POSEiDON

Pers**O**nalized **S**mart **E**nvironments to increase **I**nclusion of people with **DO**wn's sy**N**drome

Deliverable D2.6

Report on guidelines for building technology for people with Down Syndrome

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1 Introduction

POSEIDON aims at developing a technological infrastructure which supports a growing number of services to help people with Down syndrome achieving greater independence and inclusion in their everyday lives. POSEIDON was developed to support people with Down syndrome and their caregivers, parents and other relatives and other helpers. Furthermore, POSEIDON provides a platform other companies and organisations can use when developing similar services in the future.

Even before starting this project, we identified some key challenges people with Down syndrome face every day [Fidler 2005, Jarrold 2006, Brigstocke 2008, Tod et al. 2012]:

- Access to education and the support provided is very limited
- Fewer opportunities are given to people with Down syndrome to find employment
- Most people with Down syndrome find it harder to access and maintain social networks
- Sedentarism that can result in health problems for people with Down syndrome
- Public information is often in formats that are not easily accessible for people with Down syndrome (e.g. bus timetables)
- Reading and writing can be more difficult for people with Down syndrome

The POSEIDON project wanted to give priority to preferences, particular strengths and weaknesses, in order to create technology that is appealing and useful for the target group. People with Down syndrome, their immediate carers and specialists from all over Europe are co-designing our solution along the project.

In this deliverable, we try to describe our target group as computer users, and we summarise the framework and architecture of POSEIDON as well as ethical issues and issues of personalisation which were considered during the project. Furthermore, we outline the system development process which was conducted in the form of a user-centred methodology. In this section, also main results of the pilot studies are recapitulated. Finally, lessons learnt in course of the project are pointed out from different perspectives.

2 People with Down Syndrome: “characteristics”

People with Down syndrome represent a unique target group since three major types of capabilities (first cognitive, but also to some extent motor and perceptual) are affected. The capabilities and disabilities often vary to a high extent from person to person with Down syndrome. Furthermore, each person with Down syndrome shows individual characteristics related to heredity, training and the social environment around him/her. Thus, only some generalisations are possible for persons with Down syndrome. The high individuality represents a major challenge for a technical development and underlines the importance of a user-centred design approach with many possibilities for individualisations. Despite the wide range of competencies and impairments, common problems for people with Down syndrome are:

- Limitations in vision and hearing, disturbed sensory skills, including hyposensitivity when touching something, problems with fine motor movements
- Weak muscles in arms and fingers
- Limitations in short term memory and cognition, including problems with verbal auditory memory, hence it is harder to recall information that is heard than what is read or seen

- Limitations in communication skills. Delayed development of receptive and expressive language. They often understand much more than they can express (receptive language is superior to expressive language). They have a relative strength in vocabulary and pragmatics and more difficulties with morphology and syntax. They also in general have reduced speech intelligibility. This lead to problems with complex conversational skills. (Overview: Feng 2010, Lazar 2011, Bull 2011).

It is important to recognise both the strengths and difficulties a person with Down syndrome has. As McGuire and Chicoine (2006) note, most children with Down syndrome enjoy and learn from social interaction with family and friends. As time goes by, they often have good social and emotional understanding, and most are able to develop age-appropriate behaviour, if this is encouraged and expected. People with Down syndrome generally learn visually; this is probably why reading can sometimes be a strength. This means that they learn best from watching and copying other people, and may find it easier to take in information if it is presented with the support of pictures, gestures, objects and written words. Using their hands, faces and bodies to communicate is another strength, and many people with Down syndrome enjoy drama and movement because of this strength. The approach taken within POSEIDON should always build on the strengths of people with Down syndrome while keeping the possible limitations in mind.

2.1 People with Down Syndrome as computer users

The possible limitations and characteristics of people with Down syndrome have a major impact on the usage of technology and underline the need for usability focused and user centred design. The goal is not only to develop technology that is easy to use in general, the technology must also be useful to the user in spite of his/her possible limitations. The limitations in cognitive, language and motor skills all have a profound impact on computer usage for persons with Down syndrome. They have e.g. difficulties in remembering, processing information, understanding abstract concepts, reading, writing, communicating, navigating, typing and using the mouse. These limitations present major challenges both for users, designers and technicians. Nonetheless the diversity of capabilities is a problem, but many persons with Down syndrome can use PC, tablets and smart phones surprisingly well.

A study by Lazar et al. (2011) focusing on the computer usage of children with Down syndrome shows that 72 % of the sample started using a computer by the age of five. 99% of the sample had access to a computer at home, other main access points being school and library. Computers are mostly used for learning (80 %), entertainment (95 %) and communication within ones' peer group members (33 %).

Regarding possible preferences for the target group in the use of technology like computers there were some interesting suggestions in literature regarding fonts, colours, graphics, animations and buttons (Canadian Kirijian et al. 2007). This had to be combined with the standards of "Information for all.

Table 1 is based on a combination of the two sources for design guidelines. While Kirijian et al. focus on the preferences of people with Down syndrome regarding computer usage, the standard "Information for all" is made for a larger group, people with intellectual disabilities. "Information for all" is focusing on making information easy to read and to understand on different media, first of all paper. Kirijian et al. present a study on a group of 10 people with Down syndrome, carefully chosen on the basis of their computer usage. Both share the idea of using as simple wording as possible, and both strongly suggest the use of photographs and images to support the idea presented with words. The recommendations for the use of animations differ, , but this is based on different usage of the animations.. For example, if animations are always placed on the screen it can be distracting. On the

other hand, some personalized animations used as reward system can be motivating. Furthermore, a general rule is to avoid everything unexpected, like e.g. pop-up windows.

Table 1: Overview of design guidelines

Guideline subject	Preferences of people with Down syndrome	"Information for all" people with intellectual disabilities
Font	- Bright, adding depth - Large - Bold - Stylized - No font decoration	- Not serif fonts, rather Arial, Tahoma - Enough spacing between letters - Not italics and/or underlining - No shadows, especially in writing design - Large fonts, at least like Arial 14 - One font throughout text
Colour	- Darker: blue, purple, grey - Combinations of primary colours with high contrast - Tints and tones - Complimentary colours - No dull colours	- Avoid a background colour or a background with pattern that can make the contrast between text and background poorer
Graphics/Images	- Cleary identifiable - Naturally coloured not digitally manipulated - With people of similar age or older - Action images - Photographic better than illustrated - Fun and whimsical illustrations	- Photographs, drawings, symbols - Don't use images for younger people than the target age group - Clear, not too disturbing to look at - Fit to the text
Animations	- Bright colour - With motion - Animating colour - Personalized	- No animations on screen
Buttons	- Largest was clicked first - Dark background - Light text on top - Expected action clear - Framed - Arrows pointing to buttons - No spatial preference	- Large button to change size of the writing
General on websites		- No pop-ups - No large programs (hardware, internet speed restrictions) - Search tool - Easy-to-read in metadata
Homepage		- Clear what website is about - Phone number to contact person - Postal address to contact person

		- E-mail address to contact person - Easy-to-read symbol if the content is tested according to easy to read principles
Navigation		- Clearly show on which part of the website one currently is - One click to homepage - Same navigation bar on the same place throughout the website - Not more than 7-8 menu choices
Screen		- Whole text on one screen - No lateral scrolling - Menu of sections at top - Easy to return to top - Space between paragraph - No animations
Links		- Words, not pictures, should contain links - Underlining of links - Hiding long link behind word - Blue if not clicked - Purple if already clicked
Words		- Well known - Explain complex words - Use examples - No initials - Do not use metaphors - Do not use word from other languages - Use words in full, not initials - No percentages, no large numbers use “few”, “many” instead
Sentences		- Short - Direct speech - Address in 2nd person e.g. “you” - Positive - Active
Information order		- Group information about topic - Important information at the top - Repeat important information - Repeat explanation of difficult words if words are used several times

All these findings suggest that computers and computer devices are of great importance for people with Down syndrome because they can help to increase confidence and motivation through creative activities and web browsing. Using the computer has other benefits as well, including errorless

learning, patient and immediate feedback, self-paced learning and independence of learning. It should be stated also that all those benefits and useful features are dependent on developing a technology which meets the heterogeneous demands of the target group.

3 POSEIDON development framework

The POSEIDON developer framework is a collection of methodologies, infrastructure, middleware, tools, specifications etc. These are things which are used in the development of the POSEIDON prototype system and part of it, but also provided to other developers interested in developing applications for people with cognitive disabilities and to connect to the POSEIDON system. This is partly methodologies, open-source code and free tools of general use, and partly the POSEIDON infrastructure which can be used for other applications. A goal of the POSEIDON project is to foster development of inclusive services for people with Down syndrome, and a commercial POSEIDON solution needs to be extensible with new services. The development framework is the project's way of addressing these goals. Here we give an overview of the framework. The detailed description is given in the project deliverable D5.1, version 3.

3.1 Methodologies

A system development methodology specifies structured ways of creating ICT systems. The framework describes the following methodologies:

- UC-SDP: User Centered Software Development Process. This software development process focuses on the stakeholders and is tailored to the development of intelligent environments.
- eFriend: An ethics framework specifying principles for maintaining the interests of the users of ICT systems, especially within the Ambient Assisted Living field (see chapter 4).
- R4C-AS: A methodology for requirements elicitation in Context-Aware systems. It provides a structured approach to gather and define the requirements of such systems, including diagrammatic support.

The framework also includes tools to support the methodologies.

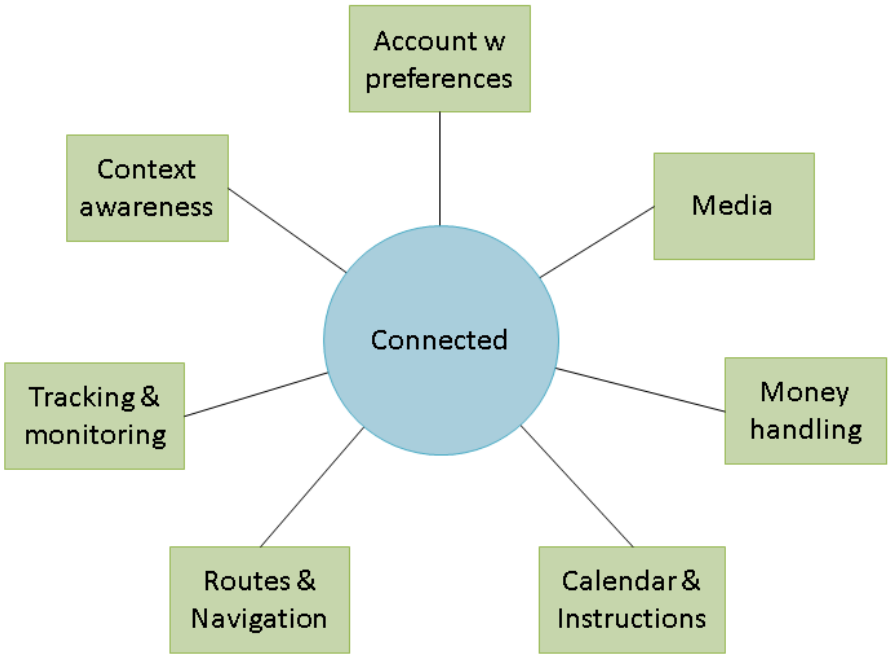
3.2 Architecture and platforms

The POSEIDON solution is a system of various end user applications and different platforms connected by an infrastructure. The framework architecture describes this infrastructure and how applications are integrated in this system. Based on the type of services we wanted POSEIDON applications to provide we have defined a set of services the underlying infrastructure needs to provide to applications. The figure below shows an abstract view of the services the infrastructure should provide and connect together.

Server-side services for holding data and providing shared access is an important part of this infrastructure. Another key part of the architecture is the supported platforms and devices for end-user applications. We make a distinction between stationary and mobile application platforms. Stationary platforms are for using applications at home or in other stationary locations and are based on laptop and desktop computers. These have large screens and various input devices, and are suited to primary user training and secondary user management tasks. Mobile platforms are smaller devices such as phones and tablets, suited to bringing with you wherever you go and to use outside. These are needed to provide notifications and guidance to the primary users. We had a goal of supporting multiple platforms for both stationary and mobile use. We specified a framework for web applications,

responsive to run on all devices. For more specialised functionality, we provided additional support for stationary training applications developed in the cross-platform framework Unity, and mobile applications for Android devices. The architecture includes middleware and interaction devices for the supported platforms.

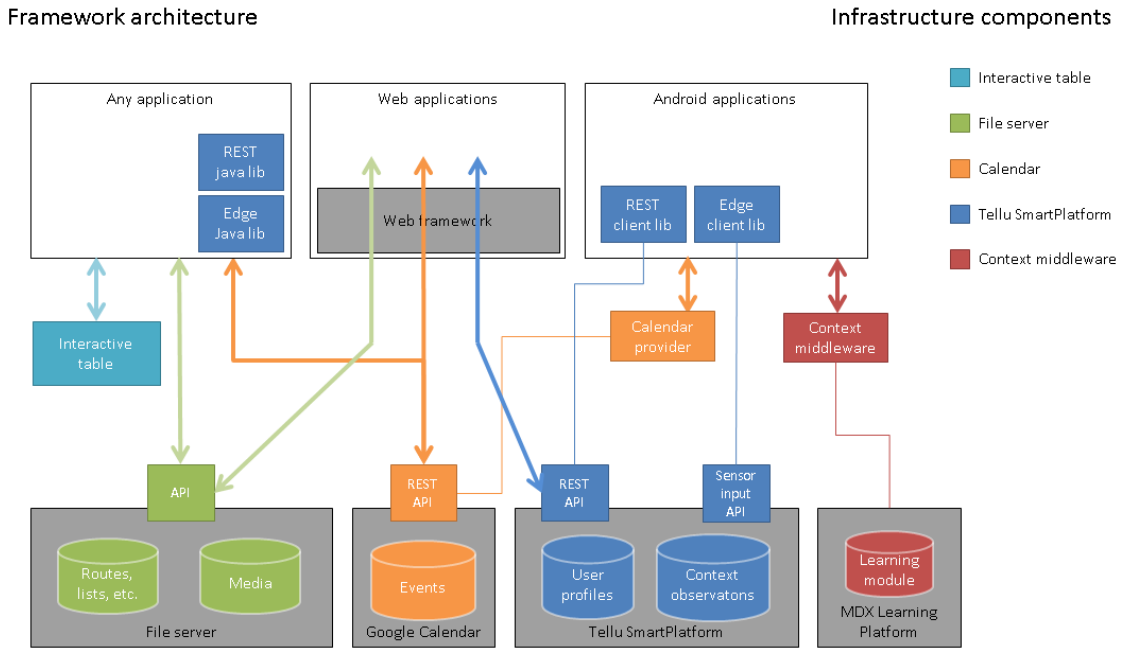
Figure 1: A service view of the infrastructure



3.3 Technology infrastructure

The technology infrastructure is provided to implement the architecture. Going through the main components, we refer to the framework architecture overview below, and start with the server-side services along the bottom of the figure.

Figure 2: POSEIDON framework architecture



The file server provides cloud storage of data for POSEIDON applications. Secondary user applications are used to define personalised instructional content with multi-media, and this is stored here for the primary user applications to access. The framework includes data specifications for routes for navigations, shopping lists for money handling and video play lists for instructions, so that new applications are interoperable with the existing ones. A calendar system is used to connect instructions to points in time and give notifications. The infrastructure uses the Google Calendar service for cloud storage of calendar events, but specifies an extended data format including instructions and multimedia, only supported through POSEIDON-enabled user interfaces. The Tellu SmartPlatform service is where POSEIDON user accounts are stored, along with a user profile. Tracked data such as mobile device position is sent here to be available for monitoring.

Another key part of the infrastructure is the Context Reasoner Middleware. It provides context awareness to mobile applications. Applications connect to it, causing it to perform acquisition of and reasoning over context, notifying the interested applications of changes. The context awareness part of the framework also includes a tool for producing context rules and a server-side for collecting data from the middleware.

The interactive table is a part of the infrastructure for stationary applications. It is a prototype of a new interaction device, which combines the size of a multitouch table with 3D hand position recognition. It is intended to be unobtrusively built into tables, allowing the user to control applications via hand gesture on or over the table.

3.4 Developer tools and components

The framework includes software and code libraries provided to developers to enable them to develop POSEIDON applications. Here is an overview of components:

- Tool support for R4C-AS: A set of tools for keeping track of requirements and creating diagrams.

- Context modelling tool: Tool for creating new rules for the context reasoner of the infrastructure.
- Android SDK: Mobile application development is facilitated by the Android application framework and Android Studio development environment.
- Web framework: Web applications are based on JavaScript and the latest HTML/CSS standards. Our recommended framework includes the AngularJS JavaScript framework and Bootstrap CSS library.
- Code libraries: Libraries provided include API for connecting to the interactive table, Java and Android libraries for the two SmartPlatform APIs, and a Unity library for connecting to the SmartPlatform and file server.

3.5 User interface design

The framework also provides specifications, information and graphical elements for user interfaces. Developer documentation includes guidelines for developing accessible user interfaces, and information about mobile and web application UI development. A user interface strategy is specified, considering user requirements. A colour palette and icons are provided, to create applications with a shared look and feel.

4 Ethical Framework in the project

We have created a framework to guide development of technology in this area with ethical considerations embedded in the development process. The framework is based on the eFRIEND ethical framework, which was created for Intelligent Environments in general.

> Jones, Simon and Hara, Sukhvinder and Augusto, Juan Carlos (2014) *eFRIEND: an ethical framework for intelligent environments development*. **Ethics and Information Technology**, 17 (1). pp. 11-27. ISSN 1388-1957. Springer Verlag.

The considerations are mapped to requirements to the POSEIDON-system:

- 7 Framework requirements,
- 20 Functional requirements,
- 10 Non-functional requirements,
- 4 Hardware constraints
- 6 Design constraints

These principles are given by the Intelligent Environments Manifesto proposed by Augusto et al (2013a) that advocates the development of systems in a manner that is aligned with a number of explicitly defined user-centred principles:

- P3—deliver help according to the needs and preferences of those who are being helped
- P5—preserve the privacy of the user/s
- P6—prioritize safety of the user/s at all times
- P9—adhere to the strict principle that the user is in command and the computer obeys

Augusto, J.C., Callaghan, V., Kameas, A., Cook, D., Satoh, I. (2013) *Intelligent Environments: a manifesto*. **HumanCentric Computing and Information Sciences**, 3:12, Springer. DOI: 10.1186/2192-1962-3-12 URL: http://www.hcisjournal.com/content/3/1/12

General principle 1: Non-Maleficence and Beneficence

- *The system should avoid causing harm to any of the users.*
- *The system should proactively seek for opportunities to assist users.*
- *The system should actively benefit users by enhancing their welfare and quality of life.*

POSEIDON aims to enhance the welfare and quality of life of its target users by enhancing their autonomy, independence and social inclusion. It incorporates measures to avoid any risk of harming the user.

The project has an Ethics Advisory Committee, comprised of experts on ethics, data protection and on the target users (representatives of Down Syndrome associations in the participating countries).

General principle 2: User-Centricity

- *Users should be placed at the centre of the development process.*
- *The type of technology and associated services should be agreed with users in advance.*
- *The system should be designed and implemented in accordance with users' wishes, ambitions and values.*
- *The systems should be customisable to dynamically evolving individual needs, preferences and requirements.*

The POSEIDON project aims to develop assistive technology in joint collaboration with primary users and their carers at every stage of the development process.

Primary and secondary users' wishes, values and needs are considered through detailed requirements gathering and analysis via surveys and face-to-face interviews with secondary and primary users in addition to questionnaires to secondary users in connection with the pilots.

From this information, a clear understanding has been gained of primary users' living situations and daily living competencies, levels of proficiency using existing technology, together with the range of physical, sensory and cognitive difficulties they experience, including areas such as motor skills, speech, writing and learning disabilities.

The POSEIDON system aims to address these challenges by providing context-specific help, information and intelligent assistance which is appropriate for different situations.

General principle 3: Multiple users

- *The system should be aware of the different needs and preferences of all individuals in a multi-user environment.*
- *The system should consider how to balance the competing rights, preferences and requirements of different users.*

POSEIDON is specifically designed for a multi-user environment and incorporates the needs and requirements of various stakeholders, including:

- Primary users (people with Down syndrome),
- Secondary users (parents / carers) and

- Tertiary users (for example, personal assistants, support workers, specialist teachers, and employers).

The project acknowledges that these requirements and preferences may need to be balanced and/or prioritized, and that they may change dynamically over time.

General principle 4: Privacy

- *Users can specify privacy levels and preferences for different services.*
- *Users decide on, and can change, levels of acceptable recording, monitoring and tracking of activities.*

The results of the requirements analysis confirm that privacy is of high importance to potential users of POSEIDON and must be guaranteed in usage outside the home. POSEIDON accordingly aims to ensure that no user's privacy is violated. Users have the ability to adjust whether the secondary user should be able to see their position when they are using the navigation functionality and to choose between different color settings. Data entered directly into the calendar in the app by the primary users are not seen in the calendar part of the POSEIDON website.

So, a general principle in our system is that when live, it should support the privacy of end-users, and provide optional user privacy settings to enable customization. Users also should be able to decide on, and vary, the level of privacy at a specific point in time.

General principle 5: Data protection

- *Users have access to the sensitive information stored about them and can decide what can be done with this information.*
- *Users can determine levels of information-sharing and disclosure.*
- *The system should seek informed consent to secondary uses of personal data by 3rd parties.*
- *The system should adhere to recognised principles and good practices of data protection.*

While the effective use of POSEIDON makes it necessary to collect and analyze personal data to provide appropriate tools for different situations. Data protection principles would be adhered to regarding informed consent for data collection, controlled access to secondary uses of personal data, and storage of (un-)necessary data according to specified time limits.

Examples on how this can be materialized in our project are: safeguarding user data at the server-side with appropriate backup, providing optional user settings to customize data storage requirements, protecting users' information security, limiting context-related data storage period, and allowing users to decide the type of information stored in the devices used.

General principle 6: Safety and security

- *The system should protect users and their information.*
- *The reliability and stability of systems must be ensured.*
- *The security of data transfer must be ensured.*
- *Adequate security measures and standards, appropriate to different environments, must be provided.*

The use of a tablet device in a public setting by vulnerable users raises potential safety issues. Location and context awareness features help the user to tackle difficult situations where they feel insecure or unsafe. Interfaces should provide a quick and reliable communication channel in order to call someone

for help. Location-tracking via GPS and emergency connectivity enable carers to know the current whereabouts of their protégés, their previous locations, and enable them to check that they had reached their destination safely. Primary users are able to contact the carer if they get lost or have problems finding their way and need help

Our system should support the safety of the end users, for examples by aiming to provide immediate access to phone call, keep track of user's position when travelling outdoors, and carers should have the possibility to request location of primary user and to contact the primary user.

Specific consideration on Reliability

Given that users may be dependent on the POSEIDON system outside the home, it must be robust, stable and reliable.

Hence it is expected that when live, framework components should have robustness and fault-tolerance comparable to non-vital commercial systems, that the system should be available 24/7, except for short periods of downtime for maintenance such as system upgrades, and reliable enough so that its services are working and available at least 95% of the time. When live, maintainability should be such that the time to get the system restored after major failure is less than one day and technical support should be available. The system is expected to provide comprehensive outdoors navigation services.

General principle 7: Autonomy

- *The system should support and enhance the independence and autonomy of its primary users.*
- *Users should have the freedom to override or "switch off" the system at any time if its performance is negatively perceived.*
- *Users should be trained to operate the system to the extent they wish.*
- *Users can determine for themselves degrees of protection, privacy and information-sharing.*

The survey and interview data suggested a strong wish from the majority of the target users to be more independent, and less reliant on carers and relatives. A high priority for POSEIDON, therefore, is to provide context-specific assistance to support autonomy and independence in the above areas. Enabling tasks to be completed independently without the need for assistance are potentially boost users' self-esteem and confidence.

Autonomy, however, as previously discussed, also means users being able to control technology. POSEIDON is adjustable to individual preferences and personal needs. Users are able to customize the system, within their framework of capabilities or with the help of their carers. While default settings are provided, POSEIDON includes the ability to override those defaults. The system allows the tracking option to be switched on or off, in line with different needs and competencies. Functions do not have to be used all the time, or in situations where support is not needed. It is recognized that too many choices and functions working at the same time could make it difficult for the user. Users, ultimately, thus have the ability to scale back or turn off the system if they feel bothered by it.

The system should promote user's autonomy and independence, support for optional interface customization to suit the end-user's needs, functionality should be customizable, should assist with activities supporting independence and inclusion, with special consideration given to the way time is represented and communicated. Third User-level contexts to be considered are: socializing, organizing the day and managing money.

General principle 8: Transparency

- *All users should be clearly informed of the pros and cons of the services offered by the system, including system capabilities, potential weaknesses, vulnerabilities and negative consequences.*
- *Users should be given notice of the existence of intelligent environment activity in an open manner.*
- *Background data processing, monitoring and surveillance should be made visible to users, where possible.*

To be in the control of the system, users' needs to understand it's (re)actions, feedback and possible uses.

Potential weaknesses, limitations and vulnerabilities in the POSEIDON system will be made transparent to users, including system operations, data collection and use, and surveillance activities.

The system should be open and transparent to users with respect to expected system functionality and weaknesses, and documentation must be provided to enable project participants and third parties to develop POSEIDON components. The system should be extensible, allowing integration of new functionality not yet foreseen. It should also provide confirmation that system has processed a request so users are informed about the inner processes of the system.

General principle 9: Equality, dignity and inclusiveness

- *The system should provide help regardless of age, technical background and ability.*
- *Affordability, fair provision, accessibility of technologies should be ensured.*
- *The system should accommodate different levels of cognition and competence.*
- *The system should reduce social isolation and not substitute for human care.*

POSEIDON is designed simply enough so that it can be used by the widest possible range of users with different potential levels of competence and cognitive ability. The system kits will be financially affordable and available in various price categories with different payment options.

Accessibility and inclusiveness also inform design and usability. In accordance with user requirements, the system avoids the need for fast reactions, fine motor skills and manual dexterity. It is generally symbol-based, rather than text-based, using gestural interaction where appropriate. POSEIDON has an attractive design and user interface that is fun and simple to operate.

The system should provide help regardless of age and technical ability, have an affordable cost, be motivating to use, with interface preferably based on symbol, icons and animations, taking into consideration aesthetical features (colors, fonts, contrast, etc.), and consider design heuristics.

Specific consideration on Social inclusion

One of the most important requirements that emerged from the survey data to facilitate communication and socializing with others. This should be done in order to reduce the risk of social isolation that people with Down syndrome face. Another requirement was to increase their independence. Social inclusion could be related to mobility and travel independence, a major factor in feeling independent and less reliant on others.

The system should be proactive (instead of reactive) in the following situations: issue reminders in the areas where the primary user has indicated that more help is welcomed (candidates: planning trips, during travelling from A to B). The first User-level context to be considered was: travelling.

We implemented the possibilities for navigation routes to be inserted into calendar appointments. There are reminders included about what to wear according the the weather forecast when a route is inserted into a calendar appointment. Additionally help offered when following a route outside and deviating too much from the planned route.

Second User-level contexts to be considered are: studying, working

5 Personalisation in POSEIDON

Personalisation in POSEIDON is anchored in the fundamental end user needs and preferences of POSEIDON's target group: persons with Down syndrome.

Personalisation has been an important issue since the beginning of the project. Personalisation in POSEIDON means that we are aiming to meet the needs of the individuals in ways that are best for them and for their user experience. The abilities may vary significantly for people with Down syndrome. For the primary end users the personalisation may mean both ordinary ICT-related accessibility and implementation of special features to meet their abilities in best possible ways.

It is implemented that both the primary end-user and the carer can do personalisation. We provide fairly simple personalisation tasks at the mobile device for the primary end user. The user may turn position tracking when using the app on and off. He/she may turn on and off high contrast on the screen.

The project provides a POSEIDON web. Through this, the carer, often family, can configure the whole POSEIDON-system to the benefit of the individual primary user. The carer can produce content for the POSEIDON-system in form of pictures, photos, videos, sound recordings and text. The carer can define routes for the navigation app and can augment the route with illustrating pictures, text and spoken messages. The calendar is an important reminder and communication service for the primary user in POSEIDON. The carer can define the elements of the calendar and how it should be presented for the primary user, depending on the primary user's abilities. The carer can give additional information to each appointment in the form of photos, videos and/or text, e.g. a video showing how to pack your school bag for tomorrow or a stepwise list for packing the sack with one item per step and photo of the item, text and/or a sound comment per step.

In POSEIDON, we strived for realisation of accessible solutions on all POSEIDON platforms (web, apps on smartphones or tablet PCs etc.). Accessibility can be viewed as the "ability to access" and benefit from some system or entity. The concept focuses on enabling access for people with disabilities, or special needs, like the universal design principles are about, or enabling access using assistive technology. We provided the possibility to change contrast in the screen for the user and a set of symbols for persons with learning disabilities to the carer. In this way we made it easier for the carer to personalise the POSEIDON-services to fit the abilities of the user.

The wide range of personalisation options in the POSEIDON system ensured that personalisation could be made:

- Across ages: it had to be personalized for children, teens, adults and elderly;
- Across ability: it had to be tailor-made for the intellectual capability of the user.

6 User-centred methodology

POSEIDON had a strong end-user involvement in all phases of the project, from end-user requirements acquisition, through systems design and implementation of technology and pilot studies to make sure that the technology met the needs and competencies of people with Down syndrome. We used

existing research methods in a co-creative way. This means that from the beginning of the project users (people with Down syndrome) and their caregivers were involved.

Pilot studies were the most thorough examination exercises for our technology. We gave three families of people with Down syndrome in three countries (UK, Germany, Norway) the product we had developed, at two different stages of development, so that it could be used in a variety of settings (e.g., at home or at school, at work and during leisure). We have worked closely with the person with Down syndrome and their carers, and wider family, to find the most appropriate way of recording data. Being flexible allowed us to obtain rich data that was then analysed and used for improvement of POSEIDON-services.

6.1 Requirements acquisition

POSEIDON used several methodologies for requirements acquisition. End-user involvement is key in all methodologies:

- An online questionnaire to assess the requirements of people with Down syndrome seen from the point of view of the carer,
- Face-to-face interviews with people with Down syndrome, to get their opinions,
- Personas and scenarios to illustrate which impact POSEIDON might have on the life of people with Down syndrome, to be used for a better understanding of the primary user's needs and problems in the project team,
- International workshops with invited participants from eight European countries, to disseminate information and get feedback from other parts of Europe.

6.1.1 Online-questionnaires

In a first step, we tried to find out what people with Down syndrome need, what they are able to handle, and what they want. Therefore, a requirement analysis was conducted in six countries (the UK, Norway, Germany, Italy, Slovenia and Portugal) started in December 2013 to assess the needs and requirements as well as the usage of technology of people with Down syndrome. We developed a standardized online questionnaire addressing parents to get a first impression on how people with Down syndrome use modern information technology.

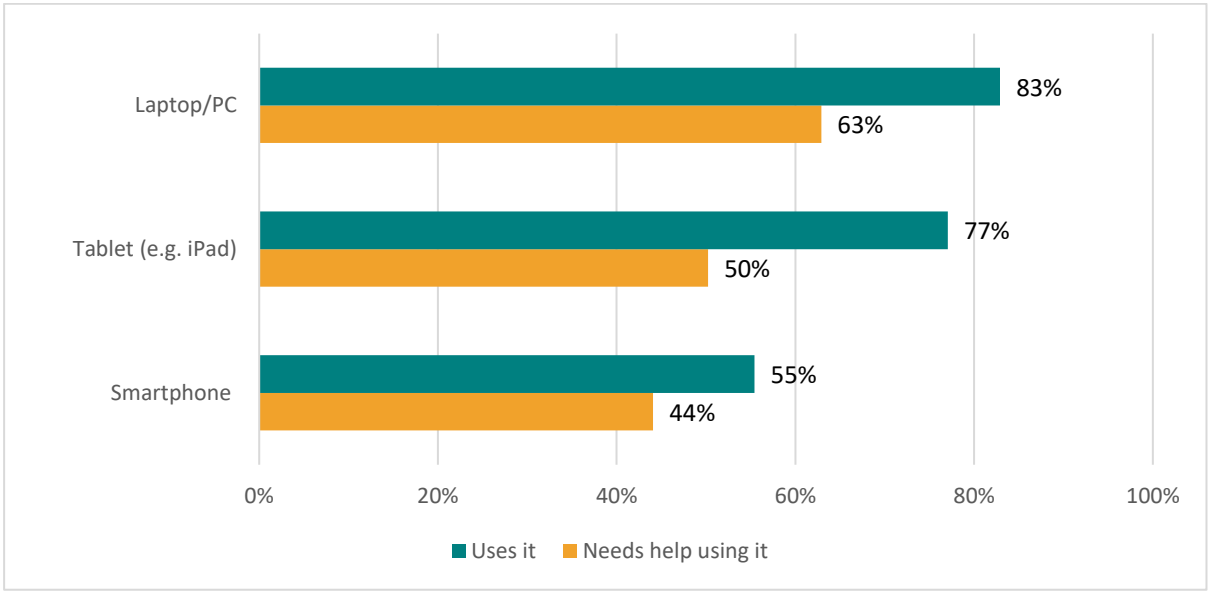
Central in these analyses was the online questionnaire on the everyday life of people with Down syndrome, their interests and the extent to which they are familiar with modern information or assistive technologies. The still ongoing questionnaire has been sent out through Down syndrome associations. In the first step, it was provided in English, German and Norwegian. Later the questionnaire was also available in Slovenian, Portuguese and Italian. Although the population of people with Down syndrome is small, 400 questionnaires were answered. The respondents were most times parents having a child with Down syndrome or people who care for them.

The first result of our investigation is that people with Down syndrome have highly divergent competencies. From the perspective of their caregivers some of them can do a lot of things on their own, some of them cannot do these things at all, and a bigger group is able to do these things with help. This includes the use of modern information or assistive technologies.

Many people with Down syndrome already use modern information technology: 83% use a laptop or PC, 77 % a tablet and 55 % a smartphone (see figure 3). This means that only a small group of people

with Down syndrome is not able to use these technologies at all. But within the group of those using these technologies about half of them need help.

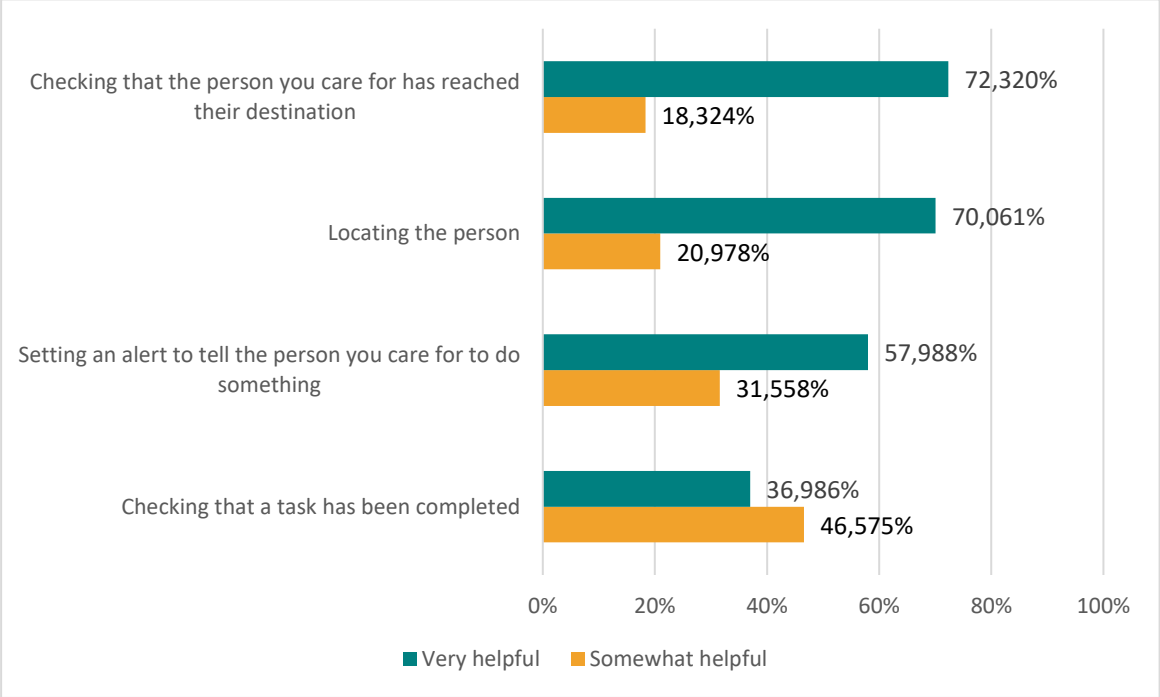
Figure 3: Using modern information-technology



The online-survey provides a broad overview on the problems people with Down syndrome have in their daily life. Questions were asked about time management, handling money, traveling, health behavior, communication, and school/work/learning. The overall impression is that there are comparatively few things people with Down syndrome cannot do at all, but many things they can do with some help. This means that there is a big chance that modern information technology will be of great help in assisting everyday life activities.

Help by information technology is also important for caregivers. They see chances that IT will make their own work easier. They hope to be better informed about the position of their protégés (e.g. whether they have reached a destination safely) or setting alerts to remind them of doing certain things (see figure 4).

Figure 4: Features of assistive technologies which would be helpful for carers themselves



The overall impression of our requirement analysis is that people with Down syndrome can gain much support from modern information technology. Especially tablets offer a big chance to become more independent and autonomous.

Our analyses show that the major feature a tablet for people with Down syndrome has to provide is an easy to handle GPS-system.

Furthermore the application

- has to be fun to use
- motivate for further usage after completing a learning task or travelling alone
- be adaptable for individual needs
- be robust
- avoid the need for fast reaction
- be able to play music
- be able to set reminder alerts
- must guarantee privacy

A topic being present in all stages of the ongoing project is ethical considerations. Not everything that is helpful can be considered as adequate from an ethical point of view. Especially the problems arising by a technology which is based on surveillance and control meets these problems. How much surveillance can be accepted? How can we make sure that the surveillance effects do not make its users even more dependent and un-autonomous? How can people with Down syndrome feel that supporting technology make them feel more independent and autonomous? These questions had to be considered in every stage of the project.

More details are found in deliverable D2.1.

6.1.2 Interviews

A very important part of the user requirements acquisition was to get feedback directly from the primary user group. To do this, project participants, mainly from the Down syndrome associations, interviewed 29 persons with Down syndrome. Of the 29 interviewees, 16 were female and 13 were male. The age range was from 14 to 38 years. 17 participants were living with their parents and 12 in sheltered homes. There is no significant difference between countries regarding their living circumstances.

The interviews were focused on:

- *Why and how is technology used?*
- *Why is a specific technology good or not good?*
- How can POSEIDON be developed to meet the user's needs?

The idea was to discuss the use of technology with the interviewed persons and gain an insight into how she/he uses technology and what is important or difficult for that specific person. We also asked if the person missed to have some information communication technology, and if so, what. The main purpose was to understand the user`s experience with using modern technology, what they liked, didn't like, used and would like to use and their level of competency in using the technology they own.

Generally, more or less all interviews show clearly, that the target group had a very strong wish to be more self-dependent. Therefore we concluded that offering new technology, which is of help in their daily life, would willingly be accepted.

More details are found in deliverable D2.1.

6.1.3 Personas and scenarios

Before the direct work with users and carers started, the project participants of POSEIDON gained a common understanding of the primary user group. A clear understanding of the target group and the situations in which POSEIDON had to be obtained. The focus was on a common understanding of the living situation of the possible users and carers and their daily life problems in which an assisting technology as POSEIDON could be helpful.

Personas are a common technique to reach such an understanding, i.e. by creating a realistic simulation of people having problems in their everyday life and showing possible solutions for these problems. We designed Personas to identify and understand the target group, to gain information about possible users of a product. Personas are fictive persons described based on relevant socio-demographic data like name, gender, age, economic situation, living conditions and other information, which could be valuable regarding the final product. In the end, personas are supposed to represent different members of the typical target group.

The whole POSEIDON-team was involved in using the personas for a better understanding of the users' needs and problems. It was also a cohesive element for the team building.

We designed Scenarios to identify and broaden the understanding of when, why and how technological supply could be helpful. Scenarios are stories, including a setting and actors to show possible use cases and tasks for the developed product. They tried to be close to reality and represent everyday life situations of the target group. It is a demonstration about how the product can be used to solve everyday problems.

The personas were developed by the project participants from the Down syndrome organizations.

More details can be found in Deliverable D2.1.

6.1.4 Workshops

Workshops that covered topics like usage of technology in general and assistive technologies, living situation, daily activities of people with Down syndrome took place with invited guests. The project organised three workshops. The first one was in Oslo in January 2014 with participants from Croatia, Italy, Romania and Slovenia. The second one was in Mainz in August 2014 with participants from Germany, Luxembourg, Portugal, Switzerland and Ukraine. And the last workshop was in Teddington, UK with participants from Ireland, France and the UK. The project invited three guests from each country to the workshops, one person with Down syndrome (primary user), her carer (secondary user) and an expert on Down syndrome (tertiary user). The idea of the workshops was to:

1. Disseminate information about POSEIDON to other parts of Europe
2. Establish step stones for translation, marketing and sales of POSEIDON-systems all over Europe
3. Get an impression of the living situation for people with Down syndrome in other parts of Europe
4. Assess knowledge about the use of technology for persons with Down syndrome
5. Get feedback on POSEIDON principles and add to the end-user requirements

In the workshops the guests with Down syndrome and their families had the chance to test the POSEIDON devises.

The first project workshop took place at the beginning of the project in Oslo, Norway. Different technological solutions were presented to the primary users (VR games controlled through Wii control, mouse/keyboard or tablet). The aim of this interaction with people with Down syndrome and caregivers was to explore user engagement with different technologies and their quality of experience.

These initial observations were used to create a mock-up of the system. This first prototype was introduced to the users during a workshop that took place in Mainz, Germany in month 8 with participants from 5 countries. We conducted a set of experiments with PUs over 2 days with the intention of assessing: the usability of our first prototype, the advantages and disadvantages of using specific proposed technologies.

This workshop was followed by a series of shorter workshops (half a day long), held primarily in London, additional ones also in Germany and Norway. These events were meant to facilitate the design of the product's functionality and interface. Developers participated in these meetings in order to gain a deeper understanding of the necessary modifications.

The last workshop took place in Teddington, UK with participants from 3 countries. For the testing, a scenario was created with different tasks in order to get feedback for final improvements at the last stage of the project.

The guests very much supported the POSEIDON thinking, and were thrilled by the fact there is a project with main task to support and independent living for the PUs.

More details are found in deliverables D6.2

6.2 Summary of user requirements

The basic concept of POSEIDON is to support both primary and secondary end users. Central in POSEIDON is a user-centred approach and co-creation with the Primary and Secondary Users.

Therefore, the findings in the interviews with the persons with Down syndrome and their carer became the main guideline for the choice of initial POSEIDON-services.

A common characteristic is that young persons with Down syndrome go to school, work or day activity centre and also to organized leisure time activities Then time needs to be managed and travel to destinations to be performed. Mobility is a central issue and most persons interviewed said clearly that they wished to be more self-dependent in their mobility. They would like to go out alone in evenings or even travel abroad alone. Both Primary and Secondary Users said that handling money is a challenging issue. Independence means the need for understanding the concept of using money and the value of money is needed.

Based on the requirements acquisition, the following application areas were chosen for the first set of POSEIDON-apps which were tested in the first pilot (summer 2015).

1. Navigation with more help than from an ordinary navigation app for the primary users.
2. A time manager in the form of a calendar with additional features for reminders and instructions.
3. A money handling training exercise.
4. A personalisation service were the POSEIDON-system could be adapted and configured to the individual user by a helper

6.3 User experience evaluation of POSEIDON

During summer and autumn 2015 and 2016 two pilot studies were conducted with in total 18 families (the United Kingdom, Norway and Germany). The families that took part in the pilots were recruited by the Down syndrome associations.

The two pilots lasted in each family at least four weeks. Members of the POSEIDON project regularly visited the families to monitor how tasks were done and offer help. For data collecting different qualitative and quantitative methods were used. The SUs had to fill in questionnaires for every device at the beginning and at the end of the pilot, we conducted interviews three respectively two times in each pilot with the Primary and the Secondary Users and we observed them during the visits while they used the POSEIDON devices.

The questionnaires mainly had three subject areas:

- Design and handling (e.g. “The font is appropriate. “)
- Fun and acceptance (e.g. “The navigation app gives the user joy. “)
- Helpfulness/Transfer of Knowledge (e.g. “The navigation app helps the user to easily navigate to different places. “)

In the interviews PUs and SUs should get the chance to talk about their impressions, problems and experiences, which were not covered by the questionnaires. There were interview questions for all applications as well as general questions. It was important to cover all topics, independent on what happened during the testing situations.

Moreover, an extended pilot, in the form of a one-day event, was conducted in all three participating countries in autumn 2015.

To make sure the pilots were conducted in a standardised manner, guidelines for pilots were created. In deliverable D6.1 more details can be found.

6.3.1 Ethical approval

Each participating country applied for the relevant ethical approval in their area if ethical approval were required.

For more detail about ethical issues see deliverable D2.4.

6.3.2 Recruitment procedures

Three people with Down syndrome were recruited in Norway, UK and Germany for each pilot by the DSAs. Each person with Down syndrome (primary user) was paired with a caregiver (secondary user). We aimed for parents to be SUs.

Potential participants received the information sheet for secondary users and the easy to read information sheet for the persons with Down syndrome describing the project and the pilot. Those interested were contacted by the researcher. The researcher then arranged a visit to explain the project in more detail and to answer any questions. A screening questionnaire was used to make sure the participant was eligible. Participants were encouraged to discuss the project with family/friends or a relevant professional before agreeing to take part. If participants agreed to take part they were asked to sign the consent form.

Among the eligibility criteria both for persons with Down syndrome and their parents were:

- Have the motivation and ability to participate
- Have a general interest in IT, not scared of IT
- WiFi access at home

The person with Down syndrome should be at least 16 years old and the Secondary User a parent.

6.3.3 Methods

Different methods and instruments were used to assess the POSEIDON applications. To get comprehensive insights quantitative and qualitative methods were used. SUs and PUs were interviewed twice: after the first and after the last visit. Moreover, the SUs evaluated the applications with the help of questionnaires. These questionnaires also had to be filled in twice – at the beginning and at the end of the pilot. Furthermore, the SUs were asked to fill in a Diary/User Protocol every time an application was used. Observation sheets should be completed by the monitors when PUs were interacting with one of the devices and they were present.

For the co-creation process it was especially important that the monitors observed and documented how the PU interacted with each part application/part application on a smart phone and PC and with the CapTap for the first time. In the first pilot the aim was to take it was even video film to see in detail how the interaction had been. This gave an even more precise documentation of what had been easy for the user and what had been difficult.

For pilot 2 the instruments were revised in order to create the result in form of case studies. In deliverable D6.4 more details can be found

6.4 Main results from Pilot 1

The families which have taken part in the first pilot liked the vision of the POSEIDON project and the ideas behind the POSEIDON applications.

The PUs liked the idea of using a screen-based tool, being reminded by a smartphone, using a new device like the CapTap and a new interaction method, having their own pictures integrated into routes

and learning how to handle money via a gamification approach. They liked mastering things and succeeding in doing something. In contrast, they didn´t like getting negative feedback, the feeling of being unsafe or the usage of unreliable products or products they are not able to use.

The SUs could imagine that the POSEIDON systems can help people with Down syndrome to become more independent. However, for reaching this aim, all POSEIDON applications and devices needed further developmental activities, especially regarding the following three main points:

- Usability and user experience
- Safety
- Personalisation

For more results, see D6.3.

After pilot 1, the applications were revised and some new functions were added.

6.5 Main results from Pilot 2

In the second pilot the system worked more reliable than during the first pilot, and many problems could be solved by the users themselves. Nonetheless, it remains a challenging system, both on the cognitive and the motivational level.

People with Down syndrome have highly different abilities and therefore need different forms of support. It was a central aim of POSEIDON to take this into consideration and to develop for every application a possibility to customize it to the abilities and needs of the person with Down syndrome. The Secondary Users customized different levels of personalization depending on the competencies (reading, spelling) and the preferences (e.g. sound of alarm, preferred routes) of the person with Down syndrome. They reported what they personalized and if they thought other functions should be personalized.

The central result of pilot 2 is that using POSEIDON can probably lead to an increasing independency and autonomy of people with Down syndrome, a better organization of daily tasks and a higher mobility. All SUs of the pilots can see the potential POSEIDON has on independency and autonomy.

Using the calendar made the PUs feel more independent although they needed some prompt adding their appointments. However, with help of the calendar app they achieved their goal remembering appointments and bringing all necessary things to school or work. Helpful in many respects was the use of the navigation system: it made travelling more secure for the PUs and was reassuring for their carers who could easily be informed about the position of their protégées.

By combining different apps of POSEIDON users could organize and conduct different tasks. They could for instance do a shopping tour completely on their own: creating a shopping list, organizing the money for the planned purchase, planning the route to the shop, using the navigation system to go there, doing the shopping, paying on their own and going back home again with help of the navigation app.

POSEIDON is a complex system, which combines and integrates different apps and the POSEIDON website. This makes testing more complicated, requiring more time than the testing of just single features. Technical problems, which had to be solved during the pilot, arose most times in complex tasks. So, for instance, it became a problem to secure that the PUs outside their homes paid sufficient attention to the ongoing traffic while concentrating their attention to the navigating device.

Personalization of tasks is the key concept in using POSEIDON. Because Down syndrome includes highly diverging problems, tasks have to be developed and modified according to different abilities. This means that a system as POSEIDION cannot be reliable in general but there can only be sufficient reliabilities for different groups.

Taking such limitations into consideration POSEIDION definitely has the potential to increase the Primary Users independence and autonomy. The Primary Users need to practice and use the functions more and over a longer period in order to adapt the system in their daily life.

For more results, see D6.4.

Also after pilot 2, the applications were revised the last time.

7 Lessons learnt

In the course of the project the consortium learned many different things. Some things were unexpected; some things turned out to be more complicated as expected before or were considered beforehand. However, we learnt our lesson and also other projects could benefit from following them if they take these points into account.

Lessons learnt which are presented below from different perspectives.

7.1 General lessons learnt

Leasons learned for guidelines for building technology for people with Down syndrome:

- Setting and adhering to deadlines for technical development for all technology partners is important to have a good progression of the technical development. The deadlines should be set so that they give sufficient time for testing and fixing bugs in internal testing and testing by persons outside the project before testing starts in a vulnerable target group.
- There should be a good testing by team members in different countries for apps and systems and the major bug fixed before used on persons new to the project.
- A short test period of e.g. one week in a family in each country should be done and additional discovered bugs should be fixed before a large roll-out of the testing starts.
- Good instructions for team member(monitors) for how to set up systems and applications to be tested should be made available to the monitors before testing in target user group starts (like the "Deployment Document for making good setting on the smart phone to prepare for the usage of the POSEIDON app on a specified smart phone and instructions for using the CapTap). Monitors can be involved in making such guidelines.
- Ensure the team members to be involved in the testing (the monitors) are properly trained before they start the pilot.
- Technicians should be present during at least the first visit to the families when testing in the target group.
- Availability of team support (from monitors and technicians) also on evenings and weekdays during the pilot is important.
- Good instructions for using the applications for SUs should be developed. This also helps monitors to learn to know the applications and devices.
- For testing impact on the lives of the target group a longer test period that 4 weeks should be used.
- Too many applications and/ or devices should not be tested at the same time in families in this target group.

- It is difficult to recruit families in this target group, especially it the testing requires a lot of time. Payment for the use of their time should be considered.
- It became more and more clear that is very important to have team members in the consortium who have children themselves with Down syndrome (6 members) and thus a lot of experiences.

7.2 Lessons learnt from the management perspective

From a management perspective, the following issues should be kept in mind.

It should be noted that the following bullet points are more general project management reminders, and not particularly for a project directed towards people with Down syndrome, their relatives and carers. However, just so it is mentioned; for all projects with user involvement, it should be rather obvious, treat all people with respect and acknowledge that no persons are equal.

- Have a project meeting for all partners very early in the project. This creates, hopefully, a good atmosphere between partners and a strong foundation for the collaboration to come. When you know each other, communication in other media, telephone, teleconference and mail becomes easier.
- Have regularly project meetings using teleconference technology. In POSEIDON, we have had bi-weekly meetings and other meetings, e.g. technical meetings, in between. This ensures that you feel the pulse of progression in the project.
- Do not forget to have physical meetings. There you can have lots of discussion also outside the meeting room, and you get to know your partners better. Use the opportunity to visit the different project partners.
- Do proper preparations before reviews with the Commission. The reviews are where you prove that you deserve the funds allocated for your project. Be sure to have an agenda which enables you to show the very best of the achievements in the project.
- The project manager should make good progress reports. Report on progress and use of resources. The reviewers will not have access to the participant portal where all economic information is declared.
- Do not think that the system architecture you agree on early in the project is not going to be modified during the project. Your insight increases during the project and you should incorporate the necessary changes. However, at the other side, some stability is also encouraged.
- Ensure that your services/systems are co-created with all stakeholders. This is what sometimes is referred to as service design.
- Be aware of IPR issues at an early stage in the project. The conditions written down in the Consortium Agreement must be adapted to reality. Lack of IPR considerations, may jeopardise the commercialisation process.
- It is an advantage to have a good balance between research organisations, businesses (both SMEs and large businesses) and user organisations in the project. The users should be partners in the project.

7.3 Lessons learnt from the perspective of the DSAs

From Down's Syndrome Association UK

There was a wide-spread interest in the application of POSEIDON amongst families in the UK Down syndrome community, and recruiting families willing to participate in the Pilot 2 was relatively easily. There was a considerable variance in competency in using IT across individuals with Down syndrome,

but equally importantly, between family-carers of the individuals. This is crucial as use of POSEIDON relies on family carers to programme routes, set-up carers web and prompt the individual with Down syndrome to make appropriate use of the applications.

A number of the UK families were most used to use IPhone handsets, and as the POSEIDON apps currently work only on Android systems. This made it necessary for the users to use two phone handsets – their IPhone and an android test phone for use with the Pilot. This was slightly cumbersome for some families.

Families involved in the UK pilot needed to spend a fair amount of time setting everything up on the carers web and getting used to using the apps. This required a time investment in the early stage of usage of the system, which then paid off once the families became more familiar with using the apps. Although families would general agree this time investment was beneficial, it is quite difficult for families who have a lot of time pressures to make this change in their daily routines.

7.4 Lessons learnt from the social research perspective

The first thing we experienced is that it was quite complicated and difficult to recruit three families in each country twice (in 2015 and 2016). The families with youths who have Down syndrome are very busy. In leisure time youths with Down syndrome mainly see friends in organized leisure activities. Often parents are involved in these activities. The involvement into a research project like POSEIDON requires a lot of time. Parents are very busy; most of them try to stay working, they care as good as they can for the person with Down syndrome and the rest of the family, and they are involved in multiple visits for health and dental care, school system and other part of the support system and write a lot of applications and for services for their child with Down syndrome. So, in the end the recruitment by the DSA´s was often very time consuming and difficult.

Moreover, we learned in that context that the families had to put much more effort into the testing than anticipated. We expected them to use 10 hours per week. The effort was in some families partly more than 10 hours. Moreover, 10 hours a week is very much time besides their obligations they have. It was hard for some parents to believe that we really meant this before start. Perhaps it was not communicated well enough that the parents should use at least 10 hours per week. This is why in pilot 2 two families dropped out and new families had to found. This one of the reasons why the two pilot studies took much more time than initially planned. Also, the effort of the monitors (the person who visited the families in the pilot and conducted the interviews and observations) was much higher because much more technical problems occurred than expected. Also, some of the technicians were more involved in visits to families and fixing bugs due to the many technical problems. All in all, the whole consortium and the recruited families had much more effort with testing POSEIDON application than anticipated.

We also learned during the project that the testing period could or should have been longer than four weeks. The Primary and the Secondary Users needed time to get used to the system and to practice the functions before they were able to handle it correctly. This occurred even if most of them were familiar with handling PCs and smartphones. Due to the short test period a real impact could not be measured. The SUs could for instance only assume that the PUs could become more independent with the help of POSEIDON. Four weeks testing was a too short period to proof if persons with Down syndrome really become more independent or more included into the society with POSEIDON. At least, all participants see the potential POSEIDON has on autonomy and independence.

We also learned that not too many applications and/ or devices should be tested at the same time in families in this target group because it was as already mentioned quite time consuming and complex for the families with a lot of tasks in these four weeks. It could be reasonable to test the different applications with different families in order to reduce the effort.

Another lesson which became more and more clear in the course of the project was that user involvement and co-creation is indispensable when developing assistive technology for people with Down syndrome. They are a unique target group with varying abilities, needs and preferences. That is why it was so much important to involve persons with Down syndrome and their carers from beginning of the project in the developmental process. Of course, this insight was obvious for the members of the DSA´s and Karde, but for the rest of the consortium who are not usually in touch with persons with Down syndrome this insight became more and more obvious.

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