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

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LIST OF ACRONYMS

Acronym	Description
WCAG	Web Content Accessibility Guidelines
UNCRPD	United Nations Convention on Rights of Persons with Disabilities
W3C	World Wide Web Consortium
WAI	Web Accessibility Initiative

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EXECUTIVE SUMMARY

1. INTRODUCTION

Against the background of the increased digitisation of almost all aspects of life and accelerated digitisation due to COVID-19, the LIVE-IT project aims to address the urgent needs associated with web accessibility for people with cognitive disabilities. The overarching goal for the LIVE-IT project is to aggregate and valorise 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'. To accomplish this goal, the LIVE-IT project is broken up into several work packages, the first of which addresses the state-of-the art with respect to web accessibility for people with cognitive disabilities.

Work Package 1 establishes the initial knowledge base and sets up activities to be carried out in the co-labs developed within the project. There are four co- labs, one co-lab per each of the LIVE-IT research partners. The co-labs are constructed 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

The following report details the purpose, methods, and findings from the state-of-the-art baseline review conducted within Task 1.1 of Work Package 1. Generally speaking, the objective of Task 1.1 was to develop a rapid yet comprehensive picture of the state-of-the-art of web accessibility for people with cognitive disabilities through academic and grey literature searches. In the next section, more detail is provided about the purpose of Task 1.1 and this review.

1.1. PURPOSE AND SCOPE

This task uses a 'scientific realist review' method (Pawson et al, 2005) to map the landscape of inclusive web accessibility, focusing on the perspective of people with cognitive disabilities. The review entails an iterative process of: searching the field for successful theory, policies and practices to support inclusive web accessibility for people with cognitive disabilities; applying quality criteria to the material identified, based on relevance and rigour to produce a short list of examples; producing a final shortlist of examples; analysing the material collected to produce a comprehensive review of state of the art; integrating the results to re-assess the original 'map' of the field, and to add new examples.

To focus this review, one overarching research question and several sub-questions were developed. The review question guiding this work is:

- What is the state-of-the-art of interventions that support web accessibility for citizens, ages 9 and up, living with cognitive impairment?

The sub-questions that add focus to this overarching question are:

- What are examples of good practices – 'interventions'- including examples of platforms and tools - that have the potential to support inclusive web accessibility for people with cognitive disabilities?
- What is the impact of successful initiatives, interventions or programmes on supporting inclusive web accessibility for people with cognitive impairment?
- What are the similarities and differences between successful initiatives, interventions or programmes supporting web accessibility for people with cognitive impairment in the different sectors (i.e. education, health, commerce, employment, etc…)?
- What are the drivers and barriers, or supports and constraints, for web accessibility for people with cognitive impairment?
- What are the key characteristics of successful initiatives, interventions or programmes on supporting inclusive web accessibility for the population under this study?
- What recommendations can be made for the future initiatives that wish to support web accessibility for citizens living with cognitive impairment?

1.2. INTENDED AUDIENCE

This document should be used as a reference by:

- European Commission
- Policy Makers
- Stakeholders
- LIVE-IT Project Team

1.3. STRUCTURE OF THE DELIVERABLE

The following report begins with the methods for the academic and grey literature searches carried out in Task 1.1. Then, screening procedures are provided so that the search conducted for this task can be replicated as the field advances. Next, the results of the search are reported. Finally, the report concludes with a discussion of implications for subsequent work within the LIVE-IT project.

1.4. RELATION TO OTHER WPS & TASKS

The state-of-the-art and audit conducted during Task 1.1 feeds directly into all other Work Packages in the LIVE-IT project. In Work Package 1, Task 1.1 added to the Task 1.2 tools and platforms audit. In Work Package 2, Task 1.1 informed best practices for co-lab methods and the development of scenarios. In Work Package 3, Task 1.1 will have contributed to features of the Open Toolkit via the identification of tools, platforms, and scenarios for the co-design labs. In Work Package 4, Task 1.1 will have contributed to the development of the makerspaces within the co-design labs, again, via the identification of tools, platforms, and scenarios for the co-design labs. Finally, Task 1.1 is contributing to Work Package 5 by generating manuscripts for publication; as of the project review in October, two manuscripts related to the Task 1.1 search methods and search results will have been submitted for review.

2. METHODS

The web accessibility baseline described in this report was developed through a realist review (Pawson et al, 2005), which involves a review of state of the art in the field as a 'halfway house' between a 'systematic review' and a 'narrative review'. The specific sources for the review include both official literature –existing research reviews and reports, bibliographic databases and academic research – and 'grey' literature: unpublished material like blogs and dissertations.

2.1. SEARCH PROCEDURES

The following databases were systematically searched using fifteen-year time limited search strings: Web of Science, SCOPUS, EBSCOhost, ERIC and ProQuest. A total of 50 search strings were developed and entered into the databases. Table 1 shows the set of search strings used. Internet searching through Google Scholar was carried out as well as forward and backward tracking of citations from studies that are included in the review. Given the multi-jurisdictional aspect of the study, local searches of the grey literature were included in this review to capture information relevant to each co-lab location. Table 2 shows possible combinations of search terms that were used in the local grey literature and Google searches to capture additional results relevant to the unique locations for the co-labs.

The result of the search has been downloaded and saved to a standard database accessible to all project team members. Duplicate results were removed. The titles and abstracts of all remaining studies were screened by a process informed by the study inclusion and exclusion criteria. Inclusion and exclusion criteria are provided in detail in the next section. All stages of the screening process are illustrated in Figure 1, below.

Table 1 – Search Strings

Search Number	Search String
S1	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “web accessibility”
S2	(neurodiverse OR neurodivergent) AND “web accessibility”
S3	“complex need*” AND “web accessibility”
S4	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “e-services”
S5	(neurodiverse OR neurodivergent) AND “e-services”
S6	“complex need*” AND “e-services”
S7	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “e-commerce”
S8	(neurodiverse OR neurodivergent) AND “e-commerce”
S9	“complex need*” AND “e-commerce”
S10	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “e-health”
S11	(neurodiverse OR neurodivergent) AND “e-health”
S12	“complex need*” AND “e-health”
S13	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “e-learning”
S14	(neurodiverse OR neurodivergent) AND “e-learning”
S15	“complex need*” AND “e-learning”
S16	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “online learning”
S17	(neurodiverse OR neurodivergent) AND “online learning”
S18	“complex need*” AND “online learning”
S19	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “e-banking”
S20	(neurodiverse OR neurodivergent) AND “e-banking”

S21	“complex need*” AND “e-banking”
S22	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “online banking”
S23	(neurodiverse OR neurodivergent) AND “online banking”
S24	“complex need*” AND “online banking”
S25	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “web accessibility tool*”
S26	(neurodiverse OR neurodivergent) AND “web accessibility tool*”
S27	“complex need*” AND “web accessibility tool*"
S28	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “user-centered design”
S29	(neurodiverse OR neurodivergent) AND “user-centered design”
S30	“complex need*” AND “user-centered design”
S31	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “accessibility widgets”
S32	(neurodiverse OR neurodivergent) AND “accessibility widgets”
S33	“complex need*” AND “accessibility widgets”
S34	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*”) AND “assistive technology”
S35	(neurodiverse OR neurodivergent) AND “assistive technology”
S36	“complex need*” AND “assistive technology”
S37	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "web accessibility"
S38	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "e-services"

S39	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "e-commerce"
S40	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "e-health"
S41	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "e-learning"
S42	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "e-banking"
S43	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "online learning"
S44	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "online banking"
S45	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "web accessibility tool*"
S46	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "user-centered design"

S47	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "accessibility widgets"
S48	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder") AND "assistive technology"
S49	(dyslexia OR aphasia OR "non-verbal" OR "down syndrome" OR "autism" OR "dyscalculia" OR "cognitive decline" OR "attention deficit disorder" OR "learning disabilit*" OR "intellectual disabilit*" OR dysgraphia OR dementia OR "cerebral palsy" OR "brain injury" OR "motor neurone disease" OR "irlen syndrome" OR "pervasive developmental disorder")AND ("web authoring tool*" OR "web evaluation tool*")
S50	(“cognitive impairment*” OR “cognitive deficit*” OR “cognitive disabilit*” OR neurodiverse OR neurodivergent OR “complex need*”) AND ("web authoring tool*" OR "web evaluation tool*")

Table 2 – Search Term Possibilities for Google Searches

General keyword group	Specific keywords
Web accessibility	Accessibility, Digital, ICT, Internet, Digital Inclusion
Cognitive disability	Dyslexia, Aphasia, Non-verbal, Dysarthria; Dyspraxia; Dementia; Alzheimer's disease; Intellectual Disability; Attention deficit hyperactivity disorder (ADHD); Autism; Asperger syndrome; Dyscalculia; Downs syndrome; Motor Neurone Disease; Brain injury; Stroke; Cerebral palsy
Type item and/or issue	Policy, Guidelines, E-Health, E-Commerce; E-Service; E-Banking; Social Media, Distance Learning; Online Safety

2.2. INCLUSION AND EXLUSION CRITERIA

Table 3, below, provides an overview of the inclusion/exclusion criteria for the review. As noted in the previous section, searches were limited to a 15-year window: 2006-2021. We decided on the 15-year window as opposed to a more standard 10-year window, because the first iPhone was released in 2007. We expected that a sharp increase in accessibility related literature might have occurred around 2007. Due to the fact that we could not identify any literature reviews specifically addressing web accessibility for people with cognitive disabilities, we felt it important to capture any related literature from at least 2007. Expanding the window to 15 years allowed us to capture the time leading up to and immediately following this watershed date.

The database search included peer reviewed studies published in English. However, if a study published in an alternate language is deemed relevant it was included. In addition, works that are returned through the grey literature search will be considered for inclusion if they are retuned in EU members state languages other than English and deemed relevant by the project team.

The review focused on citizens ages 9 and up who live with cognitive impairment. The lower age limit of 9 years was set to capture the year prior to the transition from primary school to secondary school across the multiple jurisdictions represented in this research partnership. No upper age limit was set, because the need for web accessibility when living with cognitive impairment does not diminish or stop at any particular age. In the instance where studies included participants determined to be outside of the study age range, if the mean age range of the study is 9 years of age or greater, the study was included subject to agreement by the project team members. Studies that did not focus exclusively on citizens with cognitive impairments and where the datasets presented by the study are not presented separately will be excluded from this review.

Table 3 – Inclusion/Exclusion Criteria

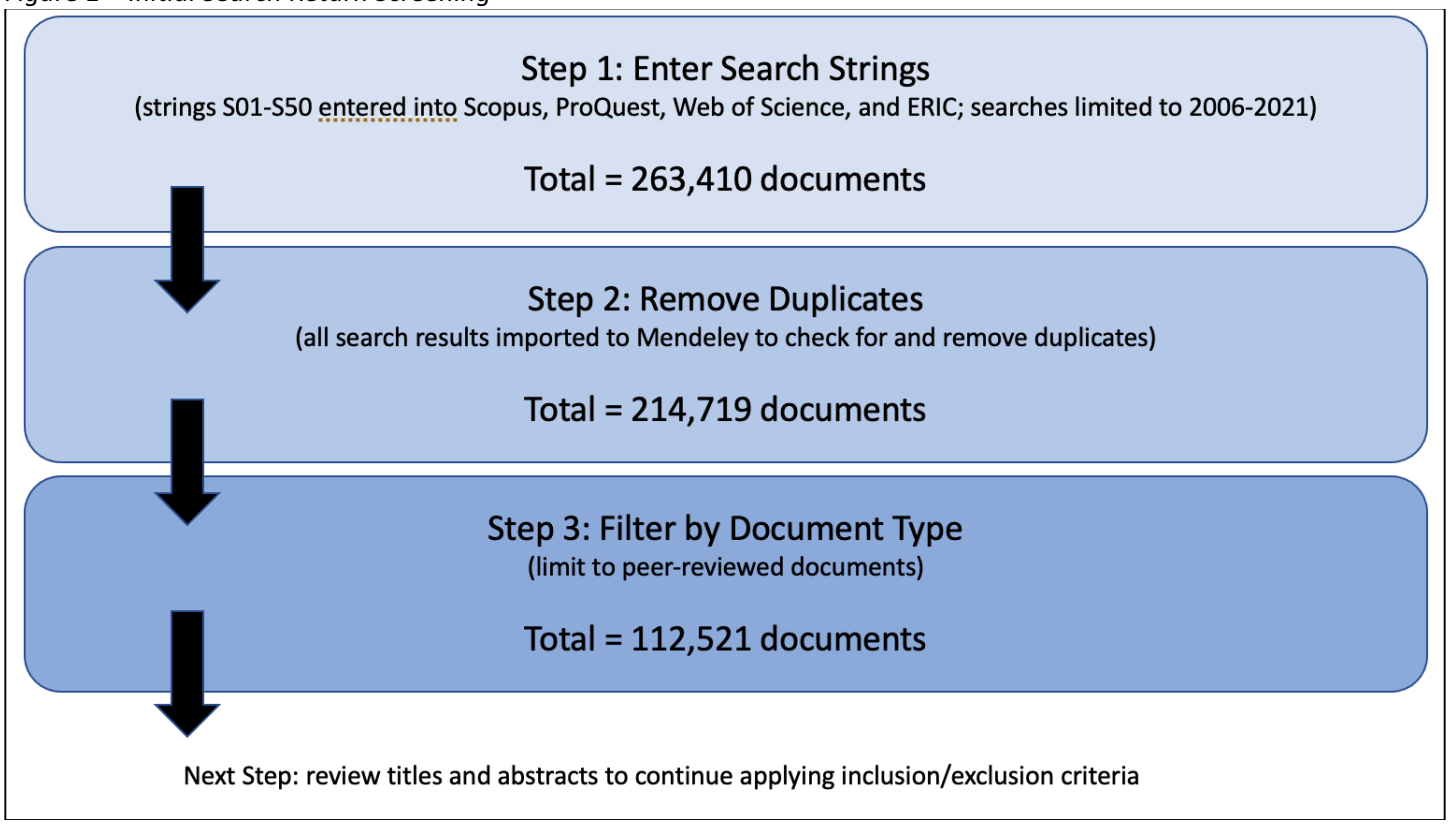
Component	Inclusion	Exclusion
Publication	2006-2021 Published in English in peer reviewed journals and/or full conference proceedings Grey literature search returns that present comprehensive reports on relevant programmes and adhere to the criteria below	Any publication prior to 2006 Not in English, abstracts only, editorials, letters. Duplicate publications Conference proceedings not presenting full papers
Geographic Location	Any geographic location	No geographic location excluded
Study Design	All study designs	No study design excluded
Population	Any age 9 years and older Experiencing Cognitive impairment	Ages younger than 9 years Not experiencing cognitive impairment
Intervention	All intervention types focused on the target population	Any intervention not focused on the target population
Comparison	All studies to be included irrespective of the presence of comparator or control group	No exclusions based on comparison group(s)
Outcome	Data and results reported	Studies not reporting any data or results

2.3. SEARCH RETURNS AND SCREENING PROCESS

A comprehensive search was conducted to determine the state of the art of web accessibility for people with cognitive disabilities. Figure 1 and Figure 2 below summarise the search process. To begin, all 50 search strings (see Table 1) were entered into the Scopus, ProQuest, Web of Science, and ERIC databases. This returned a total of 263,410 results. The results were imported to Mendeley and duplicates were removed. Removal of duplicates brought the total number of search returns to 214,719. Then, the remaining search returns were limited to peer-reviewed documents, which further reduced the number of returns to 112,521.

At this point, the title and abstract of every remaining item was screened to determine inclusion and exclusion (see Table 3). In the case that inclusion or exclusion could not be determined by reading the title and abstract, the full PDF was accessed to make the decision. After this round of screening, only 140 items remained.

Figure 1 – Initial Search Return Screening

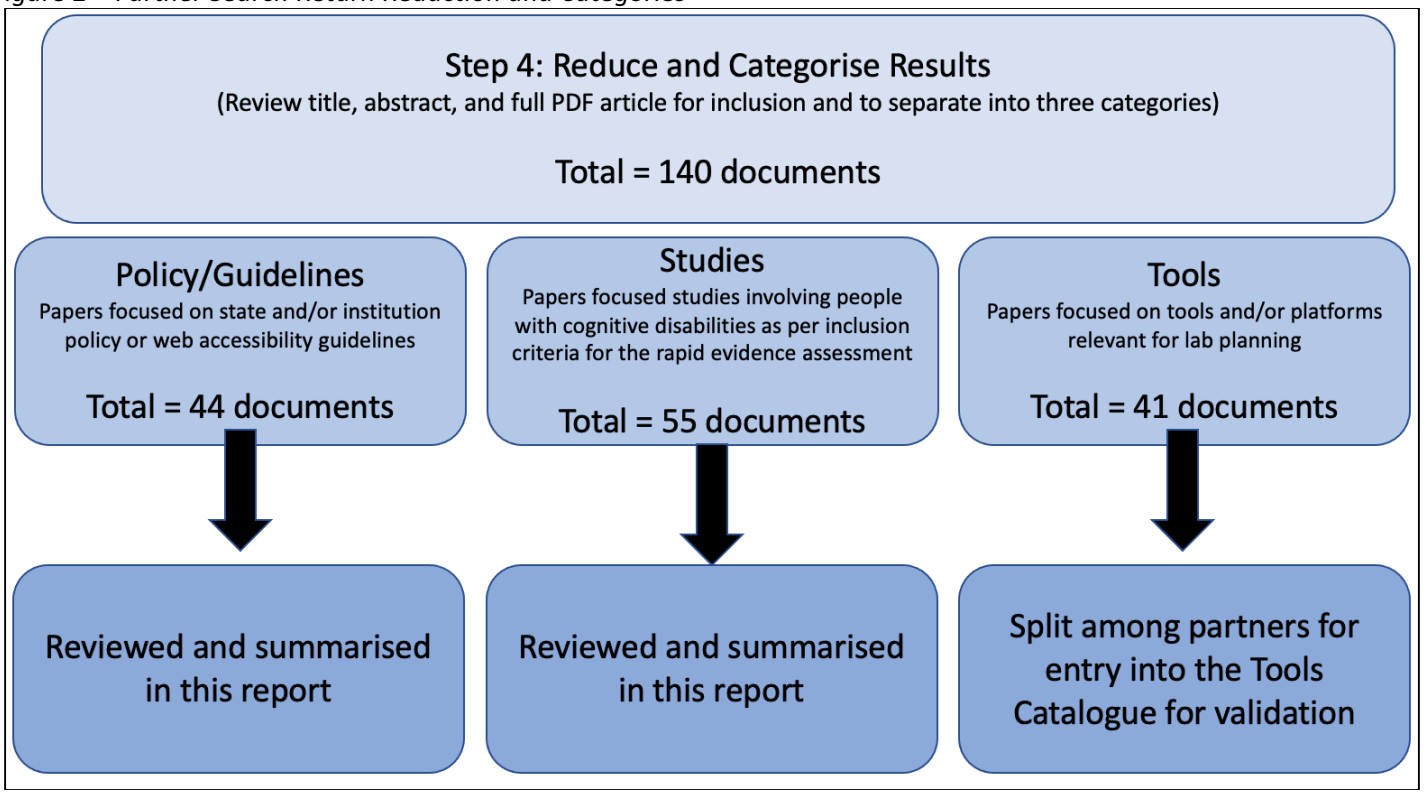


The PDFs were accessed for all 140 items, which were then categorised prior to reviewing the papers. Three categories were created based on the goals of the review and the needs of the co-design labs: Policy/Guidelines, Studies, and Tools. The Policy/Guidelines category included all papers related to state and/or institutional policy and guidelines for web accessibility for people with cognitive disabilities, and 44 papers were placed into this category. The Studies category included all papers reporting on web accessibility studies involving people with cognitive disabilities, and 55 documents

were placed into this category. The Tools category included all papers reporting on specific tools and/or platforms related to web accessibility for people with cognitive disabilities, and 41 documents were placed in this category.

As can be seen in Figure 2, only two of the three categories are included in this report: Policy/Guidelines, and Studies. The documents from the Tools category were used to populate a Baseline Catalogue that feeds into Tasks 1.2, 1.3, and 1.4 of Work Package 1 (reported in a separate deliverable). Additionally, the papers in the Tools category did not meet the inclusion criteria for the review. Using the structure of the search as a framework, this report is organised into three sections: Policy and Guidelines, Studies, and Tools.

Figure 2 – Further Search Return Reduction and Categories



3. RESULTS

The results of the Task 1.1 search are reported in this section in two main categories, as depicted in Figure 2, above. The categories structuring the reporting of results are policy/guidelines and studies. Following the results, the report with conclude with a discussion of how the results inform Task 1.2 and other elements of the LIVE-IT project.

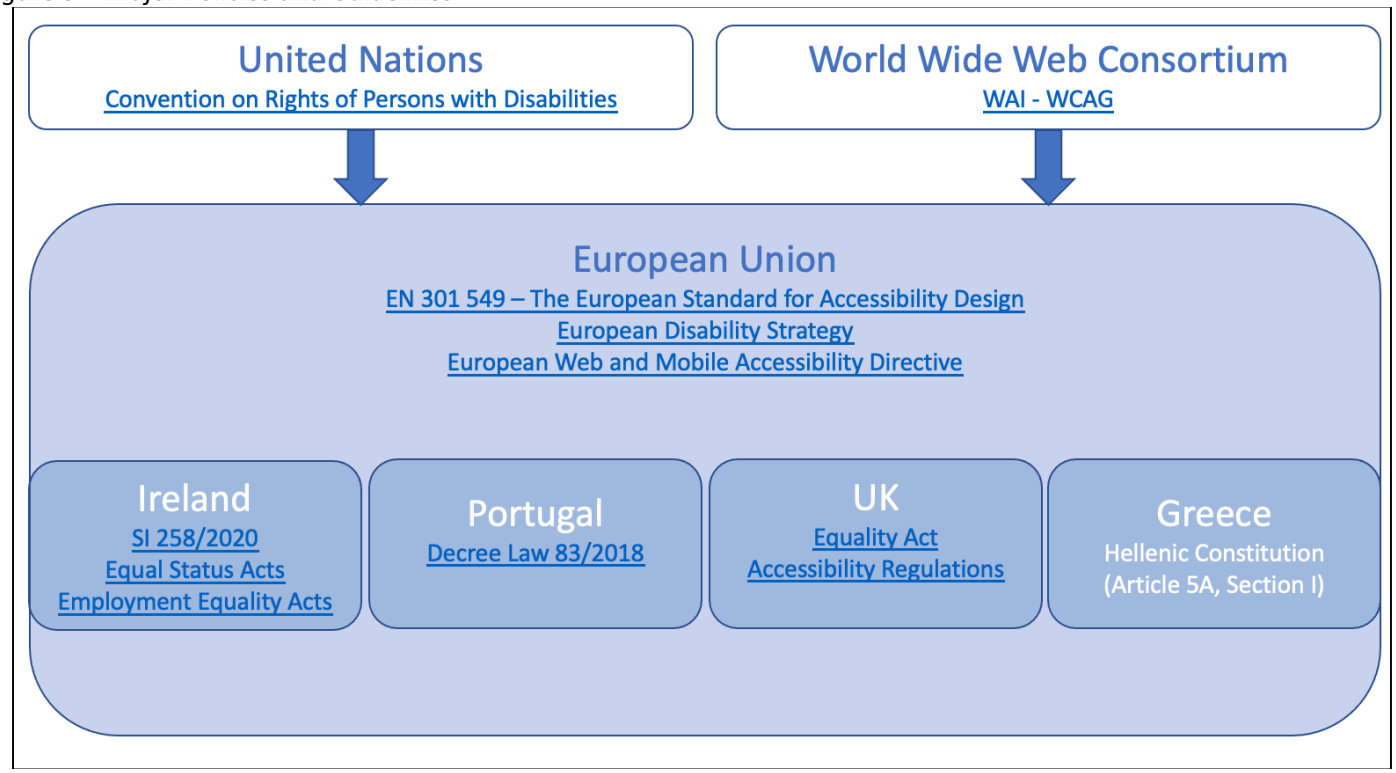
3.1. POLICY AND GUIDELINES

Initial screening in this category produced a long list of 44 articles focused on policies and/or guidelines across multiple countries. At this stage, PDF versions of the 44 articles were retrieved and read to make final decisions about inclusion in the review. This stage of screening further reduced the reviewable results to 17 articles. Articles were excluded if they focused exclusively on the United States context and/or failed to specify cognitive disability. Of the 17 articles reviewed in detail, 9 focused primarily on existing or developing guidelines and 8 focused on policies.

The geographic distribution of the policies and/or guidelines in the 17 articles reviewed are as follows: 4 from the UK (1 policy, 3 guideline articles), 2 from Italy (1 policy, 1 guideline article), 1 from the USA (0 policy, 1 guideline article), 2 from Portugal (1 policy, 1 guideline article), 1 from Slovenia (1 policy, 0 guideline articles), and 5 from the EU in general (4 policy, 1 guideline article). Tables 4 and 5, below summarize the paper type, publication date, and geographic distribution information for the articles reviewed. Additionally, Figure 3 provides an illustration of how the major policies and guidelines are related. Of the countries where labs will be hosted, two were not represented in the search returns: Ireland and Greece. Thus, a Google search was conducted to ensure that relevant policies and guidelines from Ireland and Greece were included in this review. Such Google searches did not return additional articles. Rather, the supplemental searches led us directly to government websites stating the relevant local policy for Ireland and Greece.

One policy and one set of guidelines appear to serve as the framework for the state policies reviewed. The United Nations (UN) Convention on Rights of Persons with Disabilities (CRPD) is the overarching policy that both informs and drives the EU and individual state policies. Additionally, the World Wide Web Consortium's (W3C's) Web Content Accessibility Guidelines (WCAG) serve as a foundation for EU and individual state policies. The review of the policy and guideline articles revealed that only parts of the CRPD and the WCAG are specifically included in the EU and individual state policies. Namely, the CRPD and the WCAG are more comprehensive and rigorous in their targets for accessibility than the EU and individual state policies. Figure 1, below, displays how the policies and guidelines are related.

Figure 3 – Major Policies and Guidelines



3.1.1. Guidelines

This section provides a more detailed description of the relevant findings from reviewing the 9 articles focused on existing or developing guidelines. Some articles were empirical, meaning that they involved an empirical test of web accessibility using a particular set of existing guidelines as a framework for testing, a review of existing guidelines for web accessibility, or used an empirical approach to develop new and/or more focused sets of guidelines for web accessibility. Table 4, below, provides an overview of the article types, publication date, and geographic location of these 9 articles.

The dominant set of guidelines for web accessibility, broadly speaking, are the W3C's WCAG. These guidelines have been revised since their introduction. The WCAG 1.0 were released in 1999 and subsequently incorporated into policy recommendations around the world. A decade later, the WCAG 2.0, which included additions and revisions to the WCAG 1.9, were released. The WCAG 2.0 are what appear in most policies, and are organized around the acronym POUR, as illustrated in Figure 4, below. POUR stands for Perceivable-Operable-Understandable-Robust, and these descriptors link to specifications for web pages and web apps that support accessibility at three different levels. The WCAG levels are labelled as A, AA, and AAA. Most policies require WCAG compliance at the AA level, which means that most policies do not require the highest level of accessibility. Figure 4 also captures the additions to the WCAG in versions 2.1 and 2.2. It is important to note that the WCAG is an open-source-like set of guidelines, meaning that all discussion around changes to the guidelines are public.

One major critique of the WCAG has been the lack of accessibility specifications to support people with cognitive disabilities. W3C as an organisation have recognised this problem and developed the COGA Task Force, whose mission is to improve current accessibility standards and recommend new accessibility standards focused on people with cognitive disabilities. Figure 4 also highlights the specifications in the WCAG 2.0 that support accessibility for people with cognitive disabilities. Minimal research exists on how effective the existing standards are for people with cognitive disabilities, however.

Table 4 – Guidelines PDFs Reviewed in Detail

Citation	Year	Paper Type	Country/Region
(Al-Mauwil et al, 2019)	2019	Empirical	UK
(Chadwick et al, 2013)	2013	Review	UK
(Dattolo et al, 2017)	2017	Empirical	Italy
(Goncalves et al, 2013)	2013	Empirical	Portugal
(James et al, 2014)	2014	Empirical	n/a
(Lewthwaite, 2014)	2014	Commentary	UK
(Moulin, 2010)	2010	Empirical	EU
(Raymaker et al, 2019)	2019	Empirical	USA
(Zhang et al, 2020)	2020	Empirical	n/a

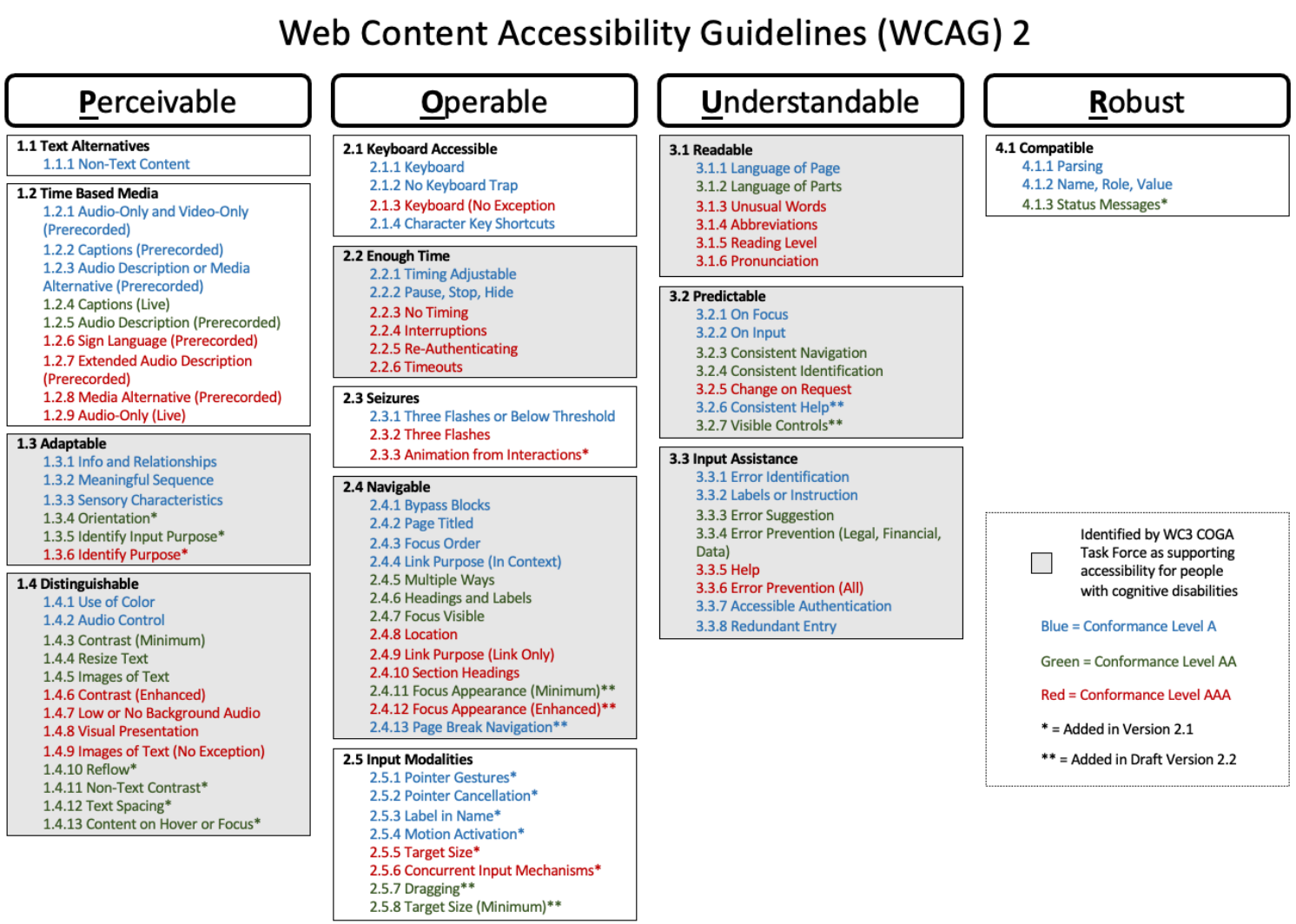


Figure 4 – WCAG 2.0

Articles focused on guidelines also provided useful definitions and frameworks that may be relevant to the lab development, lab implementation, and data analysis stages of the LIVE-IT project. Al-Mawil, et.al. (2019) provided a clear distinction between e-inclusion and e-adoption. E-inclusion "is mostly concerned with the social impact of relative differences in ICT use between different socioeconomic groups and individuals" where e-adoption "focuses instead on absolute and average figures of ICT uptake and their economic impact." Additionally, Raymaker, et.al. (2019) present a method for building and testing websites and online platforms with people with cognitive disabilities alongside a framework for considering information accessibility that has three dimensions: physical, intellectual, and social. The methodology employed by Raymaker, et.al. (2019) began with qualitative interviews to develop an understanding of participants' (people with cognitive disabilities) experiences with healthcare websites. Then, design cycles were initiated around the content, the user interface, and the interactive survey tool to be used in the actual study. These design cycles involved researchers and people with cognitive disabilities. Following this step, the healthcare website to be tested in the actual research study was tested with participants (people with cognitive disabilities) in an alpha and a beta stage. Revisions to the website were made based on feedback from the alpha stage, which was then tested again in the beta stage. LIVE-IT will take the process described in Raymaker, et.al. (2019) and apply it to multiple scenarios in multiple co-design labs.

Although informative, there are issues with the articles focused on guidelines that were reviewed for this project. First, if empirical, the studies are often framed via a deficit mindset. In other words, the frameworks, research questions, and findings tend to focus on what is wrong with the people under investigation rather than what can be improved about the websites. When there is a focus on improving the websites, the focus is primarily on text readability. Second, if theoretical, the papers or reviews tend to speak about disability more generally. Thus, there is a distinct lack of empirical and theoretical exploration into web accessibility for people with cognitive disabilities.

3.1.2. Policies

This section provides a more detailed description of what was learned from reviewing the 8 articles focused on policies. Articles involving policy for web accessibility for people with cognitive disabilities were either empirical in nature, literature reviews, or law reviews. If empirical, the paper typically reported on automated testing of specific pages of specific websites against a policy in a specific region. Reviews provided more wholistic views of how policies and guidelines worked together to produce the current state of policy regarding web accessibility for people with cognitive disabilities.

Both EU and individual state policies have taken steps to essentially codify the WCAG. Three EU-level policies drive this effort in the four countries in which LIVE-IT labs will be located: The European Standard for Accessibility Design (EN 301 549), the European Disability Strategy, and the European Web and Mobile Accessibility Directive. Within Ireland, Portugal, the UK, and Greece, policies have been enacted that either directly adopt the EU policies listed above or adopt add to the EU policies. Additions are usually in the form of requiring higher levels of WCAG conformance.

Articles focused on policies also present gaps in the literature worth filling. First, if empirical, the studies reviewed tended to rely on automated accessibility testing with limited human-computer interaction of any sort. While this is useful information that can reduce the number of research hours that need to be spent on basic accessibility issues, this method excludes the experiences, perceptions, desires, and needs of people who are actually using the website, app, or device. It is worth noting that the automatic checking of website accessibility typically reveals dismal levels of accessibility from only checking a single page. Second, if theoretical, the paper or review tends to focus on the historical backgrounds of the policies without providing clear pathways for future research with people with cognitive disabilities.

Third, the policy articles reviewed tended to frame disability very broadly or focus on physical disabilities such as vision impairments. Finally, this review did not return any articles providing insight into how the policies have influenced the real-world usability and accessibility of websites and web applications for people with cognitive disabilities.

Table 5 – Policy PDFs Reviewed in Detail

File Name	Year	Paper Type	Country/Region
(Barricelli et al, 2021)	2021	Empirical	Italy
(Delarney et al, 2010)	2010	Review	UK
(Ferri, 2018)	2018	Review	EU
(Giannoumis, 2014)	2014	Empirical	UK and Norway
(Kim, 2020)	2020	Empirical	USA & Europe
(Kous et al, 2021)	2021	Empirical	Slovenia
(Muchagata, 2019)	2019	Empirical	Portugal
(Timmers, 2008)	2008	Review	EU

3.2. STUDIES

The search results included 55 articles reporting on studies involving people with cognitive disabilities, which means that at least one well-defined group of participants within the study were people with cognitive disabilities *and* at least one goal of the study was to investigate some element of web accessibility for people with cognitive disabilities. Unfortunately, 9 PDFs were not able to be accessed. Thus, a total of 43 articles were reviewed in detail. Table 6, below, shows the full list of studies reviewed (by citation) organized by search-term related subtopics: web accessibility, user-centered design, assistive technology, e-health, e-learning, and e-banking. Articles written in English, Spanish, Portuguese, and Italian were located. No articles in Greek were returned in the searches.

Table 6 – Study PDFs Reviewed in Detail

Web Accessibility	User Centered Design	Assistive Technology	E-Health	E-Learning	E-Banking
(Holz, 2021) (Karreman et al, 2007) (Krivec et al, 2020) (Kvikne, 2021) (Moreno et al, 2012) (Morris et al, 2018) (Ophoff et al, 2021) (Passerino, 2007) (Rocha et al, 2012) (Rocha et al, 2016) (Santham, 2012) (Williams, 2013) (Williams, 2015) (Wu et al, 2019) (Yaneva et al, 2019)	(Lazar et al, 2018)	(Beentjes et al, 2020) (Benda, 2015) (Brunskill, 2020) (Fickas et al, 2008) (Gillespie-Lynch et al, 2014) (Gomez et al, 2017) (Hedman et al, 2016) (Heyn et al, 2021) (Kwan et al, 2020) (Lancioni et al, 2014) (Malinowsky et al, 2010) (McCarron et al, 2019) (Moisey et al, 2007) (Oksnebjerg et al, 2020) (Scott et al, 2013) (Wallcook et al, 2019) (Zhu et al, 2019)	(Malinowsky et al, 2014) (Zaagsma et al, 2020)	(Andreasen, 2019) (Arbelaitz et al, 2016) (Igo et al, 2006) (MacFarlane et al, 2009) (Ngubane-Mokiwa, 2021) (Williams, 2017) (Williams, 2020)	(Hahn et al, 2018)

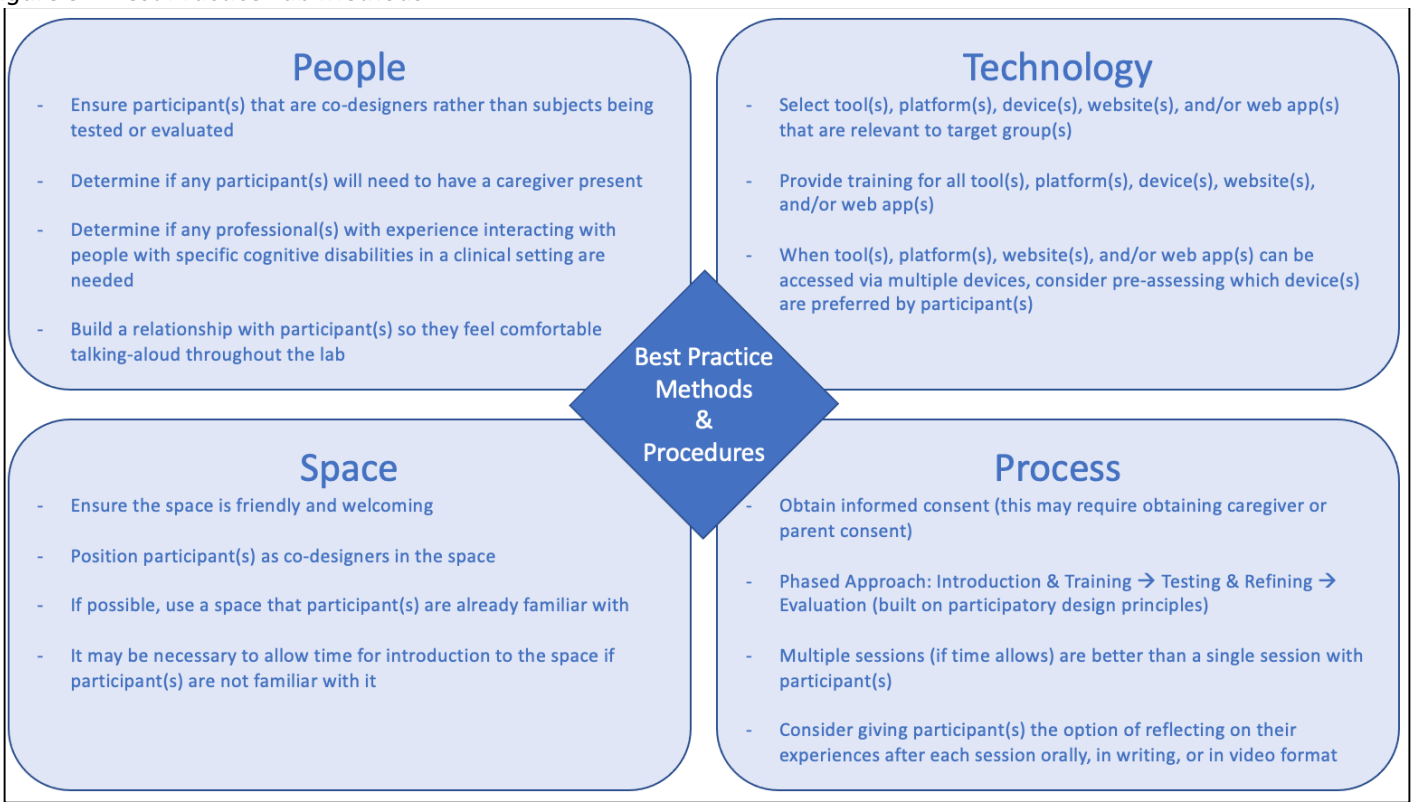
A review of these studies painted a picture of the state of the art for web accessibility in six main areas: Methods, Tool/Platforms, Policy/Guidelines, Experiences of People with Cognitive Disabilities, Studies Involving People with Cognitive Disabilities Broadly Defined, and Studies Involving People with Specific Cognitive Disabilities. These six main areas structure the remainder of this section.

3.2.1. Methods

The studies reviewed revealed two themes with respect to research methods. First, they provide examples of the methods used to date and the types of findings they can produce. Second, they provide a glimpse of more innovative

methods such as the co-design approach the LIVE-IT labs will adopt. Figure 4, below, shows how more popular methods used to date and more innovative methods combine to create some best practice recommendations for the LIVE-IT labs.

Figure 5 – Best Practice Lab Methods



Accessibility testing and usability testing that involves people with cognitive disabilities tends to involve researcher-developed websites or web applications. This happens for multiple reasons. Often the rationale is to control particular variables, to limit the number of pages, or to allow for specific modifications. There are two notable downfalls of this approach. First, this prevents the observation of challenges associated with navigating through multiple pages and/or navigating from one site to another. Second, this prevents the exploration of real-world challenges and barriers.

The majority of the studies reviewed involved text-based websites or web applications. For example, when studying information seeking, researcher-developed websites containing various levels of text-based information (simple through complex) might be used. Unfortunately, this limits the production of knowledge around how to adequately provide non-text-based methods for sharing information on the internet. Additionally, the solutions often involved presenting less material, which robs people with cognitive disabilities of developing the same sorts of understandings people who can read the complex text might develop about a particular topic.

To build websites and/or web applications, researchers often take a phased approach that involves people with cognitive disabilities at multiple stages. Initial phases often include a pilot with feedback from participants

representative of the target user group. Then, revisions take place based on the pilot data. After revisions are made, the formal study takes place, which involves user testing and/or evaluations of the website or web application. In some instances, multiple design cycles take place. This mirrors the type of approach proposed for the LIVE-IT labs.

Finally, co-design and participatory design research methods tended to yield the most relevant results. What we mean by this is that the findings from studies using these methods tended to produce tools and findings that were relevant to the lives of people with cognitive disabilities. The results also tended to be anchored in real-world scenarios rather than highly controlled experimental scenarios. Such studies often involved about 10 participants who engaged in design cycles that progressed from problematizing to designing to experimenting.

3.2.2. Tools and Platforms

As noted in the section above, many researchers opted to develop their own websites or web applications for their studies. However, some researchers used existing apps, including:

- Google apps
- FindMyApps (very poorly rated by users in study)
- iOS Maps
- Mobile Coach Technology (preferred when used with human assistance also)
- Social Support Aid (very poorly rated by users in study)
- Read & Write
- ICanEmail
- ReACT (very poorly rated by users in study)
- DigiContact
- Existing Social Media Apps (iOS and Android)
- Exiting Messenger Apps (iOS and Android)
- Newham Easy Read
- WebHelpDyslexia

Regardless of the type of website or app (built by the researcher or already existing), a few common challenges arose. First, there is often too much text on the websites or web apps. Participant feedback across multiple studies highlighted the need for more non-text options, more real photo (as opposed to animated) options, and more audio options. Also, participants warned that when non-text options drastically increased the amount of scrolling required, the solution was no better than the initial problem of too much text. Second, the cognitive load associated with searching for and selecting information from the web was frequently highlighted as problematic. Participants often had to pre-search terms or phrases for use in databases to ensure correct spelling, for example. Additionally, participants reported having to toggle between multiple sites/tools/platforms to accomplish tasks without errors, relying on image searches to avoid frustration due to spelling errors, and experiencing difficulty with filtering and verifying the accuracy of search results. Third, when the steps to open or navigate the website or web app were too complex, participants tended to abandon the website or the application during the study.

3.2.3. Policy and Guidelines

This section is included to prove a point mentioned earlier in the report. Very few studies explicitly link their findings to existing web accessibility policies or guidelines. The studies reviewed here are no exception. In the instances that

guidelines were referenced, authors cited (but did not go into detail about) the WCAG. In the instances that policy was referenced, it was typically in the American context. Thus, very little is known about the real impacts that policies and guidelines for web accessibility in the European context are influencing the lives of people with cognitive disabilities.

3.2.4. Experiences of People with Cognitive Disabilities

The majority of the studies reviewed included data from either interviews, surveys, focus groups, or some combination of the three aimed at gathering participant perceptions of and experiences with web accessibility. Several interesting themes arose from this type of data. Even if the website or web app met the highest WCAG standards, if it was not relevant to or immediately useful for the participants, then participants tended to dislike the website/web app or rate it poorly (Arbelaitz, et.al., 2016; Benda, 2015; Beentjes, et.al., 2020; Oksnebjerg, et.al., 2020). Then, beyond pure accessibility or usability, other things that are important to people with cognitive disabilities, such as opportunities to build community, share their true identities, and share expertise (Andreasean, 2019; Moisey, et.al., 2007). Finally, tools and platforms that serve to replicate existing social hierarchies or systems of exclusion need to be improved. Participants often cited social media sites in comments related to this theme (Gillespie-Lynch, et.al., 2014; Ngubane-Mokiwa, 2021; Zhu, et.al., 2021).

Additional details categorised by disability type are provided below. Please note, while the overarching goal of the LIVE-IT project is to improve web accessibility for people with cognitive disabilities rather than cater to specific sub-groups of that target population, most of the studies reviewed were developed for specific target populations. Thus, accurately interpreting their results involves contextualising the studies through consideration of the characteristics of the study samples.

3.2.5. Studies Involving People with Cognitive Disabilities Broadly Defined

One subset of studies involved participants described as having “intellectual disabilities,” “learning disabilities,” “cognitive disabilities,” “cognitive impairment,” and “mild cognitive impairment.” These studies tended to involve information seeking and information gathering through text-based websites. Balasuriya, et. al. (2021) presented people with cognitive disabilities with web articles in “simplified” and “summarised” form and found that the use of images, familiar words, and larger font sizes influenced participants’ understanding of the information presented. Although most participants found the information easier to read, some participants noted that the experience did not satisfy their desire for knowledge because less information was provided. Karreman, et.al. (2007) also provided participants with two versions of a website (home page only) to pilot an easy-to-read website design, and results showed that the easy-to-read website being piloted seemed to improve participants’ efficiency in seeking and reading information. However, only a single webpage was used, which is typical of the studies reviewed and highlights the need to explore more complex situated in real-world contexts. Rocha, et. al. (2012) also compared multiple types of webpage navigation – text-based and image-based navigation – and results indicated that image navigation increased the speed of task-completion.

Some studies provided more in-depth views of participants’ experiences and delved further into user experience than efficiency and task completion. Moreno, et.al. (2012) highlighted the fact that people with cognitive disabilities often experience frustration associated with errors due to repeatedly clicking on items and perceiving delays in webpage loading as personal errors. Brunskill (2020) spoke with students with learning disabilities and learned that students often relied on Google to proofread search terms, which adds nuance to the understandings of efficiency in information

seeking developed in studies presented above. Namely, the interaction with the link that takes an individual to the information needed is far from the only element in the web accessibility puzzle in online information seeking.

3.2.6. Studies Involving People with Specific Cognitive Disabilities

Within the set of papers reviewed three more specific groups of participants with cognitive disabilities appeared frequently: people with memory issues (i.e. dementia, aging, or concussion), people with autism, and people with dyslexia. Interestingly, studies involving each of these different groups tended to focus on issues of web accessibility related to text. People with concussions (Beaton, et.al., 2021) and people with memory loss related to dementia and/or old age (McCarron, et.al., 2019; Wallcook, et.al., 2019) benefit from the inclusion of audio, video, and picture modes of sharing information. Similarly, people with autism benefit from webpages with limited scrolling and direct navigation pathways (Eraslan, et.al., 2019; Yaneva, et.al., 2019).

The majority of the studies that included a specific group of people with cognitive disabilities explored web accessibility issues for people with dyslexia (de Avelar, et.al., 2015; Gupta, et.al., 2019; Holz, 2021; Krivec, et.al., 2020; Kvikne, 2021; MacFarlane, et.al., 2009; Morris, et.al., 2018; Ophoff, et.al., 2021; Wu, et.al., 2019). These studies all explored elements of text-based webpages or web applications, and highlighted a need for more graphical and/or visual presentation of online information. Overwhelmingly, the studies focused on specific elements of text, such as font size, amount of text, and text color with an emphasis on participant accuracy and comprehension. While these are important areas of study, the focus on such areas leaves gaps in knowledge. Some studies reviewed highlight specific gaps. Morris, et.al. (2018) show that query formulation and refining results in academic searches are barriers for students with dyslexia. Ophoff, et.al. (2021) noted that problems associated with the creation and management of passwords, distorted fonts on CAPTCHA's, and other login-related challenges also created persistent barriers for people with dyslexia.

Additionally, the search returned a few studies involving people with Down Syndrome, people with cerebral palsy, and people with Huntington Disease (Gomez, et.al., 2017; Hahn, et.al., 2018; Lazar, et.al., 2018; Santham, 2012). Generally speaking, these studies focused on the usability of particular tools and/or platforms, which is related to accessibility. Santham (2012) showed that using a Wii remote allowed people with cerebral palsy to more comfortably navigate webpages. Lazar, et.al. (2018) provided an in-depth look at conducting design research with people with Down Syndrome, which contributed to the methodological recommendations in the previous section. Gomez, et. al. (2017) investigated the ways in which an Android app developed to support people with Down Syndrome as they navigated workplace tasks and found that the combination of audio, visual, and haptic information supported participants in task completion.

4. CONCLUSION AND FURTHER DISCUSSION

The Task 1.1 state-of-the-art search developed a baseline for the existing policies and guidelines, empirical investigations, and tools and platforms for web accessibility for people with cognitive disabilities within the academic and grey literature. As noted in the introduction, Task 1.1 supports all other tasks and work packages in the LIVE-IT project in some way. Thus, the results reported above have significant implications for the project as well as the public.

First, in the remainder of Work Package 1, a tools and platforms audit – Task 1.2 – will also feed into the co-design lab development and Open Toolkit. Task 1.1 supported Task 1.2 by producing a list of 41 PDFs that included tools and/or platforms that could potentially be included in the developing tools and platforms catalogue. As noted in the body of

this report, the 41 PDFs specifically related to tools and platforms were not included in the results of the literature review, because the articles did not fit the inclusion criteria. However, the tools and/or platforms included in these PDFs were likely to be of interest in the Task 1.2 catalogue development. Thus, the 41 PDFs were split among partners for entry into a preliminary catalogue for use in Task 1.2. Additionally, all tools and platforms identified in the articles reviewed (i.e. those listed in the results section) were also entered into the preliminary catalogue for Task 1.2. Finally, the fact that many of the tools and platforms located during the Task 1.1 searches were not co-designed with nor have yet to be tested by people with cognitive disabilities highlights the importance of the LIVE-IT co-design goals.

Second, in Work Package 2, the LIVE-IT research consortium is undertaking lifeworld analysis to explore the everyday digital experiences of people with cognitive disabilities and developing scenarios for the four co-design labs. The results of this review frame and provide theoretical backing for the experiences of people with cognitive disabilities collected and analysed during the lifeworld analyses. For example, lifeworld interviews in the UK and Ireland are suggesting that people with cognitive disabilities rely on toggling between Google and other sites or apps as a self-developed work-around to cope with non-accessible web environments, and the academic literature shows that this is an empirically documented barrier for people with cognitive disabilities. The combination of published empirical data and recently collected lifeworld data highlighting a specific challenge is supporting the development of scenarios related to this challenge to be tested in the co-design labs. Additionally, gaps in the literature, namely a lack of co-design and co-evaluation with people with cognitive disabilities, supports the claim that the work to be done in the tasks for Work Package 2 (and beyond) is urgent and necessary. Finally, best practices and methods gleaned from the literature is supporting the practical planning and implementation of lab activities.

Third, in Work Package 3, an Open Toolkit consisting of the tools that allow the four consortium labs to become active co-design spaces will be generated. Because this report has fed directly into Task 1.2 and Work Package 2, it will necessarily influence the development of the Open Toolkit. However, due to the innovative nature of the co-design labs, the Open Toolkit will likely improve upon and alter the methods, tools, and platforms identified in the state-of-the-art baseline and audit.

Fourth, in Work Package 4, the Makerspaces and Hackathons, which build upon the work done in earlier work packages will also necessarily relate back to the academic and grey literature searches reported here. Finally, with respect to Work Package 5, Dissemination, this state-of-the-art search and audit have already produced two manuscripts for review. It is likely that the results reported here will also continue to frame additional manuscripts submitted for publication during the lifetime of the LIVE-IT project.

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

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DELIVERABLE 1.1, ANNEX I: LIVE-IT RESEARCH ETHICS FRAMEWORK

About this Document

This Annex provides the overall framework for implementing and monitoring ethical standards for LIVE-IT as a whole. This includes systems, procedures and tools through which data privacy and protection is implemented in LIVE-IT. In addition, the project has developed ethical procedures and tools for use in the 'Lifeworld Analysis' research implemented in work package 1 of the project. These are provided below. The document is divided into the following Sections:

- Section 1 brifely describes the sources that have been drawn on to develop the ethics framework
- Section 2 describes the LIVE-IT Data Protection and Ethics Monitoring System (DPEMS) – the framework that provides overall co-ordination and systems for DP & Ethics
- Section 3 covers the provisions of the EU General Data Protection regulation (GDPR) and how it is addressed in LIVE-IT
- Section 4 sets out Research Standards, Guidelines and Tools for Research
- Section 5 provides the guidleines and tools used in LIVE-IT's 'Lifeworld Analysis' (LWA).

Section 1: Developing the LIVE-IT Ethics Framework

The LIVE-IT ethics 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 inn 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

Section 2: LIVE-IT Data Protection and Ethics Monitoring System (DPEMS)

Overview

The DPEMS draws its focus and methodology from the frameworks and tools described above in Section 1. In addition it incorporates PRINCE2 processes and systems on risk management, since DP and 'ethical' issues and problems can be seen as a major component of risk for LIVE-IT

The methodology for the DPEMS consists of three elements, shown in Figure 1. These are:

- DP & Ethics Planning
- DP & Ethics Control
- DP & Ethics Register – the 'end product' of the process.

Table 1 summarises these elements in more detail.

As Table 1 shows, the DPEMS starts with a mapping of DP and ethical risks. This entails identifying activities and deliverables in the project that pose DP and ethical questions. On the basis of this mapping, we then need to define what are the criteria that need to be considered for each issue. This feeds into a set of descriptions of each issue, which summarises the potential problems and how these can be resolved. The final element in this first phase of the DPEMS process – the LIVE-IT Ethics Management Strategy – sets out how the process will be carried out.

Figure 1*: The DP & Ethics Monitoring System in LIVE-IT*

Table 1: Summary of the LIVE-IT DPEMS Process

Element	Sub-element	Description
Planning	DP & Ethical issues	List of activities and deliverables that pose issues for each work package
	DP & Ethical risk	List of measurable definitions of risk for each issue
	DP & Ethics management strategy	Describes how the issues will be resolved
Monitoring	DP& Ethics monitoring and management methods	Describes how the monitoring and management activities will be carried out
	DP & Ethics approval and acceptance records	Evidence that the monitoring and management activities are carried out and that each issue has been addressed and resolved
Ethics Register	DP& Ethics Register	Historical 'diary' of DP & Eethics management actions planned and undertaken and their outcomes

The second phase of the process – Monitoring – defines the implementation of this strategy. It specifies the methods for applying the DP & ethics risk assessment criteria and the procedures for recording the outcomes of this assessment.

Finally the DP & Ethics Register integrates all the results of these preceding processes and activities and provides a historical record of the DPEMS Process and its outcomes.

The next Sections set out these elements in more detail.

DP & Ethics Planning

DP & Ethical issues

The process starts with mapping the DP & ethical issues that need to be addressed. This mapping needs to be carried out for all of the LIVE-IT work-packages, covering the constituent Tasks in each and the Deliverables planned for each Task. Each work package leader is responsible for completing the mapping for their work package. The mapping is based on four descriptors:

- Task number – from the Project Workplan
- Task and/or Deliverable name – from the Project Workplan
- The issue 'owner' – who is delegated responsibility for identifying, monitoring and managing the ethics issue
- Issue description – a short summary of the DP & ethics issue that needs to be addressed

The data from the mapping is then transferred to the DP & Ethics Register (see below).

DP & Ethical risk

The risk criteria form a list of measurable definitions of the attributes of the DP & ethics issues that need to be monitored and managed- i.e. a clear indication that the risk has been assessed and can be resolved. They are derived from further breaking down the Ethics Issue Descriptions into specific and measurable attributes. Examples of risk criteria include:

- equal accessibility in participation selection process
- application of data protection procedures
- implementation of procedures on informed consent

The second task is therefore to specify the risk criteria associated with each DP& ethical issue identified. This needs to be done by each ethics issue owner.

DP& Ethics management strategy

The DP & Ethics Management Strategy proposed for LIVE-IT is divided into two elements:

- the 'generic' strategy which covers how DP & Eethics is approached throughout LIVE-IT as a whole, including how the project engages with 'external' stakeholders and actors
- the specific strategy, which covers the approach to DP& ethics internally within the project, i.e. the 'DP & ethics monitoring and management' aspect.

The generic management strategy

The generic management strategy is defined as the procedures and good practices implemented by LIVE-IT and its partners in its relations with external actors. This is based on a set of ethical standards and good practices for conducting research, drawn from a combination of sources outlined above in Section 1, and covering in addition EU and national Directives on data protection.

These standards and good practices need to be adopted in instances where a designated research activity is carried out in LIVE-IT that involves interaction with stakeholders or other actors outside the consortium. For that purpose, a ***DP & Ethics Committee***, will be created to co-ordinate and oversee that the DPEMS adopted in the project is working effectively. The Committee will be composed of:

- The project Co-ordinator
- Three nominated partner representatives.

The task and role of the DP & Ethnics Committee is:

- To ensure the systems and procedures governing Data Protection, Privacy and Ethics – as set out in this Deliverable and Handbook – are put into place
- To meet regularly to review the operation of the system
- To advise and make decisions on any DP & Ethical issue that cannot be resolved by 'risk owners', if necessary by taking appropraiet external advice.

Specific management strategy

There are two elements to the specific management strategy:

- arrangements for adoption and review of the DPEMS
- responsibilities and decision-making

Arrangements for adoption and review

The proposals for adoption and review of the DPEMS are relatively straightforward, as follows:

- initial review of this document by LIVE-IT partners
- production of final version of this document
- adoption of final version of this document
- regular review of the DPEMS by the Ethics Committee

Responsibilities and decision-making

The decision-making and responsibilities structure for the DPEMS is as follows:

- Strategic overview and operational oversight of the DPEMS is provided by the DP & Ethics Committee.
- Specific implementation of the DPEMS is provided by the 'Ethics Issue Owner' for each work package

DP & Ethics Monitoring

This provides for continuous monitoring and management of the DP & ethical issues that have been identified. Every issue identified requires:

- Timely action taken to address the identified issue by the Risk Owner
- A record of the action taken, by whom and when
- A subsequent review of the action taken by a member of the DP & Ethics Committee
- Approval of the action by a member of the DP & Ethics Committee, or referral back to the Owner of the action is not approved
- Subsequent review of the action until the action is approved.

DP & Ethics Register

This provides evidence that the DPEMS is being implemented and the DP& ethical issues that have been identified and addressed. The Register provides a historical record of the DPEMS Process and its outcomes. Responsibility for oversight and maintenance of the DPEMS Register lies with the co-ordinator. However, the Register is located on the Teamworks platfrom, and it is the responsibility of the individuals who carry out ethics monitoring and management activities, and those who finally accept and approve the deliverables, to enter the relevant information in the Register. Table 2 shows the status of the DP & Ethics Register for LIVE-IT at the 6 months stage of the project.

Table 2: LIVE-IT DP & Ethics Register, end September 2021

Issue No.	WP-Task/ N°	WP-Task/ name	Issue description	Owner	Action taken	Reviewed by	Approved by	Approval Date	Status
1	2.1	Lifeworld Analysis	Ensuring that consent is informed consent	NUIG	Students provide consent in writing prior to the meeting date. On the day of the meeting, Sara reads the informed consent information aloud and confirms that the participant consents. Participants are also regularly reminded that they can stop at any time without consequences.	PF	JC	01/09/21	Resolved
2	T2.1	Task 2.1: Lifeworld analysis	Participants asked for more information about the publications of the results	Katerina Katsouli	Discussion was held with all appropriate information explained (all is included in the documentation) (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved
3	T2.1	Task 2.1: Lifeworld analysis	Participants asked whether the collected data are going to be published	Katerina Katsouli	Explained to participants that data will be published and further information given through documentation (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved
4	T2.1	Task 2.1: Lifeworld analysis	Participants asked how will their anonymity be preserved	Katerina Katsouli	We explained that all names are translated into codes (all is included in the documentation) (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved
5	T2.1	Task 2.1: Lifeworld analysis	Teachers and caregivers had concerns about the participation of their beneficiaries	Niki Pandria	Discussion was held with all appropriate information (all is included in the documentation) (consent signed)	Poultourtzidis Ioannis	Prof. Bamidis	Sep-21	resolved
6	T2.1	Task 2.1: Lifeworld analysis	Questions asked about the safety of interacting with the tools provided	Katerina Katsouli	Experts are on site for the whole session / explanations given from experts (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved
7	T2.1	Task 2.1: Lifeworld analysis	Questions asked on whether sessions will be video recorded	Niki Pandria	We explained that no video recording will be conducted (consent signed)	Poultourtzidis Ioannis	Prof. Bamidis	Sep-21	resolved
8	T2.1	Task 2.1: Lifeworld analysis	Questions made about the observation of specialists in the focus group	Katerina Katsouli	We discussed on the purpose of the observation and the reasons for that (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved

Issue No.	WP-Task/ N°	WP-Task/ name	Issue description	Owner	Action taken	Reviewed by	Approved by	Approval Date	Status
9	T2.1	Task 2.1: Lifeworld analysis	Participants asked whether they could leave the session in between	Niki Pandria	As documentation states, we explained them that they could leave the session whenever they want (consent signed)	Poultourtzidis Ioannis	Prof. Bamidis	Sep-21	resolved
10	T2.1	Task 2.1: Lifeworld analysis	Questions made about having breaks	Niki Pandria	We informed them that they could ask for breaks whenever they want (consent signed)	Poultourtzidis Ioannis	Prof. Bamidis	Sep-21	resolved
11	T2.1	Task 2.1: Lifeworld analysis	Participants asked which personal data will be collected	Katerina Katsouli	We explained that under an encoded name (not able to be tracked) we will note their age, diagnosis, education level, city, profession, diagnosis date (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved
12	T2.1	Task 2.1: Lifeworld analysis	Participants asked about withdrawing collected data	Katerina Katsouli	We ensured them that personal collected data will be deleted upon their withdrawn and relevant request (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved
13	T2.1	Task 2.1: Lifeworld analysis	Participants asked us when will the transcripts be destroyed	Niki Pandria	We explained them that they will be preserved for a maximum of 5 years after the end of the project - 31-03-2027 (consent signed)	Savvas Anastasiadis	Prof. Bamidis	Sep-21	resolved
14	T2.1	Task 2.1: Lifeworld analysis	LWA Interviews - participant rights	Arcola Research	accessible, simplified and pictorial versions produced for interviews	GH	JC	Jun-21	resolved
15	T2.1	Task 2.1: Lifeworld analysis	LWA Interviews - participant rights	Arcola Research	Introductory sessions conducted and a gentle lead in carried out with all vulbnerable groups and participants	GH	JC	Jul-21	resolved
16	T2.2	Task 2.2: Scenarios co-design	LWA Interviews - participant rights	Arcola Research	Informed consent read to participants and Q&A sessions conducted with all participants and carers prior to interviews	GH	JC	Jul-21	resolved
17	T2.2	Task 2.2: Scenarios co-design	Presenting emergency scenarios to vulnerable participants	Arcola Research	Individuals, carers, Arcola team consulted and softly softly approach taken, based on information provided by participants and carers.	GH	JC	Aug-21	resolved
18	T2.2	Task 2.2: Scenarios co-design	Data protection concerns	Arcola Research	Arcola equipment and co-lab lead accounts used - no participant data compromised	GH	JC	Aug-21	resolved

Issue No.	WP-Task/ N°	WP-Task/ name	Issue description	Owner	Action taken	Reviewed by	Approved by	Approval Date	Status
19	T2.2	Task 2.2: Scenarios co-design	Informed Consent	Arcola Research	Project presentations and documents produced in a range of formats to accommodate a variety of participants needs	GH	JC	Aug-21	resolved
20	T2.2	Task 2.2: Scenarios co-design	Informed Consent	Arcola Research	simplified and pictorial versions produced to accommodate participant difficulties	GH	JC	Sep-21	resolved
21	T2.2	Task 2.2: Scenarios co-design	Informed Consent	Arcola Research	simplified and pictorial versions produced to accommodate participant difficulties these were read to participants unable to read	GH	JC	Sep-21	resolved
22	T2.2	Task 2.2: Scenarios co-design	Informed Consent	Arcola Research	Consent from carers sought in all appropriate cases, carers present for interviews and co-lab sessions	GH	JC	Sep-21	resolved
23	T2.2	Task 2.2: Scenarios co-design	Safety of participants and Live-IT co-lab team	Arcola Research	All London focus groups, LWA interviews and Co-lab sessions are monitored on CCTV, carers and group leaders present or in sight of all sessions	GH	JC	Sep-21	resolved
24	T2.2	Task 2.2: Scenarios co-design	Travel and personal safety	Arcola Research	All London focus groups, LWA interviews and Co-lab session participants are accompanied or travel arranged by carers or support group leaders	GH	JC	Sep-21	resolved
25	T2.2	Task 2.2: Scenarios co-design	Travel and personal safety	Arcola Research	All sessions conducted in safe premises with staff support and trained H&S staff in support (SCT)	GH	JC	Sep-21	resolved
26	T2.2	Task 2.2: Scenarios co-design	Travel and personal safety	Arcola Research	Individual health and safety issues checked with carers for all participants	GH	JC	Sep-21	resolved

Issue No.	WP-Task/ N°	WP-Task/ name	Issue description	Owner	Action taken	Reviewed by	Approved by	Approval Date	Status
27	T2.2	Task 2.2: Scenarios co-design	Informed consent	Arcola Research	Additional informed consent material and ethics checklist in use - modified versions of Easy Reading templates produced	GH	JC	Sep-21	resolved
28	T2.2	Task 2.2: Scenarios co-design	Data protection concerns	Arcola Research	All identifiable material anonymised, raw data stored on encrypted drives	GH	JC	Sep-21	resolved

Section 3: LIVE-IT: Partner Data Protection Directive and General Data Protection Directive Checklist

Definitions

Personal data

"Personal data" means any information relating to an identified or identifiable natural person ("data subject"); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to **an identifier** such as a name, an identification number, **location data**, online identifier or to one or more factors specific to the physical, physiological, **genetic**, mental, economic, cultural or social identity of that person. **Rec.26; Art.4(1)**

Sensitive Personal Data

"Sensitive Personal Data" are personal data, revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership; data concerning health or sex life and sexual orientation; **genetic data or biometric data**. Data relating to criminal offences and convictions are addressed separately (as criminal law lies outside the EU's legislative competence). **Rec.10, 34, 35, 51; Art.9(1)**

Anonymised data

The GDPR does not apply to data that are rendered anonymous in such a way that individuals cannot be identified from the data. Data that are fully anonymised (i.e., data from which no individuals can be identified) are outside the scope of both the Directive and the GDPR. **Rec.26**

Data Processing

"Processing" means any operation or set of operations performed upon personal data or sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction. **Art.4(2)**

Data Controller

"Controller" means the natural or legal person, public authority, agency or any other body which alone or jointly with others determines the purposes and means of the processing of personal data; where the purposes and means of processing are determined by EU or Member State laws, the controller (or the criteria for nominating the controller) may be designated by those laws. **Art.4(7)**

Data Processor

"Processor" means a natural or legal person, public authority, agency or any other body which processes personal data on behalf of the controller. **Art.4(8)**

Informed Consent

"The consent of the data subject" means any freely given, specific, informed **and unambiguous** indication of his or her wishes by which the data subject, **either by a statement or by a clear affirmative action**, signifies agreement to personal data relating to them being processed. **Rec.32; Art.4(11)**

Data breach

"Data breach" means a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data transmitted, stored or otherwise processed. **Art.4(12)**

Health Data

"Data concerning health" means **personal data relating to the physical or mental health of an individual, including the provision of health care services, which reveal information about his or her health status.** It expressly covers both physical and mental health. **Rec. 35, 53-54; Art.4(15)**

Checklist: compliance with GDPR for Data Controllers

1. Lawfulness, fairness and transparency		
Requirement	**What this means**	**Implemented**
1.1 Information audit to map data flows	This will identify the data that you process and how it flows into, through and out of your organisation. It will identify risks	☐ Yes ☐ No ☐ Not applicable
1.2 Documented what personal data you hold, where it came from, who you share it with and what you do with it.	Complies with GDPR's accountability principle, which requires you to be able to show how you comply with the GDPR principles, for example by having effective procedures and guidance for staff	☐ Yes ☐ No ☐ Not applicable
1.3 Identified your lawful bases for processing and documented them	There are six available lawful bases for processing. **a) Consent:** the individual has given clear consent for you to process their personal data for a specific purpose. **(b) Contract:** the processing is necessary for a contract you have with the individual, or because they have asked you to take specific steps before entering into a contract. **(c) Legal obligation:** the processing is necessary for you to comply with the law (not including contractual obligations). **(d) Vital interests:** the processing is necessary to protect someone's life. **(e) Public task:** the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law. **(f) Legitimate interests:** the processing is necessary for your legitimate interests or the legitimate interests of a third party unless there is a good reason to protect the individual's personal data which overrides those legitimate interests. (This cannot apply if you are a public authority processing data to perform your official tasks.)	☐ Yes ☐ No ☐ Not applicable
1.4 Review how you ask for and record consent	The GDPR sets a high standard for consent. Consent requires a positive opt-in. Use unticked opt-in boxes or similar active opt-in methods. Keep records of what an individual has consented to. Tell individuals they can withdraw consent at any time and how to do this.	☐ Yes ☐ No ☐ Not applicable
1.5 Systems in place for Consent to process children's personal data for online services	If you offer online services to children and you rely upon consent, only a child aged 13 or over will be able to provide their own consent.	☐ Yes ☐ No ☐ Not applicable
1.6 Registered with the relevant national Data Protection Authorities	Member states require organisations to register with national Data Protection Authorities	☐ Yes ☐ No ☐ Not applicable
2. Individuals' rights		
Requirement	**What this means**	**Implemented**
2.1 Right to be informed including privacy notices	Individuals need to know that their data is collected, why it is processed and who it is shared with. You should publish this information in your privacy notice on your website and within any forms or letters you send to individuals.	☐ Yes ☐ No ☐ Not applicable

2.2 Communicate the processing of children's personal data	You must provide children with the same fair processing information as you give adults. It will be good practice to also explain the risks involved in the processing and the safeguards you have put in place.	☐ Yes ☐ No ☐ Not applicable
2.3 Right of access	Individuals have the right to obtain: * confirmation that their data is being processed; * access to their personal data; and * other supplementary information – this largely corresponds to the information that you should be provide in a privacy notice.	☐ Yes ☐ No ☐ Not applicable
2.4 Right to rectification and data quality	Individuals have the right to have personal data rectified if it is inaccurate or incomplete. You should respond to a request without delay and at least within one month of receipt	☐ Yes ☐ No ☐ Not applicable
2.5 Right to erasure including retention and disposal	Individuals have the right to be forgotten and can request the erasure of personal data when: * it is no longer necessary in relation to the purpose for which it was originally collected/processed; * the individual withdraws consent; * the individual objects to the processing and there is no overriding legitimate interest for continuing the processing; * it was unlawfully processed (ie otherwise in breach of the GDPR); * it has to be erased in order to comply with a legal obligation; or * it is processed in relation to the offer of information society services to a child	☐ Yes ☐ No ☐ Not applicable
2.6 Right to restrict processing	Individuals have a right to block or restrict the processing of personal data. When processing is restricted, you are permitted to store the personal data, but not further process it.	☐ Yes ☐ No ☐ Not applicable
2.7 Right of data portability	The right to data portability allows individuals to obtain and reuse their personal data for their own purposes across different services. They can receive personal data or move, copy or transfer that data from one business to another in a safe and secure way, without hindrance	☐ Yes ☐ No ☐ Not applicable
2.8 Right to object	Individuals have the right to object to: * processing based on legitimate interests or the performance of a task in the public interest/exercise of official authority (including profiling); and * processing for purposes of scientific/historical research and statistics.	☐ Yes ☐ No ☐ Not applicable
2.9 Rights related to automated decision making including profiling	The GDPR provides safeguards for individuals against the risk that a potentially damaging decision is taken without human intervention.	☐ Yes ☐ No ☐ Not applicable
3. Accountability and governance		
Requirement	**What this means**	**Implemented**
3.1 Accountability - appropriate data protection policy	This can be a standalone policy statement or part of a general staff policy. The policy should clearly set out your approach to data protection together with responsibilities for implementing the policy and monitoring compliance	☐ Yes ☐ No ☐ Not applicable
3.2 Data processor contracts	Whenever you use a processor you need to have a written contract in place.	☐ Yes ☐ No ☐ Not applicable

3.3 Information risks	You should set out how you (and any of your data processors) manage information risk	☐ Yes ☐ No ☐ Not applicable
3.4 Data Protection by Design	Under the GDPR, you have a general obligation to implement appropriate technical and organisational measures to show that you have considered and integrated data protection into your processing activities	☐ Yes ☐ No ☐ Not applicable
3.5 Data Protection Impact Assessments (DPIA)	You must carry out a DPIA when: * using new technologies; and * when the processing is likely to result in a high risk to the rights and freedoms of individuals	☐ Yes ☐ No ☐ Not applicable
3.6 Data Protection Officers	Any organisation can appoint a DPO but you must do so if you: * are a public authority (expect for courts acting in the judicial capacity); * carry out large scale systematic monitoring of individuals (eg online behaviour tracking); or * carry out large scale processing of special categories of data or data relating to criminal convictions and offences.	☐ Yes ☐ No ☐ Not applicable
3.7 Management Responsibility	You should make sure that decision makers and key people in your organization are aware of the requirements under the GDPR.	☐ Yes ☐ No ☐ Not applicable
4. Data security, international transfers and breaches		
Requirement	**What this means**	**Implemented**
4.1 Security policy	You should process personal data in a manner that ensures appropriate security. establish and implement a robust Information Security policy which details your approach to information security, the technical and organisational measures that you will be implementing and the roles and responsibilities staff have in relation to keeping information secure	☐ Yes ☐ No ☐ Not applicable
4.2 International transfers	Personal data may only be transferred outside of the EU in compliance with the conditions for transfer set out in Chapter V of the GDPR	☐ Yes ☐ No ☐ Not applicable
4.3 Breach notification	The GDPR introduces a duty on all organisations to report certain types of personal data breaches to the ICO and, in some cases, to the individuals affected. A personal data breach means a breach of security leading to the destruction, loss, alteration, unauthorised disclosure of, or access to, personal data. You only have to notify the ICO of a breach where it is likely to result in a risk to the rights and freedoms of individuals.	☐ Yes ☐ No ☐ Not applicable

Checklist: compliance with GDPR for Data Processors

1. Documentation		
Requirement	**What this means**	**Implemented**
1.1 Information audit to map data flows	This will identify the data that you process and how it flows into, through and out of your organisation. It will identify risks	☐ Yes ☐ No ☐ Not applicable
1.2 Documented what personal data you hold, where it came from, who you share it with and what you do with it.	Complies with GDPR's accountability principle, which requires you to be able to show how you comply with the GDPR principles, for example by having effective procedures and guidance for staff	☐ Yes ☐ No ☐ Not applicable
2. Accountability and governance		
Requirement	**What this means**	**Implemented**

2.1 Accountability – appropriate data protection policy	This can be a standalone policy statement or part of a general staff policy. The policy should clearly set out your approach to data protection together with responsibilities for implementing the policy and monitoring compliance	☐ Yes ☐ No ☐ Not applicable
2.2 Data Protection Officers	Any organisation can appoint a DPO but you must do so if you: * are a public authority (expect for courts acting in the judicial capacity); * carry out large scale systematic monitoring of individuals (eg online behaviour tracking); or * carry out large scale processing of special categories of data or data relating to criminal convictions and offences.	☐ Yes ☐ No ☐ Not applicable
2.3 Management Responsibility	You should make sure that decision makers and key people in your organization are aware of the requirements under the GDPR.	☐ Yes ☐ No ☐ Not applicable
2.4 Information risks	You should set out how you (and any of your data processors) manage information risk	☐ Yes ☐ No ☐ Not applicable
2.5 Data Protection by Design	Under the GDPR, you have a general obligation to implement appropriate technical and organisational measures to show that you have considered and integrated data protection into your processing activities	☐ Yes ☐ No ☐ Not applicable
2.6 Data Protection Impact Assessments (DPIA)	You must carry out a DPIA when: * using new technologies; and * when the processing is likely to result in a high risk to the rights and freedoms of individuals	☐ Yes ☐ No ☐ Not applicable
2.7 Training and awareness	The organization provides data protection awareness training for all staff	☐ Yes ☐ No ☐ Not applicable
2.8 Use of sub-processors	You need to get written authorisation from the data controller before engaging the services of a sub-processor.	☐ Yes ☐ No ☐ Not applicable
2.9 International transfers	Personal data may only be transferred outside of the EU in compliance with the conditions for transfer set out in Chapter V of the GDPR. If you operate outside the EU you need to have appointed a representative within the EU in writing.	☐ Yes ☐ No ☐ Not applicable
2.10 Breach notification	The GDPR introduces a duty on all organisations to report certain types of personal data breaches to the ICO and, in some cases, to the individuals affected. A personal data breach means a breach of security leading to the destruction, loss, alteration, unauthorised disclosure of, or access to, personal data. You only have to notify the ICO of a breach where it is likely to result in a risk to the rights and freedoms of individuals.	☐ Yes ☐ No ☐ Not applicable
3. Individual rights		
Requirement	**What this means**	**Implemented**
3.1 Right of access	There needs to be a process to respond to a data controllers request for information (following an individuals' request to access their personal data).	☐ Yes ☐ No ☐ Not applicable
3.2 Right to rectification and data quality	There needs to be a process to ensure that the personal data held remains accurate and up to date.	☐ Yes ☐ No ☐ Not applicable
3.3 Right to erasure including retention and disposal	There needs to be a process to routinely and securely dispose of personal data that is no longer required	☐ Yes ☐ No ☐ Not applicable

3.4 Right to restrict processing	There needs to be a process to respond to a data controllers' request to suppress the processing of specific personal data.	☐ Yes ☐ No ☐ Not applicable
3.5 Right of data portability	The right to data portability allows individuals to obtain and reuse their personal data for their own purposes across different services. They can receive personal data or move, copy or transfer that data from one business to another in a safe and secure way, without hindrance	☐ Yes ☐ No ☐ Not applicable
4. Data security		
Requirement	**What this means**	**Implemented**
4.1 Security policy	You should process personal data in a manner that ensures appropriate security. establish and implement a robust Information Security policy which details your approach to information security, the technical and organisational measures that you will be implementing and the roles and responsibilities staff have in relation to keeping information secure	☐ Yes ☐ No ☐ Not applicable

Section 4: LIVE-IT Research Standards Policy and Guidelines

4.1. Overall Approach and Guidelines for Research

LIVE-IT promotes the principles of integrity in scientific and scholarly research incorporated in a range of frameworks, standards and guidelines as set out in Section 1 above, including the European Science Foundation European Science Foundation Code of Conduct https://www.esf.org/fileadmin/user_upload/esf/ResearchIntegrity_Report2011.pdf

Honesty in communication	**Openness and accessibility**
Reliability in performing research	**Duty of care**
Objectivity	**Fairness in providing references and giving credit**
Impartiality and independence	**Responsibility for the scientists and researchers of the future**

The LIVE-IT research project team works under the general ethics orientation to Do No Harm (non-maleficence) and Do Good (beneficence) in its engagement with research participants.

LIVE-IT also follows the principles and guidelines set out in the UK Economic and Social Research Council (ESRC) 'Research Ethics Framework' (2015). This incorporates six principles that are built into research design and practice.

1 Research should be designed, reviewed and undertaken in a way that ensures its integrity and quality

The research needs to be accountable. In practice, all members of the research team are required to:

- carry out the research activities in accordance with the project proposal, its objectives and workplan
- complete time sheets setting out the tasks carried out and the time taken to do them
- inform the project Director if and when any issues crop up around confidentiality; project delays; problems militating against completion of tasks

The research needs to be of sufficient quality. In practice this means that all members of the research team are required to implement the Quality Assurance procedures set out in Section 2.2.2 below.

2 Research staff and subjects must be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved.

In practice this means that all members of the research team need to operate under the principle of 'informed consent'. The primary objective is to conduct research openly and without deception.

The guidelines on informed consent are as follows:

- Contact details of a member of the research team will be made available to any respondent or subject who wishes to make a query about the research
- In the case of working directly with vulnerable people every effort should be made by members of the research team to deal with consent through dialogue with vulnerable people, young people and their parents (or legal equivalent)

3. The confidentiality of information supplied by research subjects and the anonymity of respondents must be respected

The guidelines on confidentiality are as follows:

- A confidentiality statement will be prominently displayed on all research instruments and schedules used in this research. All members of the research team are obliged to make this statement available to any respondent or subject involved in the research and to ensure that respondents and subjects give their consent to participating.
- The research will conform to the legal provisions on data protection that apply in all countries in which the research is carried out and with Directive 95/46/EC: Article 8 (1) and the forthcoming Data Protection Regulation Article 9 (1) - General Data Protection Regulation – (GDPR).

4. Research participants must participate in a voluntary way, free from any coercion

The guidelines on participation in research studies are as follows:

- Researchers should inform subjects of their right to refuse to participate or withdraw from the investigation whenever and for whatever reason they wish.
- There should be no coercion of research subjects to participate in the research.
- An Informed Consent statement must be provided to participants and their consent obtained, normally through them signing an Informed Consent Form.

5. Harm to research participants must be avoided

The research should be conducted in such a way that it minimizes harm or risk to social groups or individuals. In practice this means:

- The project coordinator and partners responsible for research activities will inform all members of the research team when any risks to members of the team are likely to be encountered ; what form those risks will take and what measures need to be put into place to reduce risks
- The research team members will inform the project team leader of Director when any risks to members of the team are likely to be encountered

6. The independence and impartiality of researchers must be clear, and any conflicts of interest or partiality must be explicit

The research should be conducted so as to ensure the professional integrity of its design, the generation and analysis of data, and the publication of results, while the direct and indirect contributions of colleagues, collaborators and others should also be acknowledged.

In practice this means:

- The project partners responsible for research activities will inform the project co-ordinator of any conflict of interest (which may be personal, academic or commercial) arises during the course of the study
- Members of the research team should inform the project Director if any external agency, including the client, makes an approach to them that could compromise the integrity of the research
- All reports and publications arising from the research will acknowledge the contribution of those members of the research team and any other parties who were involved in the work

The above principles and Guidelines together constitute the LIVE-IT 'Code of Conduct' which partners and their representatives are required to sign up to. The Code is provided in Section 5 below.

4.2. Management of the research and Quality Assurance Procedures

4.2.1 Contract Management Arrangements

The overall contract management for research assignments will be undertaken by a named partner staff member who will implement the following management tasks:

- Regular liaison with the client including progress reporting
- Attendance at the client meetings specified in the contract
- Management of time recording procedures and templates for the contract
- Co-ordination of monthly research team meetings over the duration of the contract

4.2.2 Research Standards and Quality

Research activities carried out by LIVE-IT partners and their staff will follow procedures that incorporate well-established research and evaluation standards including the UK Quality Assurance Agency (QAA); the British Educational Research Association; the British Psychological Society and the Economic and Social Research Council (ESRC) Research Ethics Framework – that incorporates relevant national and EC legislation governing ethics (EU Charter of Fundamental Rights; Directives on data protection; Helsinki Declaration on Human Rights) and on Data privacy and Protection. In addition, the project implements a Project Management and Quality Assurance process – set out in Deliverable 5.2 – that incorporates well-established research and evaluation standards including the UK Quality Assurance Agency (QAA);

4.2.3 Data Protection and Data Privacy

Collection and analysis of data has to follow the EU Directive 95/46/EC: Article 8 (1) and the Data Protection Regulation Article 9 (1) - General Data Protection Regulation – set out in detail in Section 3 above - and relevant national legislation. The key principles are set out below.

Directive 95/46/EC: Article 8 (1) "*Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life*".

Data Protection Regulation Article 9 (1) "*The processing of personal data, revealing race or ethnic origin, political opinions, religion or beliefs, trade-union membership, and the processing of genetic data or data concerning health or sex life or criminal convictions or related security measures shall be prohibited*".

EU and national data protection directives and regulations create srights for those who have their data stored, and responsibilities for those who store, process or transmit such data. The person who has their data processed has the right to:

- View the data an organisation holds on them.
- Request that incorrect information be corrected.
- Require that data is not used in any way that may potentially cause damage or distress.
- Require that their data is not used for direct marketing

The data protection and privacy principles that must be maintained in research are:

- Personal data shall be processed fairly and lawfully
- Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.

- Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.
- Personal data shall be accurate and, where necessary, kept up to date.
- Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes.
- Personal data shall be processed in accordance with the rights of data subjects (individuals).
- Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.
- Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

4.3 Checklist for implementing and monitoring research ethics and standards

The following research standards checklist should be used throughout execution of any research activities.

Research should be designed, reviewed and undertaken in a way that ensures its integrity and quality				
	Yes	**No**	**n/a**	**Comments/Actions taken**
Have the research activities been carried out in accordance with the project proposal, its objectives and workplan?				
Have completed time sheets setting out the tasks carried out and the time taken to do them been used?				
Has the WP leader been informed if and when any issues crop up around confidentiality; project delays; problems militating against completion of tasks?				
Has the relevant ethical risk management system been implemented for this activity?				
Has the relevant quality plan item been implemented for this activity?				
*Research staff and subjects must be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved***.**				
	Yes	**No**	**N.A.**	**Comments/Actions taken**
Have contact details of a member of the research team been made available to any respondent or subject who wishes to make a query about the research?				
Have relevant measures been implemented to deal appropriately with informed consent – particularly vulnerable people' or 'dependent people' who are unable to give their informed consent, including a relevant Informed Consent Statement and Form?				
The confidentiality of information supplied by research subjects and the anonymity of respondents must be respected				
	Yes	**No**	**N.A.**	**Comments/Actions taken**
Has a confidentiality statement been prominently displayed on all research instruments and schedules used in this research.				

Have the legal provisions on data protection that apply in all countries in which the research is carried out been implemented?				
Research participants must participate in a voluntary way, free from any coercion				
	Yes	**No**	**N.A.**	**Comments/Actions taken**
Will/Have researchers informed participants of their right to refuse to participate or withdraw from the investigation whenever and for whatever reason they wish?				
Will/Have any participants been coerced into participating in the research. Has the informed consent form, which sets out participants rights not to participate, been issued, explained and endorsed by the participants?				
Harm to research participants must be avoided				
	Yes	**No**	**N.A.**	**Comments/Actions taken**
Will/Has the WP leader informed all members of the research team when any risks to members of the team are likely to be encountered ; what form those risks will take and what measures need to be put into place to reduce risks?				
Will/Have the research team members informed the WP leader when any risks to members of the team are likely to be encountered?				
The independence and impartiality of researchers must be clear, and any conflicts of interest or partiality must be explicit				
	Yes	**No**	**N.A.**	**Comments/Actions taken**
Will/Has the WP leader informed the project co-ordinator if or when any conflict of interest (which may be personal, academic or commercial) arises during the course of the research?				
Have members of the research team been instructed to inform the project Director if any external agency, including the client, makes an approach to them that could compromise the integrity of the research. Have any such occasions occurred?				
Has a policy and procedure been put in place to register and deal with conflicts of interest?				
Do all reports and publications arising from the research acknowledge the contribution of those members of the research team and any other parties who were involved in the work?				

4.4. Examples of tools and templates for implementing the Guidelines

4.4.1 Informed Consent Form

The Informed Consent Form is a key tool in ensuring the GDPR requirements and the LIVE-IT Research Standards are implemented. It should be produced in language and terms understandable to research participants and contain the following information:

- Purpose of the LIVE-IT project and invitation to participate
- Introduction to and summary of the research

- Statement setting out that participation is voluntary
- Statement setting out how participants will be involved and what they are expected to contribute
- Benefits of participation in the project
- Procedures for answering participants questions about involvement
- Possible Risks and Potential Problems
- How Risks and Problems will be addressed
- Procedures that will be implemented in the case of incidental findings
- Statement on Participants Rights
- Statement on LIVE-IT responsibilities to participants
- How participants will be protected including insurance arrangements, if appropriate
- Right to refuse and withdraw themselves and their data from the project at any time
- Privacy and Confidentiality protection
- Commercial exploitation of project results
- Further information and contact points
- Information concerning how their data will be collected, protected during the project and either destroyed or reused at the end of the research, if plan to reuse the data exists, participants will be duly informed, and consented also for this further usage.

A Template is shown below.

LIVE-IT: INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS

Project information:

Sponsor:	European Commission, DG-CNCT
Project coordinator:	Arcola Research, London
Project Contact:	
Phone:	
email:	

This Informed Consent Form consists of two parts:

- Information Sheet about the LIVE-IT project
- Certificate of Consent to record your agreement to participants

PART I: INFORMATION ABOUT THE LIVE-IT PROJECT

What are the aim and objectives of LIVE-IT?

LIVE-IT - Living Labs and Open Toolkit for the co-design of accessible IT systems and tools – is a project funded under the EU's 'Pilot Projects & Preparatory Actions (PPPA)' programme. It's main aim is to improve access to digital platforms and tools for people with cognitive disabilities. The main objective is to set up co-design Labs – supported by an online community – involving mixed teams of users (people with cognitive disabilities) and designers - to develop an 'Open Toolbox' to support independent and inclusive access to online content and services.

Who is involved?

LIVE-IT is a partnership involving:

- Aristotelio Panepistimio Thessalonikis (AUTH), Greece
- Arcola Research LLP (ARC), United Kingdom
- National University Of Ireland Galway (NUIG)
- Universidade Catolica Portuguesa (UCP), Portugal

What does participation in LIVE-IT involve?

LIVE-IT combines a range of research activities. These activities involve collecting data and other information, for example, collecting information using various methods including interviews or group interviews or filling questionnaires. LIVE-IT will also involve people as 'co-designers' in its Co-Design Labs.

Possible risks and potential problems

None of the activities in LIVE-IT involve situations that are likely to cause physical harm to participants. The potential risks are very low and could involve

- problems with timing and participation during the project (participants may be asked to collaborate in an activity at an unsuitable time, or may feel they want to drop out of the project altogether),
- issues with the technology platforms and tools used (participants might experience challenges in using the tools),
- issues around confidentiality and protection of personal information
- unexpected issues not foreseen.

Possible benefits

Educators who take part in LIVE-IT have the opportunity to take part in a leading European project that will make a contribution to improving access to the digital world for people with cognitive disabilities and to reducing social exclusion.

Financial considerations

Participation in LIVE-IT is completely free. Participants will not and cannot be charged any fee.

Right to refuse and withdraw

Participants join the LIVE-IT project voluntarily. As a participant you have the right to withdraw from the project at any time, without providing any reason for your withdrawal. You may indicate that you wish to withdraw consent verbally or in writing; by telephone, face-to-face, in an e-mail, text or letter.

Participants may be asked about their experiences of participating in LIVE-IT when they decide to withdraw – but this is entirely voluntary.

If the activity you are participating in involves audio or video recording, you can at any time during the study ask the interviewer to stop, start or rewind the tape. You can request that content is erased.

Privacy & Confidentiality

Your identity and details in this project will be treated as confidential. The results of the research may be published for scientific purposes but will not give your name or include any identifiable references to you.

Information collected from the participants in LIVE-IT is held according to relevant EU and national laws on confidentiality and data protection.

The collected raw data (e.g. notes, information resource material, video/audio recordings) will be stored securely, and access will only be given to those responsible for analysing the data in the project consortium.

On mobile devices, identifiable data (including recordings of participants' voices) will be encrypted. If it cannot be encrypted, identifiable data on mobile devices will be deleted as quickly as possible and in the meantime the device(s) will be stored securely. On mobile devices, identifiable data (including recordings of participants' voices) will be encrypted. If it cannot be encrypted, identifiable data on mobile devices will be deleted as quickly as possible and in the meantime the device(s) will be stored securely.

At the end of the project's all collected data, including video and audio recordings, will be kept securely and accessible, controlled by the researchers at the organizations above for up to five years.

Further information about the project

Official website of LIVE-IT:

Local contact point(s)/ Information at national level and contacts for any concerns about the project

Name of Partner:
Address of Partner:
Phone:
Person responsible
national level:
Phone:
E-mail:
Partner's website:

PART II: CERTIFICATE OF CONSENT

Statement by the Participant

1. **I consent to participate in the LIVE-IT project. I have been provided with a copy of this Informed Consent Form and any questions I have asked have been answered to my satisfaction.**
2. **In relation to this project:**
   - I agree to be interviewed by the researchers.
   - I agree to allow the interview to be recorded by an electronic device.
   - I agree to complete questionnaires asking me about my opinions on the project.
   - I agree to allow LIVE-IT researchers to access and analyse information from my social media activities that I consider to be relevant to the objectives of the project (if relevant).
3. **I acknowledge that:**

(a) my participation is voluntary and that I am free to withdraw from the project at any time without explanation;

(b) the LIVE-IT project is for the purpose of research and not for profit;

(c) any identifiable information about me which is gathered in the course of and as the result of my participating in this project will be (i) collected and retained for the purpose of this project and (ii) accessed and analysed by the researchers for the purpose of conducting this project;

(d) my anonymity is guaranteed and I will not be identified in publications or otherwise without my express written consent.

By signing this document I agree to participate in this project.

Participant Name
(in capitals)

Telephone

Email

Signature

Date

Statement by the representative of the Partner taking consent

1. I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the purpose of the LIVE-IT project and the content of the Informed Consent Form.

2. I confirm that the participant was given an opportunity to ask questions about the nature and manner of participating in the LIVE-IT project, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

3. A copy of this ICF has been provided to the participant.

Name of Representative	
Name of Partner	
Email	
Signature	
Date	

4.4.2 Code of Conduct Confirmation

By filling out the form below, you confirm that you have read and understood the LIVE-IT Research Standards Policy and Guidelines and agree to adhere to its principles.

Name of Representative	
Name of Partner	
Email	

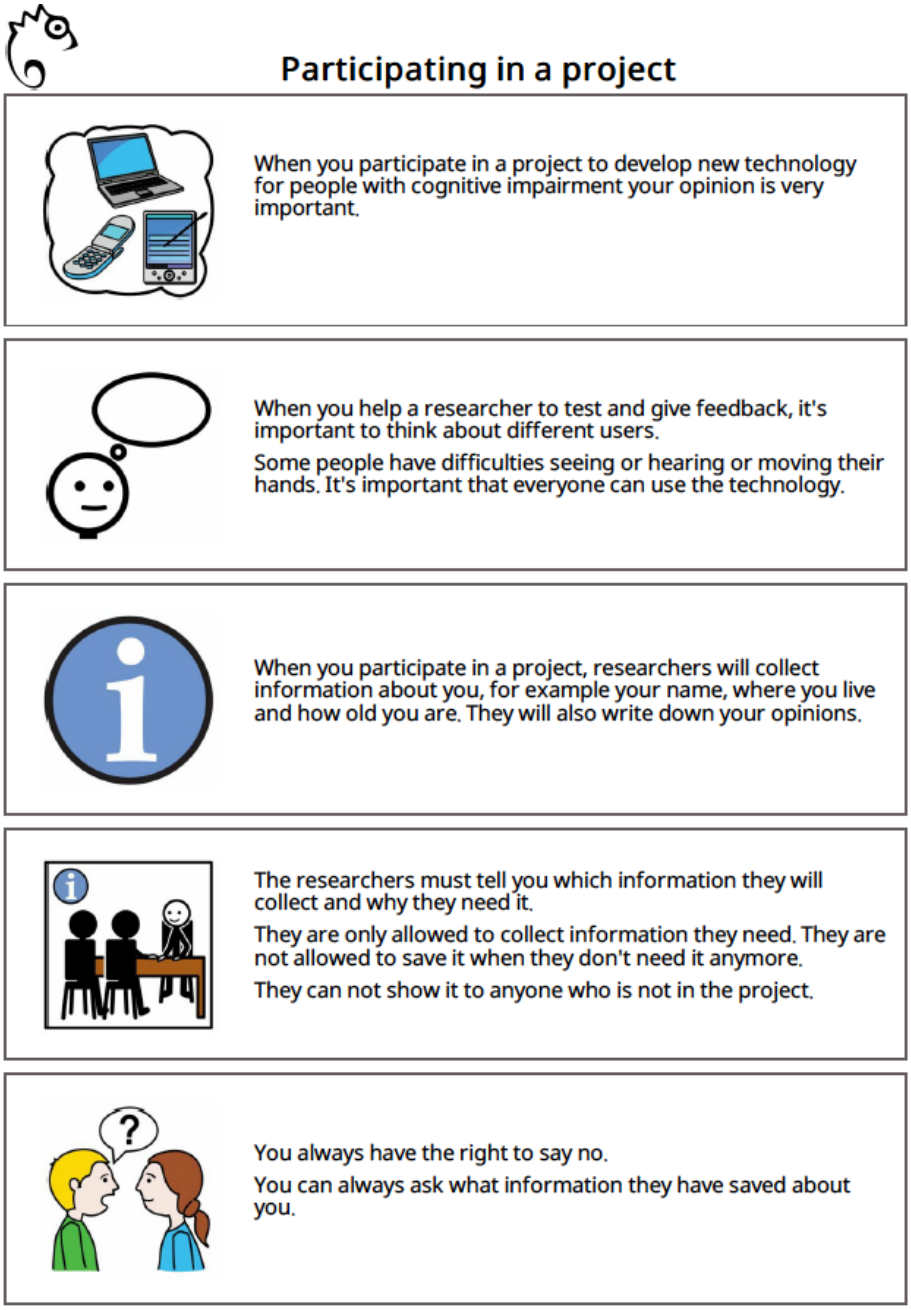
Signature	
Date	

Section 5: Ethical procedures and tools applied in LIVE-IT activities

This section illustrates how the DP & Ethics framework, system and tools set out above were applied in practice to implement LIVE-IT's 'Lifeworld Analysis' activities in work package 1 and preliminary work in the LIVE-IT 'Co-Labs' in work package 2. These frameworks, systems and tools were also shaped by good practice examples in research with vulnerable people, including people with cognitive disabilities, for example from the 'EasyReading' project.

Participation in a project leaflet

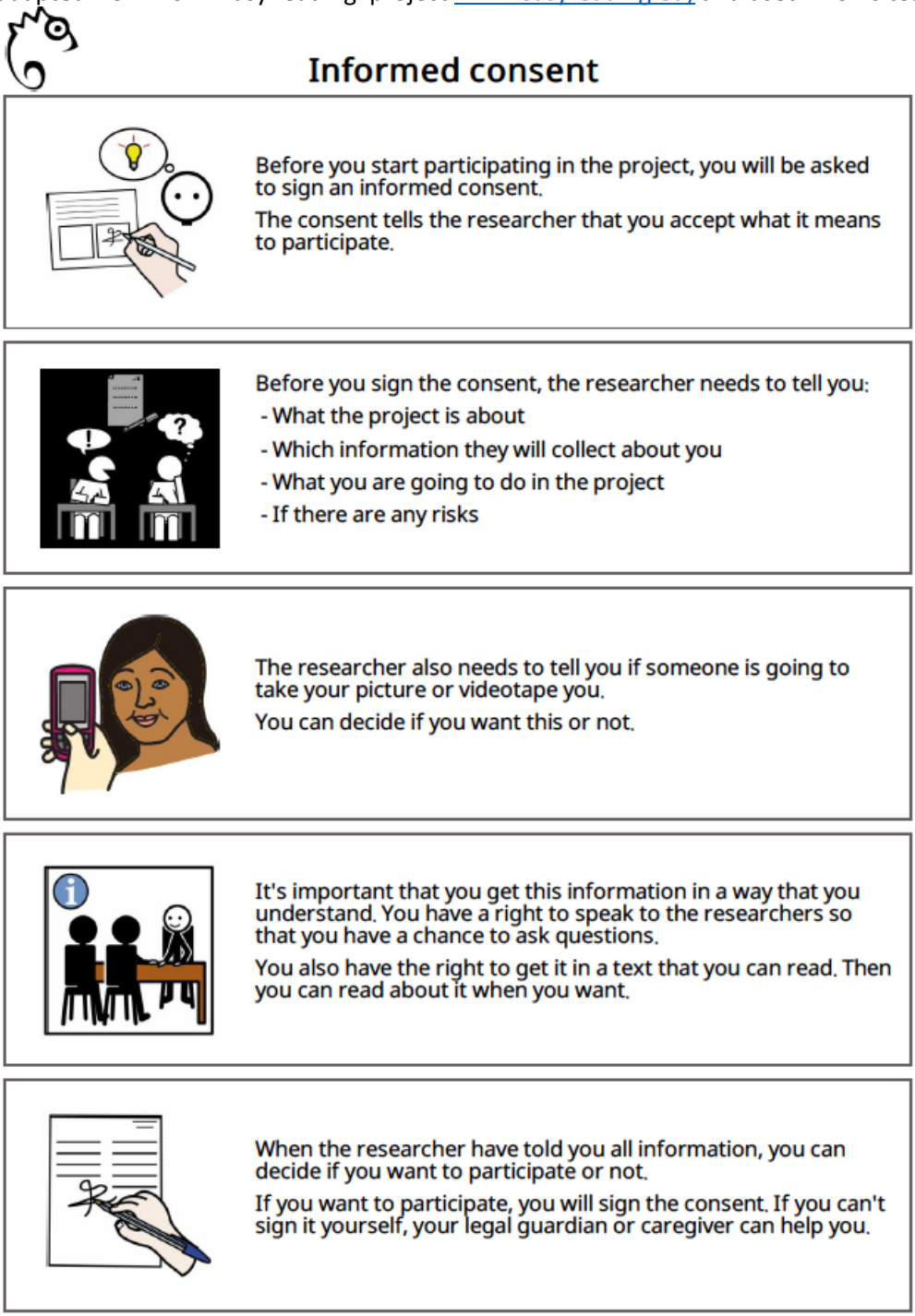
(adapted from 'EasyReading' project [www.easyreading.eu)](http://www.easyreading.eu) and used in UK sites



Informed Consent Tools

Graphical informed consent leaflet

(adapted from from 'EasyReading' project www.easyreading.eu) and used in UK sites



Informed Consent Form adapted with EasyReader

Used in UK sites

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

This consent form adapted with thanks from the Easy Read Project

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

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 ☐YES☐NO

(place, date)

(signature) _____

(if necessary, signature legal representative) _____

Informed Consent and Interview Scheduler

Used in Galway site

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

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.

1. Your Name: *

2. Your Email: *

Information and Consent Form

Used in Athens

ΑΡΙΣΤΟΤΕΛΕΙΟ
ΠΑΝΕΠΙΣΤΗΜΙΟ
ΘΕΣΣΑΛΟΝΙΚΗΣ

INFORMATION AND CONSENT FORM [1]

Version 5.0, 1 September 2021

I. INFORMATION OF INTERESTED IN PARTICIPANTS

Name of the Study:	LIVE-IT and Open Toolkit for the joint design of accessible IT systems and tools (LIVE-IT) - Interviews and group discussions
Scientific responsible:	Prof. Panagiotis Bamidis
Funding Agency:	European Commission
Editor (Responsible for processing data)	**Aristotle University of Thessaloniki (AUTH)**

Details of communication of the person in charge of the study:

Prof. Panagiotis Bamidis
Email: pdbamidis@gmail.com
Phone: +302310999310
Post Address: Medical Physics and Digital Innovation Lab, School of Medicine, AUTH Thessaloniki – 54124, GREECE

Data Protection Officer (DPO): data.protection@auth.gr

Important information:

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: Why are we conducting 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.

Participation is voluntary: Do I have to do it?

Participation in the research is voluntary. You do not need to participate in the study if you choose not to. Even, if you give your consent now, you can change your mind later withdrawing your consent.

Cost of participation: What will my participation in the study cost me?

There is no participation cost in this study.

Procedure: What will happen if you finally choose to participate?

If you choose to participate in the survey, you will be invited to participate in an interview that will take approximately 30 minutes. Alternatively, you will be invited to participate in a focus group discussion, which will have an estimated duration of about 60 minutes, with topics related to "digital everyday life". In this context, "activation questions" will be conducted aiming at guiding the discussion that will take place. The interview or discussion within the focus group will be conducted, either face-to-face or online, through the MS TEAMS application or other similar conference system, approved by the partner organizations of the LIVE-IT project, for use within their cases. During the focus group conferences, notes will be kept by the researchers, as part of the research data that will emerge from the collaborative process. Those who participate in the second interviews about the use of the digital toolkit, will use a toolkit for a few minutes to then discuss with us about its usability and the facility that it provided to your interaction with digital technologies to us help optimize it. The conversation may be recorded. In this case, it will be transcribed and pseudonymized before any analysis is performed by the LIVE-IT project researchers. The 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 interviews / group discussions related to the toolkit).

Data: What data will be collected and how long will it be retained?

In the event that the focus group interview or discussion is recorded, the recordings will be transcribed. The data and information that will result will be kept, at least until the projected end of the project (31-03-2022), with the maximum retention period, to be set up to five (5) years, after the end of the project (31-03-2027), for verification purposes.

Data: Who will receive or to whom will the personal data collected be distributed?

Personal data will not be transferred to a third country or to an international organization.

Risks: Is my participation in the project procedures dangerous for me?

Your participation is judged not to put you in danger.

Risks: Will I experience pain while participating in the project?

Your participation will not expose you to the possibility of experiencing pain.

Benefits: Will something beneficial happen to me? What it would be descripted as benefit for participating in the project?

Your participation in the project processes does not provide for any experience that will be evaluated as beneficial to you, apart from the possible evaluation of the participation experience and the satisfaction from your participation and from the experience of your contribution with your participation, in promoting scientific research and participation in the collective effort to identify factors that will contribute to the experience of improving the daily interaction of users (interface) with the digital world.

Evaluating an experience as beneficial, however, is a subjective matter.

Reporting results: How will the collected results be reported?

Upon completion of the study, the findings will be publishable (there will be the possibility of scientific publication). An information leaflet will also be published, which will be available with all the results. Thereafter, there will be dissemination of the findings to the public, through articles and briefing, on the results that will emerge.

Consent: Can I finally choose not to participate in the study? Can I change my mind?

Your participation in the study is not mandatory. You can leave the study at any time. Your consent to the study is given for two (2) years, or until it is revoked. To cancel your participation, you can either send an email to xx@gmail.com or fill out the application form at the end of this form using its mailing address of the scientist responsible for the study. In case of revoking your consent, all data collected during the study will be deleted. The right to revoke your consent, at any time, does not affect the legality of the processing of personal data, which will have occurred, based on the relevant consent, before the revocation of the latter.

How is your personal data managed and what are your rights?

The processing of your personal data is based on your consent. Your personal information will be “encrypted” and “anonymized” and will remain protected on a computer, with controlled

access. Your name, as well as any other personally identifiable information, will be encrypted and stored separately from the research data collected. This information will be accessible only by the project manager and data managers, who are bound by a confidentiality agreement. The data collected for this study will be summarized and presented in groups in the reports. Also, this consent will be insured in the area of the Medical Physics and Digital Innovation Lab, with controlled access. The research data that will be collected by you will be stored under a code number on a computer with controlled access and it will not be possible for you to be identified by the employees in the project that will carry out the scientific analyzes.

You have the right to request from the Scientific Officer access, or correction, or deletion of your personal data, or restriction of their processing, or you are given the opportunity to object to the processing of these or to exercise the right of portability of your personal data. For any inquiry or guidance regarding your rights, you could contact the Scientific Officer by sending an email to pdbamidis@gmail.com, or by calling +302310999310. Any requested change in your personal information will be completed within 30 days, from the day of your contact with the Scientific Officer.

If you have questions regarding your personal data, your rights or you believe that they are being violated, you can contact the Data Protection Officer of the Aristotle University of Thessaloniki (data.protection@auth.gr). In case you do not receive satisfactory answers, you can file a complaint to the Personal Data Protection Authority by visiting the website www.dpa.gr.

If you ultimately decide to take part in this study you will receive a copy of this form.

ΑΡΙΣΤΟΤΕΛΕΙΟ
ΠΑΝΕΠΙΣΤΗΜΙΟ
ΘΕΣΣΑΛΟΝΙΚΗΣ

II. CONSENT OF PARTICIPANT / LEGAL REPRESENTATIVE

Interviews and group discussions within the LIVE-IT project

The following
signed…….. or legal representative……
representing……
……..

I declare that:

- I have been adequately and comprehensibly informed by …… (Name of the researcher) for the purposes of the research in which I will participate and is part of the LIVE-IT research project.

- I have been adequately and comprehensively informed about the manner and sources of research funding.

- I have been adequately and comprehensively informed about what my participation in this research entails. In particular, I have been informed of all the rights and obligations I will have as a participant in the investigation, including the obligation of confidentiality (if required).

- I have been adequately and comprehensively informed of any positive or negative and immediate, short-term or long-term consequences my participation in this research is expected to have in relation to me or third parties.

- I have been adequately and comprehensively informed about how my personal data related to this research is handled and protected.

- I have been adequately and comprehensively informed about the provision and proper use of the devices I will use participating in this research.

- I have gained knowledge that my participation is voluntary and that I can withdraw from the research at any time for any reason and without any impact (as well as that the same

applies to the person I represent).

- I have gained knowledge that the responsible researcher to whom I could turn to leave the research or for any problem that arises during my participation or after the completion of the research.
- With my signature I declare that I consent to participate voluntarily in the above research.

_____ Date: ____ /____ /____
Signature of participant / legal representative Day/Month/year

_____
Full Name

ΑΡΙΣΤΟΤΕΛΕΙΟ
ΠΑΝΕΠΙΣΤΗΜΙΟ
ΘΕΣΣΑΛΟΝΙΚΗΣ

III. WITHDRAWAL OF PARTICIPANT'S CONSENT

Interviews and group discussions within the LIVE-IT project

The following signed …… would like to withdraw my consent for my participation in the LIVE-IT study, which I had given on _____ /_____ /_____.

_____ Date: ____ /____ /____
Signature of participant / legal representative day/ month/ year

_____
Full Name

DELIVERABLE 1.1, ANNEX II: Grey Literature Review

The pace of publishing peer-reviewed literature is much slower than the pace of developments in the area of web accessibility for people with cognitive disabilities. Therefore, we conducted a parallel grey literature search to our academic literature search. We consider *grey literature* to be resources that contribute to our understanding of the state of the art of web accessibility that are not strictly limited to peer-reviewed journals and conference proceedings. Such resources can include, but are not limited to: blog posts by experts in the field, deliverables from related H2020 projects, articles posted by relevant and trustworthy organisations, and other webpages or documents related to the topic of web accessibility for people with cognitive disabilities.

Our grey literature search paralleled the academic literature search in that it explored similar keywords, or search terms, but it also adapted to the needs of the project. What we mean by this is, the grey literature search was responsive to the gaps in the academic literature search, the needs of the four co-design labs, and the emergent findings coming out of the lifeworld analyses being conducted by each member of the LIVE-IT consortium. Thus, we consider this grey literature search to be a living document. While the academic search returns will not likely change much over the course of this one-year pilot project, the grey literature returns are more likely to change for fixed search terms. Additionally, the needs of the project will evolve throughout its lifetime, which will create new search terms and produce new lists of useful and relevant grey literature. "We are also monitoring relevant dedicated social media groups set up by and for people with cognitive disabilities to identify tools and other resources of interest to the project".

The following sections provide details of the grey literature search as of November, 2021. In the remaining deliverables for the project, we will include additions to the grey literature search and how they inform our evolving understanding of the state of the art of web accessibility for people with cognitive disabilities. We begin with a description of our methods. Then, we present the findings organised by theme.

Methods

This section presents the search methods and the inclusion methods for the grey literature search. The search methods refer to the process by which we located grey literature items. The inclusion methods refer to the process by which we selected grey literature items for inclusion in the review.

Search methods for the grey literature search were funnel-like in nature. The search process began with each member of the consortium using a list of recommended keywords (see Table 1, below) to develop search strings to be used in Google searches. We referred to these searches as *local Google searches*, because these searches were to be conducted using the keywords with a focus on developing a list of locally relevant and useful search returns. From here, subsequent rounds of Google searches were conducted to supplement the initial returns, further probe questions that arose from the academic literature search, and explore concepts illuminated by the lifeworld analyses.

Table 1 – Initial Search Terms

General keyword group	**Specific keywords**

Web accessibility	Accessibility, Digital, ICT, Internet, Digital Inclusion
Cognitive disability	Dyslexia, Aphasia, Non-verbal, Dysarthria; Dyspraxia; Dementia; Alzheimer's disease; Intellectual Disability; Attention deficit hyperactivity disorder (ADHD); Autism; Asperger syndrome; Dyscalculia; Downs syndrome; Motor Neurone Disease; Brain injury; Stroke; Cerebral palsy
Type item and/or issue	Policy, Guidelines, E-Health, E-Commerce; E-Service; E-Banking; Social Media, Distance Learning; Online Safety

Inclusion methods for the grey literature search were initially developed to parallel the inclusion and exclusion criteria for the academic literature search. Table 2 provides an overview of how the inclusion and exclusion criteria for search returns was modified for the grey literature search. A 10-year window was used for the grey literature search, as opposed to the 15-year window for the academic literature search. As with the academic literature search, we would include any study or any intervention involving people with cognitive disabilities ages 9 and up. The area of the inclusion and exclusion criteria that needed the most attention as we conducted the search was the *Outcome* category.

Due to the evolving nature of the field of web accessibility, especially for people with cognitive disabilities, the development of tools and resources is outpacing the ability of those doing the developing to share evidence of implementation. Initially, we hoped to be able to locate at least initial forms of data associated with early implementation for all of the grey literature items included in our review. However, that proved to be too restrictive and eliminated too many highly relevant and useful items from our review. Therefore, we decided to evaluate all grey literature search returns not clearly included on the *Outcome* dimension by asking each consortium member to review the search returns and make recommendations for inclusion based on the following criteria: local relevance, author/origin, promise, and usefulness.

Table 2 – Inclusion and Exclusion Criteria for Grey Literature Search

Component	**Inclusion**	**Exclusion**
Publication	2011-2021 Published in English and/or languages appropriate for each lab's local context Any geographic location, but priority given to publications from or highly relevant to each lab's local context	Published before 2011 Not published in English or a language appropriate for any of the labs' local contexts No geographic location excluded
Study Design	Any design	No study design excluded

Component	Inclusion	Exclusion
Population	Citizens living with cognitive impairments, ages 9 and up	Citizens not living with cognitive impairments Younger than 9 years of age
Intervention	Any intervention type	No intervention type excluded
Comparison	No comparison (control) group required for inclusion	Lack of comparison (control) group is not grounds for exclusion
Outcome	Documented implementation (can be a pilot)	No documented implementation

As noted above, the grey literature review will be viewed as a living document to be updated throughout the lifetime of the project. As of November, 2021, the consortium members agreed to include 40 grey literature items. Some of these items are different pages of a parent website, and they are counted separately due to a difference in intended audience and/or subject matter. In the next section, we present the findings from the present version of the grey literature search.

Findings

The findings from this grey literature search inform our understanding of the state of the art of web accessibility for people with cognitive disabilities. More specifically, our review of the grey literature enhanced our understanding of the state of the art in six areas: related H2020 projects, policies and guidelines, research methods, designing for people with cognitive disabilities, community resources, and centring people with cognitive disabilities. Across all six categories, the need to further involve people with cognitive disabilities at all steps of the research process and the need to expand beyond the current prevalence of text-oriented tools are apparent. However, the sections that follow provide additional detail on the findings within each category.

Related H2020 Projects

Two related H2020 projects have contributed significantly to the state of the art for web accessibility for people with cognitive disabilities in recent years. They are the Easy Reading Project and the Insension Project. The Easy Reading project worked to "develop a software for users with cognitive disabilities that supports them to access any webpage" by allowing for instantaneous personalisation involving symbolic, pictorial, and video adjustments. The Insension Project worked to "design and develop an ICT platform that enables persons with profound and multiple learning disabilities" by supporting them as they process information and communicate their needs via technology. If required to rank

the two projects in terms of relevance to LIVE-IT's goals, the Easy Reading Project is most closely related. However, the knowledge produced by the Insension Project still contributes to the state of the art of web accessibility for people with cognitive disabilities.

As shown in Table 3 the websites for the Easy Reading and the Insension projects provide multiple sources of valuable information. The Easy Reading Project makes major contributions in the areas of research methodology, user testing, and software development for and with people with cognitive disabilities. On the *Downloads* page within the Easy Reading website, a full set of ethics documents, practical checklists, risk management documents, and other items related to the collection and use of data with and from a vulnerable population are publicly available. Such documentation informed LIVE-IT's ethical framework and procedures for Lifeworld Analysis and Co-Design Labs. The Insension Project adds to the plentiful resources described above by providing links to Deliverables and publications that focus on gathering training data for machine learning algorithms to be used within a platform for people with cognitive disabilities and the development of scenarios for testing.

Table 3 – Related H2020 Projects

Author	Description	Links
Easy Reading Consortium (Athena, Dart, FunkaNu, JKU, KI-I, PIKSL, Texthelp, TUD, W3C)	Information about the development and testing of the EasyReading software	https://www.easyreading.eu/the-project/ https://www.easyreading.eu/downloas/ https://www.easyreading.eu/wp-content/uploads/2020/01/Easy-Reading-Handbook.pdf
Insension Consortium (PSNC, PHHD, JSI, CTIC,NaTak, Harpo)	Information about the development and testing of the Insension platform	https://www.insension.eu/word-packages/ https://www.insension.eu/publications/

Policies and Guidelines

Policies and guidelines drive research and private sector projects related to web accessibility for people with cognitive disabilities. In this section, we present findings related to policy and findings related to guidelines separately. Policy refers to standards for web accessibility that have been codified by various governments. Guidelines refer to standards that are widely used within the field, but not necessarily codified by governments in their full form. Generally speaking, most policy on web accessibility for people with cognitive disabilities is focused on a particular set of guidelines: the World Wide Web Consortium (W3C) Web Content Accessibility Guidelines (WCAG).

Policy

The academic literature search already presents the policies addressing web accessibility for people with cognitive disabilities in the European Union, England, Greece, Ireland, and Portugal. Ongoing *local Google Searches* conducted to support co-lab development for the LIVE-IT project produced two additional grey literature items that are included in this portion of the review. Table 4 provides an overview of these items. It is worth noting that both of these resources define web accessibility more broadly than LIVE-IT does. While this project is specifically focused on web accessibility for people with cognitive disabilities, the two resources presented below are focused on web accessibility in general. However, we include them here due to their local relevance.

First, in Portugal, an agency called The Observatory functions as an accessibility checker and tests public-entity websites for compliance with accessibility as defined by Portuguese law. As is the case for most web accessibility policy, Portuguese policy does not require the highest levels of compliance with the WCAG. However, the knowledge that The Observatory exists, and that it provides resources for web developers is useful, especially within the local context.

Second, in Ireland, an agency called the National Disability Authority (NDA) supports the development of accessible websites within Ireland. Within the NDA, the Centre for Excellence in Universal design provides links to publicly available courses on universal design for web developers. Additionally, links to country-specific resources for designing accessible websites.

Third, in Greece, the EU legislation on accessibility has been incorporated by Law 4591/2019 (Government Gazette 19 / A / 12.2.2019), which establishes a comprehensive system for recording and monitoring the compliance of websites and applications for mobile devices in the public sector with accessibility requirements and at the same time, provides the possibility of citizen feedback through the mechanism of submission of comments / reports. Regarding the accessibility of websites and applications for mobile devices of public sector organizations, all ICT actions and projects will be designed from the beginning in accordance with the principle of universal design, so that they can be used by all people, to the greatest extent possible, without the need for adaptation or specialized design, without excluding assistive devices for specific groups of people with disabilities, where required.

It is worth noting that this section lacks grey literature resources specifically targeting the UK. In the case of the UK, many of the resources already included in the academic literature search and the tools and platforms search in Task 1.2 already address the UK context. Thus, consortium members did not see a need for more UK-specific resources at this time. The grey literature list may be updated as the project continues if that changes. In the case of Greece, the various searches have yet to return local resources. This may be due to the way in which we are conducting our searches, and this will continue to be addressed throughout the project.

Table 4 – Policy Items

Title	Author	Brief Description	Link

What is the observatory?	Portuguese Observatory of Web Accessibility	Description of the Portuguese Observatory of Web Accessibility	https://observatorio.acessibilidade.gov.pt/
Web and mobile app accessibility	National Disability Authority: Centre for Excellence in Universal Design	Description of Irish accessiblity requirements	https://universaldesign.ie/technology-ict/web-and-mobile-app-accessibility/
Digital Accessibility	General Secretariat for Digital Governance and Simplification of Procedures	Description of the Greek system for recording and monitoring the compliance with accessibility requirements	https://www.secdigital.gov.gr/projects/psifiaki-prosvasimotita/

Guidelines

The academic literature search provided details about the W3C's WCAG, which is the set of standards for web accessibility currently driving both policy and research. In addition to the WCAG, the W3C also provides additional sets of guidelines to extend accessibility beyond just the web content. Table 5 provides an overview of these guidelines and related documentation that was heavily influential in the design and development of the LIVE-IT project.

W3C provides three additional sets of guidelines to serve alongside the WCAG as tools for designing accessible websites and web apps. The Authoring Tool Accessibility Guidelines (ATAG) provide a framework for making authoring tools accessible, "so that people with disabilities can create web content," and support the goal of creating more accessible web content. The User Agent Accessibility Guidelines (UAAG) explain how to make browsers, browser extensions, media players, readers, and other applications that render web content accessible to people with disabilities. Both the ATAG and the UAAG target developers and designers, and provide a roadmap for involving people with cognitive disabilities as developers and designers. Finally, the Web Accessibility Initiative Accessible Rich Internet Applications (WAI-ARIA) standards further support the development of accessible web content and web applications with a special focus on dynamic content and advanced user controls.

The WCAG, ATAG, UAAG, and WAI-ARIA all deal with accessibility in general. Therefore, a taskforce has been developed to specifically focus on accessibility for people with cognitive disabilities within the W3C's efforts. This taskforce is called COGA, and Table 5 also includes links related to COGA-specific documentation that has formed the foundation of work within the LIVE-IT project. These documents will be revisited in later sections.

Table 5 – W3C Guidelines and Related Documentation

Author	**Description**	**Links**

W3C	Information about ccessibility standards and guidelines	https://www.w3.org/WAI/standards-guidelines/wcag/ https://www.w3.org/WAI/standards-guidelines/atag/ https://www.w3.org/WAI/standards-guidelines/uaag/ https://www.w3.org/WAI/standards-guidelines/aria/
W3C	Information about cognitive accessibility	https://w3c.github.io/coga/gap-analysis https://w3c.github.io/coga/issue-papers https://w3c.github.io/coga/user-research https://w3c.github.io/coga/content-usable/ https://w3c.github.io/coga/persona/

Research Methods

The grey literature search also supplemented LIVE-IT's development of research methods for the co-design labs. As noted in the section on related H2020 projects, the Easy Reading ethics documentation formed the foundation of the ethics framework, procedures, and documentation for the LIVE-IT co-design labs. Table 6, below, provides an overview of additional resources that contribute to our understanding of the state of the art of research methods involving people with cognitive disabilities. In addition to the Easy Reading documentation, a literature review, a UNESCO publication, and a set of principles for design justice.

Both the literature review (not included in the academic literature search because it was not a study) and the UNESCO publication echo findings from all searches conducted to date. Namely, they support the fact that for real, relevant, and meaningful change to be made in web accessibility, people with cognitive disabilities must be involved in all aspects and at all stages. The authors of the literature review present an interesting framework for digital inclusion comprised of 5 dimensions: access to internet, sensorimotor challenges, cognitive challenges, technical challenges, and social codes and conventions. Each of these dimensions is further broken down into environmental factors and personal factors. This signals the importance of considering factors inside and outside the person when investigating web accessibility for people with cognitive disabilities – meaning that research cannot only problematise the person. The UNESCO publication provides interesting data related to web accessibility for people with disabilities, broadly defined. However, the call to involve people with disabilities in future work is one that must be heeded.

In order to protect a vulnerable population within our research, we conducted searches that would inform our co-design procedures. This led us to the Design Justice Network's Principles. They are a set of 10 principles for co-design with a focus on social justice and the protection of all contributors. The Design Justice Network Principles complement the W3C guidelines discussed above by adding a relational and interpersonal element to our framework for co-design.

Table 6 – Research Methods

Title	Author	Brief Description	Link
Bridging the digital divide for people with intellectual disability	Lussier-Desrochers, et.al.	2-phase literature review of the challenges people with cognitive disabilities face with respect to digital inclusion	https://cyberpsychology.eu/article/view/6738/6204
Delivering Together for Inclusive Development: Digital Access to Information and Knowledge for Persons with Disabilities	Alireza Darvishy, Deniz Erocal, Juliet Manning	Reports focused on sustainable development goals related to universal design and web accessibility for people with disabilities	https://www.ospi.es/export/sites/ospi/documents/documentos/servicios-publicos-digitales/Inclusive-Development-UNESCO.pdf

Design Justice Network Principles	Design Justice Network	10 principles developed through open peer review for inclusive desing practices	https://designjustice.org/read-the-principles

Designing for People with Cognitive Disabilities

The grey literature resources listed in Table 7 below are separated from the section on guidelines. We made this distinction for two reasons. First, the majority of these resources are extensions of the WCAG with a specific focus on people with cognitive disabilities. Second, if they are not an extension of the WCAG, they are too context-specific to be considered guidelines in a general sense. These resources are heavily focused on text accessibility features, which makes sense because much of the website and web application content is text-based. However, it is becoming apparent that there is a lack of resources extending beyond enhancing the current text-saturated reality to a new non-text dominated version of the web.

Table 7 – Designing for People with Cognitive Disabilities

Title	**Author**	**Brief Description**	**Link**
Web Design Considerations for Cognitive Disabilities	Deque University	Descriptions of accommodating cognitive disabilities in web design	https://dequeuniversity.com/tips/web-design-cognitive-disabilities
Designing Mobile Apps for Use by People with Cognitive Disabilities	Level Access	Descriptions of how to design mobile applications with accessibility for people with cognitive disabilities in mind	https://www.levelaccess.com/designing-mobile-apps-for-use-by-people-with-cognitive-disabilities/
Mobile Application Accessibility Handbook	Government of the Hong Kong Special Administrative Region	Handbook for designing mobile apps with accessibility features for people with disabilities	https://www.ogcio.gov.hk/en/our_work/community/web_mobileapp_accessibility/promulgating_resources/maahandbook/doc/mobile_app_handbook.pdf
How to create an accessible app (and why you should)	Caspar Geerlings	A set of best practices for mobile application design	https://medium.com/oberonamsterdam/how-to-create-an-accessible-app-and-why-you-should-5493f41f8bdb
Social Media User's Guide: Ensuring accessibility	University of Rochester	A set of best practices for individuals posting on behalf of the university	https://www.rochester.edu/social/guide/accessibility.html

Community Resources

The second to last category of grey literature search returns included in the review is labelled *Community Resources*. This category includes blog posts, how-to guides, and descriptions of accessibility tools whose target audience is, or at least includes, the community of people with cognitive disabilities. One might wonder why the table for this section, Table 8, is not infinitely long, as the LIVE-IT Project aims to produce an Open Toolkit for the community. Table 8 only includes the six resources listed, because the remainder of the tools and platforms that can be considered community resources are included in the database for D.1.2.

Table 8 provides an overview of the grey literature search returns labelled as community resources. Action Blocks, as a tool, will be included in the D.1.2 database of tools and platforms, but a support document for Action Blocks as well as a practitioner review of Action Blocks is included in this review. Action Blocks are innovative because they allow users to streamline complex sequences needed to execute tasks on their mobile phones and tablets in a highly personalised manner. Additionally, Action Blocks are for Android phones and tablets, which the majority of the LIVE-IT participants are using. Intrigued by the augmentative and alternative communication (AAC) features of Action Blocks, we pursued additional searches related to AAC tools, which yielded two resources related to AAC tools for iOS devices.

In addition to the Action Block and other AAC resources, two other websites stood out as community resources due to their database-like nature. First, the IncludEd provides a framework for organising existing applications from Apple, Microsoft, and Google within four dimensions: Communication and Interaction, Social-Emotional Learning and Mental Health, Sensory and Physical, and Cognition and Learning. Not only is this an exceptional and comprehensive database of tools, it is also an exemplary framework for considering the needs and challenges of people with cognitive disabilities in ways that do not overly medicalise the challenges or focus too much on a specific diagnosis. Second, the AbilityNet "how-to guides" are simple and easy to follow for all users, and they explain how to access and use various accessibility features that exist within operating systems.

Table 8 – Community Resources

Title	**Author**	**Brief Description**	**Link**
Use Action Blocks	Google	Description of Action Blocks	https://support.google.com/accessibility/android/answer/9711267?hl=en
AAC Resources: A Look at Google Action Blocks	Carole Zangari	Review of Action Blocks	https://praacticalaac.org/praactical/aac-resources-a-look-at-google-action-blocks/

AAC Apps	PRC Saltillo	Description of AAC apps for iOS	https://aacapps.com/
AssistiveWare: Proloquo2Go	AssistiveWare	Description of AAC app for iOS	https://www.assistiveware.com/products/proloquo2go
IncludEdu: Get Started	IncludEdu	Resources for educators seeking accessiblity options for students	https://includedu.online/getstarted/
Simple "How To" Guides	AbilityNet	A series of "how to guides" provided via link for using accessiblity features of various operating systems, etc…	https://mcmw.abilitynet.org.uk/

Centring People with Cognitive Disability

A prominent theme within the academic literature review is that research on web accessibility for people with cognitive disabilities needs to actively centre and involve people with cognitive disabilities. This theme has already been noted within the grey literature themes, as well. Therefore, we conducted searches focused on resources that centred people with cognitive disabilities. Beyond the related H2020 projects described above, there are two categories of grey literature that centre people with cognitive disabilities.

First, return to the Table 5, which provides an overview of the W3C resources most relevant to this project. The W3C COGA Task Force documents all centre people with cognitive disabilities. These resources include issue papers on cognitive accessibility, frameworks and recommendations for cognitive accessibility research (especially, user research), and resources related to involving people with cognitive disabilities and learning disabilities in research. Appendix A in the article on Making Content Usable for People with Cognitive and Learning Disabilities, which focuses on mapping user needs, personas, and patterns, is providing a framework for how the LIVE-IT Project will organise and track the user needs identified during Lifeworld Analysis and the literature reviews through the remainder of the project.

Second, consider Table 9, which contains the accessibility information for several social media sites identified during the Lifeworld Analysis as being the primary authoring tools used by LIVE-IT participants. Due to the fact that most of our participants have reported using social media as the only means for authoring content on the internet, we also conducted a search of various social media platforms' accessibility features. Not surprisingly, most of the accessibility features are text-centric. The academic literature review identified at least one study of an attempt to produce alternative social media

networks for people with cognitive disabilities due to the fact that many of the existing social media sites are hostile environments for such individuals. However, the further investigation of how social media can be more accessible for people with cognitive disabilities is needed.

Table 9 – Resources that Centre People with Cognitive Disability

Title	Author	Brief Description	Link
Accessibility	Facebook	Descriptions of the accessibility features available through Facebook	https://www.facebook.com/help/273947702950567/?helpref=hc_fnav
How to make images accessible for people	Twitter	Descriptions of the accessibility features available through Twitter	https://help.twitter.com/en/using-twitter/picture-descriptions
How do I edit the alternative text for a photo on Instagram?	Instagram	Descriptions of the accessibility features available through Instagram	https://help.instagram.com/503708446705527
Accessibility	LinkedIn	Descriptions of the accessibility features available through LinkedIn	https://www.linkedin.com/accessibility
Accessibility	Slack	Descriptions of the accessibility features available through Slack	https://slack.com/intl/en-ie/accessibility
Accessibility	Zoom	Descriptions of the accessibility features available through Zoom	https://explore.zoom.us/en/accessibility/