Living Labs and Open Toolkit for the co-design of accessible IT systems and tools

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LIST OF ACRONYMS

Acronym	Description
PwCD	People with cognitive disabilities
UCP	Universidade Catolica Portuguesa
NUIG	National University of Ireland Galway
AUTH	Aristotle University of Thessaloniki

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EXECUTIVE SUMMARY

1 INTRODUCTION

1.1 PURPOSE AND SCOPE

The aim of this document is to share what was learned during Task 2.2 of the LIVE-IT project. The main objective of Task 2.2 was to design and set up the LIVE-IT co-design labs - 'Co-Labs' - the main purpose of which is to host experimental and piloting activities for the LIVE-IT project – in order to further advance the state of web accessibility for people with cognitive disabilities (PwCD). To achieve this objective, Task 2.2 covered:

- Continuing to build on user needs analyses from WP1 and Task 2.1 (Lifeworld Analysis) for the purpose of identifying lab specifications
- Applying the lab specifications to designing and implementing the operational systems and procedures needed to deliver Lab services
- Designing and implementing the required ethical procedures and systems, including informed consent protocols
- Making contacts with key informants and gatekeepers to allow access to collaborating users
- Reviewing the thematic focus and settings of the labs in association with the "Makerspace" and online community activities planned in WP 4
- Starting the process of exploring solutions to the digital challenges identified through the research carried out in WP1 and Task 2.1 by mapping these challenges against promising platforms and tools identified through the research and conducting experiments in different 'scenarios of use' to find out what works, for who in which circumstances.

Information gleaned from these activities in shared in this report.

1.2 INTENDED AUDIENCE

This document should be used as a reference by:

- European Commission
- Policy Makers

- Stakeholders
- LIVE-IT Project Team
- Other researchers

1.3 STRUCTURE OF THE DELIVERABLE

This report begins with an overview of the LIVE-IT Project and an explanation of how Task 2.2 and the information shared in this deliverable (D.2.2) support the project goals. Then, the report presents details about:

- The LIVE-IT co-lab approach (Section 2)
- The ethical framework, procedures, and systems used during co-lab design and implementation (Section 3)
- Connections between user needs and co-lab specifications (Section 4)
- Emergent results from the co-labs at the time of writing this report (Section 5)
- Connections between Task 2.2 and the remaining work packages (Section 6)

1.4 RELATION TO OTHER WPS & TASKS

This report (D.2.2) and Task 2.2 serve as a bridge between WP1 and later work packages. The ethical framework and user needs mappings developed through the state of the art baseline reviews in WP1 served as a foundation for Section 3 (co-lab ethics procedures), Section 4 (co-lab specifications), and Section 5 (emergent results from the co-labs) of this report. Lifeworld analysis conducted during Task 2.1 in WP2 and the ongoing analysis of data generated within the co-design labs continuously inform mappings of user needs to existing tools and necessary innovations. The ongoing mapping of user needs to existing tools and necessary innovations will then feed into the “Makerspace,” the Hackathons, and the Open Toolkit in WP3 and WP4.

2 APPROACH

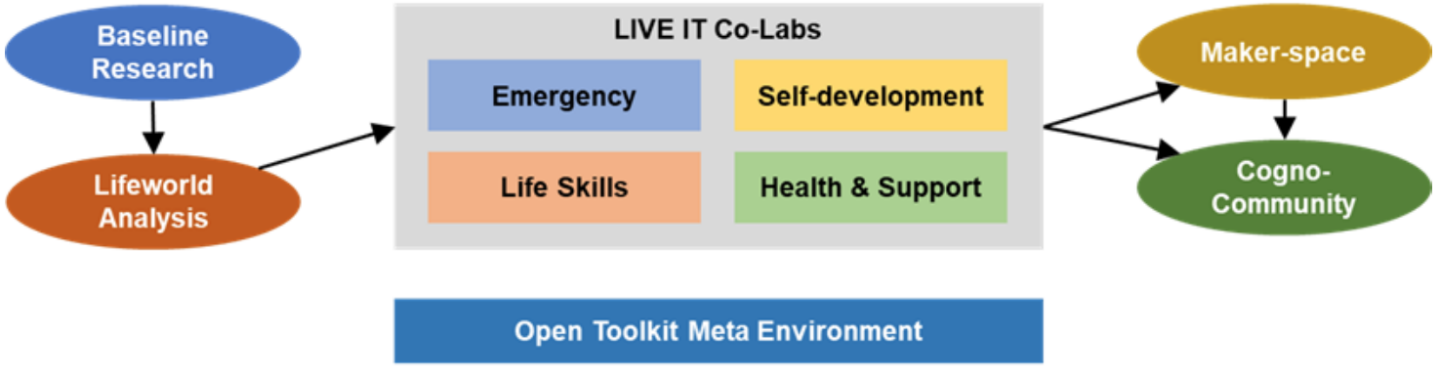
This section provides background on the LIVE-IT Project to help situate the information presented in this report. First, an overview of the LIVE-IT Project concept is provided, which includes brief descriptions of the co-design labs. Then, an overview of the overarching LIVE-IT Project methodology is provided.

2.1 LIVE-IT PROJECT CONCEPT

LIVE-IT establishes a set of co-design Labs – supported by a virtual makerspace, online community and hackathon series – that are at the heart of this purpose. Drawing on the principles and methods successfully established by the Living Lab model, the co-design Labs turn the traditional top-down, expert-driven design model on its head and use a 'design thinking' approach to enable people with cognitive disabilities to become co-architects of their own future digital world in an accessibility service model.

As the diagram below shows, the central focus of the project is on four co-Labs, each configured to the key settings in which people with cognitive disabilities engage with digital technologies in everyday life. These Labs are informed by two sets of research activities – first, baseline research that collects and valorises state of the art research in the field and, second, lifeworld analysis that reveals the barriers that prevent people with cognitive disabilities from taking advantage of the digital world. The co-Labs provide spaces for teams of people with cognitive disabilities working in collaboration with experts and designers to explore and build on available platforms and tools to re-frame and reconfigure them to their needs. The co-Labs are supported by an online 'makerspace' in which people with cognitive disabilities can experiment with promising digital tools in a real-time virtual laboratory that can identify what works and what doesn't. The LIVE-IT Cognitive Community connects an EU-wide network of design Labs – which includes people with cognitive disabilities – to the Makerspace platform.

Figure 1 – LIVE-IT Project Process Map



The combined results of experimentation in the co-Labs and Cognitive Community feed into the production of the two key project outputs – an Open Toolkit and a Meta Environment that provides guidelines, tools and good practice examples to support possible future preparatory actions and programmes in this field.
The co-Lab typology diverts from the common practice of compressing the diversity of cognitive disability impairment into one or more 'target groups', which are instead defined by exploring the settings in which people with cognitive disabilities experience digital technologies in their everyday life, or 'lived experience'. The four LIVE-IT co-labs are therefore set up as follows:

- **Life Skills Lab (Coimbra)** – Focuses on navigating and managing interactions with 'the system', including consumer transactions and related issues such as understanding contracts and small print; filling in forms; consumer rights; online security and protection; managing dates and appointments
- **Emergencies Lab (London)** – Focuses on reducing risk and increasing preparedness and resilience in emergency situations – both at the everyday level, for example health e-consulting, and at the large scale, such as the COVID pandemic – covering finding information, looking for help and support, understanding emergency procedures and instructions
- **Self-Development Lab (Galway)** – Focuses on supporting people to take advantage of the opportunities provided by digital technologies for learning, employment, personal development, involving navigation, information searching, information processing, understanding text and graphics and using animations, working with authoring systems
- **Help & Support Lab (Thessaloniki)** – Focuses on using online information and guidance systems, for example searching for and using public information tools, using complex interfaces and gateways, identifying key points from dense and 'official' documentation, navigating through guidelines

This service model is supported by the LIVE-IT Open Toolkit, providing:

- Directories of cognitive disabilities, IT platforms, services and tools, and relevant people, organisations and places
- Facilities to interlink the elements of the different directories, with an assessment of the potential of using AI to identify patterns and clusters leading to an understanding of current and future usage issues, allowing to easily develop front-end guidelines and tools
- A Cognitive Community knowledge space to support knowledge sharing between the Labs and cognitive disability groups – linked to existing networks through the TCBL ecosystem, the EU Design for All system, ENoLL and the partner networks, which include access to people with cognitive disabilities
- An online 'makerspace' that reinforces the co-design work being carried out in the Labs through supporting the broader community of people with cognitive disabilities to explore and experiment with the ideas and tools coming from the Labs

The elements of the Open Toolkit come alive through interaction between different players in the Labs and maker space but above all in a series of Hackathons that focus on specific issues such as filling forms, managing animations, interpreting numerical information, etc.

In practice, in response to the different operational environments in which the four core Labs work in the four participating LIVE-IT countries, seven Co-Labs have been set up:

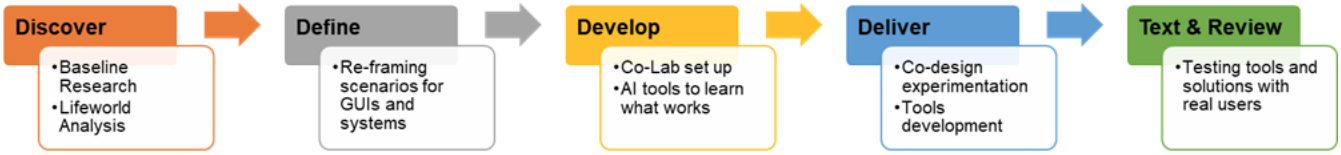
- One Co-Lab centred at NUIG in Galway, Ireland
- One Co-Lab centred at Aristotle University of Thessaloniki in Greece

- Three Co-Labs in Portugal: a 'core' Lab based at the ADFP Foundation in Coimbra and two 'satellite' Co-Labs – one based at the Colégio Bola de Neve – a 'special education' school located in Lisbon, and one based at CECD - Cooperative for Inclusion – in Sintra, providing services for people with disabilities.
- Two Co-Labs in the UK – a core Lab based at Stockwell Park Community Trust in south London, which provides a wide range of on-site and outreach services for the local community, including people with disabilities, and a 'distributed' satellite Lab in Bristol, which works with a range of local service providers.

2.2 LIVE-IT PROJECT METHODOLOGY

The overarching methodology for LIVE-IT applies a 'design thinking approach' (Rowe 1987; Gobble, 2014; IDEO, 2014). In this methodology, the innovation process is typically divided into (1) an open exploration of the problem space (i.e. to develop the right things), (2) exploration to the solution space (i.e. to develop things right), and (3) the iterative alignment of these two phases whenever it is needed. Design thinking involves co-creation through empathizing – gaining an empathetic understanding of the problem; identifying – stating the problem from a human perspective; ideating – identifying new solutions by thinking outside the box; prototyping – developing new solutions to the problem; testing – evaluating the solutions. The diagram below shows how it works.

Figure 2 – LIVE-IT Methodology



The phases in Figure 2 unfold as follows:

- **Discover (Empathise)** – gaining an 'empathetic' understanding of the presenting problem – cognitive disability and digital inclusion – through baseline research and lifeworld analysis
- **Define (Identify)** – applying a convergent thinking approach to consolidate the large set of insights from the discovery phase into a limited amount of clearly defined problems or opportunities to be solved during the follow-up phases
- **Develop (Ideate)** – applying, conversely, a divergent thinking approach to co-create multiple potential solutions for the collectively selected challenges by engaging relevant end-users and other key stakeholders to the co-creation process

- **Deliver (Prototype)** – testing and selecting which of the suggested options is the best according to impact assessment results
- **Test & Review (Evaluate)** – triangulating the results of the testing and evaluation activities, reviewing the results within the Labs and the wider community and integrating these to produce an Open Toolkit and meta-environment

The design thinking process is iterative, with feedback loops connecting back to preceding stages - for example developing a prototype may reveal gaps in the thinking applied in the 'Ideate' stage, so the process reverts back to the Ideate stage to explore additional new solutions to the problem.

This overarching methodology interconnects the following methods:

- **Scientific realist review** (WP1) – Supporting the 'discover' phase, Realist review (Pawson et al, 2005), involves a review of state of the art in the field as a 'half way house' between a 'systematic review' and a 'narrative review'. The specific sources for the review will be identified through an initial data audit, but cover both official literature –existing research reviews and reports, bibliographic databases and academic research – and 'grey' literature: unpublished material like blogs and dissertations.
- **Lifeworld analysis** (Task 2.1) – This also supports the 'discover' element of the project, capturing the narratives of people's 'lived experience' of cognitive disability in the digital world in order to draw conclusions about the situational dynamics that shape engagement with digital tools. The methodology uses a phenomenological approach (Patton, 1990) that is focused on "descriptions of what people experience and how it is that they experience what they experience". The life world analysis is carried out in a range of settings that reflect a spectrum of cognitive disability and digital experiences, involving at least 60 people in four countries.
- **Interventions Audit** (WP1) - This supports the 'discover' and 'define' phases, also using a methodology based on scientific realist review (Patton, 2005). Realist review allows researchers to look at how something is supposed to work, with the goal of finding out what strategies, platforms and tools work for which people, in what circumstances, and how. The interventions audit builds on existing databases of examples of innovative policies and interventions at EU level (e.g. FP7; H2020; Erasmus) and national level, supplemented by an on-line searches using a range of services.
- **Co-creation workshops** (WP2-WP4) – This is a key tool applied across all of the project stages to ensure that the project results reflect the perspectives and voices of people with cognitive disabilities. Taking part in the cocreation process on the one hand empowers the capacity of the different subjects and on the other hand it gives the opportunity to tailor new services to the needs of the cognitive disability community. A range of iterative co-creation and co-testing methods (e.g. 'service jam') are built into the operational process of the co-Labs, the makerspace and hackathon cycles.
- **Makerspace** (WP4) – In addition, the online 'makerspace' provides a more open and widely accessible environment in which co-creation workshops can be used to experiment and test potential platforms and tools, building on a growing body of evidence that supports the use of makerspaces for people

with disabilities – including learning and cognitive disabilities (Klipper, 2014). In particular they support 'design for all principles' by 'empowering people with disabilities to make their world' (Buehler et. al., 2015). The virtual makerspace in LIVE-IT puts together a 'box of stuff' to support this, using, for example, tools like 'SiteStyles' that enable users to individualise website design and content to their needs, and focusing in particular on tools to explore web accessibility and co-authoring.

- **Co-Labs** (WP2-WP4) – approach belongs to the family of user-centred innovation approaches and focuses on the engagement of the Quadruple Helix – research, public sector, business, and citizens – in codesign processes. User centred design and design innovation interventions are highly participatory processes that identify the most effective analysis and design tools for the objectives based on the number and nature of stakeholders and users involved, on the consistency of the expected results and on the preparedness level of the intervention context. The co-Labs are interdisciplinary service centres aiming to complete and enrich the offer of inclusive accessible web services by acting as places of social innovation for sharing skills, resources and projects. In this way, people with cognitive disabilities, private companies, research organisations and IT developers can contribute together to the construction of accessible tools and services. The co-Labs capitalise on existing partner networks – for example the ADFP Foundation's residential and support services for people with cognitive disabilities, part of the Portugal co-Lab; the Thess-AHALL (Thessaloniki Active and Health Ageing Living Lab), which is in turn a member of European Network of Living Labs –ENoLL – to ensure access to user groups, and are further supported by an EU-wide network of networks, including EIDD (Design for All Europe) and the TCBL Lab ecosystem, which further ensure user access within the LIVE-IT makerspace and online Community.

3 ETHICAL FRAMEWORK, PROCEDURES, AND SYSTEMS

This section details the ethical framework, procedures, and systems for the LIVE-IT co-labs. First, the overarching LIVE-IT ethical framework, which was developed as part of WP1, is presented. Then, due to the highly contextualised nature of the co-labs, the specific ethical procedures and systems for each co-lab are presented separately. Key similarities and differences are highlighted within each section so that those conducting similar research may use what has been learned during the LIVE-IT Project to inform their own work.

3.1 LIVE-IT ETHICAL FRAMEWORK

The LIVE-IT Project team works under the general ethics orientation to Do No Harm (non-maleficence) and Do Good (beneficence) in its engagement with research participants. Specifically, the LIVE-IT ethical framework has been developed with reference to a range of sources. These include:

- Key ethics frameworks, standards and guidlines, covering research in general and research involving vulnerable people and people with disabilities specifically
- Key texts from the academic and research fields
- Research projects aimed at developing ethical frameworks and tools for research, including projects in the 'responsible research and innovation' (RRI) field
- Previous projects in which the LIVE-IT partnership has been involved.

Ethics and data protection frameworks, standards and guidlines

- Charter of Fundamental Rights of the European Union, (2010/C, 83/02)
- Ethics for Researchers, European Commission (2013). Luxembourg: Publications Office of the European Union, 2013 - **https://ec.europa.eu/research/participants/data/ref/fp7/89888/ethics-for-researchers_en.pdf**
- European Code of Conduct for research integrity, European Federation of Academies of Sciences and Humanities (ALLEA) - **https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/horizon/guidance/european-code-of-conduct-for-research-integrity_horizon_en.pdf**
- WHO (2017) WHO code of ethics and professional conduct - https://www.who.int/
- The UN Convention on the Rights of Persons with Disabilities (UNCRPD **2006**)
- European Science Foundation Code of Conduct https://www.esf.org/fileadmin/user_upload/esf/ResearchIntegrity_Report2011.pdf
- ESRC Framework for Research Ethics (2015) - **https://esrc.ukri.org/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/**
- The General Data Protection Regulation (GDPR), Regulation (EU), 206/679

Academic and Research Texts

- Good, A (2020). Disability Research Ethics. In Iphofen, R (Ed). (2020) **Handbook of Research Ethics and Scientific Integrity** . London: Springer
- Macdonald, G. M., McNeilly, P., & Kelly, B. (2020). Ethical considerations when conducting research with children and young people with disabilities in health and social care. *Nurse Researcher*. https://doi.org/10.7748/nr.2020.e1645
- Learning Difficulties Research Team, Bewley, C. and McCulloch, L. (2006) Let Me In – I'm A Researcher! Getting Involved in Research, London, Department of Health.

- Report of Ethics Workshop on Research Involving Adults who Lack the Capacity to Consent (24 May 2011) www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy/further-guidance/educationresources/mencapworkshop
- Farmer, M and Macleod, F (2011). Involving Disabled People in Social Research Guidance by the Office for Disability Issues. London: Office for Disability Issues
- Doody O. (2018). Ethical Challenges in Intellectual Disability Research. Mathews J Nurs. 1(1): 005.

Projects on Ethics and RRI

- Pro-Res - **https://prores-project.eu/toolbox-2/**
- SATORI - **https://satoriproject.eu/framework/section-1/**
- Pro-Ethics - **https://pro-ethics.eu/pro-ethics-outputs**

  RRI-Practice **https://www.rri-practice.eu/**
- **ENERI - https://eneri.eu/e-manual/**
- RRI-Practice - **https://www.rri-practice.eu/**
- EasyReading – www.easyreading.eu

Ethics Frameworks Previously Developed by the Partnership

- EMERGENT - http://www.fp7-emergent.eu/
- RESILOC - *https://www.resilocproject.eu*
- MEDICI – www.medici-project.eu

The above sets of principles and Guidelines have fed into the production of the LIVE-IT 'Code of Conduct,' which is provided, along with more detailed information about the LIVE-IT ethics framework, in the Annex to Deliverable 1.1.

The LIVE-IT project has a clear Data Protection and Privacy Policy in place. It complies with the General Data Protection Regulation (GDPR) – which applies in all EU countries in which LIVE-IT operates. The policy ensures that we will only use personal information to help us carry out our research and to help us disseminate its results. All information obtained will be kept anonymous, will only be used for research purposes and will not be released to any third party outside the LIVE-IT consortium. To collect the research information we need, the lab activities may be recorded on audio and/or video but only with the consent of all participants. The

information collected – including any video or audio recordings – will be held in secure files that are not publicly accessible. Participants must be able to withdraw from the lab at any time without any negative consequences. In order to comply with this, we followed the steps below for data storage and data sharing:

Data Storage:

- Anonymise data as soon as possible by developing pseudonyms for participants
- Store data on secure servers and/or hard drives
- Keep files that must include identifying information protected via password

Data Sharing (dissemination/use of data outside of the partnership):

- Share de-identified/anonymised transcripts only
- Share files that must include identifying information via password protected servers
- Do not save files with identifying information from other labs to your personal devices

To protect the rights of vulnerable populations all LIVE-IT partners obtained informed consent (and assent when necessary) from participants. If a participant requires a legal representative to provide consent for them – for example, if the participant is a child, or if the participant's disability is severe enough to require a legal guardian – then consent should be obtained from the legal representative *and* assent should be obtained from the participant, when possible. The specific procedures for obtaining informed consent are provided in the next section.

Beyond obtaining informed consent, each partner must plan adequately for challenges and participant needs. Based on the information gathered from partners to date, it is recommended that partners have a plan shared with all lab facilitators related to the following (if applicable in your setting):

- Medical complications that arise during the lab activities
- Assisting participants with regulation of emotions
- Response in the event that a participant experiences a seizure
- How to reach/access appropriate support personnel

See Appendix A for the approved study protocol, which was approved by the Aristotle University of Thessaloniki ethics board.

3.2 LIVE-IT ETHICAL PROCEDURES

The LIVE-IT ethical procedures are the concrete steps and documents utilised within each co-lab to protect participants from potential harm associated with research activities. Generally speaking, the ethical

procedures can be organised into two categories: before data collection, and during data collection. Before data collection, all researchers at all co-lab locations did the following:

- Provide potential participant(s) with access to project, lab, and experiment description(s) in multiple formats (written, audio, video)
- Provide potential participant(s) with access to descriptions of potential use(s) of data collected from participant(s) in multiple formats (written, audio, video)
- Provide opportunities for potential participant(s) and/or their legal representative(s)/guardian(s) to ask questions about the project, lab, experiment(s), and use(s) of data
- Ensure confidentiality and GDPR-compliant storage of data
- Obtain **consent** from the participant(s) and/or their legal representative(s)/guardian(s) prior to data collection
- When possible, obtain **assent** from the participant(s) in the event that a legal representative/guardian must provide informed consent prior to data collection
- Obtain consent (and assent, if applicable) for ***all*** forms of data to be collected and ***all*** uses of the data
- Remind participant(s) that they may take breaks and/or withdraw from the lab/experiment at any time

If informed consent was not obtained prior to data collection, then data from that participant could not be used. Additionally, before data collection, researchers also worked to determine if the nature of participants' cognitive disabilities would require support of individuals trained in supporting particular groups. If it was determined to be needed then, ensure that such support personnel are present in the lab.

During data collection, all researchers at all locations did the following:

- Create a welcoming environment for participant(s) and anyone who must accompany the participant in the lab
- Provide breaks when requested by participant(s) and/or anyone accompanying the participant
- If participant(s) appear to be overwhelmed or frustrated, ask if participant(s) need break(s)
- Provide clear instructions and descriptions of activities in multiple formats (written, audio, video)
- Provide responsive training and technical support to participant(s)

Additionally, if any portion of data collection occurred virtually with multiple participants logging in to a meeting (like Zoom), researchers spoke with participants about confidentiality of all involved. It was recommended that participants log in to meetings with headphones or in non-public locations to protect the identities and experiences of all participants.

Because the co-labs were developed in four different contexts with multiple different vulnerable populations participating, the ethical procedures are presented by co-lab. Across all ethical procedures, a common theme is apparent: all co-labs worked diligently to honour participants' identities, wellbeing, and lived experiences.

Thus, each co-lab developed concrete steps and documents with the understanding that additional supports may need to be provided so that the unique needs of each individual participant were met. Where applicable, these additional supports are described. Finally, the LIVE-IT Project used the publicly available **Easy Reading ethics documentation** as a foundation for many ethics documents and procedures. Please refer to Appendix B for copies of the LIVE-IT ethics documents.

3.2.1 ARCOLA

The team at Arcola Research LLP established two co-lab locations in the UK: one in South London, and one in Bristol. Both labs expected to recruit participants with a complex range of neurodiversity including: Autistic Spectrum, Dyslexia, ADHD, Irlen Syndrome, Down Syndrome, Traumatic Brain Injury (Stroke), and Dissociative Seizures. Additionally, participant interaction during the Lifeworld Analysis in Task 1.2 highlighted the importance of having audio and pictorial representations of all information presented to participants. Therefore, the ethics documents and procedures for the London and Bristol co-labs were designed to be multi-modal. For example, Arcola adapted **the Easy Reading informed consent with pictures document** for use with their participants and shared it with the consortium so that all partners could access it if needed (see Appendix B).

3.2.2 UCP

The team at Universidade Catolica Portuguesa (UCP) established two co-lab locations in Portugal: one in Coimbra, and one in Lisbon. The lab in Coimbra expected to recruit participants with multiple disabilities: "cognitive deficit" with ADHD or Autism. The lab in Lisbon expected to recruit participants with more severe disabilities including but not limited to: "cognitive deficit" with emotional and temperament functions compromised, ADHD with oppositional defiant disorder, Cerebral Palsy and ADHD, and Cerebral Palsy and anxiety and depression. Additionally, the lab in Lisbon expected to recruit participants who were minors: ages 16-18. To accommodate the range of participant needs in the ethical processes, the team at UCP did the following:

- Translated the adapted Easy Reading informed consent with pictures document into Portuguese (see Appendix B)
- Developed a powerpoint presentation explaining LIVE-IT, informed consent, and the co-lab activities for participants

3.2.3 NUIG

The team at the National University of Ireland Galway (NUIG) established a single co-lab location in Galway. However, the team planned to offer co-lab activities in-person and virtually (via Zoom) for two reasons. First,

to be ready to respond to university guidance about COVID-19 procedures. Second, to meet the needs of participants who expressed a desire to continue to participate virtually at the end of their lifeworld analysis interviews conducted as part of Task 1.2. The lab in Galway expected to recruit participants with ADHD, Autism, or dyslexia as their primary diagnosis. To accommodate the needs of participants and the context, the team at NUIG developed online versions of the informed consent forms that could be read with text-to-speech tools available to the students (screen shots available in Appendix B). The online informed consent forms would store data in password protected files. Additionally, the informed consent forms were reviewed aloud with all participants prior to starting data collection.

3.2.4 AUTH

The team at Aristotle University of Thessaloniki (AUTH) established a single co-lab location in Thessaloniki. The lab at Thessaloniki expected to recruit participants with: ADHD, Autism, mental retardation, and Down Syndrome. It was expected that caregivers and/or special experts would be present in the lab sessions to both facilitate participant engagement with co-lab activities and assist when participants faced challenges in the lab. Participants with accompanying caregivers would have their caregiver by their side for the whole co-lab session in which they were participating. In order to both accommodate participant needs during the informed consent process and comply with AUTH's policies governing ethical approval, the team at AUTH took the following steps to acquire informed consent and begin co-lab activities:

- Welcome them and present them the lab's facilities
- Explain the process / experiment and the scenario to them as simple as possible and ensure they understood everything
- Go through the consent form and answer all questions until everything is clear to them
- In case they agree with all aspects of the consent form they (or their representative) sign it

Additionally, see Appendix B for the Greek informed consent form.

3.3 LIVE-IT ETHICAL SYSTEMS

The LIVE-IT ethical systems are the ways in which the theoretical elements of the overarching ethical framework were put into action within the four co-labs. In the sections that follow, descriptions of how the ethical framework presented in section 3.1 came to life, so to speak, within the co-lab settings. Examples of moments that required responsible procedural flexibility are provided for the purpose of guiding future research with PwCD. Two themes emerge from these examples: 1) the importance of the initial stages of co-lab implementation for ensuring the ethical inclusion of this vulnerable population; 2) the importance of participant-driven lab sessions.

3.3.1 ARCOLA

Co-lab facilitators in the UK co-labs have found that, it has been mostly impossible to carry out formal co-lab tools work without a period of:

- Acquaintance
- Trust building
- Introducing the Live-IT project and its aims
- Gauging the reality of participant's cognitive challenges and difficulties
- Gauging participants' capabilities with both devices and websites

Additionally, many of the participants are experiencing additional life challenges related to low income and poor support opportunities. Their participants are experiencing many layers of exclusion in their lives, coupled with concurrent and related mental health issues, and other serious existential challenges such as isolation and housing need. In early co-lab work, the facilitators immediately recognised a need to responsively adjust planned scenarios (which will be described in more detail in Section 5) to meet the needs of participants.

For example, when exploring the co-lab theme – emergencies – and imagining emergency situations, facilitators noticed the need to proceed very carefully and consult with carers in order to work out what can be suggested without causing mental and/or emotional harm. Imagined scenarios they have been wary of suggesting are scenarios involving stress or the potential loss of a carer. This is just a simple illustration, in effect it has been extremely important to engage with the 'whole', needs, wants and fears of participants in order to work ethically and effectively.

Furthermore, co-lab facilitators found it necessary to deviate from initial plans to look at accessibility tools and specific neurotypical text-based websites. They did this to find out from participants what and how they use the tech they can get access to, such as phones, tablets and pc's/laptops. Many participants avoid standard websites and technology for a range of reasons including but not limited to: preferring human interaction and support; preferring audio-visual tech usage (YouTube, TikTok, TV, Instagram, FaceTime and video calling apps) for news and information. Due to this pivot, the co-lab sessions are revealing a huge range of differing and complex combinations of cognitive challenges coupled with other personal challenges that frequently relate to mental health and feelings of exclusion or worthiness in participants.

3.3.2 UCP

Similarly, co-lab facilitators in Portugal learned during the early stages of co-lab implementation that co-lab procedures would need to be flexible and participant-centred in order to promote participant engagement. More specifically, co-lab facilitators recognised that customising lab sessions so that they focused on

participants' personal interests led to more engaged lab sessions. Additionally, facilitators noticed that participants experienced difficulty with:

- Completing the planned scenarios (which will be described in more detail in Section 5)
- Tasks related to but not initially considered part of a planned scenario
- Downloading and accessing tools selected for use within the scenarios
- Memory

For example, one of the participants didn't remember his email's password and the planned scenario for that day included email reading. All participants were interested in assisting this first participant in recovering and creating a new password through a multi-step process. Therefore, the co-lab facilitators pivoted by abandoning the original plan for the scenario and following the participant interest. The participant who had forgotten his password had several challenges in comprehending what was asked in each step, and one of the other participants guided him step by step. At one moment a code was sent to a mobile phone registered, but the participant didn't remember his own mobile phone and needed assistance of another participant to confirm his own phone number. The whole session revolved around this challenge and task. In the end the participant recovered his email and created a new password. The initial plan did not involve creating passwords, but the scenario that unfolded still presented a rich and engaging opportunity to learn with and from the participants.

Additionally, the co-lab facilitators in Portugal found that some participants were apprehensive about changing familiar procedures. For example, the impromptu password recovery scenario that unfolded revealed that participants preferred their own self-developed and non-technology-oriented workarounds such as writing passwords on paper or creating new accounts over novel solutions involving technology. The preference precluded even brainstorming potential technology-based solutions. This highlights the need to develop trusting relationships with participants, because a strong foundation of trust may help participants feel comfortable trying new approaches.

3.3.3 NUIG

In Ireland, co-lab facilitators used the results of lifeworld analysis (Task 2.1) to draft an initial plan for co-lab implementation. This plan proposed that the co-lab take one of two forms: a workshop, or a small group problematising session. The workshop idea was born out of lifeworld analysis findings that participants wanted more community around tool use, more access to tools, and more access to training on how to use tools. The small group problematising idea was drawn from the literature. Facilitators envisioned multiple possibilities with these forms. The co-lab could be run exclusively as a series of workshops. It could be run exclusively as a series of small group problematising sessions. Additionally, it could be run as some mixture of the two with small group problematising sessions potentially leading to the development and implementation

of workshops. In any of the forms, the co-lab would implement scenarios focused on self-development, which will be described in more detail in Section 5.

Co-lab participants would be university students with cognitive disabilities. Before implementing co-lab sessions with these participants, facilitators consulted two key groups of stakeholders: 1) PwCD with whom relationships had already been established during the lifeworld analysis; 2) Disability Support Services and Access Centre staff responsible for connecting students with accommodations and services. These conversations prompted the co-lab facilitators to revise their plan for implementation. Conversations with PwCD who had participated in the lifeworld analysis revealed:

- Relationship building would be essential to small group session and/or workshop success
- Individual sessions prior to larger group sessions would allow facilitators to plan for group dynamics
- Planning for group dynamics is essential because participants do not necessarily know each other
- Trust among participants as well as trust between participants and facilitators must be considered

Furthermore, conversations with Disability Support Service and Access Centre staff revealed:

- Possible negative effects of exposing to students to pay-to-access tools through the project that they cannot continue to use after the project
- Possible negative effects of asking students to take on additional tasks during an academic year with increased stress due to COVID

These conversations resulted in co-lab facilitators revising the plan for co-lab implementation in three ways. First, the co-lab would begin with individual sessions that would end with a conversation about potentially joining larger group sessions. Participants interested in group sessions would then move into small group problematising sessions. Participants not interested in group sessions would be given the opportunity to continue to engage with the project in individual sessions. Second, the co-lab would only consider pay-to-access tools that the students already have access to or open access tools. This is another reason why individual sessions are key; they allow facilitators to determine potential groupings for group sessions based on which participants have access to which pay-to-access tools. Third, the co-lab would commit to a participant-driven approach. What this means is, there may be a plan in place for scenarios, but the co-lab sessions will ultimately be directed by the participants present.

3.3.4 AUTH

Initially, the co-lab facilitators in Greece planned a series of conferences to be held online with a special school for adolescents and older adults. Lifeworld analysis activities, such as focus groups, were conducted with this special school during Task 2.1. In keeping with the co-lab theme – help and support – facilitators planned to give written online information to the participants and then ask them to visit the official web pages of the

respective services (fire department, police department, etc.) in order to seek information. Before the planned sessions, the co-lab facilitators consulted with educators at the school to learn more about the difficulties the majority of students face.

Most of the students who would be participating in the co-lab do not have expressive speech and could only perform very basic linguistic skills. For example, the students are 18-20 years old and they have a language range close to 100-250 words. Furthermore, students with wider lexical span and reading and writing skills, also face great difficulty in reading and understanding written information and transmitting the meaning.

As a result of this meeting, the co-lab facilitators revised their initial scenario plans (scenarios will be discussed more in Section 5). in order to ethically engage participants in the research. In the new plans, participants would search keywords in search engines by typing or dictating. Also, the co-lab facilitators worked to design scenarios that reflect possible realistic situations rather than abstract concepts. These changes were made in response to feedback from teachers at the school in order to make scenarios more responsive to participants needs while also including opportunities for participants to give feedback for the tools.

4 CONNECTING USER NEEDS TO CO-LAB SPECIFICATIONS

4.1 OVERVIEW OF USER NEEDS IDENTIFIED IN WP1

In WP1, an academic literature search, a grey literature search, and a tools and platforms search were conducted. Through these searches, we encountered a variety of user needs documented in a variety of ways. The World Wide Web Consortium's (W3C) document, **Making Content Usable for People with Cognitive Disabilities**, provided a clear and organised method for documenting user needs. When themes from the academic literature search, grey literature search, and tools and platforms search were compared with this method for documenting and organising user needs, they fit within the system that the W3C had developed. Therefore, the LIVE-IT Project adopted the W3C's system to document and organise user needs for the purpose of connecting user needs to tools and platforms, and also connecting user needs to scenarios and experiments.

Before sharing more about the mapping of user needs to tools and platforms and scenarios and experiments, we first explain how the W3C method for documenting user needs was adopted within the LIVE-IT Project. Table 1, above, provides a brief overview, and a more detailed explanation follows.

Table 1 – W3C User Needs and LIVE-IT Data Types

User Stories	Patterns	Scenarios
NOTE: Table structure and definitions from Appendix A in https://www.w3.org/TR/coga-usable/#objective-1-help-users-understand-what-things-are-and-how-to-use-them-1		
W3C definition: specific user needs stated simply and clearly **LIVE-IT data:** user needs stated during LWA interviews and/or focus groups; user needs stated during co-lab activities **When is data available**: now *and* it can be continuously updated throughout the project	**W3C definition**: specific designer/developer actions to address user need **LIVE-IT data**: actionable steps toward working solutions developed through co-lab activities and hackathons **When is data available**: after lab activities and/or hackathons have concluded (suggestions from LWA interviews and/or focus groups are not necessarily known to be working solutions)	**W3C definition**: narrative description of: 1) how researchers became aware of the user need, 2) what was done in the lab to address the need, 3) how participants responded to what was done in the lab **LIVE-IT data**: narrative descriptions of scenario lifecycle from LWA interviews and/or focus groups to scenario development to co-lab activities to hackathon outcomes **When is data available**: now through after lab activities and/or hackathons have concluded

The W3C document, **Making Content Usable for People with Cognitive Disabilities**, highlights 9 "key topics," or actionable areas for developers/designers. Within each "key topic," the document also presents "stories," or specific aspects of accessibility within each "key topic." What the W3C refers to as "stories" in the document, I refer to as "user story categories," because the terms presented in the W3C document are categories of user needs that are drawn from narrative descriptions of user needs. Table 2, below, provides an overview of this information.

Within the W3C document, there are 24 user story categories. The W3C document lists the categories within the table in the Appendix linked above, and also connects those categories with narratives that one would more typically associate with the word "story." Thus, it may make sense to either select excerpts from transcripts OR write narrative descriptions based on those transcript excerpts and group them by the user story categories proposed by W3C. We should, of course, also track if new user story categories are needed based on our data. Also, it is worth noting that the W3C documents does not include any user story categories for the last key topic: "test with real users." LIVE-IT will contribute directly to that category.

Table 2 – W3C Key Topics and User Story Categories

Key Topics	User Story Categories
1) Help users understand what things are and how to use them	a. clear purpose b. clear operation c. symbols
2) Help users find what they need	a. findable b. searchable c. clear navigation d. media
3) Use clear content (text, images, and media)	a. clear language b. visual presentation c. math concepts
4) Help users avoid mistakes	a. assistance and supports b. undo feature
5) Help users focus	a. distractions
6) Ensure processes do not rely on memory	a. remembering previous steps b. accessible authentication c. voice
7) Provide help and support (computer-based and human)	a. help b. support c. directions d. cognitive stress e. task management
8) Support adaptation and personalization	a. adapt b. extensions c. add-ons and API's
9) Test with real users	a. [no categories presented – this is a major aspect of LIVE-IT]

4.2 OVERVIEW OF USER NEEDS IDENTIFIED IN WP2 (LIFEWORLD ANALYSIS)

Using the W3C Key Topics and User Story Categories in Table 2 as a frame for analysis, all lifeworld analysis (Task 2.1) data was reviewed to identify user needs. We took a multi-layer approach to identifying user needs. First, we identified challenges mentioned by users during the interviews and/or focus groups conducted during the lifeworld analysis. Then, we grouped the challenges by W3C Key Topic, which we consider to be the main user need categories. We consider the W3C Key Topics to be synonymous with user needs for our data set, because the challenges identified could all be grouped by W3C Key Topic. This step was undertaken to

both confirm that the W3C Key Topics were a good match for our data and to determine if any additional user need categories should be added to the list.

Table 3 – Lifeworld Analysis Key Topic Frequency

W3C Key Topic (User Need)	Total
1) Help users understand what things are and how to use them	61
2) Help users find what they need	78
3) Use clear content (text, images, and media)	86
4) Help users avoid mistakes	54
5) Help users focus	60
6) Ensure processes do not rely on memory	75
7) Provide help and support (computer-based and human)	191
8) Support adaptation and personalization	129
9) Test with real users	0

Table 3, above, is a frequency table depicting the number of times a particular key topic, or user need, was mentioned across all lifeworld analysis activities conducted by all project partners. Note that the *provide help and support (computer-based and human)* user need was mentioned most frequently. Also, the *test with real users* has a frequency of zero, which is interesting, because that means that none of our lifeworld analysis participants mentioned testing solutions with real users. This indicates that PwCD have been so marginalised in this research that they do not see themselves as part of it.

After grouping challenges by W3C Key Topic, we also grouped the challenges by the presenting impairment. Rather than group by diagnosis, we decided to group by presenting impairment so that the findings may be more applicable to a broader audience. We define *presenting impairment* to be the primary cognitive issue related to the participant-reported challenge. This process generated 9 categories:

- Memory
- Focus
- Time and organisation
- Mood
- Physical barriers
- Reading, writing, and comprehension
- Numbers
- Digital skills
- General problems

Tables 4-12 provide counts for the specific challenges within each of these 9 categories. Please note that the totals across tables 4-12 (below) will not be identical to the totals in Table 3 (above). This is because a single challenge was seen as linking to multiple key topics. The counts and the quotes are derived from the following live documents, which will continue to grow and evolve throughout the remainder of the project:

- **ARCOLA Challenges, Tools, and Quotes Mapping**
- **UCP Challenges, Tools, and Quotes Mapping**
- **NUIG Challenges, Tools, and Quotes Mapping**
- **AUTH Challenges, Tools, and Quotes Mapping**

It is difficult to provide both an overview of big picture themes and details of individual context within a single document. The tables and quotes that follow will aim to provide an overview of what has been learned through the lifeworld analysis activities that is relevant to the co-lab scenario development. Please visit the links above for additional details not provided below, such as individual diagnoses.

Table 4, below, presents the specific challenges from the lifeworld analysis that are associated with memory. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 4 – Challenges Associated with Memory

Challenge Theme	Challenge	Total
Memory	Difficulty recalling sign in information such as passwords	6
	Difficulty recalling personal and family information	2
	Difficulty to remember which button to press each time	3
	Difficulty remembering the steps taken in a calculation when they are not shown on the screen	1
	Difficulty remembering processes	8
	Difficulty remembering appointments and important tasks	5
	Difficulty retaining information	2

Participant quotes associated with *difficulty recalling sign in information such as passwords*:

- 'He could never remember the simple passcode to access the iPad though.'

- ‘I struggle with remembering passwords, codes etc. and the different processes involved in (navigating) different sites. If I’ve established a route in my brain about how to access info, I have to remember the path to get to info. Really convoluted routes to finding stuff that are unique to me and wouldn’t necessarily make sense to others. Things I use to signpost steps.’

Participant quote associated with *difficulty recalling personal and family information*:

- “At this point [of his illness/diagnosis] he has started losing information about us, about himself. Sometimes he really struggles to remember who he was. Other times, and that's kind of shocking, he remembers everything with great detail. Like it was in a fog and then he wakes up. He remembers his wife, us…he is asking what we are doing. Then again, all his memories faint away again, and we are waiting for that glimpse of remembrance”.

Participant quote associated with *difficulty to remember which button to press each time*:

- “He faces difficulty following steps, like one series of actions with many steps. Even if he remembers that the YouTube is a platform that amuse him, he is unable to consistently take the steps to get into the application and use it.”

Participant quote associated with *difficulty remembering the steps taken in a calculation when they are not shown on the screen*:

- “I use a calculator because my, my main errors are not in…it's not in understanding the formula. I understand the formula but I struggle to execute the formula. I usually use a calculator. Usually a piece of pen and paper just to write down what was calculated just to commit it to memory because I cannot again, remember very well.”

Participant quotes associated with *difficulty remembering processes*:

- “Eventually after many times showing him how, I had left an icon on explorer for the Welsh rugby, and he managed to go to explorer, Welsh rugby union, and watch it. He would get a little bit lost and make mistakes, but because it was all on the same site more or less, he would ask for help a few times, but he was using it for a couple of years. It was very difficult for him but where he had motive which he perceived as valuable he managed.”
- “I struggle with remembering passwords, codes etc. and the different processes involved in (navigating) different sites. If I’ve established a route in my brain about how to access info, I have to remember the path to get to info. Really convoluted routes to finding stuff that are unique to me and wouldn’t necessarily make sense to others. Things I use to signpost steps.”

- "One [client] has lost contact with her daughter, who wants to communicate by text and she doesn't know how. It's a process of teaching. We've taught her how to send text messages. Its unfamiliar, learning takes longer due to processing speed being slower, short term memory issues. I have to keep repeating myself, re-explain how to do thing. I don't know if it's all the cognitive impairment or also mental health issues as they can present in a similar way to a cognitive impairment."

Participant quote associated with *difficulty remembering appointments and important tasks*:

- "I like Google Keep. Reuse the checklist, saves me time. Doesn't just disappear like on most list/task apps. Alexa, Google voice prompts, but privacy means they don't just say the reminder, instead it 'ruth you have a reminder' then you have to prompt it to tell you. If you forget or get distracted you miss the reminder."

Participant quotes associated with *difficulty retaining information*:

- "I can read, but reading a book isn't possible. I'd have to remember what I had just read, processing issues."
- "Sometimes my trouble would be tuning out in the middle of a lecture and then going from there so it's always handy to have the recording to listen back and then go "Oh, that's what they said." And then compare that with whatever notes I have or whatever notes I saved or uploaded."
- "And with the Text 2 Talk reading it to me…that was a huge help because it would take me hours to read something, and I would forget what I've read. Whereas, now I can actually finish it. I followed what I was reading and I could hear it…it was so much better for me."

Table 5 presents the specific challenges from the lifeworld analysis that are associated with focus. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 5 – Challenges Associated with Focus

Challenge Theme	Challenge	Total
Focus	Difficulty staying focused	8
	Cognitive overload in the presence of complex interfaces or too much information	9
	Cognitive overload from pop ups and others distractions	6
	Delayed processing: additional time required to take in and understand information	6

	Difficulty understanding abstract concepts such as the internet and its navigation for example understanding the structure of websites and how to navigate them using menus or buttons	1
	Difficulty communicating with people when they are not visible/there is no face-to-face contact	1

Participant quotes associated with *difficulty staying focused*:

- "If I have my task, my mindmap, that keeps me focused."
- "Concentration is difficult. 10 minute limit."
- "I find myself blanking out, especially when I've recently had a seizure."

Participant quotes associated with *cognitive overload in the presence of complex interfaces or too much information*:

- "I get lost in a rabbit hole of link after link. It's overwhelming because I work visually and I can't see where I am in the order of things. Millions of tabs. I'm like how do I need to navigate through this, I click a link then I've lost the source so I always end up with about thirty thousand tabs because I right click and open link in new tab."
- "Overload, you bake your cake, get your ingredients, get your six words to prompt you to do what you need to do to not get sidetracked. Simplify appropriately and create the appropriate gateway system, circumstances, and recognition."

Participant quotes associated with *cognitive overload from pop ups and others distractions*:

- "Websites have lots of colours, patterns, it's too distracting. Adverts, pop ups."
- "As I said, it's just the way that they organize everything, you know, it can be quite overwhelming…there's so much, but you know…that they're trying to catch the eye…there's stuff to try to catch your eye."

Participant quotes associated with *delayed processing*:

- "Can't do it. My brain doesn't register it now. Short term memory loss interfering with reading, writing, and concentration. Can't concentrate for long."
- "Encourage people to take their time, correct mistakes, delete what they need."

Focus group observer quote associated with *difficulty understanding abstract concepts such as the internet and its navigation for example understanding the structure of websites and how to navigate them using menus or buttons*:

- "Both in the preliminary tests and when interacting with the platforms, children had difficulty navigating the systems, reading web pages, and understanding the next steps in the online process. They could know from when to start when interacting with the surfaces."

Participant quote associated with *difficulty communicating with people when they are not visible/there is no face-to-face contact*:

- "Without visual cues - I can't process the information. because of the way my brain works. I have to see. If I see your mouth moving, I can hear you!"

Table 6 presents the specific challenges from the lifeworld analysis that are associated with time and organisation. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 6 – Challenges Associated with Time and Organisation

Challenge Theme	Challenge	Total
Time and Organisation	Difficulty with time management and organisation	9
	Difficulty remembering the date, day or time	1
	Difficulty finishing tasks	2
	Difficulty sequencing and completing multi step tasks	5
	Difficulty understanding time	1
	Difficulty planning for the future	1
	Difficulty avoiding or managing online distractions such as Netflix or social media	2
	Difficulties organising and managing files	2

Participant quotes associated with *difficulty with time management and organisation*:

- "'Fatigue management' is really just customised 'time management' and I was introduced to journaling and diary organisation through OT's at rehab. I find it difficult to focus if I am trying to multitask and fatigue very quickly."

- “I can spend all day trying to do one thing. Frequently spend hours in front of the laptop not quite getting stuff done.”
- “When I have to do a job on the computer I get fired, I lose my sense of time and at the same time because I know from the beginning that this will happen I get stressed and this helps me to make more mistakes.”

Participant quote associated with *difficulty remembering the date, day or time*:

- “I use my phone to tell the time, know the day/date/month.”

Participant quote associated with *difficulty finishing tasks*:

- “I have to work hard to build habits, even if I know they will help me. I find it hard to finish tasks.”

Participant quotes associated with *difficulty sequencing and completing multi step tasks*:

- “Struggle with sequencing, getting stuff done consistently. It’s hard having to organise and sequence all the steps of something, and get to the end.”
- Focus group observation - “Cognitive deficits are at such a level that they shape the functioning of working memory in different ways. Difficulty focusing on multiple stimuli, usually no more than 1 or 2 at a time let alone performing multiple procedures together.”

Participant quote associated with *difficulty understanding time*:

- “Mum manages my time. I don’t understand time (dyscalculia).”

Participant quote associated with *difficulty planning for the future*:

- “Autistic people can only see now, not ahead. They need prompting, reminding, visual timetables, text them.”

Participant quotes associated with *difficulty avoiding or managing online distractions such as Netflix or social media*:

- “It's another thing that's also common in people with autism is difficult with managing and understanding their own emotions. So, for me, if I could have…like I won’t…I would like to have to have technology to help me to like to help me to point out when I am closing to I state that I'm upset…or, like, if I get close, could help me to tell me okay you need to pause you need to do something because you're not well right now.”
- “I watch YouTube videos and Netflix. I lose time on them easily.”

Participant quote associated with *difficulty organising and managing files*:

- "What I find quite handy about Google docs is that there's a lot of add-ons that you can use. I don't want new/multiple programmes. I don't want a new app. I want something that's going to work with my existing set up. I want an ad on or a patch if that makes sense it's kind of like you want it all in one place you don't want to keep leaving and having to go somewhere."

Table 7, below, presents the specific challenges from the lifeworld analysis that are associated with mood. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 7 – Challenges Associated with Mood

Challenge Theme	Challenge	Total
Mood	Anxiety and low mood	14
	Lack of motivation	1
	Feeling isolated	5
	Fear of trying new things	4
	Difficulty with self belief and imposter syndrome	1
	Difficulty managing emotions	1
	Difficulty with handling the unknown or unexpected	2
	Need of support in getting things done	6

Participant quotes associated with *anxiety and low mood*:

- "I felt very isolated from the world when I was unable to use technology in the same way as before and as it is such an important part of my life/our world I was very worried about the potential impact on my life in the future and this did contribute in a big way to my low mood and anxiety."
- "…the amount of upsetting stuff you might see. And I would find very hard to forget an upsetting thing I've seen as opposed to someone else who might be like, 'Oh, yeah, I saw that as well,' I might be thinking about a few days later. And they would be like, 'that was a bad five minutes after that,' you know? So just kind of like being able to not…well, to set things up, and like tag things correctly. So, I've tried to like, delete certain words like so that they don't show up. But sometimes, things still set through."

- “Confidence. Nothing being confident enough, not trusting yourself. I suppose…and I suppose having all of that from a young age. Like, I suppose…because I work in childcare it has really brought to my attention that if someone tells you, you’re going to be a nobody. It's very hard to change”
- “But I need to be mindful because it's like too much information. So, if I don't, if I'm not careful about this. I have a lot of mental problems with a lot of anxiety, a lot of stimulation can disrupt my sleep, or make me not sleep. So, for me, I would say that is the, the main issue like to really filter…the…my access…to not get all the things that are out there in the beautiful world of technology and get myself lost in it.”

Participant quote associated with *lack of motivation*:

- “He is held back by a lack of motivation, inability to focus and lack of understanding.”

Participant quotes associated with *feeling isolated*:

- “Zoom Parkinson’s exercise group. Isolation is the huge thing. We have a family WhatsApp, when you can see somebodies face, it’s a very different form of communication than speaking on the phone. I would always try and include him in those conversations on WhatsApp (by showing him them). Communication feels closer when you can see somebody.”
- “I have an Autistic (and deaf) client; they have no issues, their life is online gaming. In fact they function online better than in the real world. As a result they have engaged with social services better since lockdown and things going virtual. They have chosen to stay online for appointments and I think she has stuck with us and engaged better. She prefers text over calls too. When she feels distressed she goes online/games/forums for support.”

Participant quotes associated with *fear of trying new things*:

- “I do not want her to interact with the internet or other … eeee… web things. I am afraid of them. I do not let her watch tv. So, even if she is curious about the internet , I do not feel secure enough to let her use it. I can't understand them , I do not like them. All nowadays have to do with machines, we have lost the benefits of human contact.”
- “For instance, complex programmes or things I haven’t used before are too hard. To have to learn to use them requires too much energy.”

Participant quote associated with *difficulty with self-belief and imposter syndrome*:

- “Impostor syndrome – people with ability, great coping skills, and complex problems, slip through the net, can’t get support.”

Participant quote associated with *difficulty managing emotions*:

- “Since the stroke I have no frame of reference for fear, worry, anxiety, regret or depression. Because I don't know what it is. I don't identify it. I don’t feel it like that, I have feelings but can't name or categorise them. Negative dark thoughts, but I can’t verbalise them easily. I can reach out and talk but find it hard to explain. Alarm bells when watching sensitive content - I didn't know I had such dark thoughts.”

Participant quote associated with *difficulty with handling the unknown or the unexpected*:

- “If he is presented with something without preparation he can become very frustrated and smash things.”

Participant quotes associated with *need of support in getting things done*:

- “When I want to do something I have the big picture but I haven't identified the steps to take to get there. Clearer guidance would help. Revisitable guide. Real people help.”
- “You may need someone to go through it with you. Real life support from someone who understands the issues you have.”

Table 8, on the next page, presents the specific challenges from the lifeworld analysis that are associated with physical barriers. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 8 – Challenges Associated with Physical Barriers

Challenge Theme	Challenge	Total
Physical Barriers	Difficulty in movement and motion for example due to a tremor	2
	Difficulty using a touchscreen	1
	Difficulty using external hardware/devices	1
	Visual impairment	3
	Motion sickness and vertigo	1
	Difficulty with speech and language	1
	Difficulty with spatial navigation and getting lost	1
	Risk of falling over	1
	Difficulty noticing alarms, reminders	1

Participant quote associated with *difficulty in movement and motion for example due to a tremor*:

- "Even mobile phones with big buttons aren't big enough. His physical tremor combined with his double vision makes his hand eye coordination very poor."

Participant quote associated with *difficulty using a touchscreen*:

- "They can't use a touchscreen without our help."

Participant quote associated with *difficulty using external hardware/devices*:

- "She is not able to understand the way to navigate and remember the function of each button and each device. At the end the devices cause her frustration and make her nervous."

Participant quotes associated with *visual impairment*:

- "Visual images are easier than words, I tend to have blurry vision, I disregard words in a way."
- "But now tech is too small, he has poor eyesight. Pressing the wrong buttons when scrolling."

Observer note from focus group associated with *motion sickness and vertigo*:

- "Participants experience motion sickness and vertigo."

Observer note from focus group associated with *difficulty with speech and language*:

- "Most of the children in the focus group do not have expressive speech or have difficulty enough (say a few words or their name)."

Participant quote associated with *difficulty with spatial navigation and getting lost*:

- "He can't control his hands, he can't control his body."

Participant quote associated with *risk of falling over*:

- "I strongly believe that if one device could help a person with dementia like him, surely it would be detecting risks and danger devices. For example, something like a smart house or an alarm that notify caregivers, important others or family when they are absent about a danger. Usually, we are all the time in order to protect him from falling -but even when we are absent for a while in a next-to door room we are afraid. We are also afraid when he is bathing-so something like a fall alarm would also be

useful there. And also, a director that would notice other people or movements of human beings in the house and alarm us and him simultaneously. For example, something like that it could be useful in cases a person with dementia is in danger because of thieves".

Participant quote associated with *difficulty noticing alarms and reminders*:

- "She has a smart watch alarm/timer for when she is doing activities, but when it goes off she won't remember why. She won't even acknowledge it."

Table 9 presents the specific challenges from the lifeworld analysis that are associated with reading, writing, and comprehension. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 9 – Challenges Associated with Reading, Writing, and Comprehension

Challenge Theme	Challenge	Total
Reading, Writing and Comprehension	Difficulty reading	11
	Difficulty writing	8
	Difficulty with spelling	7
	Difficulty with punctuation and grammar	6
	Difficulty reading and following instructions	3
	Difficulty filling out forms	4
	Difficulty finding information	11
	Difficulty understanding information including long and complicated text	4
	Difficulty understanding what is fake news and what is accurate news	2
	Difficulty answering calls due to not being able to read caller ID	1

Participant quotes associated with *difficulty reading*:

- "If there is a lot of reading to do, she finds it difficult. She needs to take breaks due to information overload. When there are lot of images and words its hard for her to find the information she needs."
- "He was playing Minecraft, sometimes it asks you questions. He cant read them and gets frustrated, was crying, telling me 'I want to kill myself'. He was frustrated and this is how he reacts. He's so upset."
- Observer's notes: "The vast majority of people cannot read a written text and those who can, their reading level does not exceed that of the first grade."

Participant quotes associated with *difficulty writing*:

- “I would always use like Microsoft Word, you know that app, like, that…the thing that can read it out loud? So, like if ever I'm sending an email, like, I'll copy and paste that back into like Microsoft Word and read it out loud so no there's no mistakes and then send the email.”
- “I, actually, will not send anything to any parent until someone else reads it, and they will pick up if it's wrong. And there's also…but I will not send them to someone else reads it. So, I wouldn't trust myself to send them this very simple answer, I would not do it.”
- Observer’s notes: “The majority of children cannot read or write, only some people can read or write at a very basic level like some words or their name.”

Participant quotes associated with *difficulty with spelling*:

- “When I'm writing my essays, I do not write them. I dictate them because the way I write. It's like almost every word turns red, in Word. So, I dictate them to Word.”
- “Spell Check. Um, spellcheck in like every aspect of life would be another one. Like obviously I have spell check on my phone, but then when you just say if you have to use like, you know, if you go to sound like an email, you can have spellcheck, but if people log on to, like, something else and they’re trying to…I’m trying to think of something… like forms like we used. A lot of was in, like, is it Microsoft forms? You know, and stuff that has text boxes but doesn’t do any of the formatting?”
- “There's definitely an anxiety element to having bad grammar and spelling, especially online, where like, oh, you might not…like sometimes I might sit there and I'm like, I really shouldn't say that because I probably spelt something wrong and it's like…it drives up the anxiety levels, you could just be like, I don't need to be heard, right now, or stuff like that.”

Participant quotes associated with *difficulty with punctuation and grammar*:

- “I use Grammarly pretty much all the time. Literally, any…any type of online platform…Twitter, Facebook, Instagram. I type something out, I autocorrect with Grammarly, and it feels great.”
- “The technology is good there to help. So even I would kind of hold back from texting or anything like that because I’d be afraid to check the grammar...”

Participant quotes associated with *difficulty reading and following instructions*:

- “I needed assistance from other people much more frequently so while shopping/ordering food/making complaints or responding to emails I would avoid using technology (i.e. screens) and would have to see the shopkeeper directly rather than use self-serve, I would need to call someone

and ask them to fill in some paperwork on my behalf rather than responding with an email with forms attached."
- "When a text has many instructions, I just do not read them. I do not read fast on paper here - I do not manage to read digital instructions."

Participant quotes associated with *difficulty filling out forms*:

- "Digital forms – sometimes can be so much easier, paper is really hard, word is overwhelming. One question at a time can be confusing, without the context of the other questions."
- "I might print of YouGov forms etc for clients who can't. Many people don't have access to computers, they aren't affordable for those on benefits. Or even if they can access them they don't know how to use them."

Participant quotes associated with *difficulty finding information*:

- "To know which site to go to, to get the correct information that I need is difficult."
- "But yeah, if that was like if things were more straightforward like getting your time table was just like that. Like the websites were more like I don't know how like clothing websites are. I think, older people, maybe people with dyslexia…Like, I noticed like with my parents because they're older using technology. They need a button that says click here, you know like, it needs to be obvious."
- "…and you're trying to figure out what each different person's storage style is…which is something that you know, on there, just makes it kind of exhausting to remember each and every one."
- "I spent a day and a half, trying to find a tax form, because there's so many forms of…that, you know, for somebody who only fills in this form, maybe once every three years. And, a day and a half, you know?"
- Observer's notes: "The majority of children cannot read or write, only some people can read or write at a very basic level like some words or their name. It is very difficult for them to understand abstract meanings."

Participant quotes associated with *difficulty understanding information including long and complicated text*:

- "I'm currently unable to read. I can read, but reading a book isn't possible. I'd have to remember what I had just read, processing issues."
- "The language they're using is highly academic. Use visual words. Picture words. I have problems with pronunciation. Using the right wording for the level of the individual."
- Observer's notes: "They use specific platforms from the internet for fun and as part of their education or video games. So, they are not familiar with using the internet as a search engine to extract useful information. Maybe it would be difficult for them to do without a guidance."

Participant quote associated with *difficulty understanding what is fake news and what is accurate news*:

- "I would worry about them finding incorrect information, knowing how to screen that, getting mislead."

Participant quotes associated with *difficulty answering calls due to not being able to read caller ID*:

- "I can't use it as an actual phone. So I can't actually text. And I can't actually call. It has the calling app, but I can't do it. Because I can't read. And when I call. I don't know how, like the numbers. I don't know which number because of my dyscalculia. If someone calls me, I don't know who it is, because I can't read it. And I can't remember whose number that is. So I just ignore the phone."

Table 10 presents the specific challenges from the lifeworld analysis that are associated with numbers, or numeracy. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 10 – Challenges Associated with Numbers

Challenge Theme	Challenge	Total
Numbers	Difficulty understanding numbers and carrying out basic calculations	2
	Difficulty transposing numbers correctly	2
	Difficulty making calls due to not understanding numbers	1
	Difficulty answering calls due to not being able to read caller ID	1
	Difficulty using money due to not understanding the value of money	1
	Difficulty using bank cards due to not understanding the value of money	1

Participant quote associated with *difficulty understanding numbers and carrying out basic calculations*:

- "Paying bills is a big source of stress."

Participant quote associated with *difficulty transposing numbers correctly*:

- “I can’t see a mistake if I read something. I can’t see a mistake and that…and I could read it 100 times, it can be read 200 times, I can’t see a mistake. And that's what I found very hard, because even Grammarly maybe only picks up some things, and it doesn’t catch everything…like, 2016 is a big year in childcare. I had written 1916, and I had read that 100 times, and I didn't see that mistake.”

Participant quote associated with *difficulty making calls due to not understanding numbers*:

- “It has the calling app, but I can't do it. Because I can't read. And when I call. I don't know how, like the numbers. I don't know which number because of my dyscalculia.”

Participant quote associated with *difficulty answering calls due to not being able to read caller ID*:

- “I can't use it as an actual phone. So, I can't actually text. And I can't actually call. It has the calling app, but I can't do it. Because I can't read. And when I call. I don't know how, like the numbers. I don't know which number because of my dyscalculia. If someone calls me, I don't know who it is, because I can't read it. And I can't remember whose number that is. So, I just ignore the phone.”

Participant quote associated with *difficulty using money due to not understanding the value of money*:

- “I can't even pay because I don't understand the value of money.”

Participant quote associated with *difficulty using bank cards due to not understanding the value of money*:

- “Okay, I hate bank cards. I like money. I can't even pay because I don't understand the value of money. But the thing that people don't understand is with the card, you can be anything you want, and you don't know what you're paying for. See what I mean. And that's kind of a danger in a way, if you don't understand. Because mom's like money's important. You need to know what you're using it on because you're in a budget. But if you have the card, if you have a card, especially the tapping thing (contactless), you don't know what you're spending on.”

Table 11, on the next page, presents the specific challenges from the lifeworld analysis that are associated with digital skills. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Observer’s notes from focus group associated with *difficulty navigating the internet*:

- “People in the focus group cannot navigate the internet even for the basics without the help of a caregiver. They cannot login, type, understand the meaning of symbols.”

Table 11 – Challenges Associated with Digital Skills

Challenge Theme	Challenge	Total
Digital skills	Difficulty navigating the internet	2
	Difficulty operating online in unstructured environments such as social media platforms and search engines	2
	Need of support in using digital devices	6
	Difficulty using keyboards for example due to buttons being too small	1
	Difficulty with online learning	5
	Difficulty understanding non-standard symbols or images used in place of words	6
	Difficulty avoiding risks online such as viruses, inappropriate content and cyberbullying	2
	Difficulty finding and paying for goods and services	2
	Difficulty booking appointments/activities online	2
	Lack of computer skills	4
	Difficulty finding accessible training on using digital tools	4
	Difficulty saving specific information in an accessible way	1
	Difficulty accessing digital devices or tools	4
	Difficulty navigating websites without search bars	9
	Difficulty reading text when there are no options to adjust font, size and colour	6
	Difficulty navigating complex menus on apps	7
	Lack of awareness of tools	5
	Difficulty using websites with Grammarly	2

Participant quotes associated with *difficulty operating online in unstructured environments such as social media platforms and search engines*:

- “because when there's too many options, it gets too confusing, and then you don't have the time to figure out which option is best for you, and then that just becomes overwhelming. And I think you just put it off altogether then, too, I think as well.”
- “I suppose so… Like I haven't really…I don't think I've really experienced this, but like it's this kind of like knowing which site is like reputable… or like which is, you know, like that you're not going on to sites that like aren’t giving wrong or bad information…”

Participant quotes associated with *need of support in using digital devices*:

- “You may need someone to go through it with you. Real life support from someone who understands the issues you have.”
- “I believe as a family [they have undertaken her care] we can't provide our support in that field. She needs someone who know, someone expert to constantly help her interact and understand the way that devices work”

Observation associated with *difficulty using keyboards for example due to buttons being too small*:

- Participants have difficulty using keyboards because the buttons are too small

Participant quotes associated with *difficulty with online learning*:

- “My workplace has implemented a large amount of online learning for my future career progression and while I understand the convenience and financial advantages of this it does seem very daunting to start online courses as it requires a lot of concentration. Another positive though would be that you can work through courses in short portions and do it at ‘your own pace’, but I do feel that I have a disadvantage over my peers who can perhaps concentrate for longer periods at a computer screen.”
- “Online learning is new to him. Didn't know how to use the tools. Using the pen, mouse. Just talking about the computer he runs away.”

Participant quote associated with *difficulty understanding non-standard symbols or images used in place of words*:

- “So sometimes if I'm not used to design, and if it's very like hidden in the back like the little buttons that are on the side. I don't read like well, I read, but that's majority of the time I go according to pictures and then notice like remembers where everything is on the website so if it's out of order more different than other than I have problems.”

Participant quote associated with *difficulty avoiding risks online such as viruses, inappropriate content and cyberbullying:*

- “Enormous need for relevant information and support for people hitting problems, especially those with disabilities, as they are more likely to be further isolated and possibly targeted by scammers unless they have their systems working properly.”

Participant quotes associated with *difficulty finding and paying for goods and services*:

- “Overwhelmed with finding service (electricity) suppliers. Too much information. I chose a supplier based on easy-to-use website, easy to pay. Too much choice is hard.”
- “I didn't do online shopping because I couldn't work it out. I can only buy food based on seeing it, so online didn't work for me. Or any shopping actually.”

Participant quote associated with *difficulty booking appointments/activities online*:

- “Doctors online thing that really confused me, it isn't geared to anyone who can't process stuff.”

Participant quote associated with *lack of computer skills*:

- “They may not have the gadget or skills. The parents may not have the skills either.”
- Observer’s note: “Many individuals with cognitive difficulties- such as those in our school- in addition to cognitive problems that prevent them from using appropriate digital tools, have not received adequate training, as education, unfortunately, focuses on covering very basic learning skills rather than focusing on basic digital skills, such as computer skills. This factor worsens their familiarity with digital media. Many do not even have a smartphone or computer at home, due to the area where the school is and the unfamiliarity of the population with these media.”

Participant quote associated with *difficulty finding accessible training on using digital tools*:

- “When I am in the workplace, or when I left university, like it is a big, big expense…like some of the software are quite expensive, and so…I suppose I feel like I've been lucky to getting things through the university.”
- “But it's hard to access those online resources that were in person. Because either not many people know about them or it's too complicated to get into, and you don't…well, you fear your problems will not be solved or you might not have the confidence to do it sometimes…like, you feel you might be wasting their time where they could be with someone else who need it.”

Participant quotes associated with *difficulty saving specific information in an accessible way*:

- “I’m doing open university, my module this year is online only, previously I would get a book as well, so it’s been really tricky, all the stuff on the screen. Juggling lots of information, different tabs/docs/PDFs. I got an ocular migraine. High stress, low energy, visual overwhelmed.”

Participant quotes associated with *difficulty accessing digital devices or tools*:

- ‘Many people don’t have access to computers, they aren’t affordable for those on benefits.’
- “And but yeah, as I say, going into third level was a game changer in terms of assistive technology. But like, the thing I suppose I always worry about is like, my mother always says this as well. It's like, getting to that third level…to like the place with the supports, like that's the struggle, you know? So yeah, so I don't know if that's kind of the information you were looking for, but.”

Participant quotes associated with *difficulty navigating websites without search bars*:

- “If it doesn't have like a search bar, to type in the exact word, then it can be kind of difficult."
- “if the information are like in a way messy and not clear, and not like positioned in a way that you can easily find it. So, for example I wouldn't use a system that I can’t, I can't even easily find something. I guess it's yes…I can't remember…I can't think of an example that I remember that oh this is really nice. Not right now.”

Participant quotes associated with *difficulty reading text when there are no options to adjust font, size and colour*:

- “It could not read the text for me. And it took me a week to read it because it was in columns and it was tiny letters that were distorted. And it took me about a week to actually read it with comprehension”
- “Just having more options…Even like the backgrounds…by changing just kind of ensuring that they are in applications that you can. Because a lot of applications you can’t.”
- “For example, if you have a lot of colors at the same time, it's like too much information. Like, I tend to struggle with that if it's too much information, especially from different channels.”

Participant quote associated with *difficulty navigating complex menus on apps*:

- “I don’t really like the layout of the text reader. I only used one stop and I could not figure out how to rearrange the layout of the menu.”

Participant quotes associated with *lack of awareness of tools*:

- “But I've always said that if it was something that was maybe introduced to you at a younger age, you might be able to get the benefit but it's like you're so used to…like I was studying for 18 years without any support.”
- “And it's, well the big thing for me, like, because I've noticed that with other people like some people are just afraid to ask or to inquire what they're entitled to. And I just wish that people had the confidence to do that.”

Participant quote associated with *difficulty using websites with Grammarly*:

- “I guess like there could be like certain websites not working with Grammarly…like, maybe other websites just don't like certain parts and…like certain plagiarism checkers can stop Grammarly from working properly because, you know, you might be putting in a word or text in Grammarly to check if it’s all spelled it correctly, then the plagiarism thing tings as if I've copied it from somewhere else, even though it's just Grammarly changing it. I had that problem in the very beginning of the year, where my lecturer came back and I had a 90% Plagiarism warning on a completely unique piece of work.”

Table 12 presents the specific challenges from the lifeworld analysis that are associated with general problems. The table also presents a count of the total number of times each challenge was mentioned across all lifeworld analysis activities conducted by all partners.

Table 12 – Challenges Associated with General Problems

Challenge Theme	Challenge	Total
General Problems	No FAQ section	5
	Broken URLs	7
	Difficulty finding employment opportunities	1
	Difficulty working from home	1
	Difficulty trusting new people or technology	1
	Difficulty finding non-text options	1
	Text composed with Grammarly being flagged as plagiarism by assignment submission systems	3
	Difficulty understanding and entering captcha information	3
	PDFs not compatible with T2S tools or screen readers	5
	Difficulty navigating audio files to find useful information	2
	Difficulties creating passwords and signing in	1

Participant quote associated with *no FAQ section*:

- “I get really annoyed with being ignored…or being patronized…just stick up an FAQ somewhere, you know? Now, and, you know…and then leave it up to the duration of the course, because if I'm frustrated, I might need to visit it again and take more from it than I did the first time. But really, that would be so stress relieving, if they just stuck up answers to questions.”

Participant quotes associated with *broken URL’s*:

- “The links take you places that you didn’t think they should be taking you, and then you’re back to where you started and you don’t have the information that you need. Like, I couldn't find where the login to your student profile was…”
- “Things like broken URLs….I mean, take them down, or fix them. I'm doing a lot of secondary research. So, you know, I could be doing productive stuff instead of going into something that looks like it makes sense, and meeting a broken URL…like, come on guys. Somebody gets paid to do these things, not me, so do them.”

Participant quote associated with *difficulty finding employment opportunities*:

- “There’s some good stuff online to help with employment, we have a jobs club with volunteers from a charitable organisations with laptops to help with job searches.”

Participant quote associated with *difficulty working from home*:

- “I hated working from home, useless at it, couldn’t create a routine. Covid 19 shifted us into a very virtual space in which I did not cope. Poor management from work, no team meetings. I need the physical office space, routine, structure to help me work. I did not manage to use the online tools that everyone else did. Online virtual tools didn’t help me. I think I was quite depressed at the time.”

Participant quote associated with *difficulty trusting new people or technology*:

- “There was Bristol UWE were wanting disabled people to join some work they were doing on technology in the home and they were happy to put in various technological equipment designed to help people in the home to test it. He wouldn’t do it.”

Participant quote associated with *difficulty finding non-text options*:

- “One thing that can help is like the caption of the video. You know the caption, because sometimes I'm overloaded with the sound, and even the sound of a video, like instruction in video, it's like, it's too much. So, I put it on mute, and then I just read and watch the video. So, it also helps me.”

Participant quote associated with *text composed with Grammarly being flagged as plagiarism by assignment submission systems*:

- “and he's like, “What, what happened here?” And, I'm like Grammarly…it’s never done this before, and like these issues aren't getting solved, obviously. But, at least my lecturer understood, I was able to push forward saying, Okay, I'm just gonna mark you off the plagiarism thing we're gonna get we're getting a new one.”

Participant quotes associated with *difficulty understanding and entering captcha information*:

- “Yeah. Well one thing I find really hard actually is this, you know, when they ask are you not a robot? Um, they always say like click the palm trees that are in thing…I know where they are, but somehow I never get it right and so that's something that really bothers me, because it's quite frustrating when you go and want to like purchase something or join something and this kind of is a barrier.”
- “Yeah, it's, it's kind of a loop…and I have this tolerance for getting it wrong once. And, but…because if I get it wrong once, then I can figure out where the problem is. I usually invert threes and fives, eights and threes can be tricky. But, if I don't get it right the second time, then I tend to lose complete patience with it.”

Participant quotes associated with *PDFs not compatible with T2S tools or screen readers*:

- “After talking to the professor and I explained why I would prefer if they can put the better quality scans on after that, there was no problem.”
- “What I think will be really useful for me and that maybe isn't what I don't have already…is like things that would help me read like some like physical documents so like I mean, the improvements with the types of things that can read what’s on the laptop or the computer have been really great. But like, for example, if you're on the go, or in some meeting or something like that…that I would…that you would just hand out an agenda…I think it would be really helpful to have something that could enable you to read what was on it.”

Participant quote associated with *difficulty navigating audio files to find useful information*:

- “But even getting lost in the voice note. It'd be great if you could like maybe had like a timer stopwatch or something like. And then, at least, it knows. But if it's automatically picked up on how to start the

conversation and maybe even just transcribe the first sentence, to some extent, at least you can jump down and know."

Participant quote associated with *difficulty creating passwords and signing in*:

- "He does not remember his name nor his passwords, let's say in his bank account. We are in charge of protecting his personal data and everything. We also made a YouTube account in order to store his video preferences, and also there we (meaning the family) are managing his profile."

Table 13, below, provides the frequency count for the times a challenge grouped within a particular category was mentioned across all lifeworld analysis activities conducted by all partners. For example, the Memory theme total is the sum of the frequencies for the individual challenges listed in Table 4. Note that the theme that occurred most frequently was *digital skills*. This suggests that, across all cognitive disability types and diagnoses, the accessibility of digital skills and/or digital skills training is a critical issue. The second most common theme was *reading, writing, and comprehension*. Thus, the overwhelming tendency for the internet to be primarily text-based is also a critical issue. The third most common theme was *mood*, which included many mental health challenges, which highlights the importance of considering mental health when conducting research and developing potential solutions.

Table 13 – Totals by Challenge Theme

Challenge Theme	Total
Memory	27
Focus	31
Time and Organisation	23
Mood	34
Physical Barriers	12
Reading, Writing, and Comprehension	57
Numbers	9
Digital Skills	70
General Problems	30

4.3 MAPPING USER NEEDS TO TOOLS AND SCENARIOS

4.3.1 Tools

During the baseline research (WP1) and lifeworld analysis (Task 2.1), the user needs discussed above were mapped to tools in two ways. First, user needs were mapped to tools by participants during lifeworld analysis

interviews and focus groups. Second, user needs were mapped to tools by LIVE-IT partners based on one or more of the following: information found in academic literature; information found in grey literature; use of the tool for LIVE-IT activities. The mapping as it stands at the time of this deliverable's production can be found in Appendix C. Mapping of user needs to tools is ongoing and continues during and as a result of all LIVE-IT activities. Therefore, a live version of the mapping can be found in this **document**.

4.3.2 Scenarios

The user needs discussed above are also being mapped to scenarios on an ongoing basis. The LIVE-IT definition of a scenario will be presented in the next section. User needs were mapped to scenarios for the purpose of starting the co-design labs. Again, this was done in multiple ways. First, user needs were mapped to scenarios by participants during lifeworld analysis interviews and focus groups and lab-planning sessions. Second, user needs were mapped to scenarios by LIVE-IT partners based on information from the baseline research (WP1). Third, user needs will continue to be mapped to scenarios through what is learned from the scenario implementation in the co-labs (WP2) and the participant contributions to the hackathons (WP4). A live version of the mapping can be found in this **document**.

5 LIVE-IT CO-LAB ACTIVITIES TO DATE

This section will provide details about the LIVE-IT co-lab activities that have taken place to date. The co-labs will continue to operate until the end of the pilot project, and future deliverables will continue to report on the information provided here. First, the overarching co-lab specifications – including definitions of key terms such as "scenario" – are provided. Second, the initial co-lab specifications for each of the four co-labs making up the LIVE-IT co-design lab network are shared. Third, we discuss the evolution of scenarios in the initial co-lab activities and what that means for the upcoming task of scenario validation (Task 2.4), ongoing lab activities, and the hackathons (WP 4).

5.1 CO-LAB SPECIFICATIONS

The LIVE-IT co-design labs are framed as described below:

- *Emergencies Lab* (London and Bristol): Focuses on reducing risk and increasing preparedness and resilience in emergency situations – both at the everyday level, for example health e-consulting, and at the large scale, such as the COVID pandemic – covering finding information, looking for help and support, understanding emergency procedures and instructions
- *Life Skills Lab* (Coimbra and Lisbon): Focuses on navigating and managing interactions with 'the system', including consumer transactions and related issues such as understanding contracts and small

print; filling in forms; consumer rights; online security and protection; managing dates and appointments

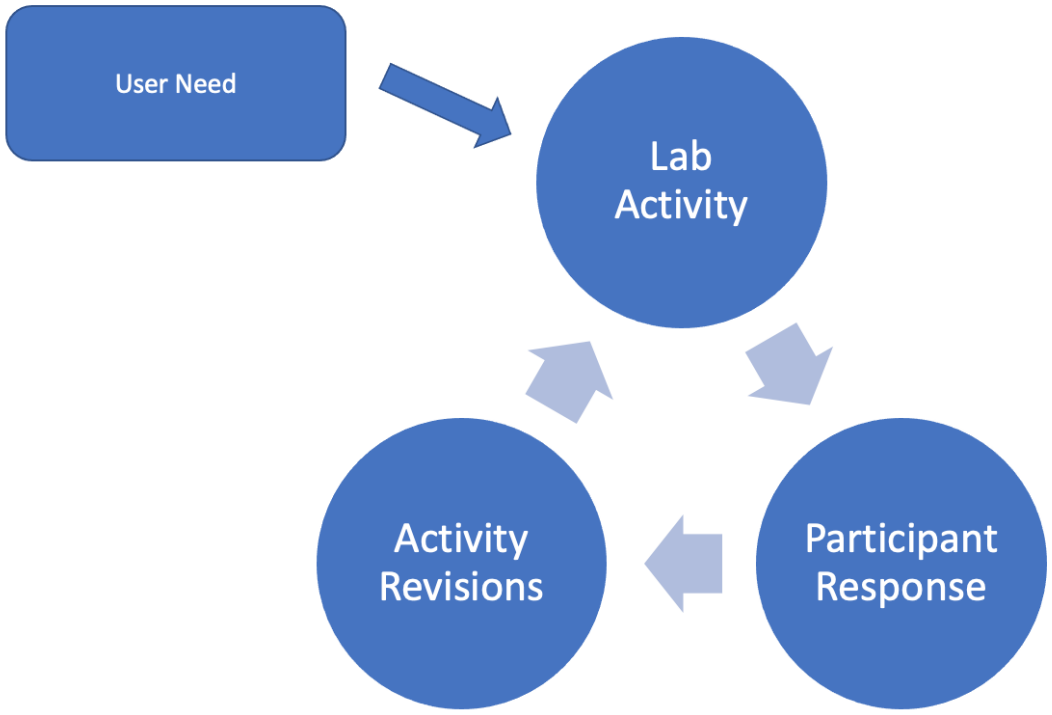
- *Self-Development Lab* (Galway): Focuses on supporting people to take advantage of the opportunities provided by digital technologies for learning, employment, personal development, involving navigation, information searching, information processing, understanding text and graphics and using animations, working with authoring systems
- *Help & Support Lab* (Thessaloniki): Focuses on using online information and guidance systems, for example searching for and using public information tools, using complex interfaces and gateways, identifying key points from dense and 'official' documentation, navigating through guidelines

Each of the four LIVE-IT consortium partners established at least one co-lab. Arcola set up two co-lab locations in the UK: one in London and one in Bristol. Similarly, UCP set up three co-lab locations in Portugal: one in Coimbra, one in Sintra and one in Lisbon. Although Arcola and UCP have each set up multiple co-lab locations, each partner's co-lab locations address the same theme. For example, both the London and the Bristol labs address the theme of *Emergencies*. Both NUIG and AUTH set up a single co-lab location in Galway and Thessaloniki, respectively. Before presenting further details about each of the four co-labs, we now define key terms and ideas that impact the organisation of all labs.

5.1.1 Defining Scenarios

The LIVE-IT Project employs the W3C definition for a scenario (see Table 1, above). The W3C defines a *scenario* as a narrative description of: 1) how researchers became aware of the user need, 2) what was done in the lab to address the need, 3) how participants responded to what was done in the lab. Thus, we at LIVE-IT consider a *scenario* to be a narrative description of the lifecycle of a user need within the project. A scenario tracks the user need from lifeworld analysis activities to co-lab activities to hackathon outcomes. A scenario includes descriptions of: problem(s) that need solution(s), platform(s) and tool(s) that could deliver a solution, and potential ways of using platform(s) and tool(s) in particular situations.

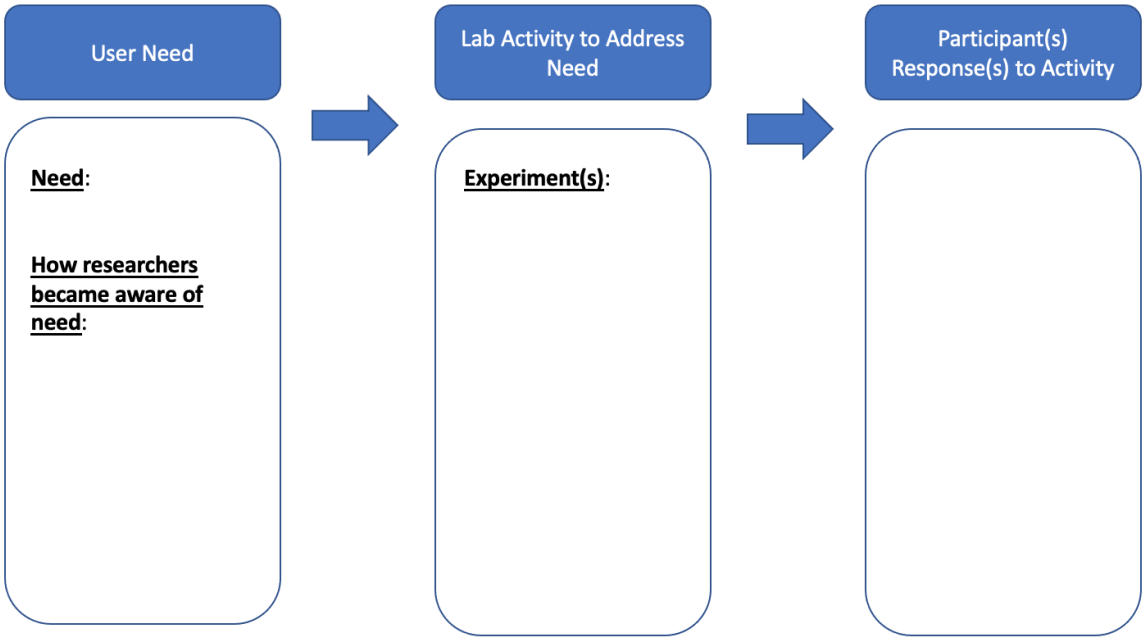
Figure 3 – LIVE-IT Scenario Cycle



5.1.2 Defining Experiments

In order to evaluate, monitor, and eventually validate scenarios, they must be broken down into testable actions or activities. To aid in evaluation, monitoring, and validating, we define an *experiment* as a testable hypothesis related to a particular scenario. Each experiment includes descriptions of: procedures guided by a hypothesis, data collection tools, and a plan for data analysis. Figure 4 shows how and where the experiment(s) fit within the scenario design. This figure will be filled in with details for each scenario developed in the LIVE-IT co-labs in their respective sections below.

Figure 4 – Scenario Design



5.1.3 Identifying Informants & Gatekeepers

Another crucial step in turning planned scenarios into actionable lab activities is to identify informants and gatekeepers. For the LIVE-IT Project, we expected informants to be those who could provide guidance and insight in service of the goals of each co-lab. Informants include, but are not limited to: disability support groups, community organisations, other researchers, and developers. We expected gatekeepers to be those who controlled access to people and/or tools. Gatekeepers include, but are not limited to: school administrators and individuals in charge of software licensing.

5.1.4 Evaluation & Monitoring Procedures

Evaluation is a cross-cutting theme in LIVE-IT. It is not covered by a single dedicated work package or activity but is delivered across four separate activities, as shown in Table 14, on the next page. Table 14 illustrates way evaluation has been written into the project proposal and implementation plan poses some challenges around coherence, overlap and duplication. An additional evaluation challenge is posed by 'hidden' evaluation activities – tasks that are not described as evaluation but which in reality include evaluation. These include two tasks from WP2:

- **Task 2.2: Scenario co-design** – which requires capture and analysis of data on how people with cognitive disabilities work with LIVE-IT team members to experiment with scenarios in the Labs

- **Task 2.4: Scenario Validation** - which requires capture and analysis of data to validate the scenarios developed in the Labs.

Table 14 – Evaluation in LIVE-IT

Activity	Description	Partner(s) responsible
3.2: Evaluation	Focuses on evaluation of the Open Toolkit, and forms part of the overall project evaluation, based on Theory of Change	Arcola, with contribution from all partners
3.3: Pilot testing	Focuses specifically on assessing the usability of the Open Toolkit	UCP, with contribution from all partners
4.4: Outcome evaluation	Focuses specifically on evaluation of the Makerspace and Hackathons	Arcola, with contribution from all partners
5.3: Monitoring and Reporting	Design and implementation of internal project evaluation, including Quality Register, Process Dashboard and Partner Survey, feeding into overall project monitoring	Arcola with AUTH

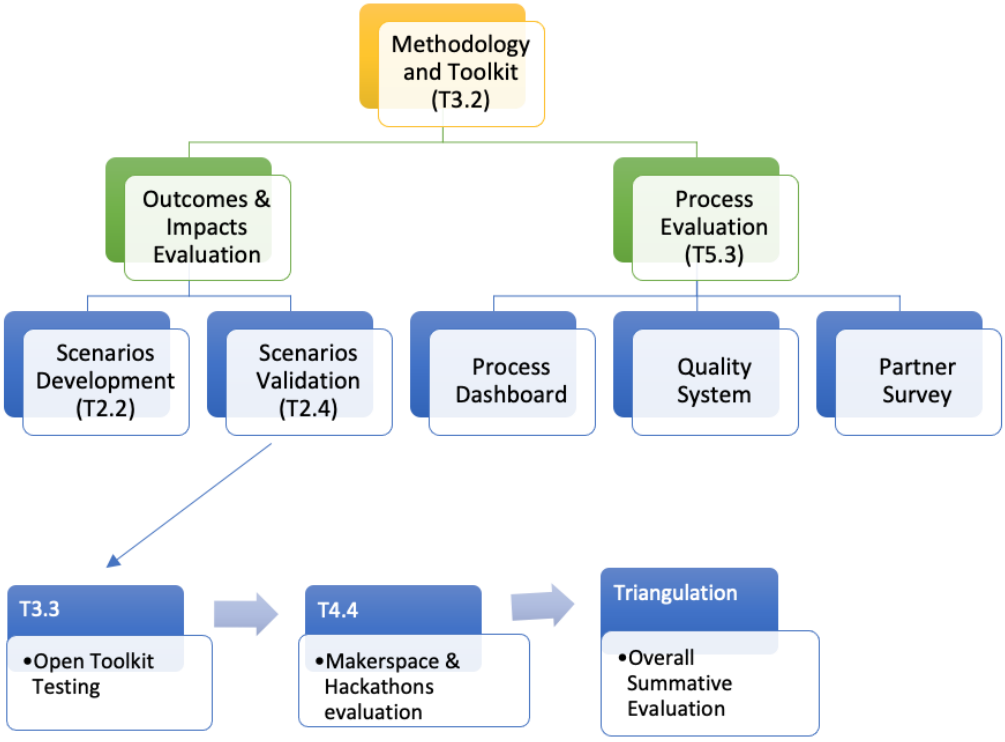
In order to meet these challenges, the evaluation effort in LIVE-IT utilised a single methodological framework, which specifies:

- The over-arching evaluation design
- The component evaluation activities that are incorporated into this over-arching design
- How these component activities relate to each other
- The evaluation purposes addressed by these component activities and the evaluation questions they address
- The methods and tools to be used to collect and analyse the data needed to answer these evaluation questions.

This is illustrated in Figure 5, on the following page. The coherence and direction of the evaluation is shaped by the over-arching Evaluation Methodology and Toolkit. This is based on a 'theory-driven' evaluation approach, using 'Theory of Change'. Theory of Change is a way of mapping the 'change journey' of LIVE-IT so you can see the connections between the 'presenting problem' it wants to solve, the expected impact on that problem at project end and everything that's supposed to happen in between. It sets out the ***presenting problem*** the LIVE-IT wants to address – i.e., people with cognitive disabilities are excluded from digital life – and ends with the change the project wants to make to this problem after it has completed its journey. In other words, the ***expected impacts*** LIVE-IT will achieve at project end, such as a better design of online content and services and increased digital inclusion of PwCD.

To get from presenting problem to expected impacts, LIVE-IT carries out ***activities*** – for example carrying out a review of state of the art and lifeworld analysis. These activities lead to the production of ***outputs*** such as the four Co-labs set up in four different countries. The utilization of these outputs lead to ***immediate outcomes*** (changes in awareness and increased knowledge), for example improved understandings of what works for the digital inclusion of people with cognitive disabilities. These immediate outcomes lead to ***intermediate outcomes*** (changes in behaviour and structures), for example digital platform designers increasing the accessibility of the technologies they design.

Figure 5 – LIVE-IT Evaluation Methodology



Ultimately, these outcomes, combined together, will lead to the longer term impacts LIVE-IT aspires to. LIVE-IT's Theory of Change shapes all the evaluation activities implemented in the project and the methods and tools these activities apply. Within the over-arching methodology, the evaluation is broadly divided into two 'modes':

- A process (or formative) mode. This focuses on monitoring the implementation of the project activities and is closely linked to the project management activities carried out in work package 5.
- An outcomes and impacts (or summative) mode. This focuses on assessing the effects of LIVE-IT activities on project 'beneficiaries' – particularly the project's key 'target group' – people with cognitive disabilities - who are involved in the Co-Labs and in the LIVE-IT online Community.

The outcomes and impacts evaluation can be seen as primarily linear in nature:

- It starts with capturing and assessing how our target group works with the project teams in the Co-Labs to explore different scenarios (Task 2.2)
- It progresses to validating the scenarios that are selected through the work of Task 2.2 as potentially providing maximum benefit to supporting the digital inclusion of people with cognitive disabilities (Task 2.4)
- The next stage of the outcomes and impacts evaluation is pilot testing the Open Toolkit (Task 3.3)
- This phase is followed by final evaluation of the Open Toolkit in the Hackathons delivered through the Co-Labs and in the broader on-line Makerspace (Task 4.4)
- The results of all the evaluation activities carried out are compared with each other and synthesised to produce a final summative evaluation of the project.

Each set of activities addresses different evaluation questions and uses different evaluation methods and tools. These are summarised in Table 15, which provides examples of suitable methods and tools. Appendix D includes all evaluation templates mentioned in Table 15.

Table 15 – Evaluation Activities, Questions, Methods and Tools

Evaluation activity	**Key evaluation questions**	**Methods and Tools examples**
Process Dashboard	Is the project meeting its milestones and targets?	Key Performance Indicators (KPIs) Partner Survey
Quality System	Are the project outputs of sufficient quality?	Peer and external review of deliverables
Scenarios Development	Which kinds of technology platforms and tools increase the digital inclusion of people with cognitive disabilities?	Observation analysis Concurrent think aloud (CTA) analysis UMUX-Lite Survey
Scenarios Validation	Are the scenarios selected for inclusion in the Open Toolkit suitable for increasing the digital inclusion of people with cognitive disabilities?	Structured co-creation workshops Walk-throughs
Open Toolkit Testing	Does the Open toolkit conform to desired standards of usability, user-friendliness and user effectiveness?	Systems Usability Survey Walk-throughs Structured interviews

Evaluation activity	Key evaluation questions	Methods and Tools examples
Makerspace and Hackathon Evaluation	How do users work with the Open Toolkit to co-design innovative solutions to key online challenges?	Observation Concurrent think aloud (CTA) analysis

5.2 ARCOLA SCENARIOS AND EXPERIMENTS (EMERGENCIES)

Arcola Research LLP is implementing two co-design labs in the UK – one in London and one in Bristol – and both lab locations are focused on *Emergencies*. This means that the labs are focused on reducing risk and increasing preparedness and resilience in emergency situations. Emergencies include the everyday level, for example health e-consulting, and at the large scale, such as the COVID pandemic. The scenarios focused on emergencies cover finding information, looking for help and support, understanding emergency procedures and instructions. More specifically, emergencies include (but are not limited to):

- Accidents requiring medical assistance
- Mental or physical illness requiring medical or psychological support
- Natural disasters
- Home/work emergencies such as gas or water leaks
- Personal challenges requiring the support of friends or support groups

5.2.1 Scenarios

As of the production of this deliverable, the *Emergencies Lab* developed four types of scenarios:

- Finding Help and Support in an Emergency (see Figure 6)
- What to do in an Emergency (see Figure 7)
- Preparing for Emergencies (see Figure 8)
- Optimising Your Phone (see Figure 9)

This list may be expanded and/or revised as co-lab activities continue and hackathons are held. Within the five types of scenarios, several experiments, or lab activities were planned. The figures below (Figure 5 – Figure 8) illustrate the connection between user needs identified prior to implementing lab activities and the scenario design. It is worth noting that these scenarios may connect with additional user needs, and the team will track these additional mappings throughout the co-lab implementation. In other words, one user need or challenge may have inspired the scenario's inception, but the scenario as enacted in reality may actually address additional (even unexpected) user needs or challenges. Finally, the figures introduce the experiments within each scenario, which will be discussed in more detail in the next section.

Figure 6 – Scenario Type 1: Finding Help and Support in Emergencies

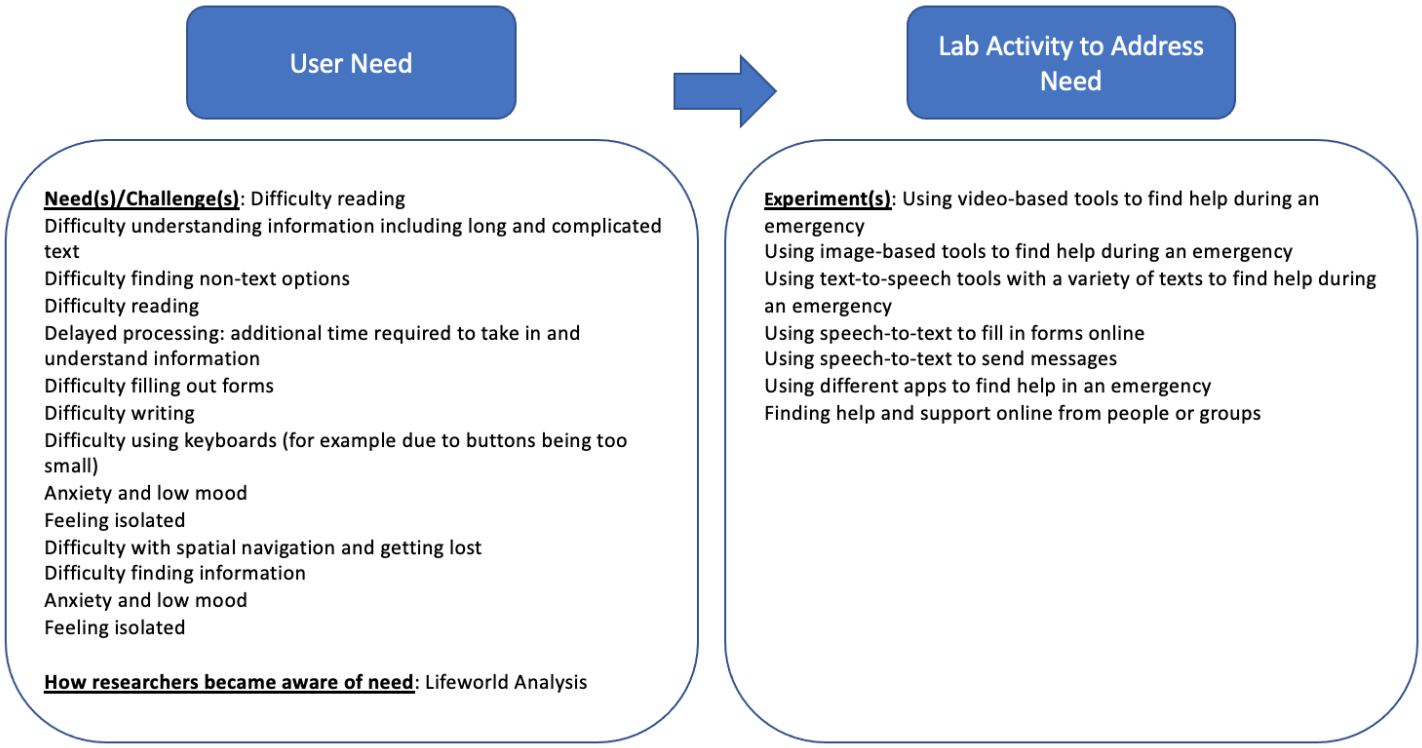


Figure 7 – Scenario Type 2: What to Do in an Emergency

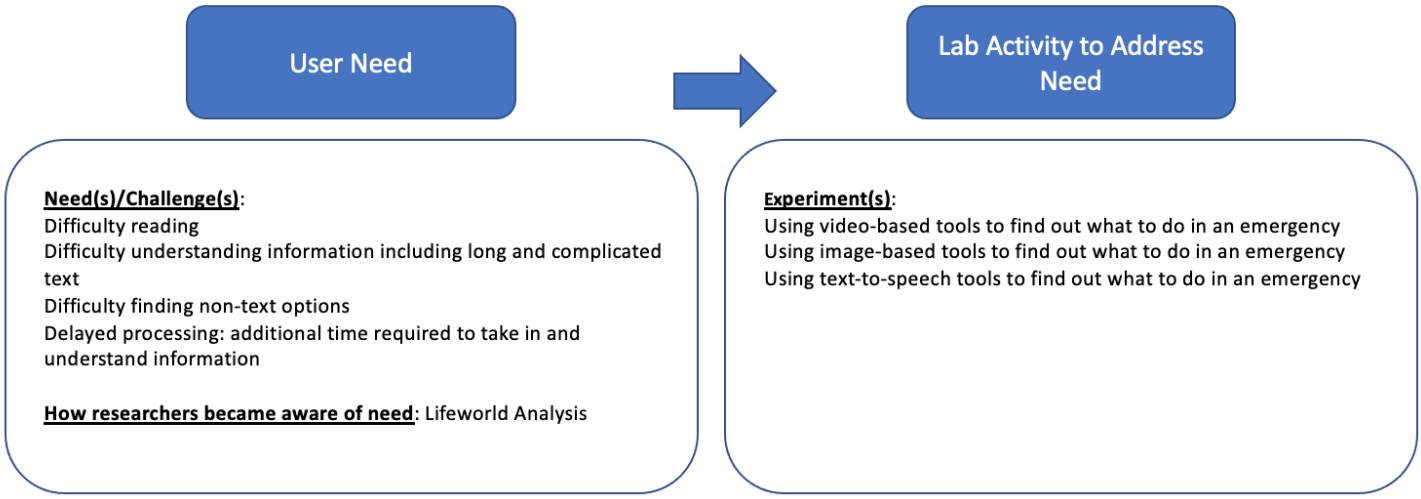


Figure 8 – Scenario Type 3: Preparing for Emergencies

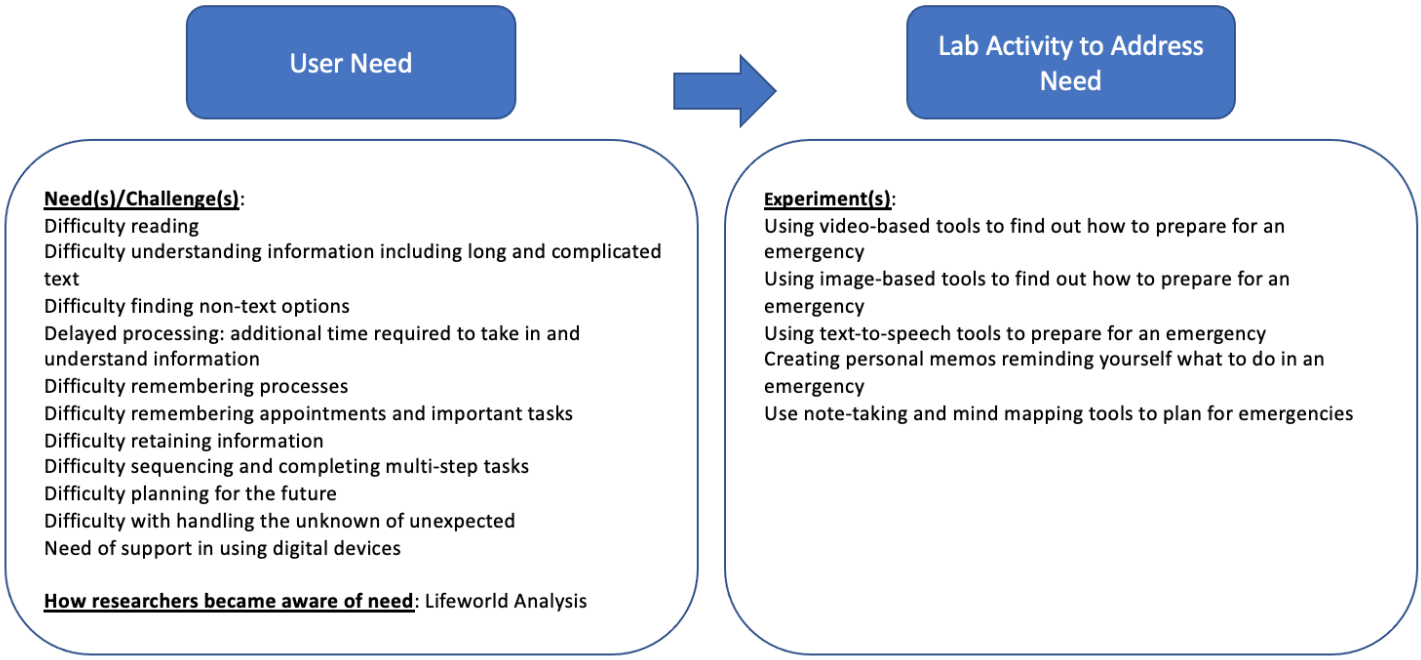
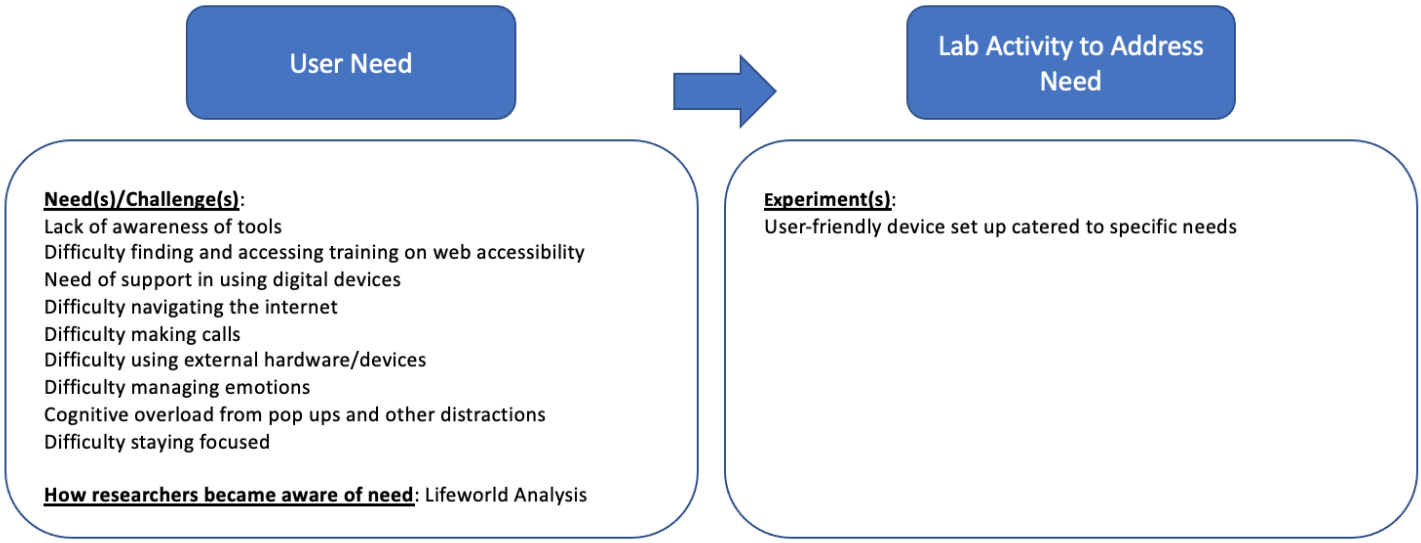


Figure 9 – Scenario Type 4: Optimising Your Phone



5.2.2 Experiments

Within each of the four scenario types initially planned for the London and Bristol *Emergencies* labs, several more testable experiments were developed. These experiments are mapped to challenges and tools, and these mappings may be revised as the co-lab activities continue – meaning that additional challenges and tools will likely be added. To provide additional detail about the experiments, we now present them by scenario category. Tables 16 through 22 map each experiment to user needs or challenges and tools.

First, the scenarios focused on *Finding Help and Support in an Emergency* generated seven planned experiments: 1) using video-based tools to find help during an emergency; 2) using image-based tools to find help during an emergency; 3) using text-to-speech tools with a variety of texts to find help during an emergency; 4) using speech-to-text to fill in forms online; 5) using speech-to-text to send messages; 6) using different apps to find help in an emergency; 7) finding help and support online from people or groups.

Table 16 – Mapping Experiment 1.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using video-based tools to find help during an emergency	Difficulty reading	YouTube TikTok
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	

Table 17 – Mapping Experiment 1.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using image-based tools to find help during an emergency	Difficulty reading	Internet browser Instagram
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	

Table 18 – Mapping Experiment 1.3 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using text-to-speech tools with a variety of texts to find help during an emergency	Difficulty reading	Easy Reader Texthelp Android Accesibility Suite IDEAL Group Reader ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Snap & Read Microsoft OS Narration Natural Readers Verbose Read Aloud Text from to Speech
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	
	Delayed processing: additional time required to take in and understand information	

Table 19 – Mapping Experiment 1.4 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using speech-to-text to fill in forms online	Difficulty filling out forms	SpeechTexter Android Accesibility Suite Voice to Text Apple Dictation Dragon Speech Text from to Speech
	Difficulty finding non-text options	
	Difficulty writing	

Table 20 – Mapping Experiment 1.5 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using speech-to-text to send messages	Difficulty using keyboards (for example due to buttons being too small)	Google Assistant Amazon Alexa SpeechTexter Android Accesibility Suite Text from to Speech Siri Apple Dictation Dragon Speech
	Difficulty writing	

Table 21 – Mapping Experiment 1.6 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using different apps to find help in an emergency	Anxiety and low mood	What3words Google Maps UK Bus Checker Get help in an emergency using your Android phone ICE Feature Uber
	Feeling isolated	
	Difficulty with spatial naviation and getting lost	
	Difficulty finding information	

Table 22 – Mapping Experiment 1.7 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Finding help and support online from people or groups	Anxiety and low mood	Facebook Instagram WhatsApp
	Feeling isolated	

Second, the scenarios focused on *What to Do in an Emergency* generated three planned experiments: 1) using video-based tools to find out what to do in an emergency; 2) using image-based tools to find out what to do in an emergency; 3) using text-to-speech tools to find out what to do in an emergency. Tables 23 through 25 show how each experiment maps to user needs or challenges and tools.

Table 23 – Mapping Experiment 2.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using video-based tools to find out what to do in an emergency	Difficulty reading	YouTube TikTok
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	

Table 24 – Mapping Experiment 2.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using image-based tools to find out what to do in an emergency	Difficulty reading	Internet browser Instagram
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	

Table 25 – Mapping Experiment 2.3 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using text-to-speech tools with a variety of texts to find out what to do in an emergency	Difficulty reading	Easy Reader Texthelp Android Accesibility Suite IDEAL Group Reader ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Snap & Read Microsoft OS Narration Natural Readers Verbose Read Aloud Text from to Speech
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	
	Delayed processing: additional time required to take in and understand information	

Third, the scenarios focused on *Preparing for an Emergency* generated 5 planned experiments: 1) using video-based tools to find out how to prepare for an emergency; 2) using image-based tools to find out how to prepare for an emergency; 3) using text-to-speech tools to prepare for an emergency; 4) creating personal memos reminding yourself what to do in an emergency; 5) use note-taking and mind mapping tools to plan for emergencies. Tables 26 through 30 show how each experiment maps to user needs or challenges and tools.

Table 26 – Mapping Experiment 3.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using video-based tools to find out how to prepare for an emergency	Difficulty reading	YouTube TikTok
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	

Table 27 – Mapping Experiment 3.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using image-based tools to find out how to prepare for an emergency	Difficulty reading	Internet browser Instagram
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	

Table 28 – Mapping Experiment 3.3 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using text-to-speech tools with a variety of texts to find out how to prepare for an emergency	Difficulty reading	Easy Reader Texthelp Android Accesibility Suite IDEAL Group Reader ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Snap & Read Microsoft OS Narration Natural Readers Verbose Read Aloud Text from to Speech
	Difficulty understanding information including long and complicated text	
	Difficulty finding non-text options	
	Delayed processing: additional time required to take in and understand information	

Table 29 – Mapping Experiment 3.4 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Creating personal memos reminding yourself what to do in an emergency	Difficulty remembering processes	Google Assistant Amazon Alexa SpeechTexter Android Accesibility Suite MindManager Quick Note Voice Notebook Google Keep Microsoft OneNote Evernote Simplenote Milanote Siri Apple Dictation Lucidspark Mindmapping Apple Notes Apple Voice Memos Ulysses Dragon Speech Microsoft Sticky Note Microsoft To-Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard
	Difficulty remembering appointments and important tasks	
	Difficulty retaining information	
	Difficulty sequencing and completing multi-step tasks	
	Difficulty planning for the future	
	Difficulty with handling the unknown of unexpected	
	Need of support in using digital devices	

Table 30 – Mapping Experiment 3.5 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Use note-taking and mind mapping tools to plan for emergencies	Difficulty remembering processes	Google Assistant Amazon Alexa SpeechTexter Android Accesibility Suite MindManager Quick Note Voice Notebook Google Keep Microsoft OneNote Evernote Simplenote Milanote Siri Apple Dictation Lucidspark Mindmapping Apple Notes Apple Voice Memos Ulysses Dragon Speech Microsoft Sticky Note Microsoft To-Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard
	Difficulty remembering appointments and important tasks	
	Difficulty retaining information	
	Difficulty sequencing and completing multi-step tasks	
	Difficulty planning for the future	
	Difficulty with handling the unknown of unexpected	
	Need of support in using digital devices	

Finally, the scenarios focused on *Optimising Your Phone* generated a single experiment: user-friendly device set up catered to specific needs. Table 31 shows how the experiment maps to user needs or challenges and tools.

Table 31 – Mapping Experiment 4.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
User-friendly device set up catered to specific needs	Lack of awareness of tools	Assistive Touch Minimal Consent Free AD Blocker Blokada 5 Android Accesibility Suite BlockBear! Voice Over Apple Voice Control Apple Assistive Touch Apple Touch Accommodations Apple Back Tap Siri Apple Accessibility Keyboard Apple Dictation Apple Predictive Text
	Difficulty finding and accessing training on web accessibility	
	Need of support in using digital devices	
	Difficulty navigating the internet	
	Difficulty making calls	
	Difficulty using external hardware/devices	
	Difficulty managing emotions	
	Cognitive overload from pop ups and other distractions	
	Difficulty staying focused	

5.2.3 Evaluation & Monitoring

Across all experiments in the *Emergencies* lab locations, the sessions are to follow the same general procedure: testing with think-aloud from participants, post-test cognitive interview questions, and post-testing reflections from participants. Thus, the evaluation and monitoring will occur using data collection tools appropriate for each phase of the experiment procedure. During the testing with think-aloud, video-recording, audio-recording, and note-taking on the observation tool (see Appendix D) will take place. During the post-test cognitive interviews, the cognitive interview protocol will be used (see Appendix D). During the post-test reflections, video-recorded and audio-recorded participant reflections will be captured and/or written reflections will be submitted using the scales in Appendix D.

5.3 UCP SCENARIOS AND EXPERIMENTS (LIFE SKILLS)

Universidade Católica Portuguesa is currently implementing two co-design labs in Portugal – one in Lisbon and one in Coimbra – and both lab locations are focused on *Life Skills*. A third co-design Lab is being developed in Sintra. This means that the labs are focused on navigating and managing interactions with "the system." This includes consumer transactions and related issues, such as understanding contracts and small print, filling in forms, consumer right, online security and protection, and managing dates and appointments. More specifically, life skills include using the internet on various devices to:

- Use transit
- Navigate employment
- Communicate with others
- Navigate healthcare
- Buy necessary goods

5.3.1 Scenarios

As of the production of this deliverable, the *Life Skills Lab* developed three types of scenarios:

- Text-to-Speech (see Figure 10)
- Translation (see Figure 11)
- Complex Tasks (see Figure 12)

This list may be expanded and/or revised as co-lab activities continue and hackathons are held. Within the five types of scenarios, several experiments, or lab activities were planned. The figures below (Figure 10 – Figure 12) illustrate the connection between user needs identified prior to implementing lab activities and the scenario design. It is worth noting that these scenarios may connect with additional user needs, and the team will track these additional mappings throughout the co-lab implementation. In other words, one user need or challenge may have inspired the scenario's inception, but the scenario as enacted in reality may actually address additional (even unexpected) user needs or challenges. Finally, the figures introduce the experiments within each scenario, which will be discussed in more detail in the next section.

Figure 10 – Scenario Type 1: Text-to-Speech

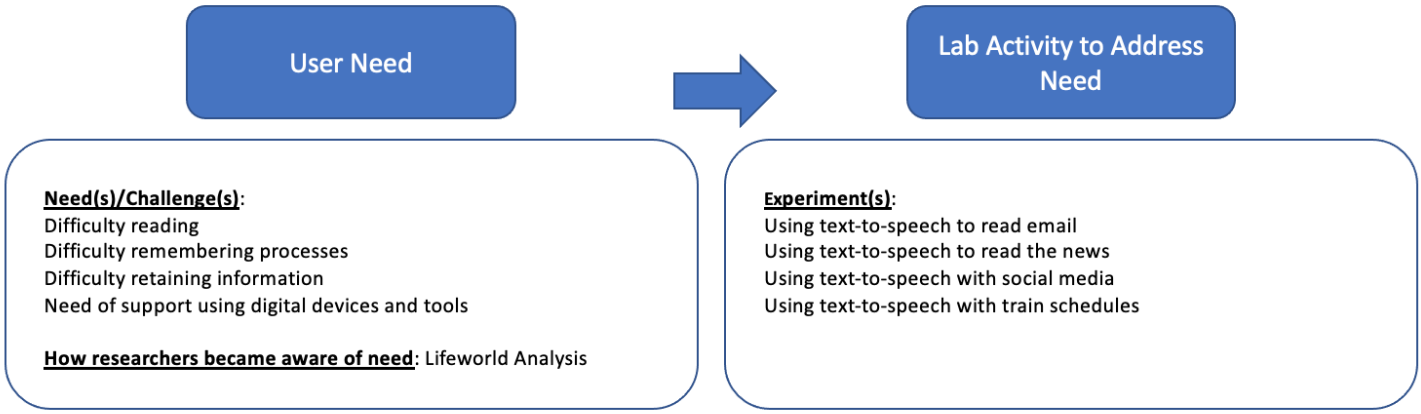


Figure 11 – Scenario Type 2: Translation

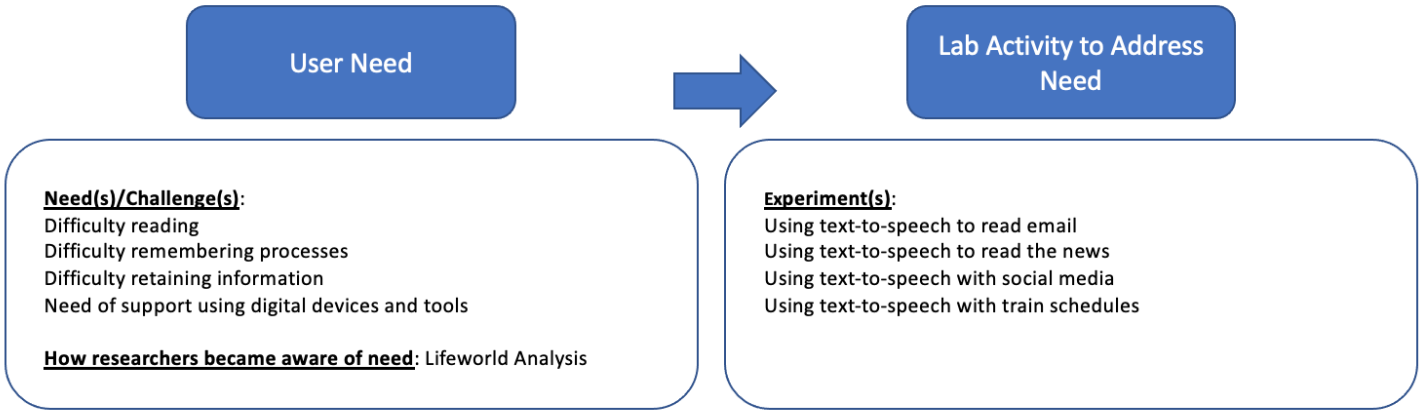
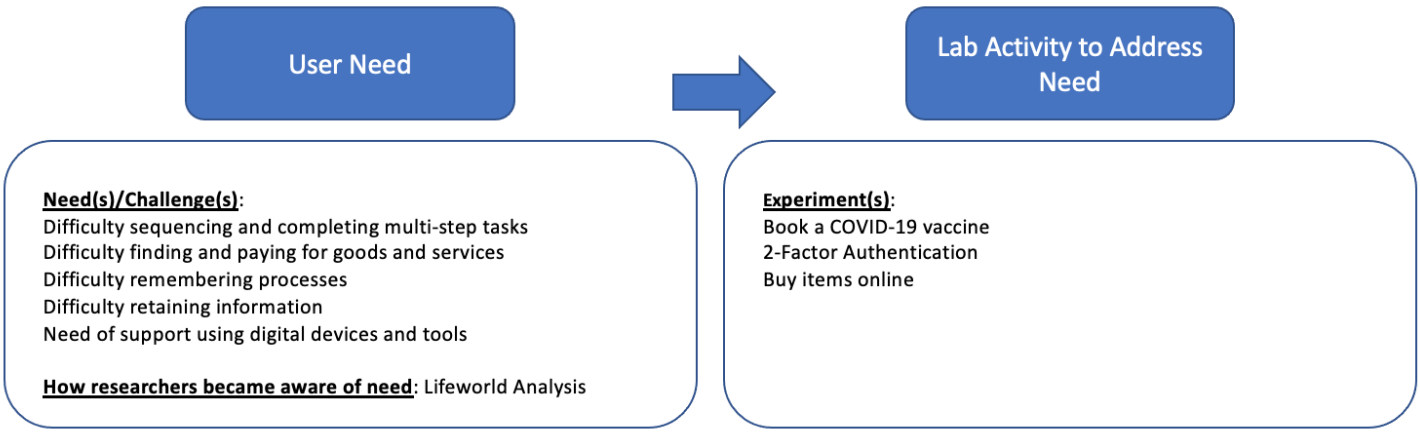


Figure 12 – Scenario Type 3: Complex Tasks



5.3.2 Experiments

Within each of the three scenario types initially planned for the Lisbon and Coimbra *Life Skills* labs, several more testable experiments were developed. These experiments are mapped to challenges and tools, and these mappings may be revised as the co-lab activities continue – meaning that additional challenges and tools will likely be added. To provide additional detail about the experiments, we now present them by scenario category.

First, the scenarios focused on *Text-to-Speech* generated four planned experiments: 1) using text-to-speech to read email; 2) using text-to-speech to read the news; 3) using text-to-speech with social media; 4) using text-to-speech with train schedules. Tables 32 through 35 show how each experiment maps to user needs or challenges and tools.

Table 32 – Mapping Experiment 1.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using text-to-speech to read email	Difficulty reading Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Microsoft Edge Gmail Text-to-speech (computer) Text-to-speech (Android phone) Magnifying glass

Table 33 – Mapping Experiment 1.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using text-to-speech to read the news	Difficulty reading Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Microsoft Edge Text-to-speech (computer) Text-to-speech (Android phone) Magnifying glass

Table 34 – Mapping Experiment 1.3 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using text-to-speech with social media	Difficulty reading Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Microsoft Edge Text-to-speech (computer) Text-to-speech (Android phone) Magnifying glass Facebook

Table 35 – Mapping Experiment 1.4 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using text-to-speech with train schedules	Difficulty reading Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Microsoft Edge Text-to-speech (computer) Text-to-speech (Android phone) Magnifying glass Train schedule website

Second, the scenarios focused on *Translation* generated three planned experiments: 1) using a language translation tool to read email; 2) using a language translation tool to read the news; 3) using a language translation tool with social media. Tables 36 through 38 show how each experiment maps to user needs or challenges and tools.

Table 36 – Mapping Experiment 2.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using a language translation tool to read email	Difficulty reading Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Microsoft Edge Gmail Chrome browser translator add-on

Table 37 – Mapping Experiment 2.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using a language translation tool to read the news	Difficulty reading Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Microsoft Edge Chrome browser translator add-on

Table 38 – Mapping Experiment 2.3 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Using a language translation tool with social media	Difficulty reading Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Microsoft Edge Chrome browser translator add-on Facebook

Third, the scenarios focused on *Complex Tasks* generated three planned experiments: 1) book a COVID-19 vaccine; 2) set up 2-factor authentication; 3) buy items online. Tables 39 through 41 show how each experiment maps to user needs or challenges and tools.

Table 39 – Mapping Experiment 3.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Book a COVID-19 vaccine	Difficulty sequencing and completing multi-step tasks Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Android phone

Table 40 – Mapping Experiment 3.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
2-Factor Authentication	Difficulty sequencing and completing multi-step tasks Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Android phone

Table 41 – Mapping Experiment 3.3 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Buy items online	Difficulty finding and paying for goods and services Difficulty sequencing and completing multi-step tasks Difficulty remembering processes Difficulty retaining information Need of support using digital devices and tools	Google Chrome Android phone

5.3.3 Evaluation & Monitoring

Across all experiments in the *Life Skills* lab locations, the sessions are to follow the same general procedure: testing with think-aloud from participants, post-test cognitive interview questions, and post-testing reflections from participants. Thus, the evaluation and monitoring will occur using data collection tools appropriate for

each phase of the experiment procedure (see Appendix D). Transcripts of all co-lab sessions will be produced. Additionally, journey maps will be produced.

5.4 NUIG SCENARIOS AND EXPERIMENTS (SELF-DEVELOPMENT)

The National University of Ireland Galway is implementing a single co-design lab in Galway, and this lab is focused on *Self-Development*. This means that the lab is focused on supporting people to take advantage of the opportunities provided by digital technologies for learning, employment, and personal development. This can involve: navigation, information searching, information processing, understanding text and graphics and using animations, and working with authoring systems. More specifically, self-development can be defined as:

- Pursuing education
- Navigating employment
- Communicating with others

5.4.1 Scenarios

As of the production of this deliverable, the *Self-Development Lab* developed three types of scenarios:

- Reading (see Figure 13)
- Writing via Dictation (see Figure 14)
- Writing via Typing (see Figure 15)

This list may be expanded and/or revised as co-lab activities continue and hackathons are held. Within the five types of scenarios, several experiments, or lab activities were planned. The figures below (Figure 13 – Figure 15) illustrate the connection between user needs identified prior to implementing lab activities and the scenario design. It is worth noting that these scenarios may connect with additional user needs, and the team will track these additional mappings throughout the co-lab implementation. In other words, one user need or challenge may have inspired the scenario's inception, but the scenario as enacted in reality may actually address additional (even unexpected) user needs or challenges. Finally, the figures introduce the experiments within each scenario, which will be discussed in more detail in the next section.

Figure 13 – Scenario Type 1: Reading

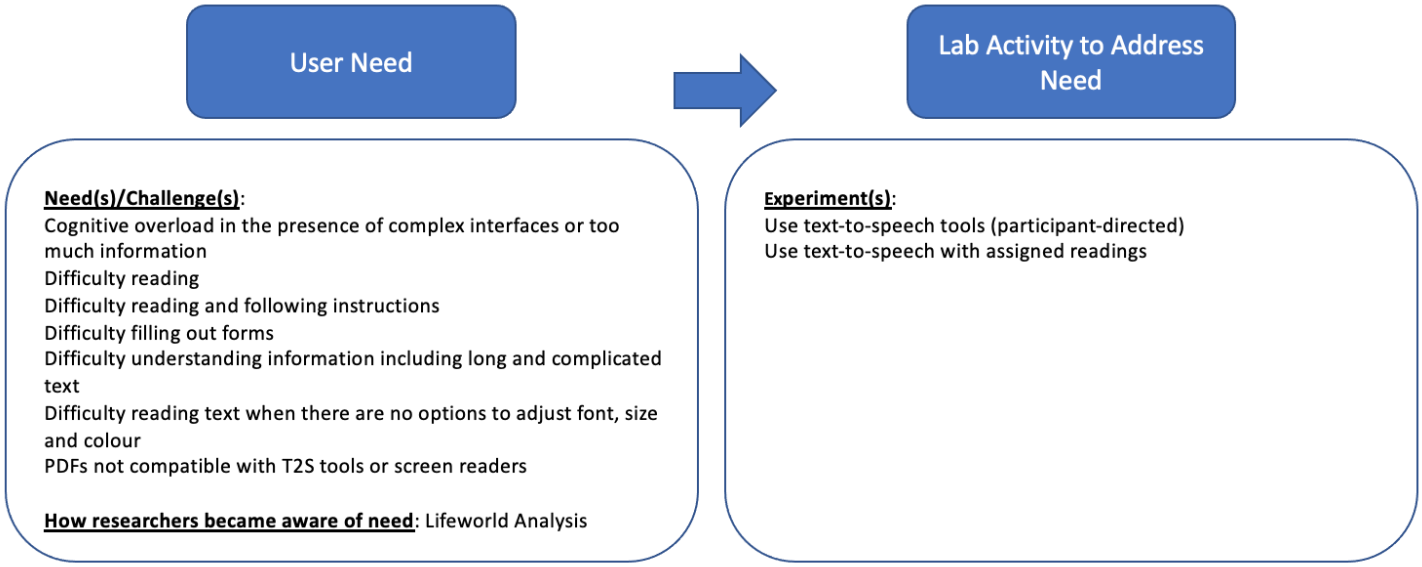


Figure 14 – Scenario Type 2: Writing via Dictation

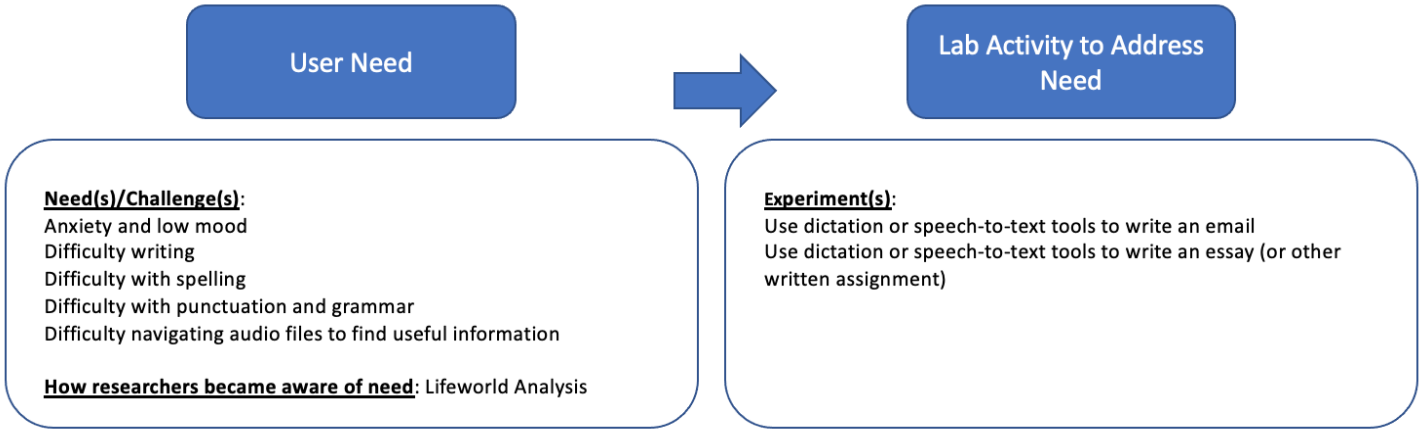
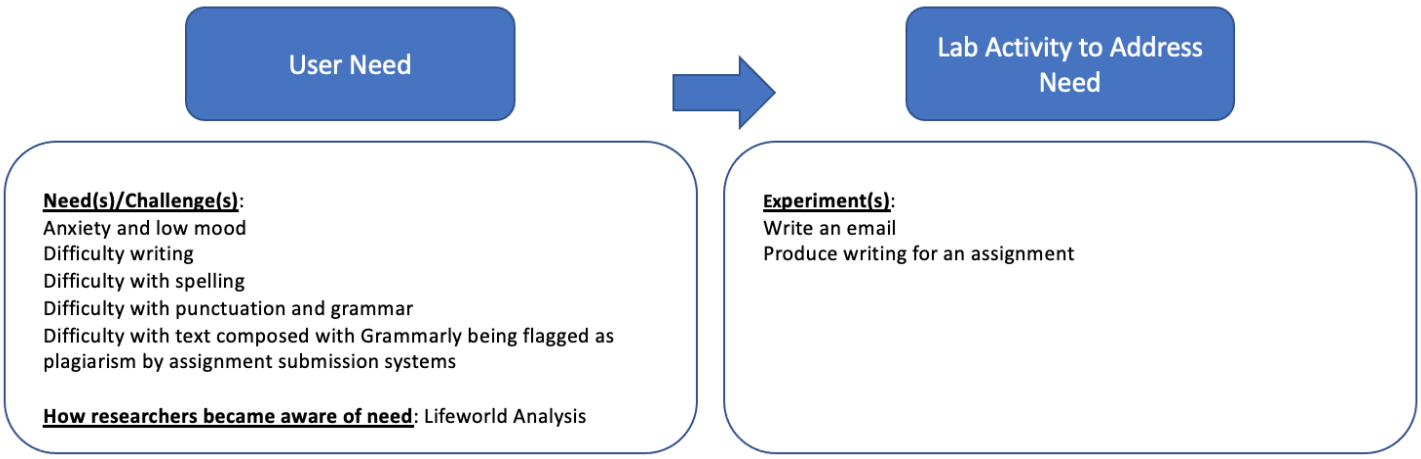


Figure 15 – Scenario Type 3: Writing via Typing



5.4.2 Experiments

Within each of the three scenario types initially planned for the Galway *Self-Development Lab*, several more testable experiments were developed. These experiments are mapped to challenges and tools, and these mappings may be revised as the co-lab activities continue – meaning that additional challenges and tools will likely be added. To provide additional detail about the experiments, we now present them by scenario category.

First, the scenarios focused on *Text-to-Speech* generated two planned experiments: 1) use text-to-speech tools (participant-directed); 2) use text-to-speech with assigned readings. Tables 42 and 43 show how each experiment maps to user needs or challenges and tools.

Table 42 – Mapping Experiment 1.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Use text-to-speech tools (participant-directed)	Cognitive overload in the presence of complex interfaces or too much information Difficulty reading Difficulty reading and following instructions Difficulty filling out forms Difficulty understanding information including long and complicated text	Easy Reading Word Texthelp Text-to-speech (Microsoft pre-installed) Natural Readers

Table 43 – Mapping Experiment 1.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Use text-to-speech with assigned readings	Cognitive overload in the presence of complex interfaces or too much information Difficulty reading Difficulty reading and following instructions Difficulty understanding information including long and complicated text Difficulty reading text when there are no options to adjust font, size and colour PDFs not compatible with T2S tools or screen readers	Easy Reading Word Texthelp Text-to-speech (Microsoft pre-installed) Natural Readers

Second, the scenarios focused on *Translation* generated two planned experiments: 1) use dictation or speech-to-text tools to write an email; 2) use dictation or speech-to-text tools to write an essay (or other written assignment). Tables 44 and 45 show how each experiment maps to user needs or challenges and tools.

Table 44 – Mapping Experiment 2.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Use dictation or speech-to-text tools to write an email	Anxiety and low mood Difficulty writing Difficulty with spelling Difficulty with punctuation and grammar	Word Dragon Otter

Table 45 – Mapping Experiment 2.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Use dictation or speech-to-text tools to write an essay (or other written assignment)	Difficulty writing Difficulty with spelling Difficulty with punctuation and grammar Difficulty navigating audio files to find useful information	Word Dragon Otter

Third, the scenarios focused on *Complex Tasks* generated two planned experiments: 1) write an email; 2) produce writing for an assignment. Tables 46 and 47 show how each experiment maps to user needs or challenges and tools.

Table 46 – Mapping Experiment 3.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Write an email	Anxiety and low mood Difficulty writing Difficulty with spelling Difficulty with punctuation and grammar	Word Google Google Docs Grammarly

Table 47 – Mapping Experiment 3.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Produce writing for an assignment	Difficulty writing Difficulty with spelling Difficulty with punctuation and grammar Difficulty with text composed with Grammarly being flagged as plagiarism by assignment submission systems	Word Google Google Docs Grammarly

5.4.3 Evaluation & Monitoring

Across all experiments in the *Self-Development* lab locations, the sessions are to follow the same general procedure: testing with think-aloud from participants, post-test cognitive interview questions, and post-testing reflections from participants. Thus, the evaluation and monitoring will occur using data collection tools appropriate for each phase of the experiment procedure. During the testing with think-aloud, video-recording, audio-recording, and note-taking on the observation tool (see Appendix D) will take place. During the post-test cognitive interviews, the cognitive interview protocol will be used (see Appendix D). During the post-test reflections, video-recorded and audio-recorded participant reflections will be captured and/or written reflections will be submitted using the scales in Appendix D.

5.5 AUTH SCENARIOS AND EXPERIMENTS (HELP & SUPPORT)

Aristotle University of Thessaloniki is implementing a single co-design lab in Thessaloniki, and this lab is focused on *Help & Support*. This means that the lab is focused on using online information and guidance systems. This can involve: searching for and using public information tools, using complex interfaces and gateways, identifying key points from dense and 'official' documentation, and navigating through guidelines. More specifically, help and support can be defined as:

- Finding relevant information
- Communicating with others
- Troubleshooting problems

5.5.1 Scenarios

As of the production of this deliverable, the *Help & Support Lab* developed four types of scenarios:

- Finding Contact Information Online (Figure 16)
- Find an Overnight Pharmacy (Figure 17)
- Navigate with Google Maps (Figure 18)
- Obtain Information via Email (Figure 19)

This list may be expanded and/or revised as co-lab activities continue and hackathons are held. Within the five types of scenarios, several experiments, or lab activities were planned. The figures below (Figure 16 – Figure 19) illustrate the connection between user needs identified prior to implementing lab activities and the scenario design. It is worth noting that these scenarios may connect with additional user needs, and the team will track these additional mappings throughout the co-lab implementation. In other words, one user need or challenge may have inspired the scenario's inception, but the scenario as enacted in reality may actually address additional (even unexpected) user needs or challenges. Finally, the figures introduce the experiments within each scenario, which will be discussed in more detail in the next section.

Figure 16 – Scenario Type 1: Find Contact Information Online

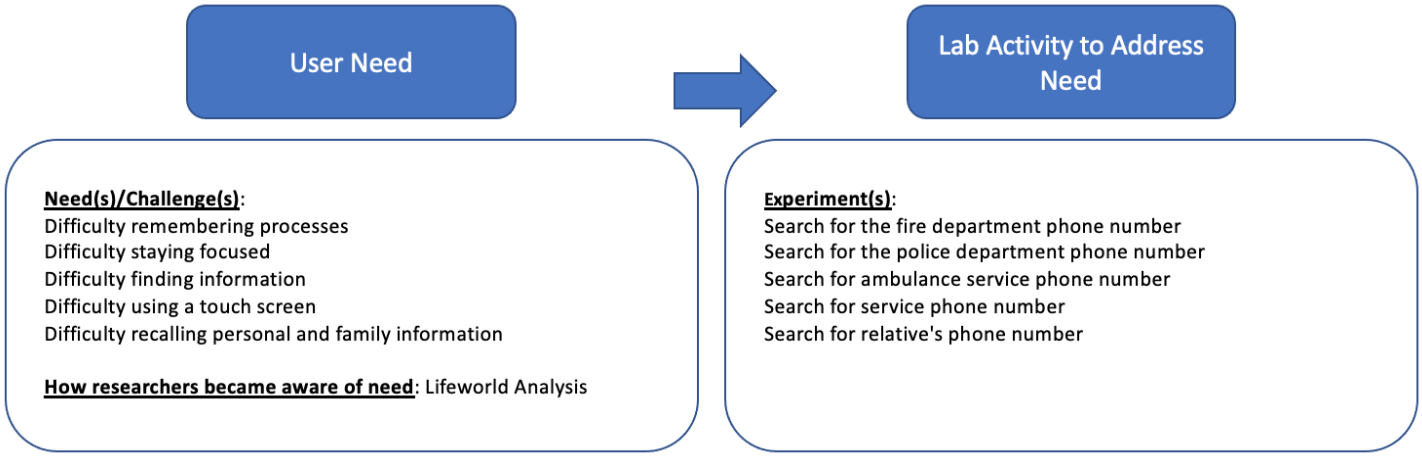


Figure 17 – Scenario Type 2: Find an Overnight Pharmacy

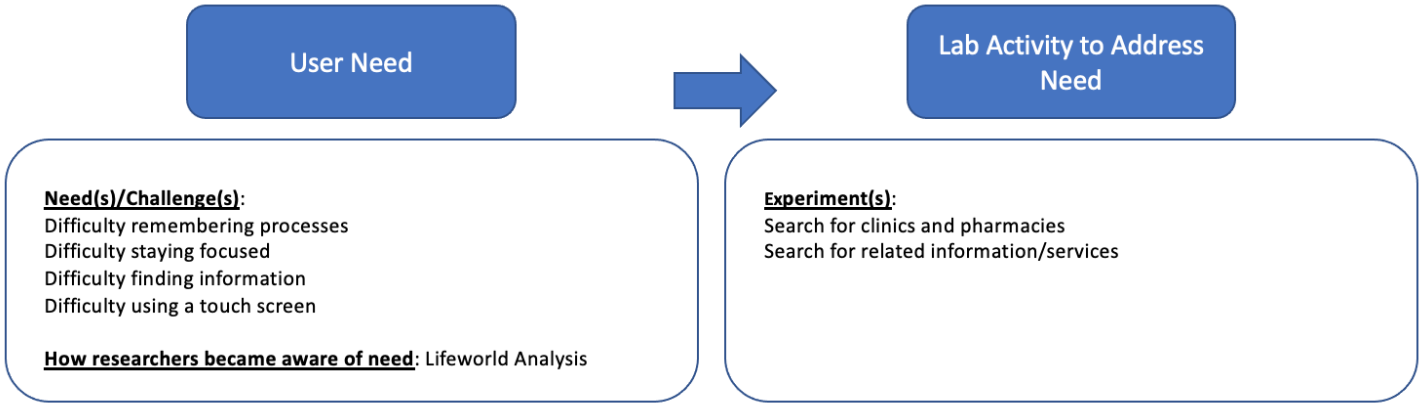


Figure 18 – Scenario Type 3: Navigate with Google Maps

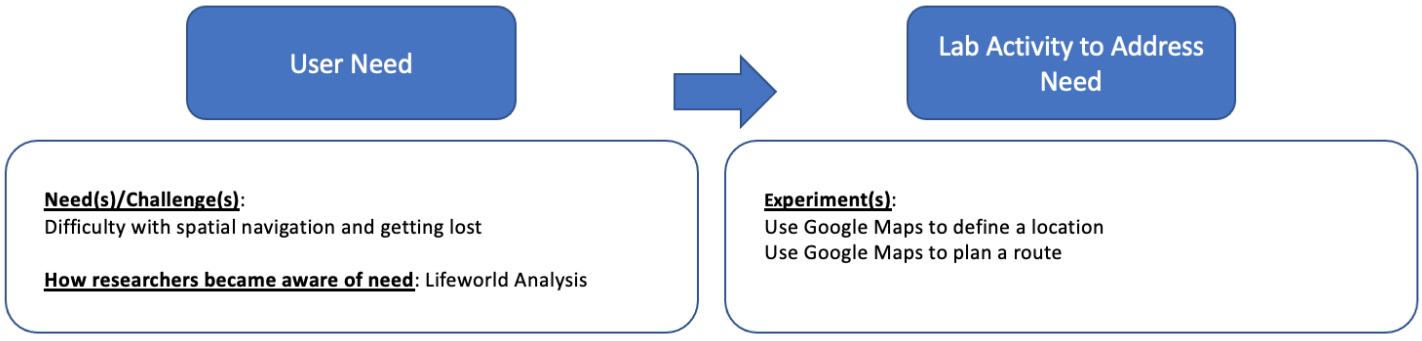
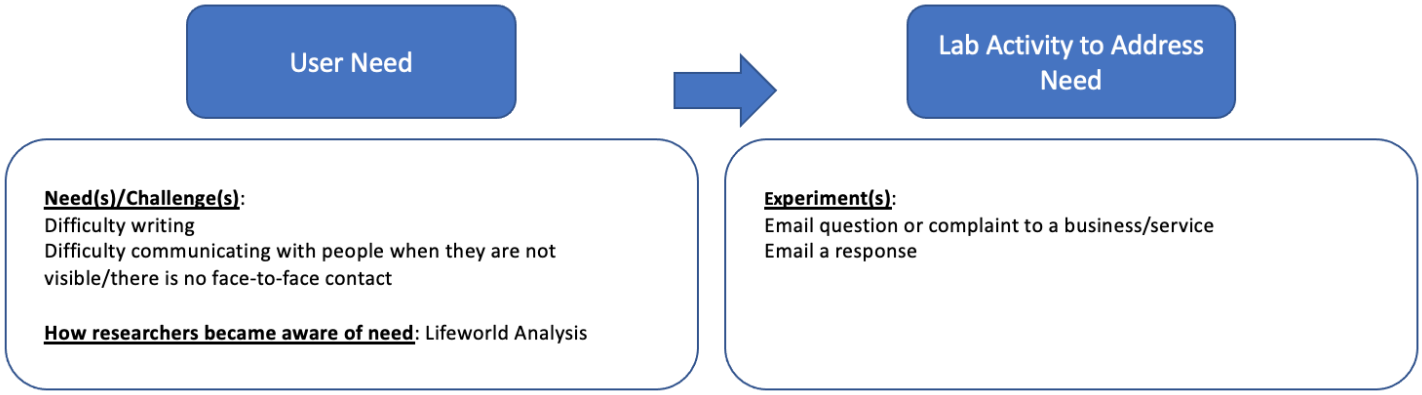


Figure 19 – Scenario Type 4: Obtain Information via Email



5.5.2 Experiments

Within each of the three scenario types initially planned for the Thessaloniki *Help & Support Lab*, several more testable experiments were developed. These experiments are mapped to challenges and tools, and these mappings may be revised as the co-lab activities continue – meaning that additional challenges and tools will likely be added. To provide additional detail about the experiments, we now present them by scenario category.

First, the scenarios focused on *Find Contact Information Online* generated five planned experiments: 1) search for the fire department phone number; 2) search for the police department phone number; 3) search for ambulance service phone number; 4) search for service phone number; 5) search for relative's phone number. Tables 48 through 52 show how each experiment maps to user needs or challenges and tools.

Table 48 – Mapping Experiment 1.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Search for the fire department phone number	Difficulty remembering processes Difficulty staying focused Difficulty finding information Difficulty using a touch screen	Microsoft Edge Google Chrome

Table 49 – Mapping Experiment 1.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Search for the police department phone number	Difficulty remembering processes Difficulty staying focused Difficulty finding information Difficulty using a touch screen	Microsoft Edge Google Chrome

Table 50 – Mapping Experiment 1.3 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Search for the ambulance service phone number	Difficulty remembering processes Difficulty staying focused Difficulty finding information Difficulty using a touch screen	Microsoft Edge Google Chrome

Table 51 – Mapping Experiment 1.4 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Search for service phone number	Difficulty remembering processes Difficulty staying focused Difficulty finding information Difficulty using a touch screen	Microsoft Edge Google Chrome

Table 52 – Mapping Experiment 1.5 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Search for relative's phone number	Difficulty recalling personal and family information Difficulty remembering processes Difficulty staying focused Difficulty finding information Difficulty using a touch screen	Microsoft Edge Google Chrome

Second, the scenarios focused on *Find an Overnight Pharmacy* generated two planned experiments: 1) search for clinics and pharmacies; 2) search for related information/services. Tables 53 and 54 show how each experiment maps to user needs or challenges and tools.

Table 53 – Mapping Experiment 2.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Search for clinics and pharmacies	Difficulty remembering processes Difficulty staying focused Difficulty finding information Difficulty using a touch screen	Microsoft Edge Google Chrome

Table 54 – Mapping Experiment 2.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Search for related information/services	Difficulty remembering processes Difficulty staying focused Difficulty finding information Difficulty using a touch screen	Microsoft Edge Google Chrome

Third, the scenarios focused on *Navigate with Google Maps* generated two planned experiments: 1) use Google Maps to define a location; 2) use Google Maps to plan a route. Tables 55 and 56 show how each experiment maps to user needs or challenges and tools.

Table 55 – Mapping Experiment 3.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Use Google Maps to define a location	Difficulty with spatial navigation and getting lost	Google Maps

Table 56 – Mapping Experiment 3.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Use Google Maps to plan a route	Difficulty with spatial navigation and getting lost	Google Maps

Finally, the scenarios focused on *Obtain Information via Email* generated two planned experiments: 1) email question or complaint to a business/service; 2) email a response. Tables 57 and 58 show how each experiment maps to user needs or challenges and tools.

Table 57 – Mapping Experiment 4.1 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Email question or complaint to a business/service	Difficulty writing Difficulty communicating with people when they are not visible/there is no face-to-face contact	Microsoft Edge Google Chrome Gmail Outlook

Table 58 – Mapping Experiment 4.2 to Challenges and Tools

Experiment	User Need/Challenge	Tools
Email a response	Difficulty writing Difficulty communicating with people when they are not visible/there is no face-to-face contact	Microsoft Edge Google Chrome Gmail Outlook

5.5.3 Evaluation & Monitoring

Across all experiments in the *Help & Support* lab locations, the sessions are to follow the same general procedure: testing with think-aloud from participants and/or carers, post-test cognitive interview questions with participants and/or carers, and post-testing reflections from participants and/or carers. Thus, the evaluation and monitoring will occur using data collection tools appropriate for each phase of the experiment procedure (see Appendix D). Transcripts of all co-lab sessions will be produced.

5.6 SCENARIO EVOLUTION

Clearly stating the intended plans for scenarios in each co-lab is important for both the ongoing work within the LIVE-IT Project and beyond the project. Of equal importance is sharing how scenarios and implementation plans were revised to meet the needs of participants. In Section 4, we shared how the co-labs started the process of revision and adopted a stance of procedural flexibility in the initial stages of lab planning and implementation. Now that the scenarios have been presented in more detail, we share more about how the co-labs have continued to revise the scenarios and procedures in the co-lab activities to date.

The following sections provide details about three areas related to revisions, flexibility, and the evolution of scenarios within the co-labs. First, we share some very brief case studies including examples of co-lab ‘pivots’.

Pivots are defined as deviations from planned experimental procedures and objectives in light of the results of ongoing monitoring of the experiment. Second, we share some early findings emerging from our flexible and participant-centred approach to conducting co-lab activities. Third, we show how the mappings between scenarios, challenges, and tools is beginning to take shape through the co-lab activities.

5.6.1 Examples of Co-Lab Pivots

We hope to have made it clear throughout Section 5 that the LIVE-IT Project always aimed to incorporate revision in the scenario development and validation process. However, knowing exactly how to revise, what to revise, and in what ways the co-labs would need to be flexible was impossible at the start. Baseline research (WP 1) and Lifeworld Analysis (Task 2.1) provided some insight, but a major takeaway of co-lab work to date is that the specific participants in each co-lab are the essential determinants of what would need to be revised. Thus, co-lab facilitators committed to tracking "co-lab pivots," or moments in which the planned scenarios or procedures had to be abandoned. Such pivots were often made in order to keep participants engaged and proceed ethically with the research. The following brief case studies are examples of pivots from each of the co-labs (all names are pseudonyms).

The Case of Ken, a 31-year-old male with Down Syndrome and related Learning and Cognitive Disabilities participating in the *Emergencies Lab* (UK – Arcola), provides an example of how allowing the participant to drive the lab session led to learning important new information about how PwCD develop understandings of emergency situations:

- Ken is enthusiastic and keen to engage. He has poor reading and writing skills but is learning and persisting. As a result, co-lab facilitators decided to be light touch with regard to text to speech tools selected for inclusion in the emergencies scenarios. Ken was interested in them, but he was keener to go to YouTube and show us what he did do on computers. There were concerns that insisting on the use of text-based sites and text-oriented tools may interfere with his determination and desire to continue his progress with reading and writing. Ken was not very interested in anything text based online, but he immediately got enthusiastic about showing us material on YouTube. Through this enthusiasm, co-lab facilitators were able to discern that Ken had an excellent grasp of emergencies, which was almost entirely picked up from YouTube and tv shows such as *The Bill*. He understood a lot about dangers, crime and things like fire. Also, he insisted on showing us how you have to get down (under the smoke) to escape a fire situation - something he had learned directly from the TV show, *The Bill*. He knew about danger from video and stage shows, he said - showing us Disney's *Jack and the Beanstalk*, *Beauty and the Beast* and some stage operatic performances. He knew some of these shows word for word and would not allow the facilitators to finish until he had sung along with the whole show. Thus, facilitators committed to following participants' lead when implementing co-lab activities.

The Case of Karolos, a 22-year-old male with Autism participating in the *Help & Support Lab* (Greece – AUTH), provides an example of how coordinating with relevant support staff and piloting co-lab activities ahead of co-lab sessions allowed co-lab facilitators to provide necessary accommodations:

- Karolos faces a cognitive disorder and he is also on the Autism Spectrum (comorbidity). Co-lab facilitators had a meeting with him to test one of the proposed co-lab scenarios. Although, he expressed great enthusiasm for his participation and seemed happy for his interaction with digital devices - we tried to perform the scenario both in PC and in smartphone – he faced great lack of concentration. During this pilot, two experts from the lab, two psychologists and a support teacher worked with Karolos. The team did two trials per device and tried to perform the scenario twice, one without the use of the tools in order to be understandable. Even in the first trial, when Karolos did not have to give feedback for the tools, he needed constant guidance and help from his educator. Then, when he had to select and use tools that are going to be included in the toolkit, he faced great difficulty selecting tools from that wide range and instead he preferred suggesting his own tools. Furthermore, when he performed the use of his own suggested tools, he needed constant help of his educator in order to use them properly. Co-lab facilitators learned that the matter of familiarization of participants and their caregivers or educators with specific functions, play a central role in tool selection. Thus, facilitators decided to have meetings with the educators before the lab-sessions, in order to help them familiarize themselves with some tools, so that they could facilitate more effectively in the process of evaluating the tools via the scenarios.

The Case of Pauline, a 57-year-old female with Dyslexia, Dyspraxia, and Dyscalculia participating in the *Self-Development Lab* (Galway – NUIG), provides an example of how consulting participants about how they would like to engage in the research activities can support increased participation:

- Pauline participated in a Lifeworld Analysis (Task 2.1) interview prior to agreeing to participate in the co-lab activities. During her very first interview, Pauline clearly communicated what terms and labels she liked and did not like. For example, she asked the interviewer to stop using the label “people with cognitive disabilities.” She preferred being addressed directly (with no reference to disability) or having her specific disabilities named. Throughout the interview, she also offered up suggestions about how to best engage with participants like her in research: allow them to express whatever emotions they are feeling with respect to the topic or activity at hand and be prepared to abandon the initial plan. When invited to participate in group co-lab activities, Pauline explained that she did not want to put herself in a position to experience the range of emotions (such as frustration and anger) that such activities might trigger surrounded by a group of strangers. Thus, facilitators decided to begin the co-lab work with individual sessions. This would allow participants to engage with the research in ways that worked best for them. Additionally, it would allow for the facilitators to establish trust with participants. Finally, it would support the development of group sessions that would honour participants’ boundaries with respect to how they wanted to participate.

The Case of Santiago, a 20-year-old male with Cognitive Deficit in the *Life Skills Lab* (Lisbon – UCP), provides an example of how an unplanned scenario can provide a valuable learning experience.

- In one session, one of the participants, Santiago, didn't remember his email's password – the scenario included email reading. All participants engaged in assisting Santiago in recovering and creating a new password through a multi-step process. Santiago had several challenges in comprehending what was asked in each step and one of the other participants guided him step by step, with minor mistakes and error-attempt moments. At one moment, a code was sent to a mobile phone registered, but Santiago didn't remember his own mobile phone and needed assistance of another participant to confirm his own phone number. The whole session revolved around this challenge and task. In the end the participant recovered his email and created a new password. Then, during the next session, he didn't remember the password again. Co-lab facilitators allowed this unplanned password scenario to take place instead of a planned email scenario. This flexibility allowed for the uninterrupted engagement of participants, because redirecting them to the planned scenario would have taken much time and effort. Additionally, the genuine interest in supporting a fellow participant led to authentic engagement among participants. This likely mirrored the participants' real-world experiences more closely than a planned lab scenario.

We share these cases as examples of how each lab revised planned scenarios in real time, because documentation of such pivots is necessary for the continued improvement of truly participatory research.

5.6.2 Early Co-Lab Findings

At the time of submission for this deliverable, formal analysis of co-lab data is in very early stages. Therefore, the early findings, or emergent findings, summarised here are themes noticed by co-lab facilitators through personal reflection associated with continuously improving lab sessions, sharing ideas with partners to support ongoing project activities, and early data analysis efforts. The remainder of this section presents some of the emergent themes from each of the four co-labs.

Emergencies Lab (London and Bristol – Arcola) facilitators have noted several challenges faced by PwCD during the co-lab sessions:

- Apps with complex interfaces or where how to make adjustments is unclear
- Apps which are not well integrated, for example participants are having to move from one app or tool to another to copy and past information (certain text to speech apps)
- Most interfaces are too small, making it difficult for people with visual impairments or motion difficulties such as a tremor
- No tools seem to have the option to adjust the size of buttons
- Apps and webpages where you can't adjust font size are frustrating

- Text based websites
- Log on and basic access issues for non-readers
- Layout and colours
- Confusing content
- Logging on and accessing tech, email, secure login
- Too much information on page (For some with short term memory issues grouped bullets and connected points were requested)
- If not simple and easily got through as a whole before forgetting the connections. Remembering passwords.
- Avoidance of text-based websites, audio and visual sites and options preferred.
- Breaking down, processing and understanding online or document text.
- Large range of co-issues and individual 'accessibility solutions' are required in most cases

Life Skills Lab (Coimbra and Lisbon – UCP) facilitators have noted several challenges faced by students with cognitive disabilities during co-lab sessions:

- Participants consider the proposed tools difficult to utilize
- The text to speech reads automatically all the text in the webpage and the user needs to select specific parts of the text if needed
- Participants propose a simplification of the tools with immediate access and eventually just a button in an accessible keyboard with just one click would be more accessible
- To obtain the COVID19 certificate is complex and needs human support throughout the whole process in understanding what is needed in each step

Additionally, a few possible solutions are emerging from co-lab sessions:

- The language translator together with the text to speech tool is very useful
- Participants consider the text to speech tool very useful in assisting their difficulties in reading and in some cases total incapability of reading

Self-Development Lab (Galway – NUIG) facilitators have noted several directions for possible improvement of existing tools from students with cognitive disabilities:

- Spell-checkers that learn your personal writing style and mistake-making style
- Grammar-checkers that learn your personal writing style and mistake-making style
- Discipline-specific spelling and grammar-checkers (or at least discipline-specific settings)
- Grammar-checkers that provide the reason why revisions need to be made
- Ability to use open access tools like the Open Dyslexic Font on all text-based material
- More accent options in text-to-speech and screen reader tools

Help & Support Lab (Thessaloniki – AUTH) facilitators have noted several problem-solution pairs established through the co-lab sessions

- Problem: The majority of the tools of the Toolkit where in English, so they were unsuitable for use in the Greek population of PwCD (who hardly maintain and develop linguistic skills in their mother language, Greek)
- Solution to that problem in the Lab: During the prelab sessions, with help from teachers and caregivers of PwCD, we select tools from the toolkit that are also translated in Greek or have a Greek version

- Problem: Many tools were not free
- Solution to that problem in the Lab: During the prelab sessions, we select from the toolkit the tools that were free of charge

- Problem: A lot of tools needed to be downloaded and the hardware (PC) of the special schools could not download them (This is a very important issue, because even when we find a solution to conduct the programmed lab sessions, the majority of public special schools and some educational organizations with PwCP, do not possess technologically updated systems (most of their PCs that public schools have are operating in Windows 7 and some tools of the toolkit need Windows 10 to run properly without functioning problems -environmental characteristic)
- Solution to that problem in the Lab: Educators and caregivers with guidance and assistance from our team, brought and used their own laptops or smartphones

- Problem: The majority of PWCD do not own or use smartphones
- Solution to that problem in the Lab: Educators used their own smartphones, when tools required use of smartphone

- Problem: PwCD could not use the tools without the help of the caregivers and educators.
- Solution to that problem in the Lab: Include educators and caregivers in the procedures

Additionally, the facilitators have noted some emergent themes from the co-lab sessions:

- Isolating chunks of text for text-to-speech tools to read presents challenges for participants
- Text-to-speech tools struggle with longer words
- Speech-to-text tools struggle to recognize what participants are saying
- Many students were not able to use the apps and tools without teacher and/or carer support

5.6.3 Ongoing Mapping: Scenarios-Challenges-Tools

As can be seen in the emerging findings, the teams at each of the four co-labs are continuously identifying challenges and possible solutions. Like in the Lifeworld Analysis (Task 2.1), we are also continuing to map the challenges to tools and participant feedback. A live version of the scenarios-challenges-tools mapping can be viewed in this **spreadsheet**.

6 CONCLUSION AND FURTHER DISCUSSION

This deliverable covered a lot of ground. It began with an overview of the LIVE-IT Project concept and methodology. Then, it presented the LIVE-IT ethical framework, procedures and systems as they related to co-lab activities. Next, it connected baseline research (WP 1) and lifeworld analysis (Task 2.1) to the co-lab specifications. Finally, it provided a snapshot of the initial LIVE-IT scenarios with examples of how those scenarios will continue to evolve. Within each section broad overviews and context-specific detail are provided to paint as comprehensive a picture as possible of a very complex undertaking. This work is complex because we are committed to both honouring individual participants and aggregating what we are learning to inspire continued improvement in the field.

To conclude, we now draw connections between the work done to develop scenarios and begin co-lab activities and other features of the LIVE-IT Project. First, we discuss connections between information in this deliverable and prior workpackages and tasks (WP 1 and Task 2.1). Second, we draw connections between this deliverable and ongoing workpackages and tasks (Task 2.3, Task 2.4, WP 3, and WP4). Finally, we end the deliverable with a discussion of implications for future work.

6.1 CONNECTIONS TO PRIOR WORKPACKAGES

Deliverable 2.2, the LIVE-IT Scenarios, builds on the early work in the LIVE-IT Project. Baseline Research (WP1) took two forms: an academic and grey literature search (Task 1.1), and an exploration of tools and platforms (Task 1.2 and Task 1.3). This baseline research combined with what was learned during Lifeworld Analysis (Task 2.1) formed the foundation on which the initial co-lab scenarios were developed. Ongoing co-lab activities are, in turn, informing revised versions of the artefacts associated with this baseline research. Most notably, the co-lab activities are helping the LIVE-IT partners refine the list of tools and platforms built during Task 1.2 and Task 1.3. Additionally, the mapping of challenges to tools is evolving as partners learn what participants currently use or are interested in using during the co-lab sessions.

6.2 CONNECTIONS TO ONGOING WORKPACKAGES

The information presented in this deliverable also informs ongoing workpackages and tasks including: Task 2.3, Task 2.4, WP3, and WP4. Either the deliverable will feed into upcoming tasks, or, as above, there is a bidirectional exchange of information between the tasks to support ongoing revisions. Connections to each are highlighted below.

Task 2.3 involves applying machine-learning tools to explore interactions between the technical attributes of the various combinations of platforms and tools used in Task 2.2 and the use behaviors of participating users. The aim of this activity is to develop clusters of attribute-use behavior combinations that demonstrate the best potential outcomes for inclusive web accessibility. Secondly, Task 2.3 will explore the potential value-added AI systems and tools could make to support inclusive web accessibility. The information in this deliverable supports Task 2.3 in the following ways:

- Provides a common framework for the unique and context-specific scenarios
- Creates a list of tools in use within the co-labs

However, in response to the external reviewers' recommendations at the project interim review, we are now implementing a more limited exploration of interactions between the technical attributes of the various combinations of platforms and tools used in the Co-Labs and the use behaviors of participating users. This will provide visual and analytical maps of these interactions in order to identify 'what works for whom in which circumstances'. The envisaged 'advisor tool', which forms part of the LIVE-IT 'Open Toolkit', and which originally expected to apply machine-learning and AI to recommend solutions to challenges posed by users, is now being developed and piloted in a more basic form, and uses a simple algorithm to propose possible tools a user might be interested in.

Task 2.4 involves validating the scenarios developed in Task 2.2 and the outcomes of Task 2.3. This will be implemented in the four Labs using structured co-creation workshops. The techniques used in the workshops will include role-playing, walk-throughs and structured brainstorming. The Lab workshops will be supplemented by online validation activities carried out through the Cognitive Community. The information in this deliverable supports Task 2.4 in the following ways:

- Provides a common framework for the unique and context-specific scenarios
- Provides examples of how to build trust and community in working towards workshop situations
- Provides a structure for developing workshop plans within each co-lab location based on initial scenarios and ongoing scenario revision

WP 3 involves the development and design of an integrated Open Toolkit with recommended tools that can be used in existing platforms and services. This Open Toolkit will include the outputs of the Hackathons and AI-

driven meta environment analysis. The information in this deliverable supports the tasks within WP3 in the following ways:

- The list of tools in use within the co-labs feeds into the toolkit development
- The exploration of combinations of tools to address sets of challenges posed in specific scenarios within Co-Lab experiments feeds into the Toolkit Guidelines on what works, for whom under which circumstances
- Scenarios and the ongoing revision of scenarios provide potential spaces for testing the toolkit

WP 4 involves setting up and managing an on-line makerspace. Additionally, it involves designing and organising 5 Pan-European, virtual hackathons that aim at addressing the accessibility challenges for people with cognitive impairments. Each hackathon will address 2-3 specific challenges. At the same time an active community is being created that will raise awareness at European level regarding web accessibility for people with disabilities and introduce the issue to numerous participants. The information in this deliverable connects the tasks within WP4 in the following ways:

- Bidirectional relationship between co-lab scenarios and makerspace
- Bidirectional relationship between co-lab scenarios and hackathons
- Scenarios and ongoing revision of scenarios provide potential spaces for testing ideas emerging from the makerspace and hackathons

6.3 IMPLICATIONS FOR FUTURE WORK

In conclusion, Deliverable 2.2 has two methodological implications for future work in the area of web accessibility for PwCD. First, the work done in WP1 and WP2 combine to indicate a need for long-term research projects. Second, the framework for LIVE-IT Scenarios, which is adapted from the W3C conceptualisation of scenarios, provides a model for future work in this area.

It should be remembered that the LIVE-IT Project is a pilot project. Therefore, much of what is being accomplished in this project will need continued exploration in future work. Baseline research made clear the fact that too much of the current work on web accessibility for PwCD is too siloed. However, the completion of Task 2.2, the production of this deliverable, and the ongoing work within the co-labs are also making clear the fact that taking such a broad approach to impacting web accessibility for PwCD is a complex and challenging task. The complexity and the challenges highlight the need for cohesive and longitudinal research programs.

Second, the scenarios presented in this deliverable are organised around a framework adapted from W3C documents and calls for research. They provide a model of how to transform the valuable information within the W3C documents into actionable and researchable co-lab activities. Additionally, they provide a model for the ethical inclusion of a vulnerable population. Finally, they provide a model for rigorous scenario revision.

APPENDIX A

ΑΡΙΣΤΟΤΕΛΕΙΟ
ΠΑΝΕΠΙΣΤΗΜΙΟ
ΘΕΣΣΑΛΟΝΙΚΗΣ

ΠΡΩΤΟΚΟΛΛΟ ΕΡΕΥΝΑΣ

Τίτλος έργου: LIVE-IT και Open Toolkit για τον από κοινού σχεδιασμό προσβάσιμων συστημάτων και εργαλείων Πληροφορικής

Τίτλος μελέτης: Lifeworld analysis: Νευροαναπτυξιακές και νευρολογικές διαταραχές (με αντίκτυπο στη γνωστική λειτουργικότητα) και ψηφιακή ένταξη. Τεκμηρίωση και κατανόηση των

ψηφιακών εμπειριών και αναγκών ατόμων με γνωστικές αναπηρίες

Ερευνητές: Εργαστήριο Ιατρικής Φυσικής και Ψηφιακής Καινοτομίας, Ιατρική Σχολή, Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης

Εισαγωγή

Μια από τις συχνότερα συναντώμενες δυσκολίες που καταλήγει να γίνεται και ένας από τους κυριότερους φραγμούς που αφορούν στην προσβασιμότητα στο διαδίκτυο είναι η ένταξη των ατόμων με γνωστικές δυσκολίες και νευρολογικές ή νευροαναπτυξιακές διαταραχές κάτω από μία στερεοτυπική διαγνωστική ετικέτα και η προσέγγιση, αξιολόγηση και «αναγνώριση» των ατόμων τελικά, υπό το πρίσμα του προβλήματος και συχνά ακόμα και «ως το ίδιο το πρόβλημα». Μέσα από διεργασίες και διαδικασίες, όπως οι προαναφερόμενες, οι τεχνολογικές παρεμβάσεις και προσεγγίσεις, στην προσπάθεια αναζήτησης λύσης, καταλήγουν, τελικά, να μετατρέπονται σε παρεμβάσεις «εκ των άνω». Συχνά, λοιπόν, σε καταστάσεις που προκύπτουν, οι ανάγκες των ατόμων με γνωστικές δυσκολίες και διαγνώσεις νευρολογικών και νευροαναπτυξιακών διαταραχών [με γνωστικό αντίκρισμα (επίδραση στη νοητική λειτουργικότητα)] - όπως και ατόμων με παρόμοιες δυσκολίες, συχνά προσεγγίζονται στις παρεμβάσεις αυτές, μόνο «επιφανειακά» (Schulz et al., 2015). Ένα σημαντικό σύνολο στοιχείων υποδεικνύει, ότι οι σχεδιαστές προγραμμάτων και οι προγραμματιστές, έχουν ελάχιστη ή καθόλου γνώση των προκλήσεων που τα άτομα με γνωστικές δυσκολίες και νευροαναπτυξιακές και νευρολογικές διαταραχές αντιμετωπίζουν όταν έρχονται σε επαφή και χρησιμοποιούν αυτές τις τεχνολογίες (Disability Rights Commission, 2004). Η έλλειψη συστηματικής έρευνας και επιστημονικών στοιχείων, για τη σχέση των διαγνώσεων που εντάσσονται κάτω από την εννοιολογική ομπρέλα της «γνωστικής αναπηρίας και διαταραχών», ενισχύουν την παραπάνω κατάσταση (Barnard and Beyer, 2009), η οποία με τη σειρά της συνδέεται με το γεγονός, ότι τα άτομα με γνωστικές δυσκολίες και διαταραχές, δεν συμμετέχουν στην έρευνα, το σχεδιασμό ή την ανάπτυξη (Borg et al., 2015). Σε σύνδεση με τις δυσκολίες που προκύπτουν από την προαναφερθείσα κατάσταση, βρίσκεται και η πρόσληψη των ατόμων με γνωστικές δυσκολίες και νευρολογικές και νευροαναπτυξιακές διαταραχές ως μια ομοιογενή ομάδα, ώστε, συχνά, οι σχεδιαστές και οι προγραμματιστές, να οδηγούνται στην εύρεση και υλοποίηση ψηφιακών λύσεων που δεν λαμβάνουν τις εξατομικευμένες και ιδιαίτερες ανάγκες των χρηστών, οι οποίες λόγω του διαφορετικού πλαισίου από όπου προέρχονται και του διαφορετικού πλαισίου που διαμορφώνεται από το διαφορετικό προφίλ των δυσκολιών που αντιμετωπίζουν και την ένταση τους (ήπιες δυσκολίες, έως πιο έντονες) (Neven, 2010; Collings et al., 2018).

Σε αυτό το πλαίσιο, ο κύριος στόχος του έργου είναι:

Να συγκεντρώσει και να αξιοποιήσει τη διεπιστημονική ερευνητική γνώση και τα ευρήματα που προσεγγίζουν το ζήτημα της σχέσης γνωστικών δυσκολίων και διαταραχών και ψηφιακής ένταξης «φωτίζοντας το ζήτημα από διαφορετικές οπτικές». Μέσα σε αυτό το πλαίσιο, στοχεύει στη συλλογή στοιχείων, μέσα από χώρους πειραματισμού που παρέχουν δυνατότητα δράσης, ώστε να υποστηριχθεί η προσβασιμότητα των ατόμων με γνωστικές δυσκολίες, προσαρμοζόμενη στις εξατομικευμένες ανάγκες και

τις αναγκαίες ρυθμίσεις που απαιτούνται για την «ομαλή προσαρμογή» και «ψηφιακή μετάβαση» κατά την καθημερινή τους διάδραση με τις ψηφιακές εφαρμογές στην καθημερινότητα τους.

Σκοπός μελέτης

Σκοπός της παρούσας μελέτης είναι η συγκέντρωση δεδομένων από εμπειρίες ατόμων με γνωστικού τύπου δυσκολίες ή νευροαναπτυξιακές διαταραχές και νευροαναπτυξιακές αναπηρίες ή/και από τους φροντιστές τους, σε σχέση με την αλληλεπίδραση τους με το διαδίκτυο και τις ψηφιακές τεχνολογίες και τα προβλήματα που αντιμετωπίζουν κατά την διάδρασή τους. Τα στοιχεία που θα συγκεντρωθούν, μέσω συνεντεύξεων και ομαδικών συζητήσεων (focus group), θα αναλυθούν, ώστε να δημιουργήσουν το πλαίσιο, για την ανάπτυξη ενός εργαλείου, το οποίο θα αξιολογεί την αποτελεσματικότητα και της δυνατότητα προσβασιμότητας των ατόμων με γνωστικής και νευρο-αναπτυξιακής υφής δυσκολίες, στον ψηφιακό κόσμο. Το έργο στοχεύει στη διευκόλυνση συμμετεχόντων/ουσών και των ατόμων με δυσκολίες γνωστικής και νευροαναπτυξιακή υφής κατά την αλληλεπίδραση τους στην ψηφιακή καθημερινότητα, μέσω της εξοικείωσης τους στη χρήση πλατφορμών και ψηφιακών εργαλείων και νέων τεχνολογιών. Παράλληλα αποσκοπεί στον προσδιορισμό αποτελεσματικών λύσεων από κοινού με τα άτομα μέσω της συμμετοχής σε δραστηριότητες συνεργασίας και συν-σχεδιασμού. Ο συν-σχεδιασμός θα γίνει στα τέσσερα εργαστήρια των εταίρων της κοινοπραξίας του έργου LIVE-IT (Ελλάδα – Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης, Αγγλία – Arcola Research LLP, Ιρλανδία – National University of Ireland, Πορτογαλία – Catholic University) παρέχοντας πληροφορίες αλλά και προτάσεις για διορθώσεις και τροποποιήσεις των διαδικασιών και εργαλείων ψηφιακής ένταξης και προσβασιμότητας.

Περιβάλλον μελέτης

Τα δεδομένα για το πλαίσιο της μελέτης θα συλλεχθούν από την ερευνητική ομάδα του έργου LIVE-IT, συνεργατών του Εργαστηρίου Ιατρικής Φυσικής και Ψηφιακής Καινοτομίας του Αριστοτελείου Πανεπιστημίου Θεσσαλονίκης.

Χρονοδιάγραμμα

Η μελέτη θα λάβει χώρα σε μια περίοδο επτά (6) μηνών, μεταξύ Οκτωβρίου 2021 και Μαρτίου 2022.

Συμμετέχοντες/ουσες

Οι συμμετέχοντες/ουσες θα είναι άτομα που έχουν διαγνωστεί με σύνδρομο Down, άτομα που έχουν διαγνωστεί με διαταραχές στο φάσμα του Αυτισμού (ΔΑΦ), συμπεριλαμβανομένων ανηλίκων, άτομα στην τρίτη ηλικία (ενήλικες) με άνοια, τα οποία, θα υποδειχθούν από συνεργάτες της μελέτης και με την προϋπόθεση, ότι θα έχουν συμφωνήσει οι ίδιοι και θα έχουν υπογράψει οι φροντιστές ή οι νόμιμοι εκπρόσωποί τους το έντυπο συγκατάθεσης που θα επιτρέπει τη συλλογή και την επεξεργασία των δεδομένων που θα συλλεχθούν για τους σκοπούς της μελέτης.

Τα κριτήρια ένταξης των συμμετεχόντων/ουσών στην μελέτη είναι:

α) να είναι άνω των 5 ετών,

β) να έχουν λάβει διάγνωση ή να αντιμετωπίζουν γνωστικές δυσκολίες που εντάσσονται στις διαγνώσεις: σύνδρομο Down, άτομα στο φάσμα του αυτισμού (ΔΑΦ), ΔΕΠ-Υ ή άνοια, ώστε να υπάρχει στην μελέτη ένα ευρύ και αντιπροσωπευτικό φάσμα των διαγνώσεων και γνωστικών δυσκολιών που επηρεάζουν την γνωστική λειτουργικότητα και

γ) να έχουν την πρόθεση να αλληλοεπιδράσουν και να μοιραστούν τις εμπειρίες τους, σχετικά με τα σενάρια «ψηφιακού αποκλεισμού» που εξετάζονται στα πλαίσια του project του LIVE-IT. Θέματα, δηλαδή, σχετικά με ζητήματα που αφορούν στην πρόσβαση σε διαδικτυακό περιεχόμενο και υπηρεσίες, συμπεριλαμβανομένων των συναλλαγών καταναλωτών, προκλήσεις προσβασιμότητας και θέματα δημιουργίας διαδικτυακού περιεχομένου.

Αναφορικά με τα κριτήρια αποκλεισμού:
Θα αποκλείονται, από την συμμετοχή στην ερευνητική διαδικασία και μελέτη, άτομα ηλικίας κάτω των 5 ετών. Επίσης, θα αποφευχθεί η πρόσκληση ατόμων, τα οποία είναι πιθανό να αντιμετωπίσουν μεγάλες δυσκολίες, κατά τη συμμετοχή τους, ή άτομα που δεν μπορούν να λειτουργήσουν σε μια ομαδική κατάσταση ή υπάρχει πιθανότητα πρόκλησης αρνητικών συναισθημάτων ή δυσφορίας, με πιθανό αποτέλεσμα, αναφορές για αρνητικές συνέπειες στην ψυχική και νοητική τους κατάσταση και υγεία. Σε ορισμένες περιπτώσεις, μπορεί να είναι επιθυμητό και χρήσιμο, οι εμπειρίες ενός ή μίας συμμετέχοντα/ούσης, να εκπροσωπούνται εξ ονόματός τους ή να υποβοηθούνται κατά την εκφραστική τους μεταφορά από έναν φροντιστή του ατόμου.

Συνεντεύξεις / ομαδικές συζητήσεις
Οι συνεντεύξεις / ομαδικές συζητήσεις θα διεξαχθούν σε δύο φάσεις, όχι απαραίτητα με την συμμετοχή των ίδιων ατόμων. Οι συμμετέχοντες της κάθε φάσης θα είναι:
α) στην πρώτη φάση 15 άτομα συνολικά σε συνεντεύξεις και ομαδικές συζητήσεις (π.χ. ομαδική συζήτηση 10 ατόμων και 5 ατομικές συνεντεύξεις) που αφορούν την αλληλεπίδρασή τους με τον ψηφιακό κόσμο, την ποιότητά της και τις δυσκολίες που συναντούν και
β) στην δεύτερη φάση 25 άτομα συνολικά σε συνεντεύξεις / ομαδικές συζητήσεις που θα διενεργηθούν πριν και κατόπιν χρήσης ενός οδηγού (toolkit) και εργαλείων, τα οποία αποσκοπούν στην διευκόλυνση προσβασιμότητας και χρήσης ψηφιακών τεχνολογιών, για την συλλογή δεδομένων αξιολόγησης και ανατροφοδότησης του toolkit.

Σχέδιο συλλογής δεδομένων
Η συλλογή των δεδομένων θα γίνει στο πλαίσιο συνεντεύξεων / ομαδικής συζήτησης (focus group), κατά την οποία θα συλλέγονται στοιχεία, δεδομένα και πληροφορίες για την χρηστικότητα ψηφιακών τεχνολογιών, εργαλείων και εφαρμογών, τις δυσκολίες που συναντώνται κατά τη χρήση τους, τα συνήθη προβλήματα που αντιμετωπίζουν κατά την διάδρασή τους με αυτές και τα εμπόδια που οδηγούν στον «ψηφιακό αποκλεισμό» ατόμων με νευροαναπτυξιακά, νευρολογικά ζητήματα με γνωστικό αντίκτυπο και διαγνώσεις και γνωστικές δυσκολίες. Η εκάστοτε συνέντευξη αναμένεται να διαρκέσει περίπου τριάντα (30) λεπτά και η ομαδική συζήτηση περίπου μία (1) ώρα - 60 λεπτά.
Οι συνεντεύξεις / ομαδικές συζητήσεις ενδέχεται να ηχογραφηθούν, και οι ηχογραφήσεις θα χρησιμοποιηθούν αποκλειστικά για απομαγνητοφώνηση των δεδομένων, χωρίς περαιτέρω κοινοποίηση των στοιχείων και θα ακολουθηθεί διαδικασία ψευδωνυμοποίησης στοιχείων. Τα κείμενα των απομαγνητοφωνήσεων από τις 15 συνεντεύξεις / ομαδικές συζητήσεις της πρώτης φάσης θα σταλούν, εφόσον ζητηθούν, στην ερευνητική ομάδα που θα ηγηθεί της ανάλυσης τους, Arcola Research LLP, UK. Τα

κείμενα των απομαγνητοφωνήσεων από τις 25 συνεντεύξεις / ομαδικές συζητήσεις που σχετίζονται με το toolkit θα σταλούν, εφόσον ζητηθούν, στο National University of Ireland, IE και στο Catholic University of Portugal, PT.

Σχετικά με την συμμετοχή: α) τα δεδομένα που θα συλλεχθούν θα χρησιμοποιηθούν, μόνο για ερευνητικούς σκοπούς, ενώ, σε περίπτωση που χρησιμοποιηθούν σε αναφορές που ενδέχεται να δημοσιοποιηθούν, εκτός του πλαισίου έργου, θα ανωνυμοποιηθούν πλήρως έτσι ώστε να μην μπορεί να προσδιοριστεί κανένα άτομο, β) οι απομαγνητοφωνήσεις της μελέτης θα πραγματοποιηθούν με ασφάλεια από την ερευνητική ομάδα που είναι υπεύθυνη στα πλαίσια του έργου, για τη διεξαγωγή της συνέντευξης ή της ομαδικής συζήτησης και τα δεδομένα που θα προκύψουν, θα διαγραφούν, μετά το τέλος του έργου (31/03/2022) ή το αργότερο πέντε (5) έτη από την ημερομηνία λήξης του έργου, δηλαδή την 31/03/2027, γ) μπορεί να γίνει αίτηση ενημέρωσης ή διαγραφής των προσωπικών δεδομένων από τους/τις συμμετέχοντες/ουσες, ανά πάσα στιγμή και δ) η αποχώρηση από τη συνέντευξη είναι δυνατή ανά πάσα στιγμή, χωρίς να απαιτηθεί αιτιολόγηση της αποχώρησης και χωρίς να επηρεαστούν από την αποχώρηση τα νόμιμα δικαιώματα του/της αποχωρήσαντα/σας.
Για περισσότερες πληροφορίες σχετικά με την συμμετοχή ή για ενημέρωση της ερευνητικής ομάδας για επικείμενη αποχώρηση, στείλτε email στο giannis.poultourtzidis@gmail.com .

Διαδικασία συλλογής δεδομένων μέσω συνέντευξης / ομαδικής συζήτησης
Οι συνεντεύξεις / ομαδικές συζητήσεις, θα πραγματοποιηθούν, είτε διαδικτυακά είτε δια ζώσης. Ξεκινώντας, θα καλωσορίζεται ο/η συμμετέχοντας/ουσα, θα του/της υπενθυμίζεται, πως η συμμετοχή είναι εθελοντική και πως η συγκατάθεση του/της είναι απαραίτητη, για την συνέχιση της διαδικασίας. Μετά την υπογραφή της φόρμας συγκατάθεσης, το ονοματεπώνυμο του συμμετέχοντα θα μετατρέπεται σε κωδικό, ο οποίος θα χρησιμοποιείται εφεξής, και θα σημειώνεται η ηλικία, η διάγνωση διαταραχής του ατόμου, το μορφωτικό επίπεδο, η πόλη διαμονής, το επάγγελμα (για τους ενήλικες με άνοια), καθώς και η περίοδος εμφάνισης της της διαταραχής (για τους ενήλικες με άνοια).
Εν συνεχεία, η συνέντευξή / ομαδική συζήτηση θα ξεκινά, αναφέροντας πως δεν υπάρχουν λάθος απαντήσεις ή τοποθετήσεις, πως όλες οι απόψεις και οι εμπειρίες είναι αποδεκτές και θεμιτό και επιθυμητό να ακουστούν. Θα υπάρχει, από την μεριά των ερευνητών/τριών που θα επιβλέπουν / παρακινούν / διεξάγουν και συμμετέχουν στην συζήτηση, μέριμνα, ώστε να μην μονοπωληθεί η συζήτηση από ελάχιστους συμμετέχοντες/ουσες, στην περίπτωση της ομαδικής συζήτησης.
Στην πρώτη φάση διεξαγωγής συνεντεύξεων, οι συμμετέχοντες/ουσες, θα κληθούν, να συζητήσουν, σχετικά με την ποιότητα διεπαφής και σχέση αλληλεπίδρασής τους με τον «ψηφιακό κόσμο» και τον βαθμό, στον οποίο θεωρητικά δίνεται η δυνατότητα, να αλληλοεπιδράσουν απρόσκοπτα και χωρίς περιορισμούς. Στο πλαίσιο της συζήτησης ή της συνέντευξης, θα αναλυθούν και θα συζητηθούν, οι προκλήσεις που αντιμετωπίζουν, κατά την διάδραση και αλληλεπίδραση με τις ψηφιακές τεχνολογίες και εφαρμογές, οι λειτουργίες των εφαρμογών και ψηφιακών εργαλείων που χρησιμοποιούν κατά την αλληλεπίδραση και ο βαθμός στον οποίο οι λειτουργίες αυτές επιτελούνται και καλύπτουν τις ανάγκες τους, η δυνατότητα «ψηφιακής ένταξης» και προσβασιμότητας, οι τεχνολογικές καινοτομίες που θα μπορούσαν να προσφέρουν βελτιώσεις στη διάδραση τους με τον ψηφιακό κόσμο αλλά και στην ποιότητα ζωής τους κατ' επέκταση,

καθώς και οι αιτίες που μειώνουν την δυνατότητα πρόσβασης και αξιοποίησης του οφέλους συμμετοχής στην «ψηφιακή κοινωνία».

Στην φάση διεξαγωγής των δεύτερων συνεντεύξεων / ομαδικών συζητήσεων που αφορούν τον οδηγό κατάρτισης (toolkit), θα παρέχετε στους/στις συμμετέχοντες/ουσες, η δυνατότητα χρήσης του εργαλείου αυτού (του οδηγού toolkit). Ο οδηγός αυτός θα περιλαμβάνει κάποιες προτάσεις από τεχνολογικές εφαρμογές και ψηφιακά εργαλεία, τα οποία χρησιμοποιούνται ως ψηφιακά εργαλεία βελτίωσης της ποιότητας ζωής και νοητικής ενδυνάμωσης των ατόμων που αντιμετωπίζουν γνωστικές δυσκολίες. Ο/Η εκάστοτε συμμετέχοντας/ουσα θα καλείται να διαδράσει με τις εφαρμογές του εργαλείου αυτού (toolkit) για κάποιο περιορισμένο χρονικό εύρος (μερικά λεπτά), ώστε να ενεργήσει ελεύθερα μέσα στον «ψηφιακό χώρο των εφαρμογών αυτών», αλλά και να εκτελέσει συγκεκριμένες εργασίες και εν συνεχεία, θα κληθεί να συζητήσει με την ερευνητική ομάδα, την γνώμη του/της για τις λειτουργίες του εργαλείου και τον βαθμό, στον οποίο τον/την βοήθησε να αλληλοεπιδράσει, αλλά και να προτείνει πιθανές τροποποιήσεις ή προσθήκες.

Οι συζητήσεις και οι συνεντεύξεις που θα διεξαχθούν είναι ημιδομημένες, δηλαδή υπάρχει προσχέδιο συνέντευξης (κεφάλαιο 9), όμως μπορεί τόσο ο/η συνεντευκτής/τρια και διοργανωτής/τρια της ομαδικής συζήτησης να αποκλίνει από την δομή αυτή ανάλογα τις απαντήσεις που λαμβάνει και την πορεία της συζήτησης, μέσα στα πλαίσια του ερευνητικού σχεδιασμού και σκοπού της έρευνας, καθώς είναι πιθανό να ανακύψουν νέες ερωτήσεις, ανάλογα με την εξέλιξη της συζήτησης, ώστε να επιτευχθεί και να μην αποθαρρυνθεί η απρόσκοπτη έκφραση των σκέψεων, ιδεών και εμπειριών των συμμετεχόντων/ουσών. Τέλος, οι ερευνητές/τριες, θα ευχαριστήσουν τους/τις συμμετέχοντες/ουσες.

Αναλύσεις

Περιγραφή ανάλυσης δεδομένων

i) Η ανάλυση των δεδομένων που θα συλλεχθούν στις πρώτες συνεντεύξεις / ομαδικές συζητήσεις, θα πραγματοποιηθεί σε 3 στάδια: α) Ανάλυση περιεχομένου μεμονωμένων συνεντεύξεων και ομαδικών συζητήσεων, β) Σύγκριση, ενσωμάτωση και σύνθεση αποτελεσμάτων ανάλυσης περιεχομένου σε «Αναφορά χώρας» και γ) Σύγκριση, ενσωμάτωση και σύνθεση αναφορών που έχουν συλλεχθεί από τις συμμετέχουσες στο έργο χώρες, στην συνολική έκθεση ανάλυσης του έργου.
Για το πρώτο βήμα, οι ερευνητές θα αναγνωρίσουν βασικά θέματα των συζητήσεων και επαναλαμβανόμενα μοτίβα που παρουσιάζουν και αντανακλούν προβλήματα που αντιμετωπίζουν τα άτομα με γνωστικές αναπηρίες στην αλληλεπίδραση τους με ψηφιακές τεχνολογίες και εν συνεχεία θα υποστηρίξουν το εύρημα τους, πχ. παραθέτοντας μια φράση ή ένα απόσπασμα της συζήτησης.
Για να ολοκληρωθεί και το δεύτερο βήμα, οι ερευνητές θα ενσωματώσουν τα ευρήματα σε μια αναφορά με τα ευρήματα της χώρας τους, ενώ στο τρίτο βήμα ο εταίρος Arcola Research LLP θα εκτελέσει την ίδια διαδικασία σε διεθνικό επίπεδο ενσωματώνοντας τις τέσσερις (4) αναφορές των εταίρων.
ii) Η ανάλυση των δεδομένων των συνεντεύξεων / ομαδικών συζητήσεων της δεύτερης φάσης θα γίνει στο πλαίσιο της ανατροφοδότησης του παραγόμενου εργαλείου - οδηγού (toolkit). Η διάδραση με το εργαλείο - οδηγό (toolkit) και η χρήση του εργαλείου, μέσω και εξαιτίας της πιλοτικής δοκιμής του, αποσκοπεί να

καταλήξει σε μια συζήτηση με τον/την εκάστοτε συμμετέχοντα/ουσα, μέσω της οποίας θα αξιολογείται το εργαλείο - οδηγός (toolkit) και θα καταδεικνύονται τα πιθανά ζητήματα που ανακύπτουν στον σχεδιασμό του και στην χρηστικότητα του, παρέχοντας στους δημιουργούς του εργαλείου - οδηγού (toolkit) αυτού, τα απαραίτητα και κατάλληλα δεδομένα, για την ανάπτυξη νέων βελτιωμένων εκδόσεών του μέσω αυτής της διαδικασίας συν-δημιουργίας.

Πρόνοιες για την ηθική διενέργεια της μελέτης

Όλοι/ες οι συμμετέχοντες/ουσες θα ενημερωθούν, μέσω ενός ενημερωτικού δελτίου, όπου θα περιγράφεται εκτενώς και με επικοινωνιακά εύληπτο (στο κοινό αυτό) τρόπο, η συνολική διαδικασία της μελέτης. Η συμμετοχή τους στο έργο θα είναι εφικτή, μόνο, αν παρέχουν την γραπτή συγκατάθεσή τους, έπειτα από την ενημέρωση που θα λάβουν. Το έγγραφο που χρησιμοποιείται, γι' αυτό το σκοπό είναι το ***«Έντυπο Ενημέρωσης και Συγκατάθεσης Συμμετέχοντα»***.

Οι συμμετέχοντες/ουσες, συγκεκριμένα, θα ενημερωθούν σχετικά με τον σκοπό της έρευνας και ότι:

1. Η συμμετοχή τους είναι εθελοντική και όχι επιβεβλημένη.
2. Μπορούν να υποβάλλουν ερωτήσεις περί της μελέτης πριν αποφασίσουν για τη συμμετοχή τους σε αυτή.
3. Θα τους γνωστοποιούνται τα οφέλη από την συμμετοχή τους στην από τη διεξαγωγή της έρευνας, αλλά και ποιοι άλλοι λαμβάνουν όφελος από την διεξαγωγή της έρευνας αυτής.
4. Θα τους γνωστοποιούνται, ο ακριβής τρόπος συλλογής, διάθεσης και προστασίας των ευαίσθητων προσωπικών δεδομένων, κατά τη διάρκεια του έργου, καθώς και η μετέπειτα διάθεση, επεξεργασία και αξιοποίηση των στοιχείων αυτών, αν δηλαδή θα καταστραφούν ή θα επαναχρησιμοποιηθούν, σε περίπτωση που υπάρχει ενδεχόμενο επανάχρησης αυτών.
5. Θα λάβουν αναλυτική και πλήρη ενημέρωση και θα ζητηθεί η σύμφωνη γνώμη τους, για τυχόν περαιτέρω χρήση των δεδομένων που θα δώσουν, κατά την είσοδο και συμμετοχή τους στο ερευνητικό έργο.
6. Θα τους γνωστοποιηθεί πως έχουν την δυνατότητα να αποχωρήσουν και να αποσύρουν τα δεδομένα τους από το έργο οποιαδήποτε στιγμή χωρίς επιπτώσεις.
7. Σε κάθε φόρμα συγκατάθεσης συμμετέχοντα/ουσας, θα δηλώνεται ενυπόγραφα τόσο ο/η ερευνητής/τρια που διεξήγαγε την ενημέρωση, όσο και ο συνολικά επιστημονικά υπεύθυνος της μελέτης.

8. Το αντίτυπο της παρεχόμενης άδειας θα αναφέρει ρητά ότι αυτές οι πληροφορίες έχουν κατατεθεί στην επιτροπή βιοηθικής του Τμήματος Ιατρικής, της Σχολής Επιστημών Υγείας, του Αριστοτελείου Πανεπιστημίου Θεσσαλονίκης (Α.Π.Θ.) πριν οποιαδήποτε αδειοδότηση και ότι όλες οι προσωπικές πληροφορίες και τα ευαίσθητα προσωπικά δεδομένα, θα έχουν ανωνυμοποιηθεί με μοναδικούς μεν, αδύνατον να ταυτοποιήσουν τον χρήστη δε, κωδικούς αριθμούς αναγνώρισης.

Οδηγός θεματικών / αξόνων όπου θα βασιστούν οι ερωτήσεις της συνέντευξης / ομαδικής συζήτησης

Οι συνεντεύξεις / ομαδικές συζητήσεις θα βασιστούν, αλλά δεν θα περιοριστούν (όπως και για τους λόγους που αναλύθηκε παραπάνω), στον ακόλουθο οδηγό (όχι εξαντλητικός). Ο οδηγός δεν αποτελεί σχέδιο συνέντευξης, αλλά αποτελεί έναν κατευθυντήριο άξονα που ορίζει τις θεματικές περιοχές και τον άξονα/ες και θεματικές περιοχές που θα διεξαχθεί η συζήτηση και τους άξονες και θεματικές περιοχές, πάνω στις οποίες, θα διατυπωθούν οι εξατομικευμένες ή ομαδικές συνεντεύξεις, διαφοροποιώντας κάθε φορά ανάλογα τις δυσκολίες και τις ιδιαίτερες ανάγκες των συμμετεχόντων/ουσών και των συμμετεχόντων/ουσών, που λόγω του ευρέως φάσματος γνωστικών δυσκολιών και των διαφορετικών διαγνωστικών και ηλικιακών προφίλ, αντιμετωπίζουν διαφορετικές δυσκολίες και διαμορφώνονται διαφορετικές ανάγκες, οι οποίες θα χρειαστεί να διαμορφωθούν με κατάρτιση διαφορετικού σχεδίου συνέντευξης, η οποία, όμως, θα βασίζεται στους παρακάτω παρουσιαζόμενους άξονες :

1. Σημειώνεται η ημερομηνία και η ώρα που λαμβάνει χώρα η συνάντηση, καθώς και ο τόπος, ο αριθμός των συμμετεχόντων (αν πρόκειται για ομαδική συζήτηση). Ζητείται από τους/τις συμμετέχοντες/ουσες, να προσδιορίσουν, αδρώς, τις προκλήσεις που συναντούν καθημερινά στις ψηφιακές τους δραστηριότητες και να παρέχουν πληροφορίες, σχετικά με την διάγνωση της διαταραχής ή της γνωστικής δυσκολίας/δυσκολιών, την σοβαρότητά της κατάστασης και την εξέλιξη της, καθώς και πότε πραγματοποιήθηκε ο εντοπισμός και η διάγνωση της.
2. Θα κληθούν / ερωτηθούν, να ονοματίσουν τις κύριες προκλήσεις («ποιες είναι») που αντιμετωπίζουν (με την επίπτωση της γνωστικής τους λειτουργικότητας, λόγω της επίπτωσης της διάγνωσης / διαταραχής / κατάστασης που διαμορφώνεται από τη νευροαναπτυξιακή διαταραχή και δυσκολία), στην προσπάθειά τους, να επωφεληθούν από τις δυνατότητες της «ψηφιακής οικονομίας και κοινωνίας» (π.χ. Ποιες δυσκολίες / προκλήσεις θα λέγατε / θεωρείτε πως αντιμετωπίζετε κατά την πρόσβαση και χρήση διαδικτυακών εργαλείων και συστημάτων συγγραφής, χρήση δημόσιων διαδικτυακών υπηρεσιών; / Ποιες είναι αυτές οι δυσκολίες; / Με ποιόν τρόπο εκδηλώνονται;)

3. Ερωτήσεις που αφορούν την προσωπική τους αξιολόγηση, για την αλληλεπίδραση του παράγοντα των γνωστικών δυσκολιών που διαμορφώνονται, γύρω από την διάγνωση που έχουν λάβει και επηρεάζονται από αυτή (λόγω της διαφορετικότητας των δυσκολιών και των καταστάσεων που αυτή διαμορφώνει) και τη σοβαρότητά της, καθιστούν την διάδραση τους με ψηφιακά εργαλεία και υπηρεσίες δύσκολη (π.χ. Θα λέγατε / αξιολογείτε / θεωρείτε πως υπάρχουν συγκεκριμένες γνωστικές δυσκολίες που καθιστούν την ψηφιακή αλληλεπίδραση πιο δύσκολη; / Με ποιους τρόπους;)
4. Ερωτήσεις που αφορούν στις δυσκολίες προσβασιμότητας στα ψηφιακά εργαλεία και την αλληλεπίδραση του παράγοντα της προσβασιμότητας με την αξιολόγηση της ποιότητας ζωής τους, (π.χ. Πιστεύετε / Θεωρείτε / Αξιολογείτε / Θα λέγατε ότι, λόγω της περιορισμένης προσβασιμότητας και περιορισμένης χρηστικότητας των ψηφιακών πλατφορμών και υπηρεσιών, επηρεάζεται η ζωή / καθημερινότητά σας; Με ποιους τρόπους;)
5. Ερωτήσεις που αφορούν στον προσδιορισμό βασικών προκλήσεων που αντιμετωπίζουν τα άτομα με γνωστικές δυσκολίες ή διαταραχές και διαγνώσεις με αντίκτυπο στη γνωστική λειτουργικότητα, πάνω στις ακόλουθες συνθήκες:
    i. Δεξιότητες ζωής - πλοήγηση και διαχείριση αλληλεπιδράσεων με το «σύστημα», π.χ. εγγραφή σε διαδικτυακά συστήματα παροχών κοινωνικής πρόνοιας; (Αντιμετωπίζετε δυσκολίες κατά την πλοήγηση σας στον ιστό;)
    ii. Καταστάσεις έκτακτης ανάγκης - λήψη πληροφοριών και υποστήριξη για τη μείωση του κινδύνου και την αύξηση της ετοιμότητας και της ανθεκτικότητας σε καταστάσεις έκτακτης ανάγκης, όπως ο COVID-19; (Αντιμετωπίζετε δυσκολίες στην επικοινωνία σας ή προσπάθεια διασύνδεσης σας με υπηρεσίες; / Μπορείτε να βρείτε πληροφορίες, όταν τις αναζητάτε; / Στην περίπτωση της πανδημίας σας καθιστούν την ψηφιακή αλληλεπίδραση εύκολο να βρείτε πληροφορίες / να έχετε άμεση πρόσβαση σε αυτές;)
    iii. Αυτοανάπτυξη - αξιοποίηση των ευκαιριών που παρέχονται από τις ψηφιακές τεχνολογίες για μάθηση, απασχόληση, προσωπική ανάπτυξη (Θεωρείτε πως προσφέρονται ευκαιρίες για ψηφιακή μάθηση / απασχόληση / ανάπτυξη; Γιατί; Με ποιόν τρόπο; Σε ποια μέσα;)

iv. Παροχή Βοήθειας και Υποστήριξης - χρήση διαδικτυακών συστημάτων πληροφοριών και καθοδήγησης, π.χ. αναζήτηση και χρήση εργαλείων πληροφόρησης του κοινού (Χρησιμοποιείτε διαδικτυακά συστήματα; / Πως τα αξιολογείτε ως προς τον βαθμό δυσκολίας;)

6. Ερωτήσεις που αφορούν στην διάδραση με την ψηφιακή εμπειρία του χρήστη, διεπαφή με εφαρμογές και υπηρεσίες, π.χ. Πώς θα περιγράφατε το βίωμα της διάδρασής σας / της διάδρασης των ατόμων με … (διαγνωστική ετικέτα) στον ψηφιακό κόσμο, σε σχέση με τις γνωστικές σας δυσκολίες;)
7. Ερωτήσεις για την επίδραση του παράγοντα της προσβασιμότητας, στη συμμετοχή, αλληλεπίδραση και την εμπειρία του ψηφιακού κόσμου (π.χ. Πώς και σε ποιες πτυχές της ζωής και δραστηριοποίησης σας, εμφανίζονται τα ψηφιακά εργαλεία και οι ψηφιακές υπηρεσίες; / Υπάρχουν συγκεκριμένες ψηφιακές εφαρμογές και υπηρεσίες από τις οποίες αισθάνεστε πως αποκλείεστε; / Θα αξιολογούσατε / λέγατε / κρίνατε πως η κακή ή η περιορισμένη πρόσβαση σε εργαλεία και υπηρεσίες οδηγεί σε καθυστερήσεις στην καθημερινή σας ζωή;)
8. Ερωτήσεις σε σχέση με γεωγραφικούς περιορισμούς και αλληλεπίδραση με την προσβασιμότητα και συμμετοχικότητα των ατόμων στην ψηφιακή διαδικασία (π.χ. Με ποιο τρόπο ο χωρικός παράγοντας επηρεάζει τη συμμετοχής σας στον ψηφιακό κόσμο; Υπάρχουν περιορισμοί που αξιολογείτε διαμορφώνουν / επηρεάζουν τη συμμετοχή σας στην διάδραση με ψηφιακά εργαλεία / την εμπειρία του ψηφιακό κόσμο [π.χ. επηρεάζει η τοπογραφία της γειτονιάς σας (επηρεάζει την πρόσβαση σας στο διαδίκτυο / την πρόσβαση σας σε ψηφιακές υπηρεσίες ο τόπος διαμονής σας / η απόσταση από σημεία εξυπηρέτησης και δημόσιες, π.χ. οι βιβλιοθήκες την πρόσβαση σας και τη χρήση ψηφιακών εργαλείων και υπηρεσιών;)]
9. Ερωτήσεις που αφορούν σε παράγοντες «σωματικής υγείας / λειτουργικότητας και ψυχικής υγείας / λειτουργικότητας» που πιθανόν ασκούν επιρροή στην προσβασιμότητα και αξιοποίηση εφαρμογών και υπηρεσιών που εμπίπτουν, στον τομέα της ψηφιακής οικονομίας και κοινωνίας, από άτομα με τις οριζόμενες από το ερευνητικό σχέδιο διαγνώσεις και τα προφίλ των γνωστικών δυσκολιών που αντιμετωπίζουν.

10. Ερωτήσεις που αφορούν στην εκφορά της άποψης τους για τις δεξιότητες, που θα ήταν ωφέλιμο / χρήσιμο, να αποκτήσουν, για να διαχειριστούν την επιρροή των παραγόντων «σωματικής υγείας / λειτουργικότητας και ψυχικής υγείας / λειτουργικότητας» στην διάδραση ή πρόσβασή τους σε ψηφιακές υπηρεσίες.
11. Ερωτήσεις που αφορούν στις λειτουργίες ή ενέργειες της κοινωνίας, που ενισχύουν διαδικασίες αποφυγής (στην αποτροπή) των ατόμων με προφίλ και διαγνώσεις με αντίκτυπο στη γνωστική λειτουργικότητα, να συμμετέχουν στα οφέλη από τη διάδραση με τον ψηφιακό κόσμο; (π.χ. Θα λέγατε / Θεωρείτε ότι έχετε πρόσβαση στον τρόπο σχεδιασμού και παράδοσης ψηφιακών συστημάτων και εργαλείων; / Σε ποιο βαθμό; / Αν όχι , γιατί; / Σε ποιο βαθμό; / Αν ναι, πως; / Με ποιόν τρόπο;). Ποιος ο ρόλος των κοινωνικών σας αλληλεπιδράσεων σε αυτή την συνθήκη; / Θεωρείτε πως οι κοινωνικές σας αλληλεπιδράσεις / σχέσεις / συναλλαγές βελτιώνουν την κατάσταση; / Αν ναι πως; / Αν όχι πως; / Με ποιους τρόπους;)
12. Ερωτήσεις που άπτονται θεμάτων ψηφιακής και κοινωνικής πολιτικής στην ψηφιακή ένταξη, π.χ. Ποιοι θα λέγατε ότι είναι οι κύριοι τομείς που χρειάζεται, να εξεταστούν / επανασχεδιαστούν, για να αυξηθεί η ψηφιακή ένταξη / προσβασιμότητα σε άτομα που αντιμετωπίζουν γνωστικές δυσκολίες (π.χ. βελτιωμένη πρόσβαση, καλύτερα προγράμματα κατάρτισης ψηφιακών δεξιοτήτων, αυξημένη προσβασιμότητα / χρηστικότητα πλατφορμών και εργαλείων);
13. Ποιες τρεις τεχνολογικές καινοτομίες, κατά την γνώμη σας, θα συνέβαλαν στην βελτίωση και πρόσβαση στην ψηφιακή ζωή των ατόμων με γνωστικές δυσκολίες;

Θα υπάρξει προσαρμογή των ερωτήσεων και των διατυπώσεων στις ιδιαίτερες ανάγκες που διαμορφώνεται από το προφίλ (ηλικιακή / χρονολογική ηλικία, δυσκολίες με βάση τη διάγνωση / μορφωτικό κριτήριο ή άλλους κοινωνικούς παράγοντες).

Ερωτηματολόγιο - Οδηγός συνέντευξης / ομαδικής συζήτησης για το toolkit

Οι συνεντεύξεις / ομαδικές συζητήσεις θα βασιστούν, αλλά δεν θα περιοριστούν στον ακόλουθο οδηγό:

1. Σημειώνεται η ημερομηνία και η ώρα που λαμβάνει χώρα η συνάντηση, καθώς και ο τόπος, ο αριθμός των συμμετεχόντων/ουσών (αν πρόκειται για ομαδική συζήτηση).

2. Οι συμμετέχοντες/ουσες δοκιμάζουν εργαλεία διευκόλυνσης προσβασιμότητας στον ψηφιακό κόσμο που παρέχονται από την ερευνητική ομάδα.
3. Οι συμμετέχοντες/ουσες θα διαδράσουν με το παραγόμενο εργαλείο - οδηγό (toolkit), εκτελώντας ελεύθερες ενέργειες, αλλά και συγκεκριμένες εργασίες που θα ζητηθούν από την ομάδα.
4. Θα σημειωθούν από την ομάδα δυσκολίες και προβλήματα χρήσης του εργαλείου.
5. Θα ακολουθήσουν διευκρινιστικές ερωτήσεις που παρακινούν την συζήτηση, σχετικά με την χρηστικότητα του εργαλείου, όπως:

   «Θεωρείτε πως το εργαλείο διευκολύνει την ψηφιακή σας αλληλεπίδραση;»
   «Συναντήσατε δυσκολία στην χρήση του; / Αν ναι, έχετε κάτι συγκεκριμένο, να αναφέρετε; / Ποια/ες ήταν αυτή/ές; / Πως θα μπορούσαν να βελτιωθούν;»
   «Ποιες λειτουργίες του εργαλείου - οδηγού, πιστεύετε / θεωρείτε / αξιολογείτε πως είναι περισσότερο χρήσιμες και ποιες λιγότερο; / Γιατί;»
   «Αν μπορούσατε να προσθέσετε κι άλλη/ες λειτουργία/ες, ποια/ες θα ήταν αυτές»;

STUDY PROTOCOL

Title:	LIVE-IT and Open Toolkit for the joint design of accessible IT systems and tools (LIVE-IT) - Interviews and group discussions
Study title:	Lifeworld analysis: Cognitive disabilities and digital accessibility. Documenting and understanding the digital experiences and needs of people with cognitive disabilities
Researchers:	Medical Physics and Digital Innovation Lab, School of Medicine, AUTH

Introduction

One of the key barriers to inclusive web accessibility is the stereotyping of people with cognitive disabilities as 'the problem'. Technology is then framed as an intervention imposed from above that will fix the problem. In this situation, the needs of people with cognitive impairments are often only superficially taken into account (Schulz et. al., 2015). There is a significant body of evidence to show that technology designers and developers have little or no knowledge of the challenges people with cognitive disabilities face when using technologies (Disability Rights Commission, 2004). This is related to the lack of scientific evidence on the relation between cognitive disability and technology (Barnard and Beyer, 2009), which is in turn linked to the fact that people with cognitive disabilities very rarely participate in research, design or development (Borg et. al., 2015). Another related issue is that people with cognitive impairments are frequently bundled together as a homogenous group, so that designers and developers impose a 'one size fits all' solution not only on a diverse spectrum of people whose digital challenges and needs stem from varied and often complex origins but on people who present with a wide spectrum – and intensity – of impairment, from very mild to very severe (Neven, 2010; Collings et. al., 2018).

Against this background, the overarching aim of the project is to:
Aggregate and valorize the insights and findings of different 'research lenses' on the relationship between cognitive disabilities and digital inclusion into actionable experimentation spaces, in order to support inclusive accessibility by tailoring design to the settings in which people with cognitive disabilities engage with digital technologies in their everyday 'lifeworld'.

Purpose of this study

The purpose of this study is to collect data from the experiences of people with cognitive disabilities and / or their caregivers, in relation to their interaction with digital technologies and the problems they face during their interaction with them. The data that will be gathered, through interviews and group discussions (focus group), will be analyzed, in order to create the framework for the development of a tool, which will evaluate the effectiveness and facilitate the accessibility of people with cognitive and neurodevelopmental texture difficulties in the digital world. The project aims to facilitate participants and individuals with cognitive disabilities in their interaction in digital-everyday-life, through their familiarity with the use of platforms and digital tools and new technologies. At the same time, it aims to identify effective solutions together with individuals through participation in collaborative and co-designing activities. The co-design will be done in the four laboratories of the LIVE-IT consortium partners (Greece - Aristotle University of Thessaloniki, England - Arcola Research LLP, Ireland - National University of Ireland, Portugal - Catholic University) providing information and suggestions for corrections and modifications to digital integration and accessibility processes and tools.

Study framework

The data for the framework of the study will be collected by the research team of the LIVE-IT project, collaborators of the Medical Physics and Digital Innovation Lab of the Aristotle University of Thessaloniki.

Timeline

The study will take place over a period of seven (7) months, between September 2021 and March 2022.

Participants

Participants will be people diagnosed with Down Syndrome, a diagnosis that ranks them in Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), including children or adolescents (i.e., under the age of 18 years of age), adults with Dementia, who will be indicated by study partners and on the condition that their carers or legal representatives have agreed and signed the consent form that will allow the collection and processing of data to be collected for the purposes of the study. The age range will vary in case of inclusion of minor participants from five (5) to fifteen (15) years.

The criteria for inclusion of the participants / substances in the study are: a) they have been diagnosed or have cognitive impairment as part of one of the following diagnoses of Down syndrome, people on the autism spectrum (ASD), ADHD or Dementia, so that there is a wide range in the sample of study participants spectrum and representative of the diagnoses and cognitive difficulties that affect cognitive functionality and b) to have the intention to interact and share the experiences, about the "digital exclusion" scenarios examined in framework of the LIVE-IT project. That is, issues related to access to online content and services, including consumer transactions, accessibility challenges, and issues of creating web content.

Regarding the exclusion criteria:
Persons under the age of 5 will be excluded from participating in the research process and study. It will also be avoided to invite people who are likely to have great difficulty attending, or people who are unable to function in a group situation or who are likely to cause negative emotions or discomfort, with the potential result being reports of negative consequences in their mental and emotional state and health. In some cases, it may be desirable and useful for the experiences of one or more participants to be represented on their behalf or to assist in their expressive transfer by an individual caregiver.

The interviews will be conducted in two phases, not necessarily with the participation of the same people. The participants of each phase will be:
a) in the first phase a total of 15 people in interviews and group discussions (e.g., group discussion of 10 people and 5 individual interviews) concerning their interaction with the digital world, its quality and the difficulties they encounter and

b) in the second phase 25 people in total in interviews / group discussions that will be conducted before and after using a toolkit, which aims to facilitate accessibility and use of digital technologies, for the collection of evaluation data and feedback of the toolkit.

Data collection plan

The data collection will take place in the context of interviews / group discussion (focus group), during which data and information will be collected on the usability of digital technologies, tools and applications, the difficulties encountered during their use, the usual problems that encounter in their interaction with them and the obstacles that lead to the "digital exclusion" of people with cognitive disabilities. The respective interview is expected to last about thirty (30) minutes and the group discussion about one (1) hour - 60 minutes.
The interviews / group discussions will be recorded, with the consent of the participant, his / her carer or legal representative and the recordings will be used exclusively for data transcription, without further disclosure of data and an "anonymization" process will be followed. The resulting transcripts will be sent, upon request, to the research team leading their analysis [(i) Arcola Research LLP, UK for the first 15 interviews / group discussions and ii) National University of Ireland, IE / Catholic University of Portugal, PT for the 25 toolkit-related interviews / group discussions)].
Regarding the participation: a) the data collected will be used, only for research purposes, while, in case they are used in reports that may be published, outside the project framework, they will be completely anonymized so that no person can be identified , b) the transcripts of the study will be carried out safely by the research team responsible for the project, for conducting the interview or group discussion and the resulting data will be deleted after the end of the project (31 / 03/2022) or no later than five (5) years from the date of completion of the project, i.e. 31/03/2027, c) an application for updating or deletion of personal data may be made by the participants at any time and d) the withdrawal from the interview is possible at any time, without requiring a justification for the withdrawal and without affecting the legal rights of the person leaving.
For more information on your participation or to inform the research team about an imminent departure, email **giannis.poultourtzidis@gmail.com** .

Data collection process through interview / group discussion

The interviews / group discussions will take place, either online or live. At the beginning, the participant will be welcomed, he / she will be reminded that the participation is voluntary and that his / her consent is necessary for the continuation of the process. After signing the consent form, the name of the participant will be changed into a code, which will be used from now on, and the age, the diagnosis of the disorder, the educational level, the city of residence, the profession will be noted (for adults with Dementia), as well as the period of onset of the disorder (for adults with dementia).
Then, the interview / group discussion will begin, stating that there are no wrong answers or positions, that all views and experiences are acceptable and legitimate and desirable to be heard. There will be care, on the part

of the researchers who will supervise / motivate / conduct and participate in the discussion, so that the discussion is not monopolized by a small number of participants in the case of the group discussion.
In the first case of interviews, the participants will be invited to discuss the quality of their interface and their interaction with the "digital world" and the degree to which it is theoretically possible for them to interact seamlessly and without restrictions. In the context of the discussion or interview, the challenges they face in interacting with digital technologies and applications, the functions of the applications and digital tools they use in interaction, and the extent to which the functions interact, will be analyzed and discussed. A discussion will be conducted also on the potential for "digital integration" and accessibility, technological innovations that could improve their interaction with the digital world and their quality of life, and the possibility of access and exploitation of the benefit of participation in the "digital society".
In case of conducting the second interviews / group discussions regarding the digital tool (toolkit), the participants will be provided with the possibility to use a toolkit. This will include some suggestions from technology applications and digital tools, which are used as digital tools to improve the quality of life and mental empowerment of people with cognitive disabilities. Each participant will be required to interact with the applications of this tool (toolkit) for a limited time (a few minutes), to act freely in the "digital space of these applications", but also to perform specific tasks and then he / she will be asked to discuss with the research team, his / her opinion about the functions of the tool and the extent to which it helped him / her to interact, but also to suggest possible modifications or additions.
The discussions and interviews that will take place are semi-structured (i.e. there is a draft interview, but both the interviewer and the organizer of the group discussion can deviate from this structure depending on the answers they receive and the course of the discussion, within in the context of research planning and research purpose), as new questions are likely to arise, depending on the development of the discussion, in order to achieve and not discourage the smooth expression of the thoughts, ideas and experiences of the participants / subjects.
Finally, the researchers will thank the participants.

Analysis

Data analysis description

i) The analysis of the data that will be collected in the first interviews / group discussions, will be carried out in 3 stages: a) Content analysis of individual interviews and group discussions, b) Comparison, integration and synthesis of content analysis results in a "Country Report" and c) Comparison, integration and synthesis of reports collected from the participating countries in the overall project analysis report.
For the first step, researchers will identify key discussion topics and repetitive patterns that present and reflect problems faced by people with cognitive disabilities in their interaction with digital technologies, and then support their finding by quoting a phrase or phrase excerpt from the discussion.

To complete the second step, the researchers will integrate the findings into a report with their country findings, while in the third step the partner Arcola Research LLP will perform the same process at transnational level incorporating the four (4) partner reports.
ii) The analysis of the data of the interviews / group discussions of the second phase will be done in the context of giving feedback to the produced toolkit. The interaction with the toolkit and the use of the tool, through and because of its pilot test, is intended to result in a discussion with the respective participant, through which the toolkit will be evaluated and the possible issues that arise concerning its design and usability will be demonstrated, providing the developers of the toolkit with the necessary and appropriate data for the development of new improved versions through this co-creation process.

Provisions for the ethical conduct of the study

All participants will be informed, through a newsletter, which will describe extensively and in an understandable way, the overall study process. Their participation in the project will occur only if they provide their signed informed consent. The document used for this purpose is the "Informed Consent Form". Participants, in particular, will be informed about the purpose of the research and that:

1. Their participation is voluntary and not mandatory.
2. They can ask questions about the study before deciding to participate in it.
3. They will be informed of the benefits of their participation in the conduct of the research, as well as who else benefits from the conduct of this research.
4. They will be informed of the exact manner of collection, disposal and protection of sensitive personal data, during the project, as well as the subsequent disposal, processing and utilization of this data, i.e., whether they will be destroyed or reused, if any the possibility of reusing them.
5. They will receive detailed and complete information and will be asked for their consent, for any further use of the data they will provide, upon entering and participating in the research project.
6. They will be notified that they have the ability to leave and withdraw their data from the project at any time.
7. In each form of consent of the participant, both the researcher who informed the participant and the overall scientific person in charge of the study will be declared.
8. The signed consent will explicitly state that this information has been submitted to the bioethics committee of the Department of Medicine, the School of Health Sciences, the Aristotle University of

Thessaloniki (AUTH) before any licensing and that all personal information and sensitive personal data will be anonymous with unique, but impossible to identify the user, identification numbers.

Topic / Axis Guide on which to base the interview / group discussion questions

The interviews / group discussions will be based, but will not be limited (as for the reasons discussed above), to the following guide (not exhaustive). The guide is not an interview plan, but a guiding axis that defines the thematic areas and the axis and thematic areas where the discussion will take place and the axes and thematic areas on which the individual or group interviews will be formulated, differentiating each time depending on the difficulties and special needs of the participants and the participants who, due to the wide range of cognitive difficulties and the different diagnostic and age profiles, face different difficulties and different needs are formed, which will need to be shaped by training different interview plan, which, however, will be based on the following axes:

1. Indicate the date and time of the meeting, as well as the place, the number of participants (in case of a group discussion). Participants will be asked to identify the challenges they face on a daily basis in their digital activities and to provide information on the diagnosis of the disorder or cognitive disability, the severity of the condition and its progression, as well as when it was diagnosed.
2. They will be asked to name the main challenges ("What are they") they face (with the impact of their cognitive functionality, due to the impact of the diagnosis / disorder / condition formed by the cognitive disability), in the effort to take advantage of the potential of the "digital economy and society" (e.g., What difficulties / challenges would you say / do you think you face in accessing and using online tools and writing systems, use of public online services? / What are these difficulties? / How do they manifest?)
3. Questions concerning their personal evaluation about the interaction of the factor of the cognitive disabilities that are formed, around the diagnosis that they have received and are influenced by (due to the difference of the disabilities and the situations that they form) and its severity, make their interaction with digital tools and services difficult (e.g., Would you say / evaluate / consider that there are specific cognitive difficulties that make digital interaction more difficult? / In what ways?)

4. Questions about the difficulties of accessibility to digital tools and the interaction of the accessibility factor with the evaluation of their quality of life, (e.g., Do you believe / Consider / Evaluate / Would you say that, due to the limited accessibility and limited usability of digital platforms and services, is your life / daily life affected? In what ways?)
5. Questions related to the identification of key challenges faced by people with cognitive disabilities or disorders and diagnoses with an impact on cognitive functionality, on the following conditions:
    i. Life skills - navigation and management of interactions with the "system", e.g., subscribing to online social security systems? (Do you have difficulty navigating the web?)
    ii. Emergencies - receiving information and support to reduce risk and increase preparedness and resilience to emergencies such as COVID-19; (Do you have difficulty communicating or attempting to connect to services? / Can you find information when you are looking for it? / In the event of a pandemic make digital interaction easy to find information / have direct access to it?)
    iii. Self-development - taking advantage of the opportunities provided by digital technologies for learning, employment, personal development (Do you think that opportunities for digital learning / employment / development are offered? Why? In what way? In what media?)
    iv. Help and Support - use of online information and guidance systems, e.g., search and use of public information tools (Do you use online systems? / How do you evaluate them in terms of difficulty?)
6. Questions related to interaction with the digital user experience, interface with applications and services e.g., How would you describe the experience of your interaction / the interaction of people with… (diagnostic label) in the digital world, in relation to your cognitive disabilities?)
7. Questions about the impact of the accessibility factor on the participation, interaction and experience of the digital world (e.g., How and in what aspects of your life and activity do digital tools and digital services appear? / Are there specific digital applications and services from which you feel excluded? /

Would you evaluate / say / judge that poor or limited access to tools and services leads to delays in your daily life?)

8. Questions related to geographical constraints and interaction with the accessibility and participation of individuals in the digital process (e.g., How does the spatial factor affect your participation in the digital world? Are there any constraints that you evaluate shape / influence your participation in the digital world / interaction with digital tools / the experience of the digital world (e.g., Does the topography of your neighborhood affect your access to the internet / your access to digital services / Does your place of residence / the distance from service points and public, e.g., libraries affect your access and use of digital tools and services?)
9. Questions concerning "physical health / functionality and mental health / functionality" factors that may have an impact on the accessibility and utilization of applications and services falling within the field of digital economy and society by individuals with the diagnoses defined by the research plan and the profiles of the cognitive difficulties they face.
10. Questions regarding the expression of their opinion on the skills that would be useful to acquire, in order to manage the influence of the factors "physical health / functionality and mental health / functionality" in their interaction or access to digital services.
11. Questions about the functions or actions of society, which enhance processes of avoidance (in prevention) of people with profiles and diagnoses with an impact on cognitive functionality, to participate in the benefits of interaction with the digital world? (e.g., Would you say / Do you consider that you have access to the way of designing and delivering digital systems and tools? / To what extent? / If not, why? / To what extent? / If so, how? / In what way?). What is the role of your social interactions in this condition? / Do you think that your social interactions / relationships / transactions improve the situation? / If so, how? / If not, why? / In what ways?)
12. Questions related to digital and social policy issues in digital integration, e.g., What would you say are the key areas that need to be addressed / redesigned to increase digital integration / accessibility for

people with cognitive disabilities (e.g., improved access, better digital skills training programs, increased accessibility / platform usability, and tools)?

13. Which three technological innovations, in your opinion, would contribute to the improvement and accessibility to the digital life of people with cognitive disabilities?

There will be adaptation of the questions and formulations to the special needs formed by the profile (age / chronological age, difficulties based on the diagnosis / educational criterion or other social factors).

Questionnaire - Interview / Group Discussion Guide for the toolkit

Interviews / group discussions will be based on, but not limited to, the following guide:

1. Indicate the date and time that the meeting takes place, as well as the place, the number of participants / subjects (in case of a group discussion).
2. Participants will try out digital accessibility tools provided by the research team.
3. Participants will interact with the generated toolkit, performing free actions, but also specific tasks that will be requested by the team.
4. The team will take notes on difficulties and problems faced while using the toolkit.
5. Questions that will stimulate the discussion about the usability of the tool will follow, i.e., Do you think the tool facilitates your digital interaction? / Did you encounter difficulty in using it? / If yes, do you have something specific, to mention? / How could they be improved? / Which functions of the tool - guide, do you think / consider / evaluate as more useful and which less? / Why; / If you could add more functions, which would they be?"

APPENDIX B

This consent form adapted with thanks from the Easy Read Project

Informed Consent

This is a declaration of
consent that all participants
have to sign.
Before you sign
you have to know and understand
the details of the research project
LIVE-IT. The informed consent is a
prerequisite to the participant
as a peer researcher within the project.

Please read this writing carefully before you sign!

What is the Project LIVE-IT about? Many
people cannot understand
the information on the internet.
They find it difficult:

- Because they cannot read well
- Or they are slow in reading
- Or quickly lose overview
- The websites are not designed with them in mind

- Or they need tools to help them

In the Project LIVE-IT peer researchers and developers research how to help people to a better understanding of and access to the internet. For example:

- We ask questions concerning problems on the internet.
- We look for tools to help on the internet.
- We test these tools and websites.

Your cooperation

Participation in this project is voluntary.

Your personal data

People who want to take part in this project allow the use and collection of personal data.

For example personal information:

- Name, gender, age
- Or questions about using the computer
- Or footage of personal discussions, pictures and videos

Living Labs and Open Toolkit for the co-design of accessible IT systems and tools

Your name will not be used public.

But pictures of you can be shown.

Each participant can revoke this permission at any time.

You are allowed to get to know,

which of your data within the project are saved or being used.

You are allowed to delete or put them right,

In doing so you have no disadvantages.

The informed consent

Agreement:

I agree to participate

in the Research Project LIVE-IT.

I provide my data,

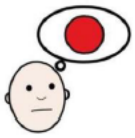
included pictures,	YES ☐	NO ☐
included videos of me	YES ☐	NO ☐

(place, date)

(signature)

(if necessary, signature legal representative)

Annex: Information to the informed consent for Tester with pictures

The informed consent This is a declaration of consent that all participants have to sign. The informed consent is a prerequisite to the participation as a tester within the project. Before you sign you have to know and understand the details of the research Project LIVE-IT. www.liveit-project.eu	 
Please read this writing carefully before you sign it!	
What is the Project LIVE-IT about? Many people cannot understand the information on the internet. They find it difficult - Because they cannot read well. - Or they are slow in reading. - Or quickly lose overview. - Websites are not designed with them in mind - Because they need tools to help In the Project LIVE-IT peer researchers and developers research how to help people have a better experience of websites and to help web developers make the internet better for you to use.	

Your cooperation

In the project, you will
try different ways of using the Internet and
tools that help
answering questions about what is easy and difficult
and what you think is good or bad

Participation in this project is voluntary.

Your personal data

People who want to take part in this project
allow the use and collection of personal data.

For example:
- name, sex, age
- questions about using the computer

Sometimes we would like to take photos and videotape when we discuss and test different things.
We might want to show the photos and the films when we present the project.
You can choose if you want to be photographed or videotaped.
You can still participate in the project even if you don't want it.

Each participant is allowed to revoke this permission at any time.
You are allowed to get to know,
which of your data within the project are saved or being used.

You are allowed to delete or put them right.
In doing so you have no disadvantages.
You can finish your participation in the project at any time. Nothing will happen if you do this.

The informed consent

Agreement:

I agree to participate in the Research Project LIVE-IT. I provide my data,

Including pictures of me □ yes □ no

Including videos of me □ yes □ no

.....

(place, date)

.....

(signature)

.....

(if necessary signature legal representative)

ΑΡΙΣΤΟΤΕΛΕΙΟ ΠΑΝΕΠΙΣΤΗΜΙΟ ΘΕΣΣΑΛΟΝΙΚΗΣ

ΙΙ. ΣΥΓΚΑΤΑΘΕΣΗ ΣΥΜΜΕΤΕΧΟΝΤΑ/ΟΥΣΗΣ / ΝΟΜΙΜΟΥ ΕΚΠΡΟΣΩΠΟΥ

Συνεντεύξεις και ομαδικές συζητήσεις στα πλαίσια του έργου LIVE-IT

Ο/Η παρακάτω υπογεγραμμένος/η.....

ή ο/η νόμιμος εκπρόσωπος.....

εκπροσωπώντας την/τον.....

Δηλώνω ότι:

- Έχω ενημερωθεί επαρκώς και με τρόπο κατανοητό από την/τον ..... (Ονοματεπώνυμο ερευνήτριας/τή) για τους σκοπούς της έρευνας στην οποία θα συμμετάσχω και εντάσσεται στο ερευνητικό έργο LIVE-IT με κωδικό ΕΛΚΕ 71516.

- Έχω ενημερωθεί επαρκώς και με τρόπο κατανοητό, για τον τρόπο και τις πηγές χρηματοδότησης της έρευνας.

- Έχω ενημερωθεί επαρκώς και με τρόπο κατανοητό για το τι συνεπάγεται η συμμετοχή μου σε αυτή την έρευνα. Ειδικότερα, έχω ενημερωθεί για όλα τα δικαιώματα και τις υποχρεώσεις που θα έχω ως συμμετέχουσα/ων στην έρευνα συμπεριλαμβανομένης της υποχρέωσης εχεμύθειας (εάν αυτή απαιτείται).

- Έχω ενημερωθεί επαρκώς και με τρόπο κατανοητό για κάθε θετική ή αρνητική και άμεση,

βραχυπρόθεσμη ή μακροπρόθεσμη συνέπεια αναμένεται να έχει σε σχέση με εμένα ή με τρίτους η συμμετοχή μου σε αυτή την έρευνα.

- Έχω ενημερωθεί επαρκώς και με τρόπο κατανοητό, για τον τρόπο χειρισμού και την προστασία των προσωπικών δεδομένων μου που σχετίζονται με αυτή την έρευνα.

- Έχω ενημερωθεί επαρκώς και με τρόπο κατανοητό για την παροχή και τον ορθό τρόπο χρήσης των συσκευών που θα χρησιμοποιήσω συμμετέχοντας σε αυτή την έρευνα.

- Έλαβα γνώση, ότι η συμμετοχή μου είναι εθελοντική και ότι ανά πάσα στιγμή υπάρχει η δυνατότητα αποχώρησης από την έρευνα, για οποιονδήποτε λόγο και χωρίς καμία επίπτωση (καθώς και ότι το ίδιο ισχύει για το άτομο που εκπροσωπώ).

- Γνωρίζω την/τον υπεύθυνη/ο ερευνήτρια/τή στην/ον οποία/ο, μπορώ να απευθυνθώ, για να αποχωρήσω από την έρευνα ή για οποιοδήποτε πρόβλημα προκύψει, κατά τη διάρκεια της συμμετοχής μου ή και μετά την ολοκλήρωση της έρευνας.

Με την υπογραφή μου δηλώνω ότι συγκατατίθεμαι να συμμετέχω εθελοντικά στην παραπάνω έρευνα.

_____ Ημερομηνία: ____ /____ /____

Υπογραφή συμμετέχοντα/ούσης / νόμιμου εκπροσώπου ημέρα/μήνας/έτος

_____

Ονοματεπώνυμο ολογράφως

ΑΡΙΣΤΟΤΕΛΕΙΟ ΠΑΝΕΠΙΣΤΗΜΙΟ ΘΕΣΣΑΛΟΝΙΚΗΣ

III. ΑΝΑΚΛΗΣΗ ΣΥΓΚΑΤΑΘΕΣΗΣ ΣΥΜΜΕΤΕΧΟΥΣΗΣ/ΟΝΤΑ

Συνεντεύξεις και ομαδικές συζητήσεις στα πλαίσια του έργου LIVE-IT

Η/Ο παρακάτω υπογεγραμμένη/ος ..... επιθυμώ να ανακαλέσω τη συγκατάθεσή μου για την συμμετοχή μου στην μελέτη **LIVE-IT**, που είχα δώσει στις _____ /_____ /_____.

_____ Ημερομηνία: ____ /____ /____

Υπογραφή συμμετεχούσης/οντος / νόμιμου εκπροσώπου ημέρα / μήνας / έτος

_____

Ονοματεπώνυμο ολογράφως

Participante no Workshop

Título do Workshop:... ..... Data:..... Local:.....	
Objetivo do workshop	*Breve descrição*
Responsável pela realização do workshop	*LIVE-IT Nome do beneficiário*

O referido beneficiário do projeto LIVE-IT garante que todos os dados recolhidos junto dos participantes são utilizados exclusivamente para efeitos de gestão e promoção do workshop.

Os dados que serão recolhidos durante o workshop incluirão o nome dos participantes e os detalhes de contacto.

A participação no workshop e a disponibilização dos dados acima referidos é voluntária. Nenhuma desvantagem pode surgir pela não participação, uma vez que, em caso de não fornecimento de dados, a sua participação no workshop não pode ser confirmada.

É livre de se retirar em qualquer momento, sem justificação, sem qualquer impacto nos seus direitos legais.

Os seus dados pessoais serão tratados em papel/de forma eletrónica pelos parceiros do projeto LIVE-IT (ver abaixo) de acordo com as seguintes regras:

- **A informação será assegurada pelo parceiro** responsável do projeto LIVE-IT e eliminada após o final do projeto (31/03/2022) ou, o mais tardar, cinco (5) anos a partir da data final do projeto, ou seja, 31/03/2027
- Apenas os membros do consórcio LIVE-IT terão acesso aos dados recolhidos. Os membros são:
  - Universidade Aristóteles de Salónica (Grécia)
  - Arcola UK (Reino Unido)
  - Universidade Nacional da Irlanda Galway (Irlanda)
  - Universidade Católica Portuguesa (Portugal)
- Os dados recolhidos nunca serão partilhados externamente por qualquer motivo, exceto para uso científico, caso em que os dados serão sempre tratados de forma agregada;

➢ Não serão recolhidos dados sensíveis, exceto dados relativos à sua saúde que serão anonimizados durante o processo de tratamento; ➢ Não está prevista qualquer transferência de dados para fora do território UE/EEE; ➢ Pode solicitar a atualização ou cancelamento dos seus dados pessoais a qualquer momento; ➢ Promoção da sua participação: É necessário um consentimento separado no caso de permitir a utilização do seu nome/imagem/intervenções gravados durante a promoção do workshop nas redes sociais, imprensa local, etc. Apenas o número total de participantes será tornado público sem pedir a sua autorização.
Serão recolhidas as seguintes informações essenciais para o workshop: • Nome, idade e e-mail de pessoa de contato • Informações relevantes para a avaliação e avaliação de impacto como inquéritos ou questionários aos participantes.

Consentimento/Assentimento	
O participante do workshop (ou seu progenitor ou representante legal) declara o seu acordo à recolha dos dados pessoais acima mencionados, pelo responsável do workshop e a sua utilização por qualquer um dos membros do consórcio LIVE-IT.	• Sim • Não
O participante do workshop (ou seu progenitor ou representante legal) dá a sua permissão para que o seu nome apareça na lista de participantes.	• Sim • Não
O participante do workshop (ou o seu progenitor ou representante legal) dá autorização para transmitir imagens e vídeos do evento no site público live-IT e/ou nas redes sociais.	• Sim • Não
O participante do workshop (ou o seu progenitor ou representante legal) dá a sua permissão para transmitir imagens e vídeos do seu evento nos canais de comunicação das organizações parceiras.	• Sim • Não
O participante do workshop (ou o seu progenitor ou representante legal) dá a sua permissão para efectuar as	• Sim • Não

atas do workshop e gravações que incluem as transcrições dos seus discursos.	
Local e data ..... Nome Apelido:... ..... Organismo de filiação: ..... Função no organismo ..... Assinatura	

Participar num projeto

adaptado do projeto Easy Reading

Quando participar num projeto sobre acessibilidade web para pessoas com deficiência cognitiva a sua opinião é muito importante.

Quando ajudar o investigador a testar e a dar opiniões, é muito importante pensar nos diferentes utilizadores.

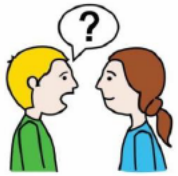
Algumas pessoas têm dificuldades em ver ou ouvir ou mexer as mãos. É importante que toda as pessoas possam usar a internet.

Quando participares num projeto, os investigadores vão recolher informação sobre ti, por exemplo o teu nome, onde vives e que idade tens. Eles também vão tomar nota as tuas opiniões.

Os investigadores devem informar-te sobre a informação que vão recolher e porque é que é necessária.

Eles só devem recolher a informação que precisam. Não poderão guardar a tua informação quando já não for necessária.

Esta informação não poderá ser mostrada a ninguém fora do projeto.



Tens sempre o direito a dizer que não.

Podes sempre perguntar que informação está guardada sobre ti.

LIVE-IT Informed Consent & Interview Scheduler

Thank you for your interest in participating in the LIVE-IT interviews! This form describes the LIVE-IT project and our interview process. Also, this form provides a space for you to share your availability for an interview.

* Required

About the LIVE-IT Project

You already read a bit about the LIVE-IT project when you told us you were interested in participating. Here's a little more information:

A main goal of the LIVE-IT project is to build labs that support the co-design of web tools and platforms that will be useful to students with cognitive disabilities. We don't want to build or use tools and platforms that are not relevant to the lived experiences of students with cognitive disabilities.

That's where you come in! We are asking for your to share your experiences with websites, web apps, and any web-based platforms. Your valuable insight will help us to understand the challenges and barriers you face. It will also help us to understand what works.

About Our Interview Process

In order to capture all of your valuable insight and use it in the lab development process, we would like to record an interview with you. The interview will be at most 1 hour long. The interview will take place on Zoom, and we will provide you with the Zoom link after you selected a time (next page). The purpose of this interview is not to evaluate or judge you. Rather, the purpose of this interview is to understand your experiences so that our research is meaningful and impactful in the real-world.

Please be assured that any and all information that you provide will be kept in the strictest confidence and anonymised. You are under no obligation to participate in this interview and have the right to withdraw at any time without providing a reason.

Your interviewer will be Sara Gartland (pictured below). Sara loves learning how to improve education by speaking directly with students. She is a postdoctoral researcher at NUIG.

Your Interviewer - Sara Gartland

1. Your Name: *

_____

2. Your Email: *

_____

3. Please indicate if you agree to participate in a recorded interview with Sara: *

Mark only one oval.

- ◯ I agree to participate in a recorded interview for the LIVE-IT project
- ◯ I do not agree to participate in a recorded interview for the LIVE-IT project

Schedule Your Interview!

If you agree to participate in a recorded interview with Sara, please find your preferred date(s) and recommend a time that suits your schedule on any date(s) that you are available. Sara is available for interviews between 10am and 7pm.

4. Wednesday, September 29th

_____

Example: 8:30 AM

5. Thursday, September 30th

_____

Example: 8:30 AM

6. Friday, October 1st

_____

Example: 8:30 AM

7. If you are not available on any of the dates listed above, please suggest additional date(s) and time(s) that suit your schedule.

_____

_____

_____

_____

_____

This content is neither created nor endorsed by Google.

Workshop participant

Title of the Workshop:..... Date:..... Place:.....	
Goal of the Workshop	*Short description*
Responsible person for the execution of the workshop	*LIVE-IT beneficiary name*

The aforementioned LIVE-IT project beneficiary ensures that all data collected from participants is used exclusively for the purpose of managing and promoting the workshop.

The data that will be collected during the workshop will include participant name and contact details.

Participation in the workshop and the provision of the aforementioned data are voluntary. No disadvantages can arise from non-participation while in case of non-supply of data your participation in the workshop cannot be confirmed.

You are free to withdraw at any time, without justification, with no impact on your legal rights.

Your personal data will be treated with paper/electronic means by the LIVE-IT project partners (see below) according to the following rules:

- **The information will be secured** by the responsible LIVE-IT project partner and deleted after project end (31/03/2022) or at latest five (5) years from the end date of the project, that is 31/03/2027
- Only members of the LIVE-IT consortium will have access to the collected data. These members are:
  - Aristotle University of Thessaloniki (Greece)
  - Arcola UK (United Kingdom)
  - National University of Ireland Galway (Ireland)
  - Portuguese Catholic University (Portugal)
- Collected data will never be shared externally for any reason, with the exception of scientific usage, in which case it will be always treated in aggregate form;
- No sensitive data will be gathered except data concerning your health that will be anonymised during the elaboration process;

➢ No transfer of data outside the EU/EEA territory is foreseen; ➢ You may ask for the update or cancellation of your personal data at any time; ➢ Promotion of your participation: A separate consent is required in case you intend to allow the use of your name/image/recorded speeches during the workshop promotion on social media, local press etc. Only the total number of participants will be made public without asking for your permission.
The following essential information will be collected for the workshop: • Contact person name, age and email • Information relevant for evaluation and impact assessment as participant surveys or questionnaires.

Consent/Assent	
The workshop participant (or her/his parent or legal representative) declares her/his agreement with the collection of the above mentioned personal data, by the responsible of the workshop and their use by any of the members of the LIVE-IT consortium.	• Yes • No
The workshop participant (or his/her parent or legal representative) gives his/her permission to appear in the list of participants with his/her name.	• Yes • No
The workshop participant (or her/his parent or legal representative) gives her/his permission to broadcast her/his event images and videos on the LIVE-IT public website and/or social media.	• Yes • No
The workshop participant (or her/his parent or legal representative) gives her/his permission to broadcast her/his event images and videos on the communication channels of partner's organizations.	• Yes • No
The workshop participant (or his/her parent or legal representative) gives her/his permission to prepare minutes of the workshop and recordings which include the transcripts of her/his speeches.	• Yes • No

Place and date .....

Name Surname:.....

Organisation of affiliation:.....

Role in the organization:.....

Signature

.....

APPENDIX C

Challenge	Tools
Memory	
Difficulty recalling sign in information such as passwords	All Devices: LastPass Norton Password Manager Avira
Difficulty recalling personal and family information	Android: Google Assistant Amazon Alexa Quick Note: Speech to text note taking app Voice Notebook: continuous text to speech Google Keep Microsoft OneNote Evernote Simplenote Milanote MindManager PowerPoint Buncee LucidChart Floaty for Sticky Notes Birdhouse iPad: Google Assistant Amazon Alexa

	Siri Apple Dictation Post-it Google Keep Apple Notes Apple Voice Memos Evernote Simplenote Milanote PowerPoint Buncee LucidChart Birdhouse Microsoft Windows: Google Assistant Dragon Speech Lucidspark Mindmapping Software MindManager Microsoft Sticky Notes Microsoft To Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard Google Keep PowerPoint Buncee LucidChart SmartDraw Birdhouse
Difficulty to remember which button to press each time	Assistive Touch AutoHotKey Microsoft Windows

Difficulty remembering the steps taken in a calculation when they are not shown on the screen	Desmos Scientific Calculator https://www.desmos.com/scientific
Difficulty remembering processes	Android: Google Assistant Amazon Alexa Quick Note: Speech to text note taking app Voice Notebook: continuous text to speech Google Keep Microsoft OneNote Evernote Simplenote Milanote MindManager PowerPoint Buncee LucidChart Floaty for Sticky Notes iPad: Google Assistant Amazon Alexa Siri Apple Dictation Post-it Google Keep Apple Notes Apple Voice Memos Evernote Simplenote Milanote PowerPoint Buncee

	LucidChart Microsoft Windows: Google Assistant Dragon Speech Lucidspark Mindmapping Software MindManager Microsoft Sticky Notes Microsoft To Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard Google Keep PowerPoint Buncee LucidChart SmartDraw
Difficulty remembering appointments and important tasks	Android: Google Calendar Google Suite: Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Microsoft To Do List, Task and Reminder Google Assistant Amazon Alexa Quick Note: Speech to text note taking app Voice Notebook: continuous text to speech Google Keep Floaty for Sticky Notes Birdhouse iPad: Google Assistant Google Calendar

	Google Suite: Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Microsoft To Do List, Task and Reminder Siri Post-it Google Keep Apple Notes Apple Voice Memos Birdhouse Microsoft Windows: Google Assistant Google Calendar Google Suite: Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Microsoft To Do List, Task and Reminder Microsoft Sticky Notes Google Keep Birdhouse
Difficulty retaining information	Android: Google Assistant Amazon Alexa Quick Note: Speech to text note taking app Voice Notebook: continuous text to speech Google Keep Microsoft OneNote Evernote Simplenote Milanote MindManager PowerPoint

	Buncee LucidChart Floaty for Sticky Notes Birdhouse iPad: Google Assistant Amazon Alexa Siri Apple Dictation Post-it Google Keep Apple Notes Apple Voice Memos Evernote Simplenote Milanote PowerPoint Buncee LucidChart Highlighter pen Birdhouse Microsoft Windows: Google Assistant Dragon Speech Lucidspark Mindmapping Software MindManager Microsoft Sticky Notes Microsoft To Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard Google Keep PowerPoint Buncee LucidChart

	SmartDraw Birdhouse
Focus	
Difficulty staying focused	Android: Avira Minimal Consent Blokada 5 Clock Timer iPad: Avira Blokada 5 Minimal Consent Clock Timer Microsoft Windows: Avira Total Ad Block Minimal Consent Cookie Notice Blocker Blokada 5 Clock Timer
Cognitive overload in the presence of complex interfaces or too much information	Android: Dolphin Easy Reader Text Help: Read and Write Android Accessibility Suite IDEAL Group Reader Liquid Mode iPad: ReadBit Voice Aloud Reader

	Text to Speech ClaroSpeak Dolphin Easy Reader Text Help: Read and Write Snap & Read Liquid Mode Microsoft Windows: Microsoft OS Narration Text Help: Read and Write Natural Readers Snap & Read Verbose: Text to Speech Read ALoud: A Text to Speech Voice Reader Text from to Speech Liquid Mode Immersive Reader
Cognitive overload from pop ups and others distractions	Android: Avira Minimal Consent Blokada 5 iPad: Avira Blokada 5 Minimal Consent Microsoft Windows: Avira Total Ad Block Minimal Consent Cookie Notice Blocker Blokada 5
Delayed processing:	Android: Dolphin Easy Reader

additional time required to take in and understand information	Text Help: Read and Write Android Accessibility Suite IDEAL Group Reader iPad: ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Dolphin Easy Reader Text Help: Read and Write Snap & Read Microsoft Windows: Microsoft OS Narration Text Help: Read and Write Natural Readers Snap & Read Verbose: Text to Speech Read ALoud: A Text to Speech Voice Reader Text from to Speech YiNote
Difficulty understanding abstract concepts such as the internet and its navigation for example understanding the structure of websites and how to navigate them using menus or buttons	Android: IDEAL Group Reader Liquid Mode Google Workspace IFTT iPad: Liquid Mode Google Workspace IFTT Microsoft Windows: Liquid Mode

	Zoom Text and Fusion Google Workspace IFTT
Difficulty communicating with people when they are not visible/there is no face-to-face contact	All Devices: Zoom WhatsApps video call Skype iPad Facetime Messenger video
Time and Organisation	
Difficulty with time management and organisation	Android: Google Calendar Google Assistant Microsoft Outlook Amazon Alexa Speech Texter - Speech to Text Android Accessibility Suite MindManager Quick Note: Speech to text note taking app Voice Notebook - continuous text to speech Google Keep Microsoft OneNote EverNote SimpleNote MilaNote Floaty for Sticky Notes Mind Map and Concept Map Maker Asana: Your Work Manager AYOA Mindmap Google Workspace Birdhouse

	iPad: Google Calendar Microsoft Outlook Amazon Alexa Siri Apple Dictation LucidSpark MindMapping Software MindManager Post-It Google Keep Apple Notes Apple Voice Memos EverNote SimpleNote MilaNote Mind Map and Concept Map Maker Asana: Your Work Manager Google Workspace Birdhouse Microsoft Windows: Google Calendar Microsoft Outlook Google Assistant DragonSpeech LucidSpark MindMapping Software MindManager Microsoft Sticky Notes Microsoft To Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard Google Keep Milanote Asana: Your Work Manager Google Workspace

	Birdhouse
Difficulty remembering the date, day or time	Android: Speaking Clock: Hourly chime voice alarm Google Workspace Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Phone clock iPad: Hourly Chime - hourly reminder Google Workspace Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Siri Phone clock Microsoft Windows: Speaking Clock: Hourly chime voice alarm Google Workspace Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Phone clock
Difficulty finishing tasks	Android: Speaking Clock: Hourly chime voice alarm Google Calendar Google Assistant Microsoft Outlook Amazon Alexa Speech Texter - Speech to Text

	Android Accessibility Suite MindManager Quick Note: Speech to text note taking app Voice Notebook - continuous text to speech Google Keep Microsoft OneNote EverNote SimpleNote MilaNote Floaty for Sticky Notes Mind Map and Concept Map Maker Asana: Your Work Manager AYOA Mindmap Google Workspace Phone timer iPad: Hourly Chime - hourly reminder Google Calendar Microsoft Outlook Amazon Alexa Siri Apple Dictation LucidSpark MindMapping Software MindManager Post-It Google Keep Apple Notes Apple Voice Memos EverNote SimpleNote MilaNote Mind Map and Concept Map Maker Asana: Your Work Manager Google Workspace Phone timer

	Microsoft Windows: Speaking Clock: Hourly chime voice alarm Google Calendar Microsoft Outlook Google Assistant DragonSpeech LucidSpark MindMapping Software MindManager Microsoft Sticky Notes Microsoft To Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard Google Keep Milanote Asana: Your Work Manager Google Workspace Clock Timer
Difficulty sequencing and completing multi step tasks	Android: Google Assistant Amazon Alexa Speech Texter - Speech to Text MindManager Quick Note: Speech to text note taking app Voice Notebook - continuous text to speech Google Keep Microsoft OneNote EverNote SimpleNote MilaNote Floaty for Sticky Notes Mind Map and Concept Map Maker Asana: Your Work Manager AYOA Mindmap

	Google Workspace Phone timer iPad: Hourly Chime - hourly reminder Amazon Alexa Siri Apple Dictation LucidSpark MindMapping Software MindManager Post-It Google Keep Apple Notes Apple Voice Memos EverNote SimpleNote MilaNote Mind Map and Concept Map Maker Asana: Your Work Manager Google Workspace Phone timer Microsoft Windows: Speaking Clock: Hourly chime voice alarm Google Calendar Microsoft Outlook Google Assistant DragonSpeech LucidSpark MindMapping Software MindManager Microsoft Sticky Notes Microsoft To Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard Google Keep Milanote

	Asana: Your Work Manager Google Workspace Clock Timer
Difficulty understanding time	Android: Speaking Clock: Hourly chime voice alarm Google Workspace Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Phone clock iPad: Hourly Chime - hourly reminder Google Workspace Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Siri Phone clock Microsoft Windows: Speaking Clock: Hourly chime voice alarm Google Workspace Google Calendar Microsoft Outlook Calendar Google Assistant Alexa Phone clock
Difficulty planning for the future	Android: Google Calendar Google Assistant Microsoft Outlook

	Amazon Alexa Speech Texter - Speech to Text Android Accessibility Suite MindManager Quick Note: Speech to text note taking app Voice Notebook - continuous text to speech Google Keep Microsoft OneNote EverNote SimpleNote MilaNote Floaty for Sticky Notes Mind Map and Concept Map Maker Asana: Your Work Manager AYOA Mindmap Google Workspace Birdhouse iPad: Google Calendar Microsoft Outlook Amazon Alexa Siri Apple Dictation LucidSpark MindMapping Software MindManager Post-It Google Keep Apple Notes Apple Voice Memos EverNote SimpleNote MilaNote Mind Map and Concept Map Maker Asana: Your Work Manager Google Workspace

	Birdhouse Microsoft Windows: Google Calendar Microsoft Outlook Google Assistant DragonSpeech LucidSpark MindMapping Software MindManager Microsoft Sticky Notes Microsoft To Do List, Task and Reminder Floaty for Sticky Notes Microsoft Whiteboard Google Keep Milanote Asana: Your Work Manager Google Workspace Birdhouse
Difficulty avoiding or managing online distractions such as Netflix or social media	Android: Speaking Clock: Hourly chime voice alarm iPad: Hourly Chime - hourly reminder Microsoft Windows: Speaking Clock: Hourly chime voice alarm
Difficulties organising and managing files	All Devices: Asana: Your Work Manager Google Workspace Google Drive
Mood	

Anxiety and low mood	Android: WYSA: Anxiety Therapy Chat Bot Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Self Esteem Self Confidence Six-Pillars: Build a Healthy Self Esteem iPad: Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Microsoft Windows: Facebook Instagram TikTok SnapChat

	Messenger WhatsApp (voice, text, picture) messages
Lack of motivation	Android: WYSA: Anxiety Therapy Chat Bot Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Self Esteem Self Confidence Six-Pillars: Build a Healthy Self Esteem iPad: Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Microsoft Windows:

	Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages
Feeling isolated	All Devices: Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages
Fear of trying new things	Android: WYSA: Anxiety Therapy Chat Bot Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Self Esteem Self Confidence Six-Pillars: Build a Healthy Self Esteem iPad: Facebook Instagram TikTok

	SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Microsoft Windows: Facebook Instagram TikTok SnapChat Messenger
Difficulty with self belief and imposter syndrome	Android: WYSA: Anxiety Therapy Chat Bot Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Self Esteem Self Confidence Six-Pillars: Build a Healthy Self Esteem

	iPad: Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Microsoft Windows: Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages
Difficulty managing emotions	Android: WYSA: Anxiety Therapy Chat Bot Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite

	Fabulous Daily Routine Planner Self Esteem Self Confidence Six-Pillars: Build a Healthy Self Esteem iPad: Emotions manager Emotions dictionary Saorsa Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Microsoft Windows: Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages
Difficulty with handling the unknown or unexpected	Android: WYSA: Anxiety Therapy Chat Bot Facebook Instagram TikTok

	SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Self Esteem Self Confidence Six-Pillars: Build a Healthy Self Esteem iPad: Emotions manager Emotions dictionary Saorsa Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages Headspace Calm Inner Hour: Self-Care Therapy Woebot: your self-care expert in CBT and mindfulness Conversation Therapy Lite Fabulous Daily Routine Planner Microsoft Windows: Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages

Need of support in getting things done	All devices: Birdhouse Google Teams Facebook Instagram TikTok SnapChat Messenger WhatsApp (voice, text, picture) messages The 32 Best Productivity Apps To Get More Done in 2021 (clickup.com)
Physical Barriers	
Difficulty in movement and motion for example due to a tremor	Android: Switch device Google Assistant Alexa Android Accessibility Suite Assistive Touch iPad Switch device Google Assistant Alexa Siri Assistive Touch Microsoft Windows: Switch Device Special keyboard Voice Computer Key2enabl

	Voice Computer for Dragon Users
Difficulty using a touchscreen	Android: Switch Access for Android Switch device Assistive Touch iPad: Switch device Siri Assistive Touch Microsoft windows: Voice Computer for Dragon Users MS Visual keyboard Key2enable Switch device
Difficulty using external hardware/devices	Android: Google Assistant Amazon Alexa Speech Texter - Speech to Text Android Accessibility suite Text from to Speech Voice typing via keyboard Switch device Assistive Touch iPad: Apple Voice Control Apple Dictation Amazon Alexa Siri Apple Dictation Text from to Speech Voice typing via keyboard ClaroRead

	Switch device Assistive Touch Microsoft Windows: Google Assistant Dragon Speech Text from to Speech MS Speech recognition Voice Computer for Dragon Users Switch device Key2enable Baddage Dolphin Grid 3
Visual impairment	Android: Be my Eyes Google Assistant Amazon Alexa Speech Texter - Speech to Text Android Accessibility suite Text from to Speech Voice typing via keyboard Switch device Assistive Touch iPad: Be my Eyes Apple Voice Control Apple Dictation Amazon Alexa

	Siri Apple Dictation Text from to Speech Voice typing via keyboard ClaroRead Switch device Assistive Touch Microsoft Windows: Google Assistant Dragon Speech Text from to Speech MS Speech recognition Voice Computer for Dragon Users Switch device Key2enable MS Screen magnifier MS Screen reader NVDA Baddage Dolphin Grid 3 ReadEZ Virtual Overlay Software
Motion sickness and vertigo	Wireless charging
Difficulty with speech and language	
Difficulty with spatial	Android: What3words

navigation and getting lost	GoogleMaps Find my phone iPad: What3words GoogleMaps Find my phone Microsoft Windows: What3words GoogleMaps Parental Controls Windows 10 (find my family)
Risk of falling over	Apple Watch
Difficulty noticing alarms, reminders	No tool identified yet
Reading, Writing and Comprehension	
Difficulty reading	Android: Dolphin Easy Reader Text Help: Read and Write Android Accessibility Suite IDEAL Group Reader Liquid Mode Snap and Read TextHelp: Read & Write CBoard Speechify

	iPad: ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Dolphin Easy Reader Text Help: Read and Write Snap & Read Liquid Mode Apple Accessibility suite Snap and Read TextHelp: Read & Write Speechify Microsoft Windows: Microsoft OS Narration Natural Readers Snap & Read Verbose: Text to Speech Read ALoud: A Text to Speech Voice Reader Text from to Speech Immersive Reader Liquid Mode Natural Readers HelperBird Snap and Read TextHelp: Read & Write CBoard Speechify
Difficulty writing	Android: Google Assistant Amazon Alexa Speech Texter - Speech to Text Android Accessibility suite

	Text from to Speech Voice typing via keyboard TextHelp (Read&Write) iPad: Amazon Alexa Siri Apple Dictation Apple Voice Control Apple Predictive Text Text from to Speech Voice typing via keyboard ClaroRead TextHelp (Read&Write) Microsoft Windows: Google Assistant Dragon Speech Text from to Speech TextHelp (Read&Write) Key2enable MS Speech recognition •Baddage •Dolphin
Difficulty with spelling	Android: Predictive text iPad: Apple Predictive Text Microsoft Windows: AutoCorrect Windows 10 Verbose Text to Speech Software

Difficulty with punctuation and grammar	Android: Grammarly Text from to Speech iPad: Grammarly Apple Predictive Text Microsoft Windows: AutoCorrect Windows 10 Grammarly
Difficulty reading and following instructions	Android: Dolphin Easy Reader Text Help: Read and Write Android Accessibility Suite IDEAL Group Reader Liquid Mode Snap and Read TextHelp: Read & Write CBoard Speechify iPad: ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Dolphin Easy Reader Text Help: Read and Write Snap & Read Liquid Mode Apple Accessibility suite Snap and Read TextHelp: Read & Write

	Speechify Microsoft Windows: Microsoft OS Narration Natural Readers Snap & Read Verbose: Text to Speech Read ALoud: A Text to Speech Voice Reader Text from to Speech Immersive Reader Liquid Mode Natural Readers HelperBird Snap and Read TextHelp: Read & Write CBoard Speechify MS Immersive Reader
Difficulty filling out forms	Android: Google Assistant Amazon Alexa Speech Texter - Speech to Text Android Accessibility suite Text from to Speech Voice typing via keyboard iPad: Amazon Alexa Siri Apple Dictation Text from to Speech Voice typing via keyboard ClaroRead Microsoft Windows:

	Google Assistant Dragon Speech Text from to Speech
Difficulty finding information	All Devices: Easy Reading Material Widgets YouTube Vimeo SnapChat
Difficulty understanding information including long and complicated text	Android: Dolphin Easy Reader Text Help: Read and Write Android Accessibility Suite IDEAL Group Reader Widgets YouTube Vimeo SnapChat Easy Reading Material iPad: ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Dolphin Easy Reader Text Help: Read and Write Snap & Read Widgets YouTube Vimeo SnapChat Easy Reading Material

	Microsoft Windows: Microsoft OS Narration Text Help: Read and Write Natural Readers Snap & Read Verbose: Text to Speech Read ALoud: A Text to Speech Voice Reader Text from to Speech Widgets YouTube Vimeo SnapChat Easy Reading Material
Difficulty understanding what is fake news and what is accurate news	No tools identified yet
Numbers	
Difficulty understanding numbers and carrying out basic calculations	Widgets YouTube Vimeo Digital Calculator
Difficulty transposing numbers correctly	No tools identified yet
Difficulty making calls due to not understanding numbers	No tools identified yet

Difficulty answering calls due to not being able to read caller ID	Android: Caller ID photo iPad: Caller ID photo
Difficulty using money due to not understanding the value of money	Android: Budget Planner Snoop Finance Money Lover Spending Manager Money Manager Expense & Budget Monefy Budget Manager & Expense Tracker App Simple Budget Monthly Budget Planner and Daily Expense Tracker iPad: Budget Planner Snoop Finance Money Lover Spending Manager Money Manager Expense & Budget Monefy Budget Manager & Expense Tracker App
Difficulty using bank cards due to not understanding the value of money	Android: Budget Planner Snoop Finance Money Lover Spending Manager Money Manager Expense & Budget Monefy Budget Manager & Expense Tracker App Simple Budget Monthly Budget Planner and Daily Expense Tracker iPad: Budget Planner Snoop Finance Money Lover Spending Manager Money Manager Expense & Budget Monefy Budget Manager & Expense Tracker App
Difficulty using bank cards	Android: Budget Planner Snoop Finance

due to not understanding the value of money	Money Lover Spending Manager Money Manager Expense & Budget Monefy Budget Manager & Expense Tracker App Simple Budget Monthly Budget Planner and Daily Expense Tracker iPad: Budget Planner Snoop Finance Money Lover Spending Manager Money Manager Expense & Budget Monefy Budget Manager & Expense Tracker App
Digital skills	
Difficulty navigating the internet	Android: Dolphin Easy Reader Text Help: Read and Write Android Accessibility Suite IDEAL Group Reader Liquid Mode Snap and Read TextHelp: Read & Write CBoard IFTT Google Workspace iPad: ReadBit Voice Aloud Reader Text to Speech ClaroSpeak Dolphin Easy Reader Text Help: Read and Write Snap & Read

	Liquid Mode Apple Accessibility suite Snap and Read TextHelp: Read & Write IFTT Google Workspace Microsoft Windows: Microsoft OS Narration Natural Readers Snap & Read Verbose: Text to Speech Read ALoud: A Text to Speech Voice Reader Text from to Speech Immersive Reader Liquid Mode Natural Readers HelperBird Snap and Read TextHelp: Read & Write CBoard Zoom Text and Fusion IFTT Google Workspace
Difficulty operating online in unstructured environments such as social media platforms and search engines	All devices: Google Workspace Microsoft Outlook Google Drive
Need of support in using digital devices	Babbage Key2enable

	Alexa Siri Google Assistant
Difficulty using keyboards for example due to buttons being too small	Android: Google Assistant Amazon Alexa Speech Texter - Speech to Text Android Accessibility suite Text from to Speech Voice typing via keyboard Switch device Assistive Touch iPad: Apple Voice Control Apple Dictation Amazon Alexa Siri Apple Dictation Text from to Speech Voice typing via keyboard ClaroRead Switch device Assistive Touch Microsoft Windows: Google Assistant Dragon Speech Text from to Speech MS Speech recognition Voice Computer for Dragon Users Switch device Key2enable

	Dolphin Grid 3 Babbage
Difficulty with online learning	Android: Zoom Skype Study Drive Your Study App Birdhouse Moodle Udemy Coursera iPad: Zoom Skype Study Drive Your Study App Birdhouse Moodle Udemy Coursera Microsoft Windows: Moodle Udemy Coursera
Difficulty understanding non-standard symbols or images used in place of words	No tool identified yet
Difficulty avoiding risks	Android:

online such as viruses, inappropriate content and cyberbullying	System child lock/controls Avira AdBlocker Minimal Consent iPad: System child lock/controls Avira Minimal Consent Microsoft Windows: System child lock/controls Avira Cookie Consent Minimal Consent BlockBear
Difficulty finding and paying for goods and services	Alexa
Difficulty booking appointments/activities online	Android: Appointfix Setmore Appointments - Appointment Scheduling App Howbout Social event planner hey pharmacist Video GP from Lloyds pharmacy myGP® - Book NHS GP appointments ipad Push Doctor - Online Doctor Appointments & Advice iPad: Appointfix Howbout Social event planner hey pharmacist Video GP from Lloyds pharmacy myGP® - Book NHS GP appointments ipad

	Push Doctor - Online Doctor Appointments & Advice Microsoft Windows: Video GP from Lloyds pharmacy
Lack of computer skills	No tool identified yet
Difficulty finding and accessing training on web accessibility	No tool identified yet
Difficulty saving specific information in an accessible way	Google Drive
Difficulty accessing digital devices or tools	No tool identified yet
Difficulty finding employment opportunities	Android: JOB TODAY: Find Jobs, Build a Career & Hire Staff Indeed Job Search Monster Job Search LinkedIn Reed Glass Door Jobsite iPad: Indeed Job Search Monster Job Search

	LinkedIn Reed Glass Door Jobsite Microsoft Windows: Indeed Monster LinkedIn Reed Glass Door Jobsite
Difficulty working from home	All Devices: Calendar Email Outlook Reminders
Difficulty trusting new people or technology	No tool identified yet
Broken URLs	No tool identified yet
Difficulty navigating websites without search bars	No tool identified yet
Difficulty finding non-text options	No tool identified yet

No FAQ section	No tool identified yet
Difficulty reading text when there are no options to adjust font, size and colour	No tool identified yet
Text composed with Grammarly being flagged as plagiarism by assignment submission systems	No tool identified yet
Difficulty understanding and entering captcha information	No tool identified yet
Difficulty navigating complex menus on apps	No tool identified yet
Lack of awareness of tools	No tool identified yet
PDFs not compatible with T2S tools or screen readers	Android: Text Help: Read and Write Liquid Mode Snap and Read HelperBird iPad:

	Text Help: Read and Write Snap & Read Liquid Mode ReadBit Voice Aloud Reader Text to Speech ClaroSpeak HelperBird Microsoft Windows: Microsoft OS Narration Natural Readers Verbose: Text to Speech Read ALoud: A Text to Speech Voice Reader Text from to Speech Liquid Mode Snap and Read TextHelp: Read & Write
Difficulty navigating audio files to find useful information	No tool identified yet
Difficulty using websites with Grammarly	No tool identified yet
Difficulties creating passwords and signing in	Avira

APPENDIX D

LIVE-IT Co-labs Monitoring Toolkit: Scenario Co-design (2.2)

This document provides guidelines for the monitoring and evaluation of activities related to **Task 2.2**. Scenario development, for which the key aims are:

- To evaluate existing solutions with participants and identify elements of good and bad design, as well as how and in what ways they can be improved. (incremental scenarios)
- To co-create potential alternative solutions to existing usability problems for PwCD (disruptive scenarios)

This toolkit provides templates to use for monitoring and data collection for the following activities:

- Monitoring tools for experiments with **existing tools**
- Monitoring tools for **co-creation** activities

The following templates can be adapted as appropriate to suit the context and scenarios of different co-lab sessions:

- 1. General observation template
- 2. Survey template for existing tools
- 3. Walk-through recording template for existing tools
- 4. Screen capture checklist
- 5. Video, audio and image capture checklist
- 6. Co-creation session observation template

1. Observation template for use with existing tools/apps

Research partner: _____
Researcher initials: _____
Date: _____
Site: _____
Participant ID: _____

Name of tools/apps: _____
_____
_____

Dimensions	Questions
Environment	Describe the space in which the event takes place. Impressions of atmosphere of the space (e.g. welcoming; friendly; forbidding) Other observations on environment
People	Who is present in this space and what are their roles? How participants interact with each other and with LIVE-IT staff? (e.g. collaborative; isolated) Other observations on participants
Scenarios	What scenarios are explored in this session? How do the participants respond to the proposed scenarios and tasks?

Objects	What technologies/tools/apps are used in this session? Do participants experience any issues/problems with using these objects?
Process	How are the technologies used over the duration of the observation? • can any problems/issues be identified that inhibit use of the technologies? • are there particular things about the technologies that appear to work well? What important things happen over the duration of the event – what are the critical incidents? For each critical incident listed, specify: • What leads up to the incident (the 'causes') • Who is involved in the incident? • What happens?

Outcomes	What would you describe as the main outcomes of the event? What would you say were the participant views on the usefulness, usability and relevance of the technologies used? Any evidence identified on how they might be improved?

2. Survey for experiments with existing tools/apps

This survey can be used to collect data on existing tools, apps and technologies used in co-lab experiments. *The use of technology will vary from participant to participant, so the term tools/app is used here, delete or change as appropriate.* This survey includes questions to collect data on:

- Usability and usefulness of the tool/app in use (UMUX-Lite)
- Emotional responses to using the tool/app
- Challenges and improvements

Date: _____

Site: _____

Research partner: _____

Researcher initials: _____

Participant ID: _____

Name/description of tool/app: _____

_____

_____

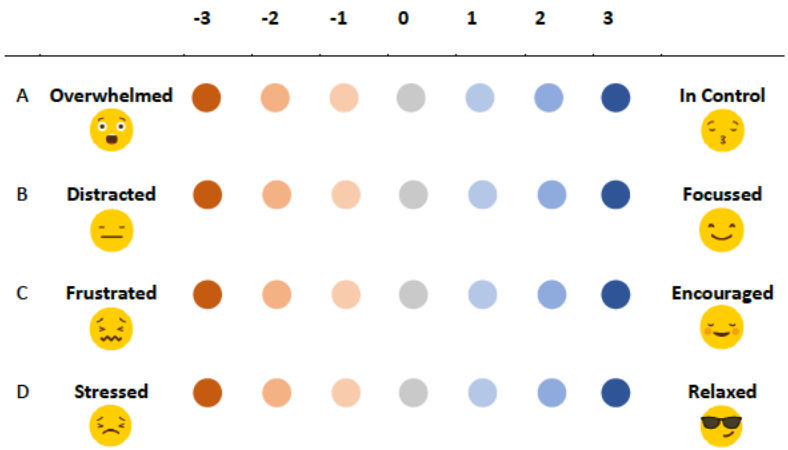
Usability and usefulness

	Strongly Disagree				Strongly Agree
1. The things that this tool/app can do **meet my needs**	1	2	3	4	5
2. This tool/app is **easy to use**	1	2	3	4	5
3. I was able to carry out the set task(s) easily with this tool/app	1	2	3	4	5

Emotional response

4. This tool/app made me **feel**:

Please look at the following list of FOUR emotions and select the circle which best represents your feeling in relation to using this tool/app/tech



Challenges and improvements

5. What were the main **challenges** you found in using this tool/app?

6. What things **worked well** about the tool/app?

7. How could you **improve** this tool/app?

Thank you for taking the time to complete this survey!

Walk-through recording template

This recording template can be used to collect data on structured or unstructured walk-throughs with existing, apps/tools or technologies used in co-lab experiments. For additional information on carrying out a walkthrough, refer to the co-lab implementation roadmap.

1. Journey map

Use the template at the end of this section to sketch out a 'journey map' which describes the steps the participant needs to take to accomplish the task/scenario. For *structured* walk-throughs, map this out beforehand. For *unstructured* walkthroughs, use the template to record the users' 'natural' journey through the scenario during or after the walk-through.

2. Phase 1

What happens in Phase 1 of the walkthrough?

- What actions are they taking? Why are they taking them?
- Describe any issues/challenges that arise
- How does the participant describe their experience? (*eg. is the tool easy to use?)*

Concurrent probing: Record follow-up questions and responses for Phase 1

Phase 2

What happens in Phase 2 of the walkthrough?

- What actions are they taking? Why are they taking them?
- Describe any issues/challenges that arise
- How does the participant describe their experience? (*eg. is the tool easy to use?)*

Concurrent probing: Record follow-up questions and responses for Phase 2

Phase 3

What happens in Phase 3 of the walkthrough?

- What actions are they taking? Why are they taking them?
- Describe any issues/challenges that arise
- How does the participant describe their experience? (*eg. is the tool easy to use?)*

Concurrent probing: Record follow-up questions and responses for Phase 3

3. Journey time

Collect data on journey time throughout the whole scenario, eg:

- How long does it take the participant to become familiar with the scope of the platform/tool from the first glance?
- How long it takes the participant to understand the resources available on the platform/tool?
- Does it take the participant a long/short time to accomplish each stage of the scenario?

4. Summary of user journey

Write a summary of the participant's journey, highlighting in particular the relevant learning points from the journey with regard to:

- **Usability** of the platform, tools and features
- **User-friendliness** of the platform, tools and features
- **Intelligibility and understanding** – how easy is it to understand what the platform/tool is for? How easy is it for the participant to understand the scenario?
- **Navigability** – how easy is it for users to navigate around the platform/tool and find what they are looking for?
- **Problems and challenges** users encounter
- **Recommendations for improvements** to the platform, tools and features.

Journey map template

Persona:

Expectations:

Scenario:

Phase 1:	**Phase 2:**	**Phase 3:**

Insights:

This template was adapted from NN Group (Source: https://media.nngroup.com/media/articles/attachments/JMTemplate.pdf)
For additional info on journey-mapping, see https://www.nngroup.com/articles/journey-mapping-101/

Video, audio and image capture procedure checklist

If permitted, video and audio recorders can be used to capture co-lab experiments with existing tools and more open-ended co-creation sessions. If the session can be recorded in real-time, video and audio data can be analysed afterwards using 'ex-post' analysis tools.

If video and audio is not permitted, use a camera to photograph key breakthroughs (eg. sticky note table, prototypes) supported by field notes (eg. using observation template).

1	**Permissions:** Ensure all ethical guidelines have been followed and informed consent has been obtained from all participants (including carers and assistants) to audio and/or video record the session (and/or take photos)	☐
2	**Device power:** Ensure all recording equipment is fully charged and there are spare batteries or necessary chargers to hand	☐
3	**Data storage:** Ensure SD cards have sufficient space for recording the session (and spare SD card(s) are available if necessary)	☐
4	**Camera placement:** Set up placement of cameras / audio recorders, etc. to ensure best capture of participants' design activities. Have at least one video / audio recorder per group	☐
5	**Verbal assent:** On starting the session, repeat information about videoing and/or audio recording the session so participants are aware, and obtain verbal assent	☐
6	**Record:** Begin recording the session (double check devices to ensure they are recording)	☐
7	**Image capture - during:** Where possible, take photos of important developments and activities	☐
8	**Image capture - post:** At the end of the session, take photographs or video of all relevant design artefacts (participant notes, mind maps, stickies/post-its, storyboards, prototypes, etc)	☐
9	**Idea capture:** Capture any important thoughts, design ideas or revelations from the session either through audio/video or hand written field notes (i.e. use observation template)	☐
10	**Data transfer and storage:** Transfer data to a secure hard-drive, store and back-up in accordance with ethical guidelines and partner organisations' data management procedures.	☐

5. Observation template for use with existing tools/apps

Research partner: _____
Researcher initials: _____
Date: _____
Site: _____
Participant ID: _____

Name of tools/apps: _____
_____
_____

Dimensions	Questions
Environment	Describe the space in which the event takes place. Impressions of atmosphere of the space (e.g. welcoming; friendly; forbidding) Other observations on environment
People	Who is present in this space and what are their roles? How participants interact with each other and with LIVE-IT staff? (e.g. collaborative; isolated) Other observations on participants
Scenarios	What scenarios are explored in this session? How do the participants respond to the proposed scenarios and tasks?

Methods	What co-design methods and materials are used? How do participants respond to these methods/materials? How should they be changed/adapted next time?
Objects	What technologies/tools/apps are used in this session? Do participants experience any issues/problems with using these objects?
Process	Report on the co-creation process and using design thinking methodology with participants **Empathise and Define:** How do participants describe the problem space? • can any problems/issues be identified that inhibit use of current technologies? • What other issues are discussed? **Ideate:** • What ideas are generated by participants? • How are they developed? **Prototyping:** • What artefacts were produced? (take photos if possible) • Describe how the materials were used • How do they represent participant ideas for new technologies/solutions?

	What important things happen over the duration of the event – what are the critical incidents? For each critical incident listed, specify: • What leads up to the incident (the 'causes') • Who is involved in the incident? • What happens?
Outcomes	What would you describe as the main outcomes of the event? What would you say were the participant views on potential new solutions for technologies which support the digital inclusion of PwCD?