295.

<https://doi.org/10.1145/1878803.1878878>

Judge, S., & Lysley, A. (2005). *OATS - Open Source Assistive Technology—A way forward*. 3.

Judge, T., Matthews, T., & Whittaker, S. (2012). Comparing collaboration and individual personas for the design and evaluation of collaboration software. *Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems - CHI '12*, 1997. <https://doi.org/10.1145/2207676.2208344>

Korn, O., Holt, R., Kontopoulos, E., Kappers, A. M. L., Persson, N.-K., & Olson, N. (2018). Empowering Persons with Deafblindness: Designing an Intelligent Assistive Wearable in the SUITCEYES Project. *Proceedings of the 11th PErvasive Technologies Related to Assistive Environments Conference*, 545–551.

<https://doi.org/10.1145/3197768.3201541>

- Kuniavsky, M. (2004, September 14). *Extending a Technique: Group Personas—Boxes and Arrows*. <https://boxesandarrows.com/extending-a-technique-group-personas/>
- Makers Making Change*. (n.d.). Retrieved February 8, 2021, from
<https://www.makersmakingchange.com/>
- Makey Makey – Joylabz Official Makey Makey Store*. (n.d.). Retrieved February 8, 2021, from <https://makeymakey.com/>
- Mankoff, J., Hayes, G. R., & Kasnitz, D. (2010). Disability studies as a source of critical inquiry for the field of assistive technology. *Proceedings of the 12th International ACM SIGACCESS Conference on Computers and Accessibility*, 3–10.
- Marcus, A., Aykin, N., Chavan, A. L., Prabhu, G. V., & Kurosu, M. (1999). SIG on one size fits all?: Cultural diversity in user interface design. *CHI '99 Extended Abstracts on Human Factors in Computing Systems - CHI '99*, 342.
<https://doi.org/10.1145/632716.632925>
- Matthews, T., Whittaker, S., Moran, T., & Yuen, S. (2011). Collaboration personas: A new approach to designing workplace collaboration tools. *Proceedings of the 2011 Annual Conference on Human Factors in Computing Systems - CHI '11*, 2247. <https://doi.org/10.1145/1978942.1979272>
- McKenzie, J. (2022, February 4). *Grey literature: What it is & how to find it | SFU Library*. <https://www.lib.sfu.ca/help/research-assistance/format-type/grey-literature>

- Meissner, J. L., Vines, J., McLaughlin, J., Nappey, T., Maksimova, J., & Wright, P. (2017). Do-It-Yourself Empowerment as Experienced by Novice Makers with Disabilities. *Proceedings of the 2017 Conference on Designing Interactive Systems - DIS '17*, 1053–1065. <https://doi.org/10.1145/3064663.3064674>
- Nagy, D., Yassin, A. M., & Bhattacherjee, A. (2010). Organizational adoption of open source software: Barriers and remedies. *Communications of the ACM*, 53(3), 148–151. <https://doi.org/10.1145/1666420.1666457>
- Nichols, D. M., & Twidale, M. B. (2006). Usability processes in open source projects. *Software Process: Improvement and Practice*, 11(2), 149–162. <https://doi.org/10.1002/spip.256>
- Nielsen, J. (2012, January 3). *Usability 101: Introduction to Usability*. Nielsen Norman Group. <https://www.nngroup.com/articles/usability-101-introduction-to-usability/>
- Nielsen Norman Group, W. L. in R.-B. U. (n.d.). *Personas Make Users Memorable for Product Team Members*. Nielsen Norman Group. Retrieved August 7, 2021, from <https://www.nngroup.com/articles/persona/>
- Norman, D. (2021, March 23). *People-Centered (Not Tech-Driven) Design | Essay by Don Norman | Britannica*. <https://www.britannica.com/topic/People-Centered-Not-Tech-Driven-Design-2118618>
- Nutter, D. (2006, August 11). *OATS Meeting Aftermath*. Open Source Specialist Group. <https://ossg.bcs.org/blog/2006/08/11/oats-meeting-aftermath/>

OATS. (2016). In *Wikipedia*.

<https://en.wikipedia.org/w/index.php?title=OATS&oldid=723701445>

O’Kane, A. A., Hurst, A., Niezen, G., Marquardt, N., Bird, J., & Abowd, G. (2016).

Advances in DIY Health and Wellbeing. *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems - CHI EA ’16*, 3453–3460. <https://doi.org/10.1145/2851581.2856467>

Okerlund, J., & Wilson, D. (2019). DIY Assistive Technology for Others: Considering Social Impacts and Opportunities to Leverage HCI Techniques. *Proceedings of FabLearn 2019 on - FL2019*, 152–155.

<https://doi.org/10.1145/3311890.3311914>

Olson, J. S., & Kellogg, W. A. (Eds.). (2014). *Ways of Knowing in HCI*. Springer New York. <https://doi.org/10.1007/978-1-4939-0378-8>

Phillips, B., & Zhao, H. (1993a). Predictors of assistive technology abandonment. *Assistive Technology*, 5(1), 36–45.

Phillips, B., & Zhao, H. (1993b). Predictors of Assistive Technology Abandonment. *Assistive Technology*, 5(1), 36–45.

<https://doi.org/10.1080/10400435.1993.10132205>

Plaisier, M., & Kappers, A. (2021). Social Haptic Communication mimicked with vibrotactile patterns—An evaluation by users with deafblindness. *The 23rd International ACM SIGACCESS Conference on Computers and Accessibility*, 1–3. <https://doi.org/10.1145/3441852.3476528>

Pressman, R. S., & Maxim, B. R. (2020). *Software engineering: A practitioner's approach* (Ninth edition). New York, NY. McGraw-Hill Education.

Pruitt, J., & Adlin, T. (2006). The Persona Lifecycle: Keeping People In Mind Throughout Product Design. In *The Persona Lifecycle* (p. i). Elsevier.

<https://doi.org/10.1016/B978-0-12-566251-2.50022-8>

Rajanen, M., & Iivari, N. (2015). Power, Empowerment and Open Source Usability. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, 3413–3422.

<https://doi.org/10.1145/2702123.2702441>

Rajapakse, R., Brereton, M., Sitbon, L., & Roe, P. (2015). A Collaborative Approach to Design Individualized Technologies with People with a Disability. *Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction on - OzCHI '15*, 29–33.

<https://doi.org/10.1145/2838739.2838824>

Ravneberg, B. (2012). Usability and abandonment of assistive technology. *Journal of Assistive Technologies*, 6(4), 259–269.

<https://doi.org/10.1108/17549451211285753>

Roark, B. (2010). *Scanning methods and language modeling for binary switch typing*. 9.

Roedl, D., Bardzell, S., & Bardzell, J. (2015). Sustainable Making? Balancing Optimism and Criticism in HCI Discourse. *ACM Transactions on Computer-Human Interaction*, 22(3), 1–27. <https://doi.org/10.1145/2699742>

- Rogers, Y., & Marsden, G. (2013). Does he take sugar?: Moving beyond the rhetoric of compassion. *Interactions*, 20(4), 48–57.
- Sack, W., Détienne, F., Ducheneaut, N., Burkhardt, J.-M., Mahendran, D., & Barcellini, F. (2006). A Methodological Framework for Socio-Cognitive Analyses of Collaborative Design of Open Source Software. *Computer Supported Cooperative Work (CSCW)*, 15(2–3), 229–250. <https://doi.org/10.1007/s10606-006-9020-5>
- Sharp, H., Preece, J., & Rogers, Y. (2019). *Interaction Design*. 657.
- Stappers, P. J. (2007). Doing Design as a Part of Doing Research. In R. Michel (Ed.), *Design Research Now* (pp. 81–91). DE GRUYTER. https://doi.org/10.1007/978-3-7643-8472-2_6
- Stappers, P. J., & Giaccardi, E. (n.d.). 43. *Research through Design*. 91.
- Steinmacher, I., Chaves, A. P., Conte, T. U., & Gerosa, M. A. (2014). Preliminary Empirical Identification of Barriers Faced by Newcomers to Open Source Software Projects. *2014 Brazilian Symposium on Software Engineering*, 51–60. <https://doi.org/10.1109/SBES.2014.9>
- Sun, W., Zhang, X., Guo, C. J., Sun, P., & Su, H. (2008). Software as a Service: Configuration and Customization Perspectives. *2008 IEEE Congress on Services Part II (Services-2 2008)*, 18–25. <https://doi.org/10.1109/SERVICES-2.2008.29>
- Sundar, S. S., & Marathe, S. S. (2010). Personalization versus Customization: The Importance of Agency, Privacy, and Power Usage. *Human Communication Research*, 36(3), 298–322. <https://doi.org/10.1111/j.1468-2958.2010.01377.x>

- Theil, A., Buchweitz, L., Fuentes, M., & Korn, O. (2020). Co-Designing Assistive Tools to Support Social Interactions by Individuals Living with Deafblindness. *Companion Publication of the 2020 ACM Designing Interactive Systems Conference*, 79–83. <https://doi.org/10.1145/3393914.3395869>
- Theil, A., Buchweitz, L., Gay, J., Lindell, E., Guo, L., Persson, N.-K., & Korn, O. (2020). Tactile Board: A Multimodal Augmentative and Alternative Communication Device for Individuals with Deafblindness. *19th International Conference on Mobile and Ubiquitous Multimedia*, 223–228. <https://doi.org/10.1145/3428361.3428465>
- Thingiverse—Digital Designs for Physical Objects*. (n.d.). Retrieved February 8, 2021, from <https://www.thingiverse.com/>
- usability.gov. (2013, October 8). *Usability Evaluation Basics*. Department of Health and Human Services. <https://www.usability.gov/what-and-why/usability-evaluation.html>
- World Health Organization (Ed.). (2001). *International classification of functioning, disability and health: ICF*. World Health Organization.
- Xu, C., Israr, A., Poupyrev, I., Bau, O., & Harrison, C. (2011). Tactile display for the visually impaired using TeslaTouch. *Proceedings of the 2011 Annual Conference Extended Abstracts on Human Factors in Computing Systems - CHI EA '11*, 317. <https://doi.org/10.1145/1979742.1979705>

Zimmerman, J., Forlizzi, J., & Evenson, S. (2007). Research through design as a method for interaction design research in HCI. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '07*, 493–502.

<https://doi.org/10.1145/1240624.1240704>

Appendices

Appendix A: Glossary

- **Affordance:** an action possibility formed by the relationship between an agent and its environment. Dokumaci (2014) defines the affordance for people with disabilities as a sequence of steps they create to combat the barriers they face in everyday life.
- **Assistive Technology (AT) design phenotype:** a conceptual design (for example, for switch activated writing system) and a configuration of software and hardware components that can be tailored in different ways for different users and use cases (e.g., main app plus specialized input devices, such as switches).
- **Assistive Technology (AT) instance:** a specific instantiation of a phenotype, tailored for a specific user/context. Many, even slightly different, ATs can all be instantiations of the same given design phenotype.
- **Configuration, Software:** tailoring an instance of software through changing pre-defined parameters
- **Customization, Software:** tailoring that happens through making changes to the source code of software, in order to add functionalities beyond the configurable limit. These changes are initiated by users.
- **Edge scenarios:** A scenario of use that is possible but rarely happens.
- **Personalization:** tailoring of a system based on user data initiated by the system.

- **The SAWS ‘user circle’:** refers to an assemblage of people collectively using SAWS. In the center of the circle is the user in the role referred to as the ‘writer’. The role is typically occupied by a person with hearing and vision impairments (direct user). Around the center are other circle members, which can include an intervenor, close family members, friends, teachers, and potentially others. The concept of the ‘user circle’ is used to refer to the collective which needs to be able to set up the system, to configure the SAWS app, to get it going, to make modifications to the configuration as needed, and all other activities related to the use of SAWS. The particular activity of writing text is something that the writer should be able to do on their own.
- **Software Product Line (SPL) Development:** or software product line development, refers to software engineering methods, tools, and techniques for creating a collection of similar software systems from a shared set of software assets using a common means of production.
- **Usable (specific to phenotype + support resources):** referring to the ability of the user circle to collectively be able (i) at the outset, to customize (decide on which parameter values to use, given the available parameters) and instantiate (launch with those specific parameters) so that writing is afforded (to the direct user) (ii) at any later time, to re-engage to respond to changes in the user scenario that may arise over time for the particular user.

- **Usable (specific to SAWS writing):** referring to the ability of the writer to set up, learn, discover, and utilize the SAWS system to write without undue effort and to be able to continue using SAWS system independent from the help the close circle or other assistance.
- **User Scenario:** a structured description of a situation or event that a potential user (or buyer) of a product is likely to experience as they seek to achieve their goals.
- **Writing:** Refers to all forms of activities that are part of the act of writing, such as composing text within text-based asynchronous communication processes (e.g., interpersonal communication), as part of doing schoolwork or creating work products (e.g., document preparation), as part of a diary (e.g., self-reflection in which one's audience is one's self), and other activities in which writing takes place.

Appendix B: Workbook

Background

Switch Activated Writing System (SAWS) was first designed and implemented by the head of the PiET lab, Professor Melanie Baljko, to enable a 16-year-old girl with deaf-blindness and motor disabilities to write. This system makes use of scanning methods on a large screen so that the user can navigate through the options and choose the option they want. The list of options presented on the screen can be list of letters, numbers, etc. that they choose when writing; list of contacts; list of functions (usually represented through symbols).

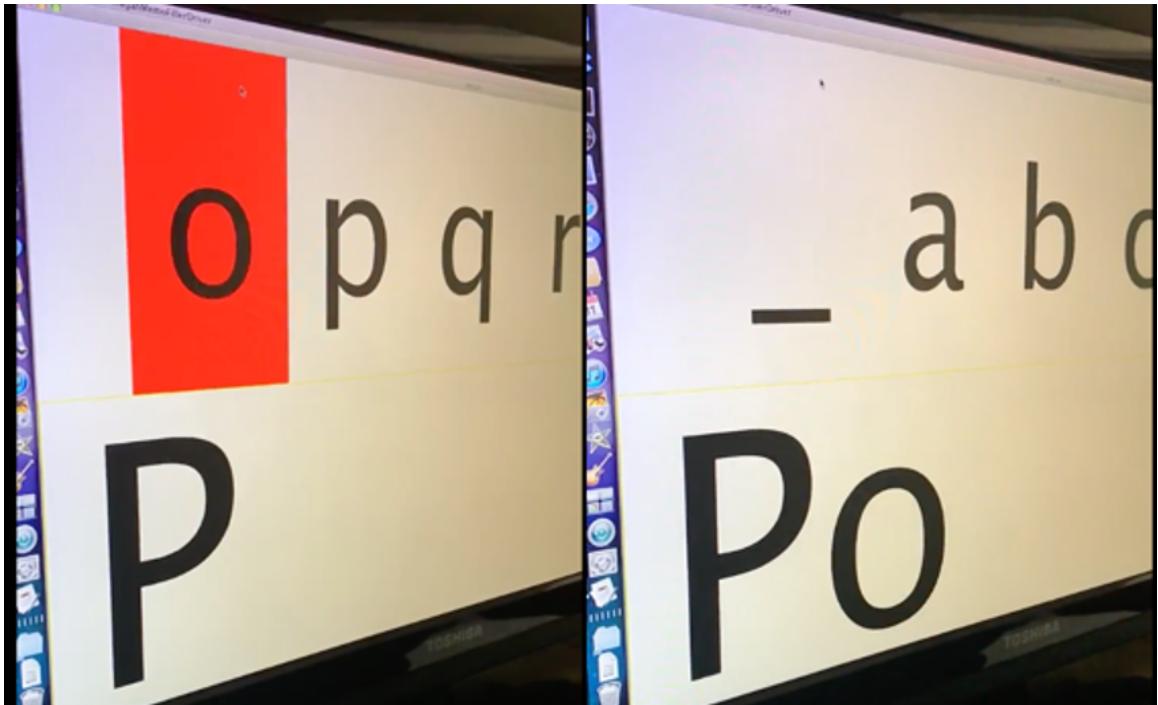


Figure 0-1 A snapshot of the current Switch Activated Writing System (SAWS). Letter ‘o’ is chosen in the current scan.

After using SAWS for 10 years, her family contacted the lab requesting some adjustments to the writing system that has been used by her the whole time.

The lab received two videos of her working with the system and explaining her problems with the system as she went on. Her caretaker tried to narrate the process and re-enunciate the words she was saying.

The videos of these sessions are confidential and cannot be shared online. However, the problems she had with the system over the course of its usage are documented and listed here:

- The order of alphabets to choose from needs to change from alphabetical order to most-frequently-used order
- More characters for punctuation need to be added.
- More options for formatting the document (e.g. inserting indents, having paragraphs) need to be added.
- More options for styling text, e.g. choosing font faces, sizes, and colors.
- The possibility to choose the file names (and possibly format). Initially, the output files are generated automatically based on a timestamp.
- The possibility to change some parameters of the system, such as dwell time on each character.

Even though a workbook by nature is a collection of proposals defined by Gaver (2011) as “very rough collages of alternative devices that explored a range of personal and idiosyncratic possibilities”, we tried to bring a bit of structure to each proposal. Therefore, In each section, we tried to follow the same order of material for easier access for future readers.

Even though notes were being made through the meetings and records of the thought processes and ideas were existent, the idea of using a workbook to document the design process was something adopted much later after the start of the project. Therefore, this workbook might be more of a summary of what has been done than a step by step report of all the thought processes, ideas, etc. The goal of this workbook however is to document

of the future thought processes, ideas, challenges, breakthroughs, and suggestions for further exploration.

Initial goals of the project

We started by thinking about how we can adjust the system to the current needs of its user.

But the main issue was that the current needs of the user will not remain the same for long.

And it is not efficient or convenient for her to reach out every time she needed a change.

Initial goal of the project was to make a configuration panel for SAWS, so that M and her close circle can change and adjust the parameters when they feel the need.

SAWS can be used by other people with similar disabilities/abilities

The request for SAWS software revision also activated the goal to deploy SAWS more widely and through an open-source distribution. SAWS can be shared as a configurable sustainable SAWS phenotype that can be instantiated according to each user's needs. If this system could help one person for 10 years, maybe if it could be adjusted to the needs of another person with similar impairments, it can help them too.

Challenges

What ICT support infrastructure (model for deployment and maintenance) will best empower the (helper) community to sustain the SAWS system, given the expected evolution of both the software and the support resources?

Given this specific tailor-made SAWS, which \textbf{software variation management model} to employ when creating the phenotype SAWS?

What type of instantiation process (i.e., instantiation guide and additional support resources) do we have to design so that the phenotype can be usable?

Obstacles

A series of in-person data collection and observation sessions were planned, but unfortunately, due to the situation caused by COVID-19, a redesign of the research project was needed to move away from these forms of data collection. During the outbreak of COVID-19 in Canada, contact was lost with M's family, for unknown but probably completely understandable reasons. The situation dictated a redesign of the research project.

We need infrastructure

We realized that enhancement of SAWS, making SAWS configurable or building the SAWS phenotype and the support resources cannot be done once. We needed prolonged maintenance and sustainability. Aside from that, the infrastructure should provide support resources and points of contact for people who need to instantiate the system for their use. This infrastructure can act as a hub, connecting the people with impairments and their families to designers and developers to talk about their needs and request their changes.

Goals

The goal at this point is to build an infrastructure where:

- People can access the phenotype system
- People can get help for configuring an instance of the system and using it
- People can access the support resources

- UX designers can co-ordinate the needs of the people with the OS Community (including configuration settings, etc.)

Process

We followed double diamond of design as our main process model.

Challenges

Even though there are several DIY/OS communities for Assistive Technologies (such as Makey Access, Thingiverse, and Makers Making Change), no open-source platform for design of AT has been located.

There are researches showing that Open-Source Software generally has poor usability and that is due to

- Lack of design knowledge of people contributing to the development of open-source technologies
- Lack of contribution of usability experts
- Lack of suitable means of documentation and representation of data, design ideas, and decisions
- Lack of proper channels for usability experts and end users to access the decision makers with their concerns

Therefore, in order to build the infrastructure, critical underlying components needed to be created to address the issues above, that is to **provide means of inclusion for people with skills other than software in the design process.**

Therefore, the main challenge is identified as finding/developing the right means for increasing the inclusion of people in the design process of AT. Such means are also necessary to carry on the design tasks and so are preliminary to the creation of the infrastructure.

We need the right tools to increase inclusion and eventually build the infrastructure

It seemed that explicitly documenting the designers' mental models of the users is key. Reviewing the literature, personas were identified as the most important representation tool introduced to explicitly model the users of a system. According to Cooper, making these mental models explicit helps to prevent design pitfalls, like falling for edge cases, elastic users, and self-referential design. Cooper also states that personas are a strong communication tool, which helps people involved in the design to communicate their ideas through a model that does not change to fit the needs of the stakeholder.

Challenge

How can persona representations be leveraged into open-source AT in order to build inclusion?

Solution

First, we had an analysis of the user population that will be using the infrastructure. The groups using the infrastructure devide into two main groups; the people who use the SAWS instance for the purpose of writing, and the helpers whose goal is to contribute to the SAWS phenotype, or configure the settings as per the SAWS users' request.

User Profiles	Community of Users	1	People with deaf blindness and motor disabilities with little to no technical knowledge	3	Close circle of 1 with no technical knowledge
		2	People with deaf blindness and motor disabilities with enough knowledge to use the system	4	Close circle of 1 with enough technical knowledge
		5	Close circle of 2 with no technical knowledge	6	Close circle of 2 with enough technical knowledge
		7	Designers/ Usability Experts		
		8	Developers of the OSS Community		
		9	Other helper communities/ organizations/ groups		
		10	Other people willing to help the community of helpers with little to no expertise in Design of Assistive technologies or development with the platforms used to develop SAWS		
	Community of Helpers				

Figure 0-2 Grouping of the users of OSSAWS

We created 10 (conventional) personas to represent the different archetypes that use the system.

To provide the possibility of tracking the changes for the personas, and making them more easily updatable and sharable, we decided to make a *markdown* version of the personas. Markdown personas can be shared on GitHub alongside code, prior to the creation of the infrastructure. Markdown personas can be easily rendered to visual representations. Therefore, their use is not limiting the designers not familiar with coding from taking part in the project.

Obstacles

Initially, user groups 3 and 4 were clustered with groups 5 and 6 respectively, due to goals being similar in the duos. However, these groups react differently in similar scenarios. For example, in a scenario where a person from user group 2, has enough technical knowledge, and can guide their family from user group 5 to operate a specific task, but a person from user group 1 with a family from user group 3, needs more support resources to accomplish the same task. Therefore, user groups 3 is different from user groups 5, because the direct users (person with deaf-blindness and motor impairments) of the system around which these groups are formed are from different user groups, with different levels of technical knowledge which affects their needs. And thus, merging user groups 3 and 5 leads to misrepresentation of the users. The same reasoning can be applied to groups 4 and 6. Yet, this connection is not reflected well when the direct user is studied separately from their close circle.

Analysis/ Discussion

In summary, individual personas overlook the collaboration and interactions of the family members and are not representative of the collective goals of the group.

We need a group persona representation

A study of the literature yielded some reports of different types of group personas previously introduced to model groups, usually within an organization.

Cooper suggests Organizational Personas, made from aggregating individual personas presenting them alongside the goals and behaviours of the organization, to be used for

representing the organization. Kuniavsky (2004) suggests a form of group personas mainly based on group goals and drives.

But maybe the most complete model for group personas was introduced by Matthews et al., called Collaboration Personas. These personas are intended to represent the organizational groups with a focus on their collaboration and interactions. The template suggested by Matthews, has four main attributes:

1. Group Goals
2. Work Style
3. Leadership
4. Stability of the members

Challenge

How can persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group and decision-making dynamics of this open-source AT?

Solution

We created markdown collaboration persona templates with the following attributes:

- Group Name
- Group Picture
- Group Goals
- Work Style
- Leadership

- Stability of the members

We added the first two attributes from the individual persona model to increase empathy.

This template, like the earlier template, affords the possibility of changes to be tracked and being sharable.

Analysis/ Discussion

The focus in the collaboration persona model is on the group nature of use in the *organizational setting*. There are two main issues with using such model in the design domain of OS AT:

The characteristics modelled with Collaboration Personas are for organizational settings

The characteristics used to model the users in the collaboraiton persona are intended for organizational settings. The nature of the groups they are modeling differs from those of AT. Therefore, some of the information they illustrate are expendable in the realm of assistive technology and a family setting of use. For example, the attribute stability of the members shows whether the members of a team in an organization stay in the team or get swapped out frequently. Such characteristic is not adding any useful information in the case of an family setting, where most members usually stay the same.

Collaboration Personas do not capture the characteristics needed in OS AT Design

There are important characteristics of the family groups that need to be represented through the representation models, but collaboration personas fail to capture them. And that is because collaboration personas were created for a different design domain. One of these

characteristics is the heterogeneity of the members in terms of knowledge, experience, and expertise. In an organizational setting, people are usually hired through a process that assesses their knowledge and skills regarding the tasks they will be assigned. Whereas, in a family, people are not hired or chosen based on their skills. They come together from different backgrounds with different levels of knowledge, abilities, skills, and motivations. This highlights an important difference between an organizational construct and a social construct like a family. The use of collaboration personas for a social setting like a family is not effective as it does not reflect the diversity of knowledge, skills, and experience of the members.

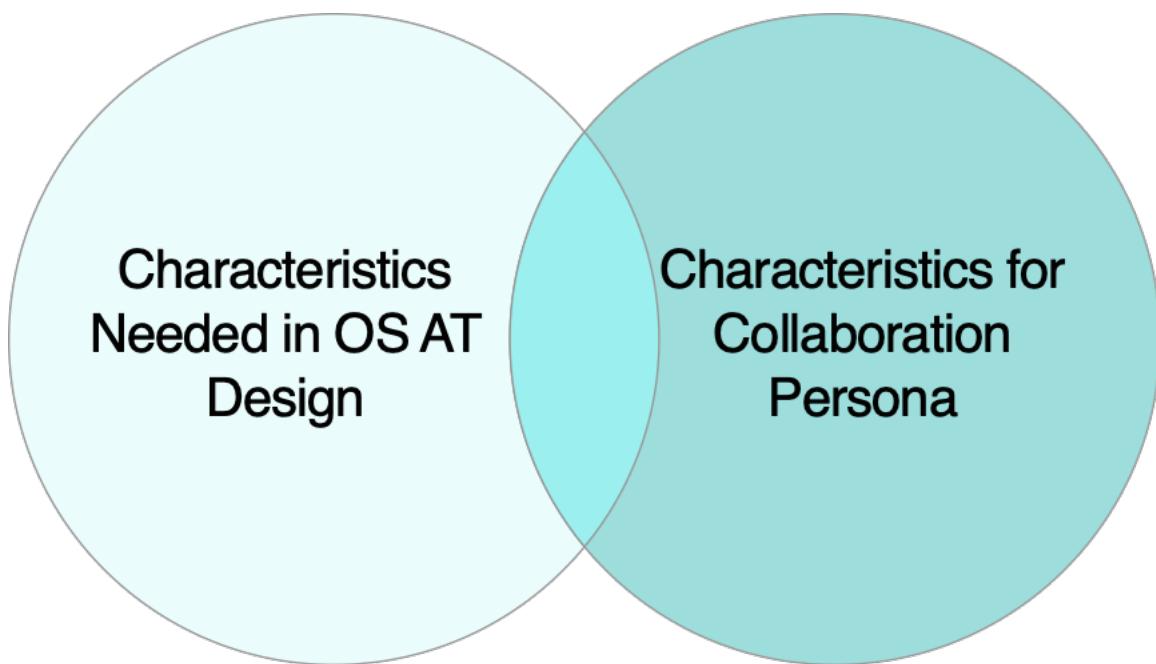


Figure 0-3 Comparison of the characteristics pertaining to OS AT vs Organizational settings

We need group personas representing the users of this design domain

Based on the points raised, there is a need for a group persona that is capable of representing the members of a social group like a family.

Searches for such personas had little success. Therefore, we aimed to create such personas to be used when designing OS AT.

Challenge

How can persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group and decision-making dynamics of this open-source AT? How to do so in a way that considers the heterogeneity of the users in terms of their knowledge, experience, and expertise?

Solution & Discussion

The initial idea at this point was to make a persona, representing a group with their group goals, alongside attributes that explain the knowledge, experience, and expertise level of the family.

However, this form of representation overlooks the uniqueness of the direct users and their goals and characteristics. Even though, people in a family work in a group and collaborate to get the system installed, configured, etc., the main act of using the system to write resides with the direct user. Therefore, a group representing attributes of a social group like a family is not enough for properly representing the direct user and their close circle in the context of using AT.

We need a hybrid persona representation

At this point, we realized that the direct user should have a prominent presence in the persona representations. The goals and characteristics of the direct user are far too pivotal in making the design decisions that they cannot be overshadowed by the lesser and yet important goals and characteristics of their close circles.

However, if we isolate the direct user in an individual persona, we will face the same issues discussed in the first round of using individual personas, which is that the collaboration and interactions between the members are going to be overlooked.

Challenge

The challenge stays the same:

How can persona representations be leveraged into open-source AT in order to build inclusion? How to do so in a way that builds upon the group and decision-making dynamics of this open-source AT? How to do so in a way that considers the heterogeneity of the users in terms of their knowledge, experience, and expertise?

Solution

We propose to embed an individual persona, representing the direct user, inside a group persona, representing the close circle. The template of such a persona will be as followed:

OS Persona Template (v.3)

Individual Attributes (direct user):

- Individual Archetypal Name, *altered, now referring to the archetypal name of the direct user*

<ul style="list-style-type: none"> • Individual Archetypal Picture, <i>altered, now referring to the archetypal picture of the direct user</i> • Demographic Information, <i>added</i> • Impairment(s) (Access Barriers), <i>added</i> • Goals, <i>altered, now referring to the goals of the direct user</i> • A bio/explanation of their experience can be added to the persona to increase relatability, <i>added</i>
<p>Group Attributes (direct user + close circle):</p> <ul style="list-style-type: none"> • Group Archetypal Name, <i>altered, now referring to the archetypal name of the family (direct user + close circle)</i> • Group Archetypal Picture, <i>altered, now referring to the archetypal picture of the family</i> • Group Goals, <i>altered, now referring to the goals of the family</i> • Knowledge, experience, expertise, <i>added</i>

Table 8 - Template for personas provided by the PISHI Concept

This template, as well, will be shared and used in markdown to provide the possibility of tracking changes, version control, etc. We call the concept emerging from this practice: **Persona Inclusion for open Source assistive tecHnology Innovation (PISHI)**.

Analysis/ Discussion

Personas created using the PISHI Concept are representing an assemblage of the person with impairments and their close circle (family members, intervenors, friends, etc.). The structure of the templates and their saliency in capturing the characteristics of the people they are representing within the design domain, makes them usable in OS AT.

The persona template in the PISHI Concept has two components, one to represent the whole circle of use and one component to represent the direct user. This leads to an additional focus on the person with impairments, as the main focus of the design, alongside capturing group nature and characteristics of use through the group component. For example, there are two attributes in this template to represent the persona goals; (Individual) Goals and Group Goals. While the latter models the collective goals of the circle of users, the former focuses on the individual goals of the direct user.

The template is also salient in its capture of the characteristics of the users in this design domain. As mentioned earlier, the collective knowledge, experience, and expertise of the family members in this design domain is an important characteristic that can guide design decisions. This relevant characteristic to the design domain was overlooked in earlier models of group personas, such as the collaboration personas, because of certain assumptions regarding the knowledge and skill level of people hired to work in a team. Therefore, using the personas created by following the PISHI Concept, we were able to model the users of an AT in a way that is representative of their group nature and collective goals and characteristics.

The performance of the different persona models is summarized in the table below.

	Individual Personas	Collaboration Personas	PISHI Personas
Level of Granularity	Strong	Weak	Strong
Goal Capture	Weak	Strong	Strong
Salient Characteristics Capture	Weak	Medium	Strong
Inclusion (content)	Weak	Medium	Strong

Figure 0-4 Comparison of the performance of different Personas in representing the users of OS AT

PISHI Concept increases process inclusion

The templates created have the ability to be altered and to have their changes track over time (e.g., via a “Git diff”). They can be shared and accessed on Git repositories easily. Therefore, they provide the means of including people in the design **process** of OSS.

PISHI Concept increases content inclusion

PISHI Concept describes a family construct that has a person with impairments in the center. The group collaborates using their collective knowledge, experience, and expertise to accomplish their collective goals. The individual characteristics, goals, and needs of the person with impairments remain the focus of the design, while the group nature of use is

acknowledged and designed for. Thus, PISHI Concept provides the means of including the **people** in the design process of OS AT.