Living with Hearing Loss in a Connected Home

White Paper

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PETRAS
THE PETRAS NATIONAL CENTRE OF EXCELLENCE FOR IoT SYSTEMS CYBERSECURITY

Table of Contents

Acknowledgements

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Building on PETRAS-BRE IoT in the Home Demonstrator, our research and outputs have synergy with PETRAS' portfolio for 'human in the loop' and 'supporting people with special requirements,' alongside PETRAS catalyst projects, such as the 'Intelligible Cloud and Edge AI' and 'Cyberphysical Social Machines'.

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Executive Summary

This paper provides insights into the requirements and expectations of people with hearing loss in engagement with connected devices at home, derived from a questionnaire and a stakeholder workshop, and supported by relevant literature. The paper details challenges facing people with hearing loss in engagement with connected technologies and identifies priority areas for technology intervention and development.

The workshop was organised by the PETRAS National Centre of Excellence for IoT Systems Cybersecurity. It was attended by representatives from technology companies and various UK groups for people with hearing loss (both profoundly deaf and hard-of-hearing, as well as cochlear implant users), some individual end-users with various types of hearing loss, and researchers.

Key challenges

Our analysis of the workshop data surfaces four key related challenges for people with hearing loss in engagement with technologies in daily life, particularly at home. These challenges are very similar to some of the challenges emerging from the social research in the IoT in the Home Demonstrator project[1]. The significant differences for those with hearing loss are in the priority and acuteness of requirements, as well as the severity of consequences of absence or failure or malfunctioning of the technologies that people with hearing loss rely on. The four related challenges are:

- Communication barriers;
- Dependency (on technology and hearing people);
- Limited agency or internal sense of control;
- Exclusion.

Whether they like it or not, people with hearing loss may depend on a hearing person or technologies (e.g. hearing aid and voice recognition to text) to communicate and interact with the hearing world. While technology intervention can reduce needs for help from hearing people, it inevitably increases dependency on technologies. This can lead to people with hearing loss feeling out of control, especially when communication technologies do not function as expected, often without any back-up, failsafe or contingency plans. Without reliable technologies – mainstream and/or specialist[2] – to bridge the gap between visual- and voice-based (oral) communications, people with hearing loss are at risk of isolation and exclusion.

[1] https://www.petrashub.org/iot-in-the-home-demonstrator/

[2] In this report, the terms "specialist" and "assistive" are used interchangeably to indicate technologies specially designed to meet the needs of people with hearing loss, by contrast with "mainstream" technologies designed for mass markets.

Priority areas for technology intervention and development

Using personae to stimulate discussions and record people's collective judgement on requirements, values, and expectations of connected technologies, the following technology development priorities for people with hearing loss were identified:

- **Specialist technologies**:
  - Hearing aids with directional sound features and connectivity with phones
  - Live captioning or subtitling and/or live video BSL interpretation, including a signing "daemon" or "avatar"
- **Mainstream technologies**:
  - Adaptive Home Hub: A device that links all the household appliances, senses their operation, and translates signals of completed tasks, alerts and alarms into (for example) vibrations or flashing lights, with different modes for when users are asleep and awake, and easy transitions between them.

Chapter 1 Introduction: The project

People with hearing loss have the same aptitude to capitalise on technologies that they can access as anyone else. Research shows regular usage not only of assistive technologies but also of mainstream connected technologies, such as smartphones and connected domestic appliances (e.g. thermostats), among both young [1] and older adults [2] with hearing loss. In fact, mainstream technology advances hold great potential to enhance independent living, making daily activities and social participation easier. However, not all mainstream technology advances are compatible with the requirements of people with hearing loss. Historically, adaptations have been retrofitted to mainstream technologies to make them usable by people with special needs. Accessibility has been a secondary consideration, creating integration barriers [3].

1.1 Rationale & Objectives

To work properly for any group of people, technology design needs to be grounded in their diverse requirements and context of use [4]. To obtain initial insights into the technology requirements and context of use of people with hearing loss, we organised a workshop with representatives of technology companies and various UK groups for people with hearing loss (both profoundly deaf and hard-of-hearing, and cochlear implant users), as well as some individual end-users with different types of hearing loss. The aim was to enable participants to speak of their own hopes and concerns about connected and digital technologies in their homes, and collectively envision improvements in these technologies. Aligned with the Capability Approach to disabilities [5], this research focuses on what people with hearing loss would like to be able to achieve in their daily (domestic) life and how connected technologies can help them realise that[3].

1.2 Workshop Design & Methods

The workshop was preceded by an online questionnaire completed by potential workshop participants and a few others. The pre-workshop questionnaire provided an early view of prospective participants' types of hearing loss, their household arrangements, and their technology appetite and exposure. This information fed into the design and organisation of workshop activities and language accessibility services and was also of interest in its own right.

The workshop was designed based on two principles of exploration: deliberation and personae.

Deliberation is described as a talk-based process to achieve mutually acceptable solutions to social problems through open exchange of and reflection on experience, story-telling, opinions, argumentation and persuasion [6] [7]. The value of this process lies in collective decision-making based on empathetic reasoning.

[3] This contrasts with the medical model of disabilities, which focuses on missing bodily functions or abilities.

Personae is a useful tool for design and development of technology, serving as prompt for users to envisage the technology usage in the co-design process and critique existing technology without fear of offence [8]. In this workshop, the co-creating of personae was adapted to serve as a tool for eliciting and recording participants' values, preferences and expectations of technology.

This combined method allows researchers to observe and meaningfully engage with the thinking that shapes participants' value judgements and decisions. Discourse analysis is used to identify the objectives, priorities and expectations underlying participants' proposed technology solutions.

Chapter 2 Living with Hearing Loss: Problem Definition

To begin to understand the requirements of people with hearing loss and their primary context of technology use, we explore the adjustments they have to make and the challenges they face in daily life and engagement with technologies at home. The analysis of their personal accounts surfaces four key interrelated challenges associated with their hearing loss: communication difficulties, dependency, limited agency, and isolation or exclusion because of access barriers. In section 2.1 we discuss how these four challenges interrelate through reviewing existing relevant literature, and showing how it relates to the workshop discussions. Section 2.2 then provides a detailed account of the workshop findings.

2.1 Four interrelated challenges for people with hearing loss

The experience sharing among workshop participants at each table began as if the adjustments they made to accommodate their hearing loss were a normal part of life – a non-problem. However, conversations soon concentrated on the limitations of the adjustments, and what they have had to trade off, revealing participants' frustrations. The co-existence of feelings of both normality and frustration correlates with the complex and contentious perceptions of hearing loss recorded in studies concerning the social and cultural aspects of d/Deafness[4] [9] [10].

In line with existing research [9][11], the workshop discussions indicate that participants do not see themselves as any less able than hearing people. However, frustrations with the limits that available mainstream products and services set on the functional and aesthetic aspects of their adjustments indicate a perceived disadvantage of being d/Deaf. Echoing this perception is the similarity between participants' remarks and those of the hearing people participating in the IoT in the Home Demonstrator research [12][13]. The significant difference, however, lies in the greater importance to d/Deaf people than to the hearing majority of difficulties arising in technology use.

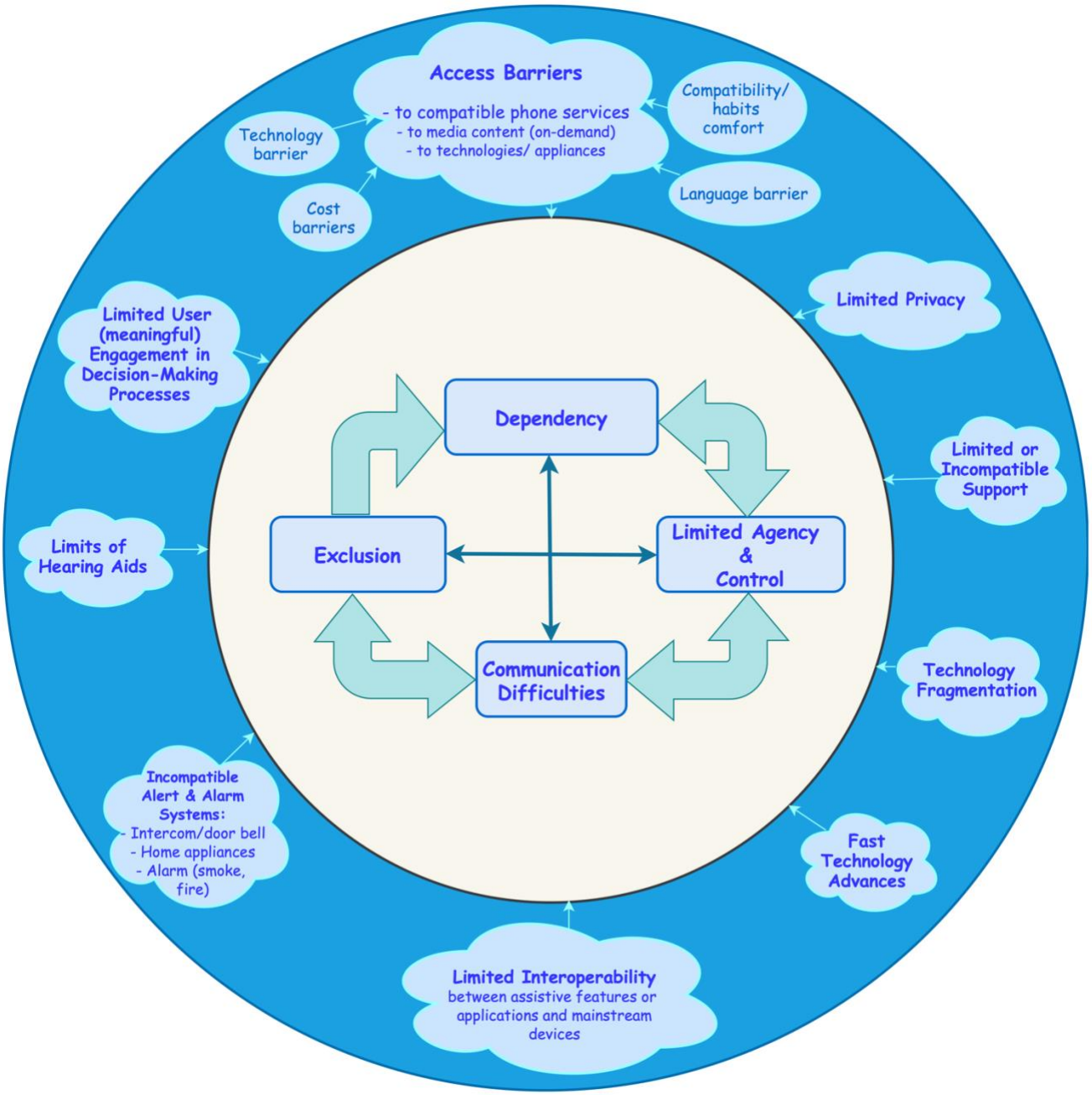
The discussions concerning the adjustments made to accommodate hearing loss at home revealed difficulties that shape participants' problem definitions (See Figure 1). The key difficulties include:

- limited or unequal accessibility (compared to their hearing counterparts) to products and services,
- limited privacy,
- limited interoperability between assistive features or applications and mainstream devices,
- technical support,
- technology fragmentation, resulting in difficulties staying apace with the fast-changing technologies,
- the breadth and complexity of emerging technologies,

[4] Here, 'Deaf' (capital D) refers to people (often) with profound, usually pre-lingual, deafness and some others who communicate using sign language and identify with the Deaf Community and its culture, while 'deaf' (small d) refers to people with hearing loss who do not identify with the Deaf Community and its culture.

- incompatibility between audible alerts and alarms, which are more suitable for the hearing majority, and the visual-based communication of people with hearing loss,
- functional and aesthetic limits of hearing aids,
- accuracy of assistive technologies such as voice recognition to text.

Figure 1. Difficulties, challenges and problem definition



Through exchanges of these personal difficulties, the participants' discussions were focused on certain topics and further developed into various identified challenges. Of these, *dependency*, *limited agency or internal sense of control*, *poor communication* and a *sense of isolation* most struck a chord with participants. Hearing people also experience these challenges, especially as they grow more dependent on, or delegate more of their decision-making and control to, technologies. The differences are in the frequencies with which people with hearing loss find themselves in disadvantageous situations and the severity of the consequences of such situations.

The analysis of the experiences of workshop participants with various forms of hearing loss indicates a dialectical relationship among dependency, limited agency, poor communication and isolation. Compared to hearing people, people with hearing loss are more prone to experiencing dependency on either other (hearing) people or technologies in their interaction with the outside (mainly, hearing) world. Such dependency limits their agency and exacerbates existing communication difficulties, resulting in isolation or exclusion which also contributes to dependency. Communication difficulties can also directly restrict agency of people with hearing loss as well as increasing their risks of isolation.

2.1.1 Access Barriers

The right of equal access to services has long been an up-hill battle for the d/Deaf and hard of hearing communities and permeates all aspects of life, including the legal [14], education [15], and health care systems [16][17], as well as media and information services [18][19][20][21].

Examples of such accessibility issues have been recorded in the concerns regarding telecommunications and broadcasting services raised by the National Association of Deafened People (NADP) [22]. NADP highlighted three key issues with currently the only telephone relay service available in the UK, known as Next Generation Text Relay Service (NGTS), in its response to the Department for Digital, Culture, Media and Sport (DCMS) Consultation on "Reforming Consumer Advocacy in Telecoms"[23]. These include difficulties in 1) setting up the NGTS application, 2) making and particularly receiving calls, and 3) slow transcription speed, rendering conversations slow and disjointed. As for the broadcasting services, including on-demand services, a report by the Communications Consumer Panel [24] highlights that "68% of on-demand programming did not offer any accessibility provision". These include on-demand programmes offered by both the UK public broadcasters and subscription television services. Academic research also found that the potentials of the digital switch-over to realise greater provision of subtitling and improvements in accuracy have not been realised: audiences with hearing loss still experience difficulties in accessing quality subtitling [20].

Interviews with informants who are knowledgeable about ITV and Channel 4 revealed that the limited availability of subtitling and in-vision BSL interpretation for on-demand content results from two key factors: technical barriers and costs. Both noted that subtitling for on-demand services is not mandatory. Even for public broadcasters, 100% subtitling is not necessarily a

requirement for scheduled linear programming. The ITV informant noted that the technical barriers meant that subtitling could not be displayed properly, if at all, on some viewing platforms due to the absence of common communication protocols across various viewing platforms. The Channel 4 informant noted that in-vision BSL interpretation is more difficult to produce and thus raises production costs, rendering provision of such accessibility features not cost-effective.

2.1.2 Communication Difficulties and Limited Agency

Research shows links between communication difficulties, satisfaction in modes of communication as well as support to communicate, and emotional distresses experienced by people with various types of hearing loss in both adults and children [25][26][27]. These communication difficulties complicate social participation of people with hearing loss in various contexts, including within family life or personal relationships[28] [29] [30], education [31] [32], health care [33][34] and employment [35]. These research findings correspond with the frustration and stress participants reported when technology-mediated adaptations fail to achieve satisfactory adjustments to accommodate their hearing loss.

Limited efficacy, or ability to effect changes towards a desired social and technical outcome, is experienced by the general public, as observed in citizens' dissatisfaction with the way technology operates [36] and disappointment with the government's decision-making [37]. However, for people with hearing loss this is more serious: the impact of top-down decision-making in technology design-development and provision could undermine their safety. For example, alert and alarm systems that are incompatible with these users' habits, household conditions and modes of communication could result in their missing a fire alarm.

Likewise, complicated terms and conditions [38] and limited understanding of how digital technologies operate, particularly in the context of IoT [13], have been reported as problematic among the general population. Contributing factors for all include the complex nature of networked digital technologies as well as the lack of transparency concerning security and data handling. For many prelingual d/Deaf people, processing of written oral language presents an additional difficulty, due to their limited rule-based syntactic knowledge, which serves as the basis for integration of accurate word recognition into more intricate knowledge domains and structures [39] [40] [41]. This creates an additional burden on this group of users, thus making them more vulnerable to tech-abuse or exploitation than their hearing peers.

Moreover, people with hearing loss, particularly those who are profoundly deaf and rely predominantly on BSL to communicate, are likely to be more restricted in their responses to technology abuse, misuse, malfunctions or failures that have implications for their safety and security. The consequences of such restriction can be rather severe, particularly in emergency situations. The BSL users attending the workshop exhibited a sense of helplessness when asked about how they would cope with emergency situations in their home, especially if the technologies or the hearing person they rely on are not available. Some said that they would

"probably die" because they would not be able to get the support they need in time due to the language barrier.

Many assistive technologies for people with hearing loss are designed to compensate for the hearing loss [42] [43]. Examples of these include hearing aids, FM listening systems, FireHawk fire alarm systems, Bellman Visit systems, and telephone alert systems[5]. Beyond these specialist technologies, some mainstream technology advances such as the Internet, video-conferencing and text-based communication technologies have been used to enhance communication accessibility and social participation of people with hearing loss [2]. Frequent use of smart phones and personal computers have been reported among d/Deaf and hard of hearing people, specifically to facilitate text-based communication and online information access [1]. Short Message Service (SMS) or instant messaging applications are heavily relied on for social and personal interactions [44] [45].

But there are limits to the support technologies, particularly specialist or assistive technologies, can provide. Our analysis of the experience workshop participants shared shows that such limits stem from misalignment between users' aesthetic tastes and habits of use, and what markets deem profitable to produce. For specialist devices, the medical model of disability is often prioritised over users' aesthetic tastes or habits of use. Users are also left with the burden of devising their own back-up strategies, as observed in the case of electricity outage and flat batteries disrupting connectivity. There are efforts to address some aesthetic elements of choices (of hearing aids), extending the design consideration of hearing aids, which has traditionally been function oriented, to address the emotional and socio-cultural needs of users [46] [47]. However, more needs to be done to accommodate diverse users' habits, accessibility requirements, preferences and personalisation.

2.1.3 Isolation or Exclusion

Communication difficulties are known contributing factors to social exclusion, poor mental health and wellbeing experienced by many people with hearing loss [48] [27]. The analysis of the workshop discussions indicates that isolation and exclusion resulting from limited access to and availability of reliable technologies and services to bridge the gap between visual- and oral-based communications manifests in three ways: relational, technical and functional.

The relational dimension is observed when communication difficulties entail challenges in social participation and relationship building in various contexts including family life [29][30], and relationship building with peers in educational [31] and employment [35] contexts. Examples from the workshop of this relational challenge appear in the sub-section on *loss of hearing and loss of social contact* (see 2.1.3).

[5] Examples of all these and much else can conveniently be viewed at https://www.actiononhearingloss.org.uk/shop/.

The technical dimension manifests in "exclusion by design" through missing or poor accessibility features, including language accessibility, particularly in mainstream products and services.

The functional dimension of isolation and exclusion revolves around limitations experienced by people with hearing loss in carrying out daily activities, retaining their directional control over and intentional use of products and services that are important in their lives. Both the workshop and research [3] show that these limitations result, mainly, from the mainstream oralist cultures that shape social, business and design/development practices.

The UK Equality Act 2010 [49] and the United Nations (UN) Convention on Disability Rights [50] exist to enforce, protect and promote the rights of disabled people. On the technical front, efforts have also been made to design more accessibility, including sign language, into mainstream technologies, as observed in the attempts to make a voice assistant respond to sign language [51] [52] and the development of Google's "*Live Transcribe*" [53]. However, specific policy and regulatory tools are required and need to be regularly reviewed in light of fast-changing technologies, to ensure equal safety, security, privacy and reliable accuracy for users with special requirements.

2.2 Workshop findings:

Workshop participants identified communication difficulties, dependency, limited agency or internal sense of control and a sense of isolation to be most problematic. Following are their accounts.

2.2.1 Communication Difficulties

Workshop participants' discussions indicates that there are two dimensions to communication: functional and relational. In the functional aspect, communication supports daily tasks, for example, business arrangements, education, and receiving or requesting healthcare services. In the relational dimension, workshop participants exhibit clearer signs of distress as they exchanged their experiences of personal communication difficulties.

Loss of hearing & loss of social contact

> **T3P2**: "… a sudden profound hearing loss… puts a very different complexion on the family dynamics. You know, it can cause marriage break-up and all sorts of things."
>
> **T3P5**: "When I became deaf, I lost some friends because you can't any more chat on the phone. You say no because you can't go to a noisy place."

Limits of assistive and mainstream technologies

> **T2P2:** "I have to say that I just have this simple analogue hearing aid, but I know someone who has a very sophisticated digital one, thousands of pounds and all the rest of it connected to an iPhone, and it seems like he is never free of problems…"

T2P6: "I think as far as it is uncomfortable, he doesn't like people seeing him wearing it. He is 16. But he also finds it too noisy, I think it is very distracting."

T3P2: "I was thinking, the fact uninterruptable power supplies [UPS], I have to have one in France because the power goes up and down when there is a thunderstorm, and you are typing away and you suddenly lose what you're doing, so I've got UPS."

T3P4: "It needs to come in in the UK because the UK is moving from PSTN to IP[6], so for people who are vulnerable, they should have a back-up supply so they can still access the phone…it made me think, in terms of your own broadband, your own network, for it to continue working, you need electricity, so you need a back-up supply."

Reliable technologies become obsolete while replacement technologies work less well

T2P1: "So before on the landline phone you used to be able to get text and it is something that a lot of people with hearing loss used to rely on to get the text translation of voice calls. That has stopped, they stopped making that phone and it is a service that people really rely on and BT brought out an app which was supposed to replace that but it has been a poor translation of that service, so the one thing we have always been, or we get a lot of that is *keep that service*."

Limited personalisation

T2P5: "…two people are never the same, so while there is lots of solutions it is ability to personalise it, for example … you talked about flashing alerts, but some people prefer vibrations and having the choice of one or the other is not ideal either, there needs to be a lot more work with different users, a diverse set of users so that people can personalise it more to what they want instead of just being told: Oh it is accessible because it has a flashing light or there is a screen on the side with subtitles. Different people like different things and it is being able to personalise that."

These communication difficulties contribute to other issues of dependency, limited agency and isolation or exclusion.

[6] Public Switched Telephone Network to Internet Protocol (referring to the current move for telephone calls to be made over broadband connections). The traditional PSTN provides electricity to phones that are wired into it, but broadband does not, so it cannot be relied on for emergency use (any more than cordless phones can).

2.2.2 Dependency

As part of their adjustment strategies at home and elsewhere, workshop participants reported that people with hearing loss rely on others (hearing family members, friends or carers) and/or technologies to bridge their communication gaps. People with hearing loss naturally prefer visual-based communication [9]. The hearing majority on the other hand tend to make heavy use of oral methods although they can be more flexible with modes of communication. Participants felt that building diverse and adaptive accessibility features into mainstream consumer products and services, particularly ones powered by connected technologies [3], would benefit many people, both with and without hearing loss. Despite the perceived technical feasibility of more diverse and adaptive accessibility features, their availability is still very limited across digital products and services.

Workshop participants exhibited increasing levels of frustration as they discussed the limits of the adjustments set by the available human support and technologies. This frustration triggered reflection on how much participants rely on the support of their hearing family, friends, and carers, and technologies. This reliance is problematic in various circumstances.

Limited accessibility: Phone services

> **T1P1**"First, we talked about phone calls. With all British Sign Language user group, at the moment, to make phone calls, we use Typetalk, it's called NGT - New Generation Technology. We need to use English. We need to write in English, but a lot of deaf people use British Sign Language, so English is not their first language, therefore their use is not that great. But there's not a lot of resources out there. Also, when you receive a call, a phone call, it's quite difficult. We need to rely on people, a person who can speak, to receive that phone call and tell us what is happening. Also, we receive a lot of voicemails which is [a] problem and we need somebody to translate what the person is saying… But what about my privacy? What about our privacy and our right to access information directly? That is not acceptable really."
>
> **T1P2**: "Or sometimes with service delivery, shopping for clothes or parcels, fast-track, sometimes they send you, they call you to say, "We are outside, or we are there" and then they call to say, "We missed the delivery because we called you.""

Limited interoperability

> **T2P1:** "One recent example was a hearing aid that is connected to iPhone, and when Apple did their latest software update the app stopped talking to the hearing aid, so people with that hearing aid in that app were left for a week without being able to control their hearing aid and of course Apple took a week to fix that software but in that time people were left without being able to control it."

T3P1: "The interoperability of alarm systems is an issue, because there is actually a British Standard for smoke alarms for deaf and hard of hearing people, BS 5446 part 3, and there's only one smoke alarm system in the UK that meets that standard, and it sets levels of vibration level, the light intensity. The Bellman doesn't meet that standard but there is another, a FireHawk, that produces a smoke alarm to that standard[7], but then you have the mainstream fire alarms that don't do anything for deaf people at all, like Nest, or other smart home technologies that don't meet that standard. So, they don't have a vibrating pad or a flashing light..."

Limited accessibility: Media content, including public service media

T3P2: "Subtitling, particularly when it's time shifted, because they don't always -- ITV, for example."

T1P2: "… A lot of programmes are subtitled, but on-demand or relay, actually there's not that many subtitles unfortunately. On mobiles, or Sky Go, there is no subtitles at all. For example, I pay a full subscription, but it doesn't match my need at all because there are no subtitles… Also, if I can add, there is not enough in-vision, so usually it's late at night that you would have a sign language interpreter translating the programme, or on iPlayer there is no in-vision at all, there is no interpreter translating the programme that I want to watch."

Alerts, alarms and doorbells

T1P2: "Personally, I live in a big block of flats, so I don't know who's outside the main door. I don't even know that they're outside. So, there is an intercom system in my flat, but you need a video screen to be able to see that somebody is outside, so I end up missing deliveries and things like that. Luckily, with my mobile phone, that does help, alleviate the problem, although it doesn't solve the original problem."

T3P2: "We recognised, I think, the most difficult problem still comes from alarms and how these are sent around. There is the problem of localising what the alarm is, and although there are solutions in terms of Bellman vibration, it's still going to be a big problem when we have wi-fi connecting everything in terms of standardisation between different types of alarms; how this is going to be done."

[7] https://www.actiononhearingloss.org.uk/live-well/our-community/our-blog/our-top-five-smoke-alarms/ provides information on these two, and other, proprietary alarms which may be suitable for people with hearing loss.

Accuracy of support technologies

T2P2: "From an accuracy point of view, they are just disappointing. The timing, what is very important to me as a deaf person, is to be able to hear the actor [on stage at the theatre or at the cinema]. When you get the subtitles correctly timed, I can hear the actors with their intonations and their voices. When the subtitles come late, you lose all that... Years ago Sony came out with some wonderful glasses for the cinema … lightweight and you could see subtitles and everything was accurate and so on...So, some lighter weight glasses would be a real help and much, much better software to get the timing right."

2.2.3 Limited Agency and Control

Participants reported limited agency and sense of control resulting from both internal and environmental factors. Internal factors include technical skills (for example in adjusting device settings), and reading comprehension. Environmental factors include the availability of the right type of support, and the availability, accessibility and appropriateness of mainstream and assistive technologies. The circumstances in which participants experienced limited agency and control include:

Social service & provision of assistive technologies

T1P1: "…Two things we talked about. Older technology, for example, Mountcastle bell[8]. So, just briefly, back in the old days, when the doorbell went, all the lights in the house would flash. That technology became obsolete, and now there are portable flashing devices, but you have to carry around with you in the house, which means you have to have it on you to know the doorbell is going. So, if you are in a big family home with lots of rooms, if you are in the wrong room, you are not going to know the doorbell is going. Although it's supposed to be an improvement in technology, it's actually made life more difficult in a family home."

T3P4: "I think one of the problems of trying to get an accessible equipment is, because you don't quite understand how they're used, they are recommended by a hearing person. You are looking at something from two different ends, and a hearing person thinks this is a good thing, but when you actually look at it you find, no, it's not suitable for you."

Understanding how technology works, implications for safety and security

T2P1: "I think people who are more tech savvy seem to get on with it really well but people who are not very comfortable with tech, people who have used a smart phone, it is really difficult all of a sudden to put something on an app and start using the service. It is not very, I struggle to set it up myself and not very intuitive, so that is one of the things we have been told about."

[8] A former range of doorbells for the hard of hearing, offering extra loud ringing and flashing lights.

> **T2P3:** "In terms of safety, it is people with bad intentions that understand how you hack things. So, if you did have a doorbell that told you when someone was there, someone could tap into that and disable it to do something bad. And it kind of has always been the bad people there and I think as well with general technology, when people get scared about it because people don't understand...

2.2.4 Isolation or Exclusion

This is observed in the cases of phone services, on-demand media services (both public and commercial), alerts, alarms and doorbells (see 2.1.1). On this particular issue, workshop participants expressed frustration, disappointment and expectation for greater involvement in the design and development processes of emerging technologies:

> **T3P4** "… you've got all these different mainstream devices that are popular for people that are hearing, but they don't necessarily encompass the accessibility features, and so what happens is you then get a side-lined element of one or two products that would just be suitable for people with a hearing loss, but they tend to be small and not be developed … that much … people who actually have a disability should be the ones that are involved in the testing…at an early stage…"

Because people with hearing loss are rarely involved in designing or developing mainstream technologies, they are often still excluded by access barriers. Barriers of cost, language, technical difficulty and time are discussed below.

Cost barriers: As hearing loss can reduce job opportunities, some people with hearing loss may have low incomes and be unable to afford certain technologies.

> **T1P1:** "Also, we have something called like sign video, sign relay, which is quite expensive altogether, so the use of it is quite difficult."

> **T2P3:** "… a concern is having enough money… generally [and to buy technologies]"

Language barriers: Language barriers exist both for information about a devices or service, and second within the device or service itself. These barriers apply predominantly to people whose first language is BSL and who have limited written language skills.

> **T1P1:** "…a lot of deaf people use British Sign Language, so English is not their first language…But there's not a lot of resources out there."

In line with the observations made in the NADP's response to DCMS' consultation on "Reforming Consumer Advocacy in Telecoms" [22], not all workshop participants were aware of the NGTS, while the ones who use NGTS reported problems with the delays in transcription speed as well as making and receiving phone calls. All workshop participants who rely on subtitling for television services reported inconsistencies in availability of subtitles for both

scheduled and on-demand services, but more so for the on-demand services or poor or "out-of-place" display of subtitles. They also reported a distinct lack of BSL interpretation, known as 'in-vision', for BBC iPlayer and little or no 'in-vision' on other on-demand services.

Technical barriers: Technical barriers may arise from, for example 1) retrofitting of accessibility features in mainstream devices and services; 2) technology fragmentation, so devices do not talk to each other or work seamlessly to achieve the required result, and 3) difficulties in setting devices up, such as configuration, setting appropriate accessibility, security and privacy preferences, and integrating new and existing devices and systems.

> **T2P4:** "Another thing that we always find when talking to people is technology, new technologies coming out all the time, when it is first built accessibility is not built into the design… for example, the latest phone release but then accessibility features come later … so people with hearing loss or any disability are at a disadvantage, not able to access the same devices as everyone else …"

> **T2P5:** "Fragmentation... having lots of different devices connected up and doing one thing that don't necessarily belong together. Too many bits of technology."

> **T3P3:** "we have all these wonderful stuff that improve our lives, but … in order to improve our lives, we've got to have the know-how to put all these things into it, and … someone like myself who's not technically minded, wondering how are we going to cope with putting all these things in there?"

Time barriers: The time required to identify fit-for-purpose technologies, understand how the technologies work and set them up is often more than individuals can afford to spend. This is a problem for both the hearing population and people with hearing loss, but its effects are more serious for people with hearing loss. For example, people who lose their hearing, post-lingually, may be less prepared to adjust to their newly acquired hearing loss, or (especially if older) may experience greater difficulties in learning to operate new technologies. Moreover, the importance of the adjustments means that when they lose their hearing, people are likely to be under great time pressure to learn about helpful technologies.

> **T3P4:** "I don't think it's just about technical... I think the key thing…is that they are time poor. They haven't got a lot of time to research. They rely on other people to do it for them, and it's not easily accessible for them."

Chapter 3 Imagining Connected Technologies with People with Hearing Loss

Given the problems workshop participants identified, their interests in connected technologies gravitate towards the potentials of these technologies to address their communication gap with the hearing world. Specific requirements, values and expectations of connected technologies vary, depending on demographic factors, types of hearing loss, socio-economic circumstances, (oral) language skills and preferred mode of communication. These details of the personae that workshop participants created are summarised below. The full persona profiles are in the Appendix. Persona gender was unimportant for all three groups.

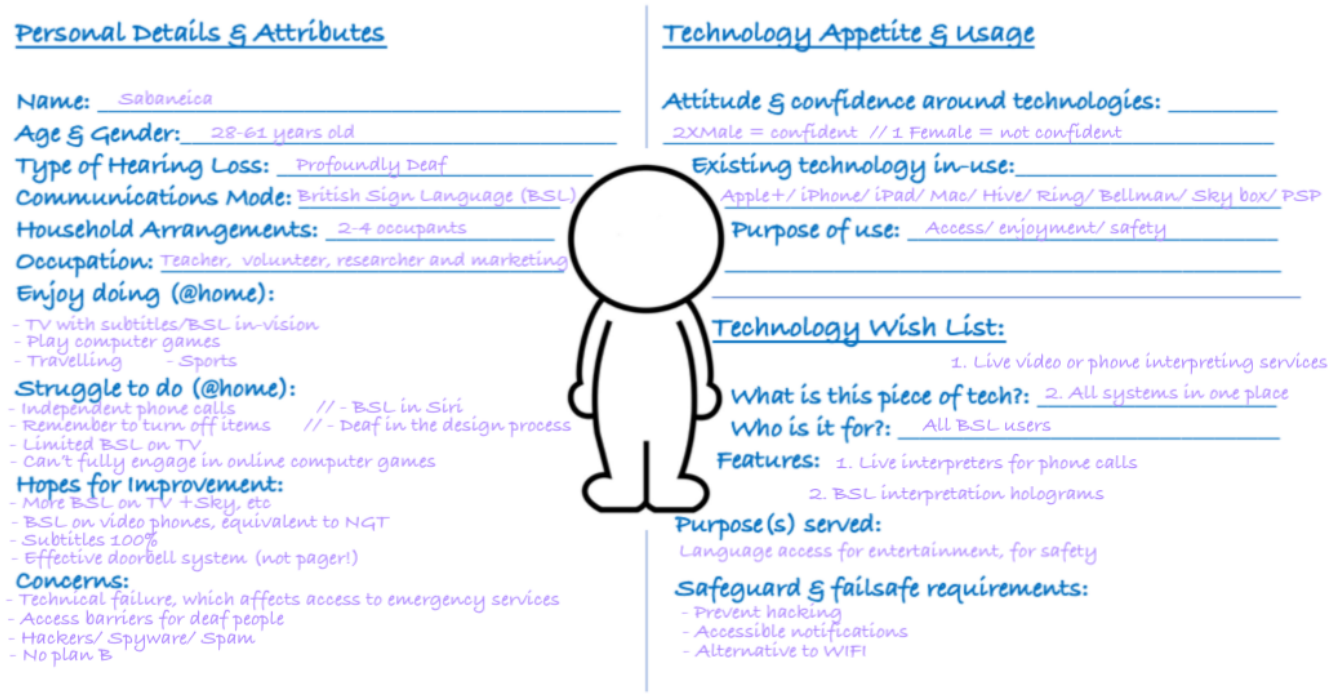
The analysis of the personae indicates that participants share the view that the younger generation are likely to be more open to experimenting with new technologies and more confident around technologies than the older generation. Age combined with types of hearing loss and people's preferred mode of communication shapes preferences and priorities for technology solutions.

The common goal for tech-interventions articulated in the workshop, irrespective of demographic factors and types of hearing loss, is to achieve smoother, more independent, dynamic, secure and private communication both with people and with devices predominantly developed by and for the hearing majority.

3.1 User profiles and technology concepts

Specific proposed technology concepts depend mainly on age and types and acquisition of hearing loss. This was observed in the development of the personae, and their corresponding technology appetite and requirements. In the workshop three personae were created by three separate break-out groups, each with different demographic, communication mode and hearing loss profiles.

Figure 2: Persona 1



Participants in this group gave their persona a broad age range, recognising that the younger version is more confident around technologies than the older generation. Reflecting their own experience, they decided that this persona would have low levels of awareness and understanding of risks associated with the increasing attack vectors of hyper-connectivity. Like many people, including the hearing majority, this persona finds it difficult to detect the risks associated with connected technologies. However, due to the existing language barrier – insufficient BSL interpretation services - they deemed that the persona would suffer more severe consequences of the same risks hearing people face, especially in emergency situations. Given the type of hearing loss, this persona would prioritise live BSL interpretation holograms over voice recognition technologies.

Figure 3: Persona 2

Personal Details & Attributes

Name: Chris
Age & Gender: 45 years old
Type of Hearing Loss: Sudden severe bi-lateral hearing loss
Communications Mode: Spoken language
Household Arrangements: Married with 2 children
Occupation: Retail assistant
Enjoy doing (@home):
- Gardening
- Playing with kids
- Watching TV

Struggle to do (@home):
- Having conversations with family
- Telephone calls
- Socialising with friends
- Hearing doorbell

Hopes for Improvement:
- Better hearing aids - more focused

Concerns:
- Not being able to or limited understanding of technology available
- Not having enough money to buy technology and pay bills

Technology Appetite & Usage

Attitude & confidence around technologies:
Modest but not aware of new technology possibilities
Existing technology in-use: Alert systems,
Sophisticated hearing aids available through NHS or social services
Purpose of use: Communication support

Technology Wish List:

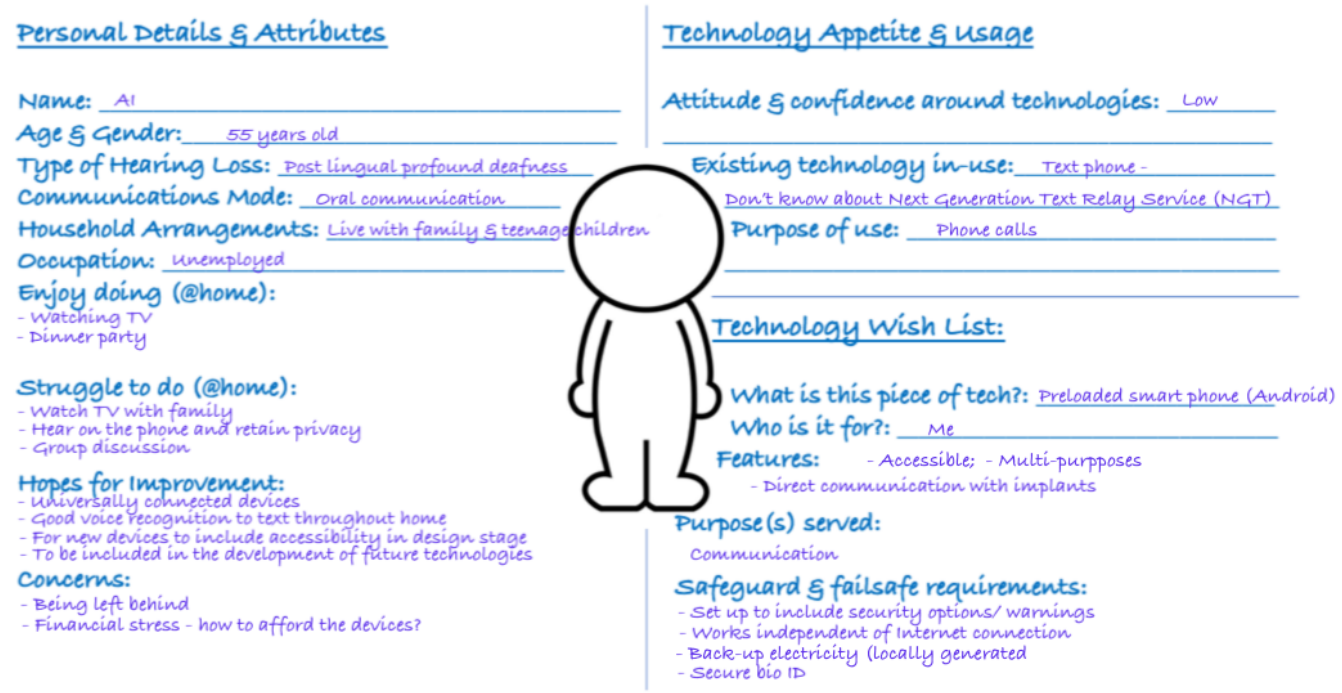
What is this piece of tech?: Hearing aids plus pager/alerter
Who is it for?: Self
Features:
- Directional sound features
- Connectivity/ interoperability with smart phones

Purpose(s) served:
- Alleviate problems of communication

Safeguard & failsafe requirements:
- Better understanding of how the device operates
- Contingency plan in case the device fails
- Alternative communication support (e.g. voice recognition to text)

Following similar general assumptions about age affecting technology confidence and appetite, participants in this second group deemed that this persona would have moderate confidence and appetite for technologies. Given the type of hearing loss and household arrangements, this persona's priorities are in technologies that support communication with family members, particularly children. These include sophisticated hearing aids, particularly ones that connect with smart phones and alert systems. Like Persona 1 and many hearing users of connected devices, the risks associated with connected devices are not obvious to this persona. Given that this persona used to have, but suddenly lost, hearing, participants decided that this persona expects the hearing aids to embody natural auditory capabilities and functionality, such as directional sound features.

Figure 4: Persona 3



Similarly, the design of the third persona reflects participants' assumption that the older generation (55 years old) is likely to be more "awkward" with technology. Reflecting this persona's low confidence around and low appetite in digital technologies, this persona has limited exposure to digital technologies and only uses text phones. This persona was designed to represent the characteristics and socio-economic circumstances of people who lost their hearing later in life, then struggled to catch up with new technologies and thus to stay in employment[9]. This persona would be very concerned about safety, security and privacy when interacting with technologies, as well as with their affordability. The persona struggles to enjoy watching TV with the family and has a difficult relationship with the teenage children. A simple piece of technology that serves multiple purposes and interoperates with hearing aids, as well as providing accurate voice-recognition-to-text, is a priority.

[9] This type of person was not present in the workshop, but was very familiar to participants.

3.2 Priority areas for technology interventions and development for people with hearing loss

From these broad problem definitions (Chapter 2) and user profiles (Section 3.1) emerge three technology development priorities for people with hearing loss:

- Hearing aids with directional sound features and connectivity with smart phones and other oral-based devices
- Live captioning or subtitling and/or live video BSL interpretation
- Adaptive Home Hub: A piece of technology that connects with all the household appliances, senses their operation and translates notifications of completed tasks (e.g. washing machine), alerts (e.g. doorbell) and alarms (e.g. smoke, fire) into either vibrations or flashing lights. Vibration alerts need to take place in a device that is right by a person all the time (e.g. a wearable, or a powerful under-the-pillow vibrator). Flashing lights need to be noticeable across the whole house. Different modes will be needed for when users are asleep and awake, with easy transitions between them.

Participants identified both specialist (e.g. hearing aids and live captioning) and mainstream technologies (e.g. smart phones), indicating that this group of users are open to both. Interoperability between specialist and mainstream devices and across household appliances is very important to them, as reflected in the demand for connectivity between hearing aids and mainstream devices.

The demand for live captioning or subtitling and live video BSL interpretation corresponds to specific language accessibility requirements, but can also be integrated into existing and emerging mainstream devices and services. For example, live captioning or voice recognition-to-text applications can be built into a smart TV and wearable or hand-held devices, such as a smart watch and a smart phone, to address the limited and inconsistent language accessibility features in existing telecom (e.g. phone) and on-demand broadcasting services (see 2.2.1).

Efforts have been made to develop live captioning services for d/Deaf theatregoers [54] and on smart phones [53]. However, accuracy of such technologies varies. Unlike similar professional services (speech-to-text reporting)[10], there is no minimum accuracy standard for voice recognition-to-text technologies, and no requirement to explain the conditions required for the greatest accuracy. Nor are such services regulated or considered as assistive technologies in the way that hearing aids (for example) are.

The concept of the adaptive home hub echoes the appetite of people with hearing loss for improved accessibility of mainstream smart domestic appliances. Many such appliances are

[10] In the UK, human-based language accessibility services and the standards of such services, which include accuracy and other codes of conduct, are regulated by the National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD)[55]. It is worth noting that, with Artificial Intelligence (AI), the accuracy of speech recognition-to-text technologies could, in the future, exceed the current accuracy standard of qualified speech-to-text professionals.

already in the homes of people with hearing loss though lacking fit-for-purpose accessibility features. This highlights opportunities for developers and manufacturers of these appliances, when diversifying their product, to raise their standing in d/Deaf and hard of hearing markets. This is achievable through designing in sensors and interoperability between domestic appliances and mobile phones or wearables as well as house lighting systems to enable adaptive notification of complete tasks (e.g. washing machine), alerts (e.g. doorbell) and alarms (e.g. smoke alarm). The idea of an adaptive home hub could also be extended to support the development of 'smart' assistive living that supports users with hearing loss – a condition developed by many in the aging population - as well as other types of disability. Efforts have been made to research, prototype and test the possibilities of disability-friendly smart homes [56] [57].

Like smart homes for the hearing majority, careful consideration is vital to understand safeguard and failsafe requirements of people with hearing loss and other types of disabilities. Much research has investigated technical solutions for securing smart homes [58][59][60]. However, deeper understanding is needed concerning users' behaviours, technical skills and knowledge that shape use of these solutions. These findings build on those of the PETRAS-BRE IoT in the Home Demonstrator project which derived insights into safeguards and failsafe requirements for hearing occupants, including a recommendation for connected devices and systems to be set by default to revert back to manual (rather than smart) mode, as a contingency plan in the case of technology failure [61].

3.3 Core values, requirements and expectations of connected technologies

The analysis of the pre-workshop online questionnaire, the workshop discussions and the persona profiles highlights accessibility as the key barrier for people with hearing loss to use mainstream products and services (see 2.2.1) irrespective of people's appetite for, confidence around and exposure to digital technologies. Key values include security, data protection, privacy, integrity and interoperability. Participants expect to see features that support these values in the connected devices. These values should thus be built in to connected devices, so that they are compatible with the expectations and requirements of the participants, as well as other users.

Accessibility: Given the long-standing accessibility issues, workshop participants expect accessibility features to be available as standard, not an additional or secondary feature, across the diverse range of mainstream products and services.

Security, data protection and privacy: Workshop participants expressed expectations for 'easily accessible' security and privacy settings, highlighting their desire for agency, or internal control, and awareness of their and others' varying technical skills and resources. As part of security solutions, participants also articulated their expectations of diversity in types of secure biometric ID recognition (e.g. voice, fingerprint and facial). Acknowledging that technologies may fail, due not only to malicious tampering but also to flat batteries or power-cut and lost

connectivity, participants considered back-up batteries and means for connectivity other than Wi-Fi as failsafe options.

Integrity: Workshop participants referred to the confidentiality requirement and other etiquettes prescribed in the code of conduct that communication professionals providing services for people with hearing loss, including speech-to-text reporters (STTR), have to abide by [62]. The code of conduct also prompted participants to consider a requirement for computerised speech recognition-to-text applications and services to be held initially to an accuracy standard similar to that applied to the STTR professionals.

Interoperability and adaptivity: Participants clearly value and expect interoperability across both mainstream and specialist products and services. Such an appetite for interoperability is most obviously observed in the features of the connected hearing aids and adaptive home hub, which should be able to sense or identify and adapt to users' accessibility requirements.

Chapter 4 Conclusion: Realising the inclusive connected world

To realise the inclusive world in which connected technologies are leveraged to support safe and secure independent living and facilitate smooth, dynamic and effective communication, making everyday life and social participation more fulfilling for all, requires cross-sector coordination. Based on the problems and priority areas for technology intervention identified by participants in the stakeholder workshop, following are initial steps for stakeholders to consider.

For businesses and concerned organisations:
Mainstream products and services have already made their ways into the homes of people with hearing loss. More can enter the d/Deaf and hard of hearing market segments (and others) by designing in fit-for-purpose and adaptive accessibility features as well as interoperability with other domestic appliances and assistive devices. As one of the hearing participants who lives in a d/Deaf household noted, devices with visual alerts (e.g. flashing lights) catering to d/Deaf users can also be useful for the hearing household members. In this way, mainstream appliances and services with diverse and adaptive accessibility features stand to bring good return on investment. The same applies for specialist devices and services such as real-time captioning, that may have broad market appeal and interoperate with mainstream devices and services.

- *Inclusive design:* Mainstream technology companies and developers should involve groups of users with various accessibility requirements from product design through to testing processes.
- *Industry and user collaboration:* Mainstream technology companies and developers should work more closely with specialist device developers and organisations representing or working for people with special requirements. This effort could improve interoperability between mainstream and assistive devices and services.

For makers of standards and policies:
Government and standard bodies have important roles to play in minimising risks associated with connected technologies and guard against exploitation or neglect of people with special needs while continuing to foster innovation. Existing standards, codes of practice and regulatory proposals or amendments can be extended to explicitly include safeguard and failsafe measures, as well as promoting the inclusion of accessibility features in mainstream products and services.

Examples of standards, policies, regulations and regulatory proposals that could expedite the realisation of an inclusive, (equally) accessible, safe, secure, interoperable and reliable connected world include:

- The Code of Practice for Consumer IoT Security[11]
- The regulatory proposals on consumer IoT Security[12]
- ETSI TS 103 645[13]
- Code of Conduct for Communication Professionals[14]
- Communications Act 2003

Recommendations deriving from this report will be put forward to relevant policymakers, Government, businesses, technology companies and organisations representing people with hearing loss. We urge all who participate in the computerised and networked world to consider the voice of the stakeholders present in the workshop, so as to rethink how they design, develop and deliver connected technologies that facilitate independent living and inclusive social participation for all.

[11] See: https://www.gov.uk/government/publications/code-of-practice-for-consumer-iot-security
[12] See: https://www.gov.uk/government/consultations/consultation-on-regulatory-proposals-on-consumer-iot-security/consultation-on-the-governments-regulatory-proposals-regarding-consumer-internet-of-things-iot-security
[13] ETSI TS 103 645 is the first globally-applicable industry standard for consumer IoT security, published by the European Standards Organisation. See: https://www.etsi.org/deliver/etsi_ts/103600_103699/103645/01.01.01_60/ts_103645v010101p.pdf
[14] The Code of Conduct for Communication Professionals is a safeguard for the rights of deaf and hearing people involved in, or affected by, all aspects of communication. See: https://www.nrcpd.org.uk/documents/professional_standards/NRCPD_Code%20of%20Conduct_April2012.pdf

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Appendix: Personae

Profile 1 (Figure 2):

Type of hearing loss: profound d/Deafness at the pre-lingual stage

Age: 28 – 61

Mode of communication: BSL

Occupation: Teacher/ volunteer/ researcher/ marketing

Tech appetite, confidence: The younger generation are more confident around technologies. The older generation are often not as confident around technology.

Risks awareness: Irrespective of age and tech confidence, many people have low level of awareness and understanding of risks associated with the increasing attack vectors of hyper-connectivity. It is not very easy for people to detect these risks before they turn into real harms. However, d/Deaf people are at risk of suffering more severe consequences of the same risks hearing people face due to the existing language barrier – insufficient BSL interpretation services.

Critical problem: Communication in case of emergency.

Everyday struggle: Human-to-human communication and human-to-device communication (e.g. communicating/interacting with household appliances)

Key barriers:

- Language * For those with pre-lingual d/Deafness, BSL is their first language. Some may not have alternative functioning oral languages. Some may acquire degrees of functioning oral languages. However, this situation limits the usefulness and effectiveness of speech-to-text or voice recognition to text technologies among people with pre-lingual d/Deafness. There is a high demand for live BSL interpretation to enable access to voice-communication services and other human-human communication.
- Technical failure

Desired tech interventions:

- *Deaf-aware home hub*: A piece of technology that connects with all the household appliances, to sense the operation of these devices and translates the sound of notification of completed tasks/cycle, alerts and alarms (e.g. smoke alarm/detector, fire alarm) into either vibrations or flashing lights. For vibration as a form of alert, this should be linked to a wearable device that a person is wearing all the time. For flashing lights, this type of alert/alarm signal should be visible/noticeable across the whole house. This tech intervention is proposed to address the human-device communication, underpinning much of domestic activities.
- *Live video BSL interpretation or BSL hologram*: This option responds to heavy reliance on BSL interpretation in communication with most hearing people.

Both tech interventions imply a desire to address the dependency issue. In this case, a dependency on a hearing person and/or BSL interpreters.

Safeguard & failsafe requirements:

- Alternative means for connectivity (alternative to WiFi)
- Accessible (e.g. in BSL and/or plain English) notifications, warning, manuals

Profile 2 (Figure 3):

Type of hearing loss: Sudden-severe bilateral hearing loss (post-lingual) (note: This person used to have normal hearing and uses oral language. This person may acquire BSL as a second language. This person still has some hearing abilities.)

Mode of communication: spoken (oral) language

Age: 45

Gender: Male / gender neutral

Occupation: Retail assistant

Tech appetite, confidence:

- moderate – not aware of new technologies, limited understanding of technology available and how it operates.
- Sophisticated hearing aids
- Other assistive technologies provided by social services

Risks awareness: Unsuspecting of risks and consequences of risks associated with connected devices.

Critical problem: Looking after children, keeping them safe, in the home while dealing with jobs and other stress outside the home.

Everyday struggle: Human-human communication and socialising (this applies to communication with hearing family members and other hearing individuals in other contexts.)

The aesthetics of hearing aids are matters of concerns among young and female users. The aesthetics of the hearing aid among these users are more than just a lack of comfort but something that affects users' pride, image and self-confidence.

Key barrier:

- Technical skills/knowledge (barrier to access to technology)
- Affordability of assistive technologies and other related technologies
- Cosmetic/aesthetic elements of the hearing aid affects young users' self-confidence. This affects the usage of this device (e.g. not wearing it all the time) and therefore affects the fine-tuning and user-device personalisation.

Desired tech interventions: Assistive technologies – hearing aid with directional sound features and connectivity with the phone. (This is to alleviate problems with communication.)

Safeguard & failsafe requirements:

- Contingency plan in case the device fails;
- Alternative communication aid (e.g. a live transcription or an equivalent) in case the user doesn't want to wear it all the time;
- Better understanding of how the device operates.

Profile 3 (Figure 4):

Type of hearing loss: Profound deafened (note: This person used to be able to hear and still uses oral languages.)

Age: 55

Mode of communication: Oral language

Gender: Male

Occupation: Unemployed

Tech appetite, confidence:

- Technology awkward;
- Only uses text phones;
- Has limited exposure to digital technologies.

Risks awareness: Scared of everything related to technology, especially data leak and breach of privacy.

Critical problem: Affordability of support technologies

Everyday struggle:

- Watching TV with family, which includes hearing teenage children with whom this person has a complicated relationship.
- Hear on telephone
- Loss of privacy (no/limited private conversation due to requirement of speech to text service to relay the message)
- Group conversations

Key barrier:

- Availability & affordability of voice recognition/speech to text technologies;
- Accuracy of speech-to-text technology
- Complicated relationships with family members, particularly children. This affects the extent and scope of support individuals with hearing loss can get from their hearing family members.

Desired tech interventions: A preloaded smartphone (Android) that

- Serves multiple purposes;
- Communicates directly with hearing aid or cochlear implant;
- Provides accurate voice recognition to text.

Safeguard & failsafe requirements:

- Easily accessible security settings and options
- Alternative to or work independently of Internet connection
- Back-up electricity (locally generated)
- Secure biometric ID recognition (e.g. voice)