POSEiDON

Ethics in POSEIDON

POSEIDON services

At the end of the project, POSEIDON will have provided the following prototypes, which will be made ready for commercialisation (see: http://www.poseidon-project.org/product/)

- App for users with Down syndrome
  This app supports daily planning and traveling. The main menu gives the user with Down syndrome the following options:

  o   Routes – Start navigation by using planned routes or a new route.
  o   Map – View current position on Google Maps.
  o   Calendar – View planned events and add new events.
  o   Preferences – Turn on/off position tracking and choose colour themes.

- Web for carers
  On this web site the carer can make personal calendar events and shopping lists that will appear on the user´s smartphone with photographs, voice messages, signs and possibly videos. The carer can also track the user´s position and mark important places on the map.

- Home Navigation app
  The Home Navigation app aims at helping people with Down syndrome to learn how to walk a route. This computer app offers functionalities for both the carer and the user with Down syndrome.

- Money Handling apps
  o   Money Handling Training
       Money Handling Training app (on PC) aims to train the users in handling money so that they are better prepared when they go shopping. Click on the item below to learn more about the app.

  o   Money Handling Assistance
       Money Handling Assistance is a shopping app (on smartphone) that supports the users on the spot – when they are out shopping.

- Social network for primary and secondary users
  The social network, or what we actually regard as the POSEIDON ecosystem, is a web based service which acts as one single point of access to share and get all high quality relevant information (news, research, practical info, experiences), apps and e-learning for secondary and primary users of Down syndrome.

The social network will encourage socialising for the primary users. Discussions will be moderated to monitor language and inappropriate statements. In addition, the POSEIDON services supports

mobility by making appointments and provide support for traveling for visiting friends or leisure activities. The primary users can also enter appointments by themselves.

There is an emphasis on clean and simple human-computer interfaces, responsive design, personalisation features and context-awareness.

In addition, POSEIDON will provide an infrastructure/framework for third party developers to develop apps/services and set of apps/services for the target group.

Ethics, privacy and security in POSEIDON

Deliverable D2.4 Safety, Privacy and Ethical Considerations is a document compiling all safety, privacy and ethical main considerations to be observed. It will be followed independently in dedicated actions within other Work Packages given their importance on the acceptance of the final product and the impact of the project as a whole. The document has an emphasis on:

- Person, including the areas with need for support and targeted aid given
- Technology, including requirements for a successful and safe use
- Research, including modalities for involving people with special needs.

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 informed by the Intelligent Environments Manifesto proposed by Augusto et al (2013a) that advocates the development of systems in a manner, which 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 taken into account through detailed requirements gathering and analysis via surveys and face-to-face interviews with secondary and primary users.

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 DS),
- secondary users (parents / carers) and
- tertiary users (for example, personal assistants, support workers, specialist teachers, healthcare professionals, employers and local authorities).

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 and their carers will have the ability to adjust privacy levels and to specify which personal data can be accessed and for what purposes it can be used.

So a general principle in our system will be 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 analyse personal data to provide appropriate tools for different situations, data protection principles will 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 will 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 will be 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 possibility to request location of primary user and to contact the primary user. Also it should provide device level access security and network level security for mobile components.

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 will be 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 1 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 on the part 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 will potentially boost users' self-esteem and confidence.

Autonomy, however, as previously discussed, also means users being able to control technology. POSEIDON will be adjustable to individual preferences and personal needs. Users will be able to customize the system, within their framework of capabilities or with the help of their carers. While default settings will be provided, POSEIDON will include the ability to override those defaults. The system will allow for some functions 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 recognised that too many choices and functions working at the same time could make it difficult for the user. Users, ultimately, will 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 integration, with special consideration given to the way time is represented and communicated . Third User-level contexts to be considered are: socializing, healthcare, 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 user knows what is going on.

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 will be 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 will also inform design and usability. In tune with user requirements, the system will avoid the need for fast reactions, fine motor skills and manual dexterity. It will be generally symbol-based, rather than text-based, using gestural interaction where appropriate. POSEIDON will have 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 (colours, fonts, contrast, etc.), and consider design heuristics

Specific consideration on Social inclusion

One of the most important requirements to emerge from survey data was the facilitation of communication and socializing with others, in order to reduce the risk of social isolation that people with DS face, and increase their independence. Social inclusion was in turn found to be closely 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: issuing reminders in the areas where the primary user has indicated more help is welcomed (candidates: planning trips, during travelling from A to B). First User-level contexts to be considered are: travelling, communicating.

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

When live, 'safety net' plan for foreseeable situations (e.g. bus does not arrive and no connection) should be in place.

The system should provide support for further social integration at leisure time. It can include photos of faces for known people in the communication tools, organize photos collection for social interaction and sharing, and support for other functionality, e.g. notable landmarks while in transit to aid orientation. Carers should have possibility to request emotional state of primary user for two-way reassurance that there are no problems and to ensure primary user feels supported. The system should give priority to plans involving public transport and trip planners should focus on the next few steps and use familiar landmarks to guide.