

POSEiDON

PersOnalized Smart Environments to increase Inclusion of people with DOWn's syNdrome

Deliverable D2.2

Report on Measuring of Impact

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Contents

- 1. Introduction..... 3
- 2. Areas POSEIDON might have an impact on..... 3
- 3. Measuring the Impact 4
 - 3.1 Questionnaires 4
 - 3.1.1 Everyday life competencies and feature usage of primary users 4
 - 3.1.2 Carer stress and perceived helpfulness..... 6
 - 3.2.Interviews..... 7
 - 3.2.1 Primary and secondary users 7
 - 3.2.2 Tertiary user 7
 - 3.3 Diaries..... 7
 - 3.4 Technical Monitoring..... 7
 - 3.5 Other options 8
- 4. How outcomes are measured in POSEIDON 8
- 5. Conclusions..... 10

1. Introduction

POSEIDON aims at developing a technological infrastructure which supports a growing number of services to help people with DS (Down syndrome) achieve greater independence and inclusion in their everyday lives. POSEIDON will be developed to support people with DS and their caregivers, parents and other relatives and helpers. Furthermore POSEIDON will provide a platform other organizations can use when developing similar services in the future.

To ensure POSEIDON achieves its overall aim, the developmental process will follow a user centered approach and involve primary, secondary and tertiary users at each step of the process. The success of the Project and its impact will be measured throughout its life and following completion.

The Project will identify specific scenarios where people with DS can be supported in achieving greater independence through the use of technology. However POSEIDON could have a longer term impact of raising the profile of people within their communities and their ability to contribute to that community. Such an impact will be determined by societal change to which POSEIDON will be a contributor.

At the beginning of the project information was gathered about what is important for the stakeholders. These aspects will be considered throughout the Project to ensure maximum impact.

This document will discuss the areas POSEIDON is expected to impact upon in the lives of people with Down's syndrome and their families, how that impact is to be measured, and finally what conclusions can be drawn.

2. Areas POSEIDON might have an impact on

POSEIDON is expected to have an impact on different stakeholders and in several areas. The overall aim of the Project is to positively influence the lives of people with DS, by providing a framework to support them in overcoming the daily challenges they face. POSEIDON aims to create opportunities for people with DS to become more active members of society by supporting independence. It will facilitate improved communication through technology, help in the areas such as of mobility, empowering people with DS to travel safely on their own to reach their designated locations, e.g. school, work place or leisure.

POSEIDON will also have an impact on the everyday life of secondary users, e.g. parents or caregivers. With the help of POSEIDON communication with the primary user will be easier and it could be possible to leave notes, schedule appointments and set reminders. This will reduce the time needed for organization by parents or caregivers.

Through the adaption process of POSEIDON and the associated improvement of quality of life for people with DS and their peer group more members of society will benefit from ICT advantages. This inclusion will likewise create new business opportunities centered on these stakeholders and their requirements. This could be seen in the development of new products for people with DS or other disabilities and new associated services. For these products and services POSEIDON and its user centered approach will be a starting point, since the features included in POSEIDON contribute to more inclusion, independence and autonomy, while raising awareness.

3. Measuring the Impact

Measuring the success of POSEIDON will be done through a mix of approaches. Developing assistive technologies for people with cognitive impairment makes it important to involve their carers. Information gained from primary, secondary and tertiary users will support the project in having the greatest possible impact.

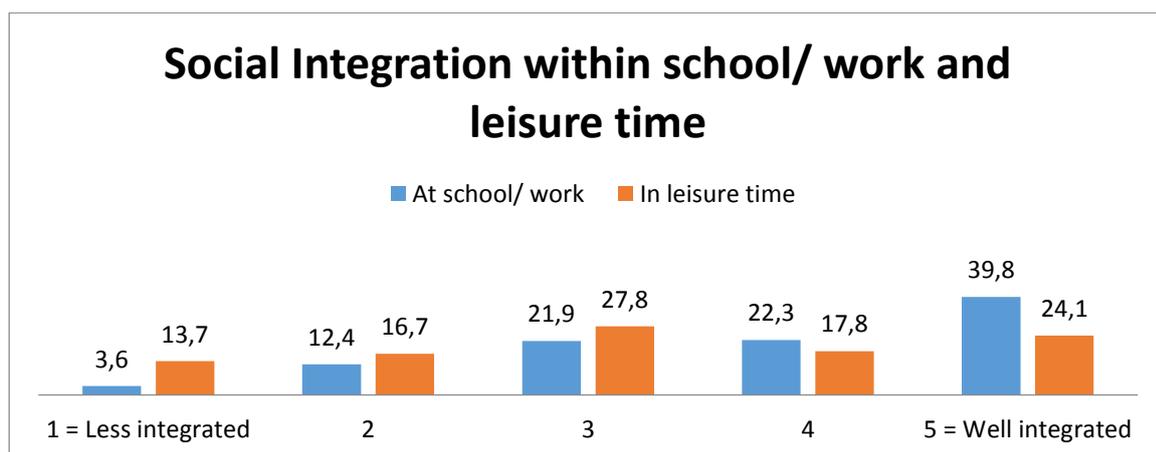
For measuring the impact several instruments and methods will be used:

- Questionnaires
- Diaries
- Observations
- Interviews
- Technical monitoring

These instruments will measure what impact POSEIDON has on primary, secondary and tertiary users. Some aspects will be addressed repeatedly to show improvement during the time of the project.

3.1 Questionnaires

Questionnaires will be developed to gather standardized data about the usage of POSEIDON and any related preferences or problems. To get a widespread perspective there will be various specific questionnaires for primary, secondary and tertiary users. Primary users will be supported when necessary to complete questionnaires by their carer or a member of the POSEIDON team. Interviews with care givers will inform primary user interviews where appropriate.



Picture 1 Integration of people in DS at school/work and leisure time (N=276; Age:10+)

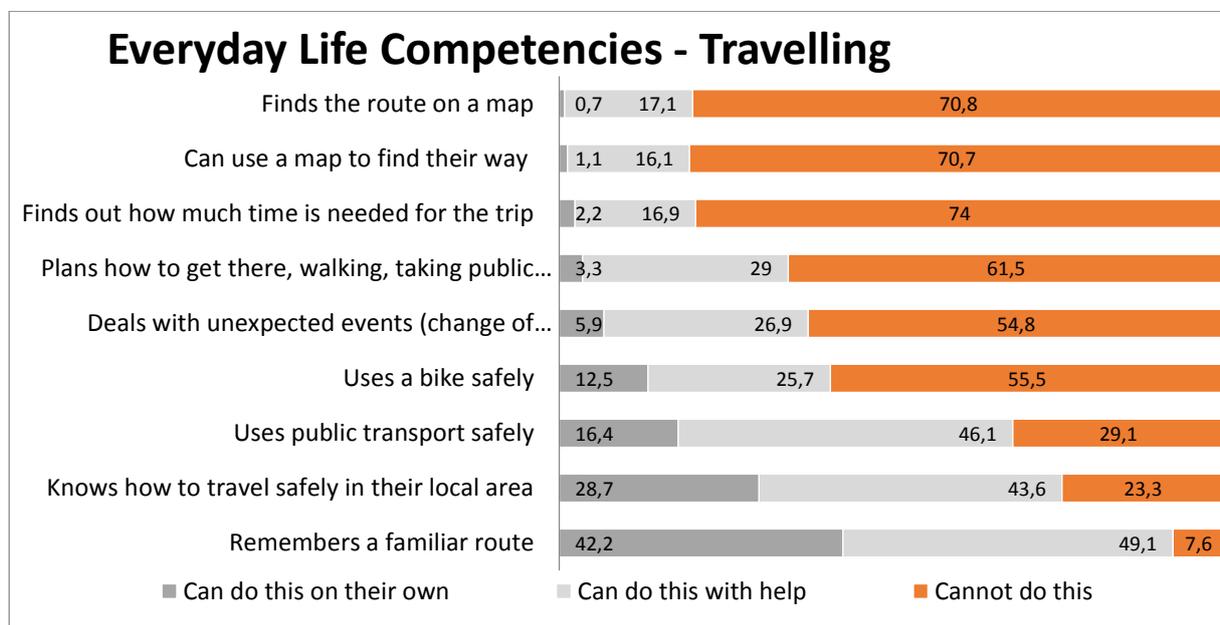
3.1.1 Everyday life competencies and feature usage of primary users

The main purpose of POSEIDON is to enhance the inclusion and independence of people with DS. Results of the requirement analysis (D2.1 Report on Requirements) indicate that only 39.8 percent of

people with DS are well integrated at their school/ work and only 24.1 percent in the questionnaire survey are well integrated within their respective leisure time activities (picture 1). POSEIDON aims at increasing social integration.

For people with DS to achieve inclusion within their communities and independence support for their everyday activities is required. POSEIDON aims to achieve greater control and independence for people with DS in their everyday life.

Within the online survey, the foundation of the requirement analysis, different communication, socializing and school/work/learning abilities were assessed. Furthermore money and time management strategies were assessed. We also asked questions about travelling since travelling is seen as an area where POSEIDON could have a major impact. Secondary users indicated to what extend people with DS are able to travel. They indicated whether they could manage these activities on their own, with help or not at all. This deliverable does not claim to present the results of the requirement analysis. It rather uses its approach to get an impression of how impact can be measured. For this purpose, some results referring to travelling are presented (picture 2).



Picture 2 Everyday Life Competencies – Travelling in percent (N=276, Age: 10+) DS

Picture 2 depicts, what percentage of people with DS (indicated by their parents/carers) are able to do the above activities. In our survey most people were over 10 years and mainly between 10 and 20. The overall aim of POSEIDON is to increase the number of people who perform the above activities with the appropriate level of support. That said there are limitations as some of the shown competencies regarding travelling cannot be addressed, e.g. using a bike safely. This approach can be applied to all other areas. In order to make qualitative assessments, competencies of people with DS have to be assessed before and after the two one month field trials. This approach ensures an accurate measurement of the increase in competency in relation to POSEIDON .

The following are examples of areas of competency that that can be covered by the questionnaires:

- Travelling about
- Communication

- Socializing
- School/work/learning
- Time management

These were the most highly rated competencies within the requirement analysis. All the user groups will complete these questionnaires in order to gather information.

The questionnaire will address the usage of different features POSEIDON offers. It will be assessed how often they are used and if difficulties occur while using them. When there is no opportunity for comparison (e.g. through already available similar apps), these questions won't be asked before the introduction of POSEIDON. If there is the opportunity for comparison those already existing competencies will be queried before the usage of POSEIDON. Furthermore these aspects will be assessed continuously during the test trials in order to document changes over time.

The following possible features can be covered by the questionnaire:

- Travelling features
- Communication features (video calls, auto completion etc.)
- Entertainment features (music player, learning tools.)
- Organizational features (reminders, alerts, etc.)

Emotional aspects like wellbeing, liking, self-confidence, independence and acceptance are of interest and will be covered as well. Those will also be captured via questionnaires. Since these aspects might be subject to fluctuations, they will additionally be assessed through diaries, providing ongoing information in relation to POSEIDON.

3.1.2 Carer stress and perceived helpfulness

POSEIDON aims to support not only people with DS but their caregivers and so the extent to which they also benefit from POSEIDON will be measured.. This can be done via questionnaires. Accurate measurement of the direct impact of POSEIDON, will be done twice: before and after the usage of POSEIDON. This enables the Project partners to draw direct conclusions, about the degree of impact.

Different aspects will be covered by these questionnaires:

- Perceived stress levels
- Time spend organizing the life of people with DS
- Concerns of the safety of people with DS while travelling alone
- Time spend on technical difficulties of POSEIDON
- Time supporting people with DS using POSEIDON
- Reliability of POSEIDON
- Usage and related problems of several features POSEIDON will offer

3.2. Interviews

One essential part of the impact measurement of POSEIDON will be interviews with primary, secondary and tertiary users.

3.2.1 Primary and secondary users

Primary and secondary users will be interviewed before and after the two four weeks test trials. Besides standardized questionnaires they should have the opportunity to mention their expectations, feelings and experiences. This will ensure that issues not raised by the questionnaire are covered. By interviewing them, individual experiences made within the test trials can be assessed, problems and doubts discussed. During the interviews the POSEIDON-team will observe the impact of POSEIDON upon the lives of the pilot participants.

3.2.2 Tertiary user

Tertiary users, teachers, supervisors or service providers, up to now have not been systematically integrated into the project. They will be asked later in the developmental process once the first prototype is ready to be tested. They will advise upon how to integrate POSEIDON within the infrastructure of the pilot participants' community. This is an essential aspect of ensuring the success of the project.

3.3 Diaries

POSEIDON will be given twice to the users for a period of four weeks respectively. Diaries can provide a comprehensive insight into user behaviour, and highlight individual experiences, problems and successes. Unlike questionnaires, diaries provide in-depth data over a specific timescale. Diaries help detecting changes in behaviour and usage. The project will make use of a partly standardized method. Some categories like responses to experiences (e.g. feeling of success, stress level) will be given. On the other hand participants can freely report and comment what kind of experiences they had. Writing the diary should be a collaborative process between primary and secondary users. Secondary users will act as prompter and support in the recording of main events (e.g. travelling a new route alone) primary users will add their feelings and emotions in relation to this event. Recording can be done in a variety of formats: written, photographs, pictures, video, sound record. It is important for all project partners to have information about the user experience at specific points of interaction. This information can be matched to log data (see 3.4 Monitoring) in order to analyze the positive and negative aspects of POSEIDON and inform it's the next stages in its development.

3.4 Technical Monitoring

Information gathered by diaries will be accompanied by data from observations of the participants including their individual subjective responses to the technology. Measuring the frequency at which a function is used and situation in which it is used will gather important insights. The use of the technology by pilot participants over a specific time period will inform the developers about whether the need for support when using POSEIDON decreases over a period of time. These results also can be compared with the ones gained by interviews with family members and caretakers.

3.5 Other options

Another option to measure if POSEIDON is well received by the users will be the willingness to pay for and/or keep it at the end of the trials. Overall two field trials will be conducted in every country, the feedback of the first trial will be used to adapt the system according to the results. The redeveloped prototype then will be evaluated in the second trial. At the end there will be a product which is tailored to the potential user's needs and abilities. The evaluation results will be disseminated and the product will be demonstrated by the project partners at conferences, exhibitions and in scientific journals to increase the awareness of POSEIDON.

4. How outcomes are measured in POSEIDON

The proposed measure of success is summarized in the table below. The expected outcome “Enhanced quality of life for people at risk of exclusion, including people with disabilities, older people and people with low digital literacy and skills” is connected with the following indicators of success: 50% of the representatives of the target groups have to rate POSEIDON as an assistive technology which enhances independence and autonomy of people with Down`s Syndrome. In addition more than 50% should like using POSEIDON. To achieve those indicators of success it is essential that every intended user group is able to master the developed technology. Achieving or even exceeding all those success indicators is necessary for rating the development of POSEIDON a success. The measurement of these indicators will be performed via the already mentioned instruments. See the table for detailed representation of the expected outcomes and their proposed measure of success.

| Expected Outcomes | Proposed Measure of Success | How the Measurement will be done |
|---|--|---|
| Novel accessibility solutions for user groups at risk of exclusion. | <ul style="list-style-type: none"> One novel service/application with many functions that is available for people with DS (primary user group) and other intellectual disabilities. Results of testing in primary user group positive so development/production and marketing of the product will proceed. Interest organisations for DS and also for other persons with intellectual disabilities, support the product and will spread information about it (at conferences etc.) because they think it is useful. | The measurement of these outcomes can be done more precisely during the last trimester of the project as part of the preparations for bringing the product to market. |
| Enhanced quality of life for people at risk of exclusion, including people with disabilities, older people and people | <ul style="list-style-type: none"> More than 50% of representatives for target group (including parents, carers, teachers) find that our product makes people with | <ul style="list-style-type: none"> This will be captured via Interviews with representatives of the target group and through |

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| <p>with low digital literacy and skills.</p> | <p>DS more independent and autonomous in their daily life.</p> <ul style="list-style-type: none"> • More than 50% of persons in target group like to use the product. | <p>questionnaires during the pilots.</p> <ul style="list-style-type: none"> • Mastering of the technology will be measured through observations during the pilots by the POSEIDON-team and observations in daily situations by relatives during the test phase. Furthermore interviews will give input about major challenges using POSEIDON. Those interviews will be conducted with relatives, caregivers and if possible with people with DS. <p>These measurements will be done through the pilots [months 10 and 20] and the user group workshops [months 3 ,10 36] which will allow us to trace the variations in response in relation to the evolutions of the system.</p> |
| <p>Strengthened possibilities of employment to non highly specialised professionals.</p> | <p>The more independent and autonomous in daily life the greater is the chance of employment for people with DS and other intellectual disabilities. Increased independence within the environment will be measured by:</p> <ul style="list-style-type: none"> • be evidenced by an increasing response to technical triggers rather than ‘being told what to do next’. • result in relationships that depend less on instruction and more on engagement, to better facilitate mutual relationships. | <ul style="list-style-type: none"> • An increased response to technical triggers will be observed during the pilots by the POSEIDON-Team. <p>These measurements will be achieved through a combination of information gathered by the kits on their usage and the feedback provided by the users in each pilot via questionnaires and interviews with the primary users.</p> |
| <p>Improved competitiveness of</p> | <p>The US is ahead of Europe with regard to ICT devices and programmes for</p> | <p>The measurement of these will be performed along the life of</p> |

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| <p>European ICT industry in the field of inclusive smart environments and services.</p> | <p>people with intellectual disabilities (for example Ablelink Technologies). Our service/application will reduce the gap. Our service/application will be adaptable to different countries, cultures and languages. This will be tested in different European countries. A measure of acceptance is that relevant organizations for targeted beneficiaries find that the product is good and say so at conferences, meetings etc. to increase the use of the product.</p> | <p>the process by contacting those who are interested in the project from any dimension via an online survey or interviews. The findings will be compiled and summarized for the final report.</p> |
| <p>Wider availability and effectiveness of developers' tools for creating inclusive smart environments (targeted to SMEs, key mainstream industrialists, open-source developers, and other less technical developers).</p> | <p>The aim of POSEIDON is to make some relevant inclusion services and a framework which should enable a wide range of developers to provide services for people with DS. Increased number of inclusion services and interest will be measured by:</p> <ul style="list-style-type: none"> • Number of developers participating in POSEIDON social media. • Number of companies providing POSEIDON services. • Number of POSEIDON apps/services provided in different countries. • The methods and architecture developed for the product establish a best practise from which others can learn. | <p>Some of these measurements can be only performed partially and at late stages of the project (after month 30) when the system is fully fledged and we can start transitioning to market deployment. Findings and evidence of these will be described in the final report.</p> |

Table 1 How Outcomes are measured in POSEIDON

5. Conclusions

The presented methods and instruments will help to measure the impact of POSEIDON. Since none of these approaches covers all areas, it is of great importance to combine all of them. Subjective data given by primary, secondary and tertiary users and objective data e.g. gained from technical monitoring have to be compared. This will avoid a one-sided viewpoint and reassure the reliability of the findings. Furthermore this approach will illustrate the relationship between results and clarify conclusions made about the impact of POSEIDON.