



EDECT – Final Report

Phase 2 – November 2014 to July 2015

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1 Introduction

The impact of population ageing and the presence of disability pose significant social and economic challenges to individuals, families and societies across the world. But with the right policies we can take advantage of the opportunities to address these challenges. In the EU, there are 80 million disabled people, which is more than 15% of the population. For example in the Netherlands there are 1.8 million disabled people, in France there are 9.6 million and in the UK 10.7 million. There are an estimated 5 million wheelchair users in Europe, with around 1.26 million users in the UK, France, Belgium and Netherlands¹. These individuals have varying degrees of reduced mobility and often rely heavily on their care network and the best technology made available to them in order to live their lives the best they can.

One challenge is to enable disabled people to maximise their independence and to remain in their own home. The use of assistive technology is one of the ways to help people to stay at home for as long as possible, to improve their quality of life and enhance their social inclusion. However without appropriate support the provision of assistive technology may not have a positive benefit in the user's life and in some cases may even have a negative impact on their quality of life and that of their family/carers. Moreover, empathy and an understanding of the importance of the use of assistive technology in maintaining the user's dignity are skills that the care network and those that design assistive technologies must also employ in order to add value to the users' lives.

In order to address some of the issues in meeting these challenges, EDECT, a Cluster of two interrelated Interreg IVa projects was formed. The project partners were from the Dignity in Care project² and the SYSIASS³ project.

The goal of the EDECT cluster is, therefore, to help identify how to empower disabled people through responsive care, assistive technology and ethical reflection. The best way for this empowerment to be achieved is by putting the users at the centre of care and technology. It also needs to be recognised that the whole process for provision of assistive technology must be included when planning the provision of technology and support of that technology. This includes assessment, development, provision and on-going support.

The 2nd phase of the EDECT cluster has two main objectives:

- To devise a methodological approach for developing assistive technologies that involves stakeholders from the beginning. Stakeholders include users and their families, informal care givers, healthcare professionals, academics, businesses, voluntary organisations etc.
- To develop a range of practical, internationally-transferable tools to evaluate assistive technology in an ethical and dignified manner. Thereby to integrate the long term training and support needs of all stakeholders into this development process and to identify a general framework for provision of assistive technology into the lives of users and the care network.

The first objective is a direct response to articles of the UN Convention on the Rights of Persons with Disabilities, especially those related to Independent Living (Art. 19, 20 & 21). The European Union acceded to the convention on 2010 (2010/48/CE). Following the human

¹ 2013, <http://www.newdisability.com/wheelchairstatistics.htm>.

² <http://www.dignity-in-care.eu/portal/welcome>

³ <http://www.sysiass.eu/>



rights of the Convention, the partnership between users and organisations requires a shift in power from the services to the users, to enable users to be in control of their lives expressing choice and will and to establish support services that are driven by users. Involving the stakeholders from the beginning of the process of the creation of assistive technology⁴ should ensure the acceptability of the technology and a real improvement of the quality of life of the end-user.

⁴ This process is called co-creation, or co-design, or co-production

2 Methodology

In order to achieve the cluster goals, two activities have been selected to provide a means to systematically develop and evaluate, in iterative fashion, the methodology for examining the effectiveness of assistive technology and its provision. The stakeholders have been immersed into the technology through practical evaluation organised on four Pilots (one by each country involved in the cluster: UK, NL, FR and BE). The first activity focussed on the evaluation of a new assistive technology (a driving assistance for a powered wheelchair developed through the SYSIASS project) by the powered wheelchair users and had, as its main objective, the improvement of the tools to be used for the evaluation. The second activity focussed on a use of an assistive technology already available on the market (an Alternative and Augmentative Communication Aid software used on an iPad) as a tool to evaluate the effectiveness of training of carers in terms of better understanding the perspectives and needs for supporting users of that assistive technology and the effectiveness of that training to increase carer empathy for those users. The main objective was to improve the methodology to be used for the training of carers by involving mainly healthcare professionals, students and representatives of association of disabled people in the evaluation process.

In order to use the assistive technology on the Pilot tests, it has been found from previous experience that it is necessary to build up some simulation sessions. It is necessary that these sessions be as close as possible to the real life situations of disabled people. First versions of the simulation sessions were designed by the cluster team and then improved using feedback from the participants in the pilots.

It has also been found from previous experience that questionnaires provide a suitable measure of feedback from technology evaluations as well as of the ethics issues. This experience brought to the EDECT cluster came out of the two previous projects which the partners of this cluster were involved with. During the first part of the cluster for pre-tests and post-test questionnaires were developed by the partners to obtain the views and feelings of a wide range of stakeholders. These questionnaires have been improved based on the feedback obtained from the participants to the activities in the four Pilots.

2.1 Powered Wheelchair (PWC) Activity

2.1.1 Introduction

This activity piloted a study into obtaining user feedback for the development of a driving assistance system to improve the safety and confidence of the user when using a Powered Wheelchair [PWC]. To achieve this, disabled people test drive a powered wheelchair with the driving assistance device over a predefined indoor circuit.

The following goals were set for this trial:

- participant experience driving a PWC using the new assistive technology [Driving Assistance system]
- collection of the participant feedback about the relevance of trials related to improving user safety and confidence when using a PWC
- collection of participant feedback related to the relevance of the questionnaires used
- analyse the output from a NASA Task Load index questionnaire modified for powered chair use
- develop analysis tools for the drive data

- develop the methodology to correlate the subjective with objective data analysis
- collect the feedback of participants related to the question “Using assistive devices has to enhance and fit in with ‘good care’ (‘good care’ involves four main issues: respect, autonomy, empowerment and communication)
- development of the methodology - questionnaires and driving test – based on the pilot outcomes

It is expected that due to the diversity in participant age, physical and cognitive abilities, and medical condition there will be a significant impact with their ability to fully engage with the questionnaires.

2.1.2 Participants

Twelve powered chair users volunteered to participate in this evaluation; six male and six female, with ages ranging between 17 and 64. One of the inclusion criteria was that they were expert drivers; however one of the participants rated their ability as average [5/10] and another below average [4/10]. Two participants had their conditions since birth, the remainder had become disabled through acquired injury or illness. All participants signed informed participation and image consent forms.

2.1.3 Methodology used

1. Invitation of the participants by sending a letter of invitation and a Participant Information Sheet
2. A brief introduction (10 minutes) to the test and experiment, signing of the consent forms to participate in the test and for use of images taken during the study
3. Pre-Session: Semi-structured interview before the driving session *using two Pre-session Questionnaires – one focussing on technical issues and one on Ethical issues*: Based on the first Pilot experience it was decided that the pre-session questionnaires should be filled before the day of the Pilot to reduce fatigue levels and to allow the participants to focus on the driving session and providing feedback after the tests.
4. The driving session on a simulated indoor test course
5. Observer recording and analysis of driving times and events.
6. Video Recording and analysis of each session
7. Post-Session: Semi-structured interview *using a Post-session technical Questionnaire and a post session ethics questionnaire* to provide participant feedback on their experience and to collect ideas on how the driving assistance and the evaluation process might be improved.
8. NASA Task Load Index Questionnaire used after the tests to compare the load experienced by the user due to the factors of mental and physical activity, time pressure, performance, effort and frustration between driving the PWC with and without the driving assistance device.
9. Electronic recording and analysis of user joystick activity during the driving sessions.

The participants drive a powered wheelchair with the driving assistance device in an indoor test course environment.

The test course was developed to have the following features:

- the trial is carried out in a reproducible, controlled and safe environment
- the same test course can be used at each Pilot location
- the test course to be modified if so required without needing to find a specific location
- easy to set up and dismantle

During the tests a data recording system (developed within a related Interreg IVa Cross Channel project [COALAS⁵]) recorded the participant joystick activity with and without the Driving Assistance system. Additionally information about the participant, the run start and finish events and other events during the drive [e.g. collisions] were also recorded.

After the driving session three further questionnaires were administered:- the “Post-Session Participant Technical Questionnaire” which explored the participant’s experience of driving the PWC with and without the driving assistance system and their thoughts on how such a system could be developed and improved, the “Post-Session participant Ethics Questionnaire” which explored the participants views on being a PWC user and on being involved in the pilot, and the “NASA Task Load Index Questionnaire” to investigate whether it is possible to obtain a more objective measure of the task load experienced by the participant when driving the PWC.

2.2 Alternative and Augmentative Communication Aid (AAC) Activity

2.2.1 Introduction

AAC refers to a wide range of techniques and technology that are used to supplement or replace speech and handwriting. When considering these different methods it is usual for a representation of the options for communication to be used. These can be objects, photographs, pictures, symbols, or written word/text.

This AAC-experiment is intended to give participants an introductory immersion into a simulated real-life situation (role play). This gives them an opportunity to experience what it is like to be a user of an AAC-tool and to be the communication partner of a user of AAC. The experience includes training in how to use the technology and a practical simulation/role play scenario that would be similar to a typical day-to-day task undertaken by users, carers and other support staff.

There are two major elements to this AAC-experiment: First, there is the training of members of the care network in the use of a communication aid so that they can provide the user with technical support. Secondly, there is the genuine experience of what it is like to rely on a communication aid for all verbal communication. The intention is to give the participants some idea of the challenges faced by both the user and the carer in using such technology. The whole experience, it is hoped, will help the participants/stakeholders develop their empathy for users of communication aids which will in turn lead to enhancing the support provided to users and the interaction between users and carers.

The goals of the trial in the four pilots are to:

- Develop a methodology to better enable the stakeholders to support people with speech impairment by experiencing what it is like to be deprived of usual communication capacities and to have to resort to technological assistance to communicate and express themselves
- evaluate the methodology of this training experience, in particular the way the participants’ empathy and insights may be affected by this training
- build a set of tools to be used in training of stakeholders

⁵ <http://coalas-project.eu/indexen.php?p=home>

- deepen the experience-based learning process through debriefing, in order to better understand the use and implementation of AT from both the perspective of the service user as well as the professional
- collect quantitative and qualitative data from participants through questionnaires, video recording, debriefing, and participants' observation
- explore variations in the pilots, if any identified, amongst the four countries involved that may be due to factors such as cultural differences

2.2.2 Participants

A group of 28 different professionals, carers and students agreed to participate in this evaluation: 11 male and 17 female, with ages ranging between 23 and 64 years. Before the session they were informed about the goals and purpose of the experiment. They all agreed to simulate the role of being a care-receiver and a care-giver during the session, to fill in questionnaires provided and to participate in the debriefing. All participants signed informed and image consent forms.

2.2.3 Methodology used

1. *A brief introduction* (15 minutes) to the test and experiment including a presentation of the EDECT project and goals; goals of the pilot test; role play and simulation as didactic method of experience based learning; context of the role play.
2. *Pre-Session Questionnaire*: to fill in before the simulation. The questionnaire has two parts:
 1. technical aspects on participants experiences with communication aids
 2. ethical aspects split into questions on using AAC in daily life and questions on participating in the AAC role-play.
3. *Introduction to the AAC-App on the iPad*, followed by a short practical session using the AAC communication aid device.
4. *The AAC simulation session*: The participants were instructed to pair up. In each pair one person was a simulated-caregiver and the other a simulated care-receiver. A script with a scenario was handed out to be used to play the role and build up the simulation. The simulated care-receiver was in hospital and had lost the ability to speak and write. The simulated care-giver also had a script to use and the focus of the interview was on the evaluation of the situation and voicing the care-receiver's short, medium and long term hopes and fears. The care-receiver could only express his/her needs and plans for the future by using the communication aid. In the second part of the session, the participants changed roles and continued the interview. Each part of the simulation lasted around 70 minutes. Between the two parts the lunch was served. In the first two pilots the simulation was on-going during the lunch. In the last two pilots the simulation was interrupted and the participants were given a break. This was based on the feedback from the participants in the first two pilots.
5. *Debriefing* included a guided discussion with the participants on their experience to collect the participants' subjective impressions of the simulation session. After the 2nd pilot it was agreed to include open questions in the debriefing to stimulate reflection and expression. Each participant was given the opportunity to share his/her experience. Six open questions were used to structure the focus group session:
 - a. Overall, how useful did you find the test-session?
 - b. How satisfied are you with the preparation process?
 - c. To what degree of immersion did your role-experience give you when testing the communication device?

- d. What was the most valuable part of the test-session?
 - e. How satisfied were you with the coaching during the test-session?
 - f. How can the test-session evaluation be improved?
6. *Post session questionnaire* to provide more structured feedback on the experience and to collect ideas on how the training and evaluation process might be improved. The participants had to fill in this questionnaire after the debriefing. The questionnaire was divided in three parts:
- a. Training and role play
 - b. Ethical aspect, split into questions on using the AAC communication aid, being involved in the training in daily life and questions on participating in the AAC role-play.
 - c. Overall evaluation questions about the questionnaires and test methodology.

2.2.4 Data recording

The simulation and role play session and the debriefing were video recorded for later analysis. Pre-session and post-session questionnaires regarding both technical and ethical aspects in the AAC-training were completed by all the participants. In addition participant observation was undertaken which permits researchers to see the world as participants see it, allowing them to develop a rich understanding and appreciation of the nature of the problems by extracting meaning from events and situations, and to grasp the subtleties of cultural variation (Polit, Beck & Hungler, 2001). The researcher participated in the functioning of the test-group and observed and recorded observation within the context and experiences that are relevant to the participants. The observations were focused on four areas of interest:

1. the observable event
2. personal impressions
3. global interpretations
4. meta reactions

The various methods of data collection were focused on the structure and set-up of an observation grid. (see also below 3.2.4)

3 Preliminary findings

3.1 PWC Activity

3.1.1 Participants

For the first two pilots only two participants per site took part because the methodology was still at an early stage; spare time was left available for the modification of the methodology from feedback and the experience of practical application. Once there was confidence in the methodology then four volunteers participated in each pilot.

| Participant ID | 001 | 002 | 004 | 005 |
|--|-------------------------------|--------------------------------------|--|----------------------------------|
| Age | 22 | 46 | 18 | 17 |
| Gender | Male | Male | Male | Male |
| Profession /Occupation | College Student | Mechanical Engineer | Student | Pupil High School |
| Diagnosis | Cerebral Palsy | Left side paralysis following stroke | Duchenne MD | Duchenne MD |
| Number of years using a PWC | 15 | 3.5 | 11 | 9 |
| Type of Chair | Rear Wheel Drive Spectra Plus | Mid Wheel Drive | Rear Wheel drive Quickie Jive | Front Wheel Drive Quickie Jive R |
| Have they received training to drive the powered chair? | No | Yes (in the hospital) | No. Only a course on how to drive a mobility scooter | No |
| Ability to drive | Excellent | Excellent | Excellent | Excellent |
| Country | UK | UK | NL | NL |
| Pilot | 1 | 1 | 2 | 2 |

| Participant ID | 008 | 009 | 010 | 011 |
|---|--------------|--------|--------------------------------------|-------------------|
| Age | 30 | 56 | 64 | 30 |
| Gender | Female | Female | Male | Male |
| Profession /Occupation | - | - | President of a county MS association | - |
| Diagnosis | Brain Injury | MS | MS | Brain Injury |
| Number of years using a PWC | 2 | 15 | 16 | 1 |
| Type of Chair | Meyra smart | | | Salsa R2 Quickie |
| Have they received training to drive the powered chair? | Yes | No | Yes | Yes/still running |
| Ability to drive | 8/10 | 8/10 | 9/10 | 5/10 |
| Country | FR | FR | FR | FR |
| Pilot | 3 | 3 | 3 | 3 |

| Participant ID | 012 | 013 | 014 | 015 |
|---|----------------------------------|--------------------------------------|----------------------|----------------------|
| Age | 53 | 17 | 47 | 39 |
| Gender | Female | Female | Female | Female |
| Profession /Occupation | - | Student | Full time mother | Full time mother |
| Diagnosis | Cerebral palsy (premature birth) | | MS | Tetraplegia |
| Number of years using a PWC | 15 | 2 | 4 | 12 |
| Type of Chair | Storm Invacare FWD | Puma 40 FWD | Salsa Sunrise FWD | Permobil C500 RWD |
| Have they received training to drive the powered chair? | No | Yes, with my therapist, but only few | No | No |
| Ability to drive | 7/10 | 4/10 | 9/10 | 9/10 |
| Country | B | B | B | B |
| Pilot | 4 | 4 | 4 | 4 |

The participants took part in pre- and post-driving session technical and ethical questionnaires. A summary of the data and analysis of these questionnaires will now be presented.

3.1.2 PWC questionnaires and analysis

3.1.2.1 PWC general observations

3.1.2.1.1 Data_collection

Because the Ethics questionnaire was found to be difficult to understand, too demanding and took too long to fill out, fatigue became an issue. When combined with the driving session and the post-session questionnaires the whole experience took too long and was too tiring, both for the participants and for the administrators of the questionnaires. As a result the Ethics Questionnaires were refined and reduced in length. It was agreed after the first pilot both pre-session technical and ethics questionnaires should be administered at least a day before the pilot. However the need for semi-structured interviewing requires an interviewer to be present. This was not always practical for the remaining pilots for geographical and resource reasons.

The post-session questionnaires were completed together with the evaluator. This semi-structured method of data collection is especially important for obtaining feedback on the questionnaires and for additional information relating to the use of powered chairs. It was noted that some of the answers could have been explored to provide more useful information and to help the user examine their experiences as a PWC user. However for some of the pilots semi-structured interviewing was not possible. This was evident in the quality of the responses obtained. Also it was recognised that the interviewer should have familiarity with PWC use or have been given some training with respect to the questionnaires.

Additionally the question was raised whether fatigue due to the length of the questionnaires was a more significant issue for Brain Injury participants. It may be possible to evaluate this at a later trial

For the question *“What would you want from a chair with driving assistance ...”* could participant 15 have been encouraged to think about those circumstances when driving a PWC was difficult and also to reflect on the needs of others who drive PWCs? For example some of the participants said they did not need assistance, but that new drivers would. Further discussion on the positive and negative aspects of the users’ experience of PWCs may have provided more useful input into the design of PWC and features that users might find useful.

This aspect of semi-structured interviewing is important as the goal of this element of the EDECT pilot is to obtain feedback from experienced user which can inform the design of PWCs.

3.1.2.1.2 Translation

The translation of the questionnaires also highlighted the challenges of translation into a different language and culture. It was deemed the best way for it to be translated was by the interviewers, because they know what kind of information is being sought. Even within the same language as for example Dutch, there are differences in vocabulary between Flanders and the Netherlands. These differences can affect the results.

3.1.2.2 PWC technical questionnaires

3.1.2.2.1 PWC general_introduction

In general the technical questionnaires did not pose any difficulties for the users. There was general satisfaction about their content and length.

3.1.2.2.2 Importance of powered chair in life

All the participants use their chairs 24/7 and stated how essential powered chairs were to all aspects of life. They emphasised the importance of reliability, appropriate technical support and comfort if they are to maintain their independence.

All the participants valued and enjoyed being involved in the driving aspects of the pilot study and all but one tolerated the lengthy questionnaires.

All were enthusiastic to be involved in future studies, which indicate that the general methodology that the participants are exposed to is acceptable.

3.1.2.2.3 Training for driving a PWC

Apart from the participants from the pilot in France, the participants stated that they didn't receive any training apart from that at handover. Some said that they didn't receive any training. This is very unlikely and indicated that the interview process was not very robust as this response should have been investigated by the interviewer.

3.1.2.2.4 Limitations when using a PWC

Typical limitations experienced which can result in loss of autonomy when dependent on a PWC are:

- accessibility factors which can result on loss of autonomy
 - Weight and size for getting into cars – restricts freedom
 - Access to public space – dependent on government policy.
 - Within public spaces e.g. chair and tables in way. Chair has to be manhandled.
 - Requiring help to transfer into vehicles and from the PWC impacts on independence.
 - Carer's not good at driving chair – training and set up of chair required.
- reliability
 - of the chair
 - of the service organization – Importance of support
- programming of one of the chairs made it difficult to drive as it is too aggressive when turning
- not being able to go out independently with friends because of lack of suitable transport and not being a driver
- inability to avoid potholes; this comment was unique to the Gits pilot; are pavements worse in Gits than in Vlissingen, Lomme and Canterbury?

Note: This information could be used in designing the training methodology for those who care for PWC users, those who prescribe PWCs and those who design and develop PWCs.

3.1.2.2.5 User feedback of chair development

The importance of providing the participants with the opportunity for involvement in the development of a powered chair was evident from their feedback.

For example:

- A rear-view camera for reversing
- autonomous chair for transfers to and from a bed or chair
- use of the Driving Assistance system as a training aid for experienced users in new environments

- feedback to the user
 - requires a range of options necessary to suit each user, a combination is also useful so that the user can focus on driving and then look at a display for more information if so required
 - the type of feedback has to be adapted to the user's needs
- detection of kerbs and potholes

3.1.2.3 PWC ethics questionnaire

During the evaluations and discussions with the participants the PWC users emphasised the need for respect, they also expressed the need for empowerment. It is therefore acknowledged that these should be elements of any training package for carers of PWC users, and in general for anyone interacting with a user of assistive technologies.

Previous work has shown that "good care" was best organised around four main themes: respect, autonomy, empowerment and communication. For each theme, we proposed to the participants some items (among proposals 6-8) which should define the themes and ask them to classify in order of importance 3 items.

After the first test, the participants have been again asked to classify the 3 most important items. The results of the rankings therefore concern 10 participants (2NL, 4FR, 4BE).

For the respect, the most used items to define it were "Respect for others" (7/10), "Confidentiality" (6/10) and "Self-respect"/"Taking account"/"Awareness" (5/10). It's important to mention that all the French participants as well as a Belgian one ranked in the first position the "Self-respect", while the others thought that the best definition of the respect should be "Respect for others" (1NL & 1BE), "Awareness" (2BE) or "Taking account" (2BE).

After the tests, the most used item stayed the "Respect for others" (7/10) but only one Belgian participant ranked it in the first position. The "self-respect" was mentioned by 5 participants and 4 of them (at least one participant by country) put it on the first position (1NL, 2 FR and 1 BE). The "confidentiality" and "awareness" still stayed mentioned by 5 participants.

The autonomy was the most related with "having choice (7/9⁶) but only 2 participants (one French and one Flemish) ranked it in the first position. The "independence" was the item most chosen in the first position (4/9; 1NL, 2FR, 1 BE) and 6/9 participants chose it as relevant item to define the autonomy. The item arriving in the third position is "making decision" (4/9). After the tests, the participants still thought that autonomy is the most related with "having choice" (6/10) but two more participants put it in rank 1 (1NL, 2FR, 1BE). "Being able to make decision" was chosen by 5 participants while only 3 chose it before the test.

Furthermore they thought that using a PWC gave them more autonomy, scoring a 10 in both the pre- and post- evaluation questionnaire.

The most chosen items to describe empowerment were "Self-worth" (8/9⁷, 1 BE ranked it in the first position) "Self-esteem" (7/9, ranked in first position by 4 participants: 1NL, 1 FR, 2 BE) and "Feeling valuable in relation to others" (6/9, 1 NL ranked it in the first position).

⁶ The question didn't appear in one of the French questionnaire because of a printing problem

⁷ The question didn't appear in one of the French questionnaire because of a printing problem

After the test, the three predominant items chosen remained the same, but their order changed: “Feeling valuable in relation to others” (8/10, 1 rank 1: BE), “Self-esteem” (7/10, ranked in first position by 5 participants: 1NL, 3 FR, 1 BE) and “Self-worth” (6/10, 1 NL & 1FR ranked it in the first position).

Four items are predominant to define communication: “Time giving” and “Explaining information” (both 7/10 and rank 1 respectively 4/10 and 3/10) and “Non-verbal communication” and “Verbal communication” (both 5/10 and rank 1 respectively 2/10-1NL, 1BE and 1 (BE)/10). It is interesting to highlight that after the test, the most important item became “Understanding information” (8/10, ranked 3 times in first position by a participant from each country) whereas until the test, only 4 participants thought that communication is related with that item and nobody put it in rank 1. “Time giving” and “understanding information” still remained important items for the communication (6/10) far ahead of the items “Non-verbal communication” (1/10) and “Verbal communication” (3/10) thought as being important before the test.

The AAC session investigated the immersion of carers into the world of the user, in order to determine whether this would generate a better understanding of what was required for developing these technologies and their support structure. Feedback from the participants showed that the importance of involving the user in the development process was emphatic, the majority of respondents scoring 10 out of 10 in the scale of 1-10 although the scale of the range was thought to be too great and confusing.

The PWC-user participants were highly motivated to participate in the test and to contribute to the improvement of the PWC. They felt recognized as people and not just as users of the technology; this was because the test team had involved them by asking them for their advice.

3.1.2.4 PWC NASA TLX

3.1.2.4.1 General

The participants are being asked to remember elements of the driving experience such as “mental activity”, “physical activity”, “performance”, “frustration” etc. when driving with and without the Driving Assistance (DA) system. These are volatile memories and feelings, therefore it is thought to be important to administer the test immediately after the driving session.

The NASA TLX is cognitively complex and there is uncertainty whether it has been administered in a way that the participants have fully understood. This will be further aggravated if the interviewer is tired and the participants are tired and have cognitive deficit because of their condition. These issues were clearly identified, and common through all the Pilots however it is an internationally recognised method and should provide a more objective measure of task load if these challenges of fatigue and comprehension can be overcome.

3.1.2.4.2 Outcome of tests

If the measures are reliable then the TLX scores indicated that in general the users found the load of driving with DA on greater than off. This is likely for several reasons, because users:

- are expert drivers and therefore the system does not add much to their ability to avoid collisions
- can adapt to driving a different wheelchair fairly quickly
- were given insufficient time to adapt to driving with DA

- have their trajectory modified by the system which changes the response of the chair differing from that of a standard chair
- were so keen to start the trial with minimal practice that they were not really familiar with driving with DA on

This increase in load correlated in general with the observed increase in joystick movement with DA on and with the increase in time required to complete the test run with DA on.

The outcome of the NASA TLX for Pilot 4 indicated that the participants found the use of the DA system less of a load than driving without it, a complete polar reversal. This was in all likelihood due to the testers having changed their approach, the methodology evolving, by explaining carefully, with demonstration, what the system was trying to do. However the time taken to drive the course and the user joystick movement are greater with the DA on than off. This indicates that the task was more difficult with the system on.

However it was also evident that the majority of the participants were quite fatigued by the time the test was administered, which coupled with its cognitive complexity may have affected their responses.

The administration of the NASA test now needs to be refined and further evaluated.

3.1.3 PWC data analysis

The introduction of the bus recording system has made new analyses possible such the joystick travel distance, collision reduction and the run timing. The technical and clinical value of this will be investigated in the future.

It is hoped that this data will be of future use in:

- evaluating how the user is driving and adapting to the driving assistance system
- helping to understand the relationship between the subjective response of the participant to the driving experience and the measured parameters from the PWC control system.
- developing a tool to monitor user performance over longer periods of time for diagnostic use.

3.2 AAC Activity

3.2.1 Participants

The following two tables present the participant stakeholder breakdown across the four pilot trials. Tests conducted in the UK and in France did not include any students among the participants; this has an impact on the average age of both groups (respectively 43.63 and 47.17 years). The group of academics being the oldest age group, with an average of nearly 53 years, groups of health professionals and other professions are close to the average for all participants.

In each group one of the participants was not a native language speaker; this could have implications on the trend during the test (comprehension of the language used by the interviewer) or the answers to open questions in the questionnaires.

We could also note that the participants were mainly professionals in Pilot 1 and 3, and students in Pilot 2.

TABLE 1 : PILOTS: LOCATION, NUMBER OF PARTICIPANTS, GENDER AND MEAN AGE

| Test | Location | Participants (#) | Female (#) | Male (#) | Age (mean) |
|-------|----------|------------------|------------|----------|------------|
| Test1 | UK | 8 | 3 | 5 | 43,63 |
| Test2 | NL | 8 | 3 | 5 | 40,25 |
| Test3 | FR | 6 | 5 | 1 | 47,17 |
| Test4 | BE | 6 | 6 | | 41,17 |
| Mean | | 28 | 17 | 11 | 42,89 |

TABLE 2 : PROFESSIONS AND CLASSIFICATION USED

| Test | Academic | Professional | Student | Other | Total |
|------------|----------|--------------|---------|-------|-------|
| Test1 | 1 | 4 | 0 | 3 | 8 |
| Test2 | 3 | 0 | 4 | 1 | 8 |
| Test3 | 1 | 3 | 0 | 2 | 6 |
| Test4 | 1 | 2 | 1 | 2 | 6 |
| Total | 6 | 9 | 5 | 9 | 28 |
| | | | | | |
| Age (mean) | 52,83 | 45,78 | 23,00 | 44,63 | 42,89 |

Academics: Researcher; Social worker/teacher; Teacher; Teacher/researcher; Test specialist

Professional: Carer; Clinical Scientist; Health care professional; Medical doctor in physical medicine; Occupational therapist; Professional AAC services; Rehabilitation physician ; Speech therapist

Students: Nurse Student; Occupational therapy Student

Other professions: Administrative; Administrator; Governmental representative; Innovation Manager; Project Manager; Representative of association of disabled people

3.2.2 AAC questionnaires and analysis

The questionnaires developed for the analysis of the AAC-activity proposed by the EDECT team included 4 types of responses:

- free answers to open questions
- closed Answers yes / no
- responses using a scale of 0-10
- responses by ranking from 1 to 3 for 6-8 items (ethical questionnaires)

3.2.2.1 Questions to explore: Experience with Communication Aids

A first series of questions was intended to assess participants' knowledge of communication aids. Unsurprisingly, professionals have a better knowledge (5-10) than other types of participants. Academics scored less on knowledge (rated from 1 to 3). 16 participants (mainly in professional group) have supported a person with communication problems. These are the professionals and students who feel they have a better ability to communicate than other occupations and academics (6.78 and 5.40 vs. 2.57 and 1.83). Only the French participants had no training to communicate or develop communication aids; the other

participants (75%) reported that they have received some form of training. Almost all participants reported that they have or are currently using a Smartphone or tablet.

3.2.2.2 Pre- and post-session questionnaires: Ethical issues

A second group of questions was concerned with ethical issues. Previous work has shown that "good care" was best organised around four main themes: respect, autonomy, empowerment and communication. These four themes were the subject of two questions: one where the participants classified 3 items in order of importance (among proposals 6-8) and the other a ladder.

The classification of items was proposed to the participants after the first test. The results of the rankings therefore concern 20 participants (8NL, 6GB, 6BE). For comparison, we introduced the responses of two tests, corresponding to 30 participants in total (20 AAC and 10 PWC).

ABOUT RESPECT

Respect for others and respect for oneself were the two most important concepts before and after the experiment. Sensitivity to the notion of privacy is greater after the test. The concepts of respect for the privacy of others and awareness of others were only chosen by a few people.

Participants felt that the use of a communication aid leads to greater respect of the disabled person, the average response at the end of the test was from 6.93 to 7.50. English and Flemish participants, health professionals and women were most sensitive to this dimension. Regardless of the group considered, all data show a positive progression after the session.

ABOUT AUTONOMY

The two important concepts in the dimension of autonomy are "Having a choice" and "being able to make decisions." Their classification is reversed after the experiment.

The third concept, independence, was more important to participants before test 4 and tends to fade slightly after.

Participants felt that the use of a communication aid gives more autonomy to people with disabilities, with a score of 8.04 before and 8.32 after the test.

The test made the Flemish participants more aware of this dimension and also the professionals. The Dutch, academics and other professionals have meanwhile revised their judgment, as there is a slight decrease in scores.

Here it is interesting to note that overall men and women have changed their mind slightly in opposite directions after the test: for men the score changes from 8.27 to 7.89 and for women, from 7.88 to 8.56.

ABOUT EMPOWERMENT

This proved to be a difficult dimension for the French to grasp, who hesitate in the differences in meaning of their translation between independence, autonomy, empowerment ... Empowerment translated into French implies "Independence" and resulted in a difficulty answering two of the questions. Indicates the challenge in translation where words which have different meanings in one language may be synonyms in another.

However, the notions of self-esteem, to feel for others' counting and consciousness of one's own value are clearly predominant, the other three proposals were ranked 5 times.

This notion has 8.04 to 8.46 for all participants. However, it is very prominent for the English (8.63 before / after 9.50) and professionals. The notion is lower for the French before they experienced the test (score 6.50). Similarly women changed their score for this notion from 7.88 to 8.65, while men did not significantly alter their sensitivity to this dimension (8.27 vs. 8.11).

ABOUT COMMUNICATION

It is the dimension where all proposed items were retained, and where in fact the choices are more diffuse. The two items "provide information" and "include information" are predominant in the selection of participants before and after the experiment. However, "verbal communication", "nonverbal communication" and "comfort" form a second group of items that was far from negligible, and "time giving", which had a little score at the start, joined the second group after the test.

It is interesting to note that in Pilot 3, in France, it was observed that the participants used non-verbal communication (hand gestures, nods...) in addition to the communication device itself, the latter coming in this case as a secondary means for communication. This dimension is clearly reflected in the post-test answers session 3 (4/6 second selected item).

Participants believe that using a communication aid makes communication with others and participating in conversations easier, with a score of 8.30 (before test).

The highest score is allocated to the dimension of communication in comparison to other dimensions of respect, autonomy and empowerment, which is probably not surprising in the context that the test is using a communication device. As with the other dimensions it is a priori perception and expression of an expectation that actually is quite strong. It is also the only dimension whose score decreased after the test, from 7.92. This is true for most groups with the exception of Flemish academics who did not change their scores.

It is curious that men place this dimension higher than women, both before and after (8.64 vs. 8.06 before, 8.22 vs. 7.75 after).

3.2.3 Debriefing

After the simulation and a short break the debriefing was conducted by a facilitator using the questions as presented in the methodology (see above). The debriefing was valuable to stimulate reflection on what really matters and acknowledge the feelings of respect for each other. But it still remains a simulation. Based on the feedback of the participants we may conclude that the simulation session in the AAC-test could reach the projected goals and was experienced as a useful didactic method to enhance reflection, awareness and insights. The effect can be reinforced with the engagement of disabled people. To have a long-term effect, the session has to be repeated.

3.2.4 The setting up of an observation grid

The Communication Aid activity was monitored by Alexandre Oboeuf, a researcher associated to The Medical Ethics Centre of Catholic University of Lille in order to set up an observation grid⁸. Together with the filling-up of questionnaires, the organization of on-the-

⁸ See annexed documents: Alexandre Oboeuf, *Construction d'une grille d'observation, Activité d'Aide à la Communication (AAC)*. Contribution du Centre d'éthique médicale, Université Catholique de Lille, 18 pages, 18 Juin 2015; and **Synthesis in English of :**



spot debriefings and a participating observation work, the setting-up of **an observation-based analysis grid** was thought of during the progress of the experimentation itself. Such a grid, when constructed, allows the observer to get interested in what people do and not only in what they say they do. What we suggest is the deployment of an observation grid, while the tablet is being used by the participants. The purpose of this analysis grid-based observation is to observe and decipher the relationships between participants, space, time and to the tablet during the whole simulation activity. As a corollary, this meticulous observation-based monitoring provides two opportunities for the EDECT project: i) the opportunity to highlight “what works” thanks to the tablet and its core assets, ii) but also the opportunity to help bring out the non-actualised abilities and to launch a reflection around the users’ “communicational deficiencies”. All this brings out interesting lines of approach and perspectives fuelling a reflection about the evolution of the electronic device (see point 4.2. below).

4 Cluster Outcomes

The goal of the EDECT cluster was to help identify how to empower disabled people through responsive care, assistive technology and ethical reflection. From the cluster team’s point of view, the best way for this empowerment to be achieved is by putting the users at the centre of care and technology. We proposed in this cluster to develop with the stakeholders a methodology and tools to be used to test AT and train the stakeholders to provide support to the users in a more empathetic way. In order to realise our objective we proposed to test two different activities on four Pilot tests. One activity more focussed on the test of new assistive technologies while the other one investigated the immersion of healthcare professionals and other identified stakeholders into the world of the user, in order to determine whether this would generate a better empathy for what it is like to be a user of these technologies and understanding of what was required for developing these technologies and the structures to support users and carers.

The questionnaires, semi-structured interviews and debriefings were used in the Pilots to provide the stakeholders’ feedbacks and helped the ongoing building and adaption, in a co-creation process, of the methodology as well as the tools.

The questionnaires were designed and on-going improved not only to measure how useful the new assistive technology is for the users, but also to collect precious ideas on how to improve the technology as well as the support and to enhance the reflexion of stakeholders on the meaning of a good care through assistive technology.

The need to translate the documents from English into French and Dutch led to the identification of difficulties with expression and understanding due to language and cultural differences. Nevertheless, it was also a great opportunity to improve the clarity of the questions and to keep them as simple as possible.

Thanks to the diversity of the stakeholders involved in the four pilots, and the richness of feedbacks obtained we were able to improve the methodology and the questionnaires as well as to have new ideas for useful future developments.

Alexandre Oboeuf, *Construction d’une grille d’observation, Activité d’Aide à la Communication (AAC)*. Contribution du Centre d’éthique médicale, Université Catholique de Lille, 12 pages, 18 Juin 2015.

Feedback from the participants showed that the importance of involving the user in the development process was emphatic.

The involvement of volunteers of differing medical conditions and ages into the PWC activity in the pilot trials helped to inform the development of a methodology – especially the questionnaires – which can be adapted to suit volunteers with differing cognitive and physical abilities. We could provide now a robust methodology for obtaining user feedback in the development and assessment of the PWC and eventually for other AT.

The participation of the AAC activity of 28 stakeholders allowed the team to assess and develop a training activity for all stakeholders to make them aware in the limits, frustrations and other feelings that disabled people must have in real daily life events and help to develop more empathy for disabled persons, more attention for support and understanding. It was suggested that the collaboration with real service users in the test could enhance this experiential learning process. An important issue also mentioned was the need to repeat the training in order to realise a long-term effect.

The cluster results are the following:

1. A methodology and associated tools for development and assessment of the PWC

The methodology itself can be said to consist of:

- using questionnaires to obtain the stakeholder/user/participant views before using the assistive technology
- using a safe driving circuit to evaluate the assistive technology which can be replicated at all Pilot sites.
- observing the stakeholder/user/participant during evaluation of the assistive technology
- using questionnaires to obtain the stakeholder/user/participant views after using the assistive technology
- using the NASA TLX to determine if the overall experience/set of tasks were within a range such that the collected data could be said to represent normal day to day tasks
- recording the user joystick activity for analysis of driving patterns.

The following tools were developed:

- Participant Information sheet about the tests and their goals and Participation & Image consent forms to be signed by each participant
- A safe indoor driving circuit which obtained the Ethical permission for clinical evaluation and was approved by the users as being challenging enough
- Technical pre-session and post-session questionnaires, available in English, French and Dutch, allowing valuable feedback to be obtained on the development process and to user needs and ethics pre-session and post-session questionnaires, available in English, French and Dutch to explore the participants views on being a PWC user and on being involved in the test.
- Equations for the analysis of user joystick activity.
- NASA Task Load Index Questionnaire adapted for PWC evaluation in English, French and Dutch to obtain a more objective measure of the task load experienced by the participant when driving the PWC.
- Observer Technical System Questionnaire necessary for the observers to note the identified items to be monitored (e.g. the number of collisions, the running time, the number of manoeuvres)

Notes:

- In order to obtain rich feedback from the questionnaires and for additional information relating to the use of powered chairs, semi-structured interviews are necessary. It is also recognised that the interviewer should have familiarity with PWC use or have been given some training to understand the underlying concepts in the questions. The pre-session questionnaires have to be filled out before the tests, in order not to overload participants.
 - The training of interviewers is mandatory for using the questionnaires. Moreover, it will also be important, and challenging, to adapt the questions for participants of differing cognitive ability.
 - It is necessary to be sure that the participants have enough time to finish all the assessment in a relaxed way, in order to be sure that the responses are not motivated by other issues, such as the desire not to miss the last bus home.
 - This methodology as well as the questionnaires can be adapted for the development and assessment of any assistive technology.
- 2. A methodology and associated tools as a didactic method for experiencing what it is to be a user of an AAC-tool to develop the empathy for users to communication aids and enhancing the support provided to the users.**

The methodology itself can be said to consist of:

- using questionnaires to obtain the stakeholder/user/participant views before using the assistive technology
- a short training to learn how to use the assistive technology
- using a simulation session where they have to use the AAC-tool and follow a scenario defined in advance
- observing the stakeholder/user/participant during the simulation session evaluation of the assistive technology
- using a debriefing session including guided discussion on the experience
- using questionnaires to obtain the stakeholder/user/participant views after using the assistive technology

The following tools were developed:

- Participant Information sheet about the tests and their goals
- Participation consent & Image consent to be signed by each participant
- A scenario for tests
- Technical pre-session and post-session questionnaires, available in English, French and Dutch, allowing valuable feedback to be obtained on the development process and to user needs and ethics pre-session and post-session questionnaires, available in English, French and Dutch to explore the participants views on being involved in using the AAC tool, on being involved in the training in daily life and on participating to the test.
- An observation grid specifically adapted to this particular activity. Such a grid will be useful for future communication activities with disabled people in order to evaluate the appropriation process of the technology by the users and the corresponding feelings of the users.

Note: These methodologies as well as the questionnaires can be adapted for the development and assessment of any assistive technology.

5 Conclusions

5.1 What was good?

The main objective of this cluster has been to devise a methodological approach that involves stakeholders from the beginning for both developing assistive technologies and integrating the long term training and support needs of all stakeholders into this development process. Moreover a range of practical, internationally-transferable tools to evaluate assistive technology in an ethical and dignified manner has been proposed.

The four Pilots enabled the cluster team to improve the methodology over the period of this project based on the feedback received from the participants, mostly in Pilot 1 and 2.

It was possible to involve a range of stakeholders in the project from different countries and with various experiences. In total, 40 people participated to the pilot tests over the 4 countries; first of all the users with their family and then academics, Health Care Professionals/Clinicians and representatives of associations of disabled people. 8 nursing students from the Netherlands were involved in the Canterbury and Vlissingen pilots because they have a project assignment from their program. They carried out the observations together with the other cluster partners and were coached by their lecturer. They contributed by giving suggestions for improving the pilot and the various questionnaires. 3 occupational therapist students were involved in Pilot 4. Two were engaged in the PWC to conduct the semi-interviews and one in the AAC-test as a participant.

It was very valuable for these upcoming young professionals to work and learn together with experienced professionals and users. This experience contributes to the development of their critical ability which is expected from bachelor educated respectively nurses and occupational therapist.

The AAC activity participants were very enthusiastic and evaluated the AAC-test as very useful to gain more empathy and insight on the needs of AT-service users. They would recommend it to colleagues and everyone who is engaged in the production and implementation of AT.

The PWC activity volunteers, who were experienced and expert drivers, stated that they found driving the course challenging with or without driving assistance system. However they thought that the level of difficulty was about right for testing the new technology. They appreciated the opportunity to be involved in the evaluation and were able to make valuable contributions to the on-going development of the technology. In general they were keen to be involved in future evaluations.

The development of joystick activity hardware and software will provide the basis for future understanding of driving characteristics and how the user adapts to and uses the PWC with and without driving assistance.

To collect quantitative and qualitative data different methods were used in the two experiments: pre- and post-session questionnaires filled in by participants, notes taken by the facilitator during debriefing, video recording, participant observations in all pilots.

The pre- and post-session technical and ethics questionnaires were designed and improved thanks to the feedback from the participants. The translations into French and Dutch also



raised some interrogations on the meaning of the questions and helped to improve their comprehension in all three languages.

The debriefing used in the AAC activity was a very useful way to stimulate and enhance the reflexion of the participants on the experience that they had and what they learnt.

The formation and development of a unified, enthusiastic and dedicated EDECT team from the Ethics [Dignity in Care] and technology [SYSIASS] projects. This resulted in the sharing of new ideas and the development of learning for all members.

5.2 What was learnt?

The main objective of this cluster has been to develop a methodology for the assessment of both the development of assistive technology and the implementation of that technology in an ethical and beneficial fashion such that the technology is of practical use to all stakeholders whilst delivering the ultimate goal of being suitable to empower the end users of that technology. To this end it is concluded that the development of any methodology must include input from all stakeholders, with the main input from the end user.

The collection and analysis of the data in a multi-cultural context was a very challenging process. It is important to try to use, when possible, digital questionnaires to allow automatic data processing.

It was found in general, as expected, that the meaning of the questions in the questionnaires had to be clarified with the participants in order for them to understand what was being asked of them. The initial sets of questions were designed to draw out these problems allowing them to be developed and thus to evolve into questions that are clearer and more understandable.

The semi-structured interviewing using the questionnaires is an important method of obtaining rich feedback, especially from the disabled people. One conclusion drawn from the pilot trials conducted by the EDECT partnership has been the identification of the need to involve an experienced practitioner, such as a psychologist, to assist with the formulation of the questionnaires, and an experienced interviewer to administer these questionnaires or to train the interviewers.

The Pre-session questionnaires should be filled out before the pilot day in order to reduce the load on the participants as well as on those who administer the tests, especially when the participants to the tests are disabled people.

The PWC Technical Questionnaires have been found to provide valuable feedback to the development process and to user needs. Observations of the responses to the Ethics questionnaires have raised the following recommendations, that:

- they are valuable to help the other stakeholders understand what is important to the user
- the ethics questionnaire needs only to be carried out pre-session
- the data could be used in developing the training of health care professionals and other stakeholders that participate in the development and the implementation of assistive technology.

The recording of joystick activity provides rich data for future analysis and understanding of the interaction between the user and the technology and how that technology could be better refined to meet the needs of the user.



The NASA TLX questionnaire (used in the PWC activity) could provide a more objective measurement of the workload using the new assistive technology. In order to clarify and simplify the questions, further work is required to find words which better define the concepts behind the questions. The interviewers will need to be trained (maybe by making a video and putting it on-line). Further work is required to assess whether it is possible to develop the questions for participants with differing cognitive abilities, and this applies to all the questionnaires.

For the AAC activity the purpose of the session, the preparation of the participants before the experience as well as the guidance of the reflection session (debriefing or feedback) afterwards must be done by a facilitator who is well trained. The script used in the AAC activity was discussed, because it wasn't general enough to be felt by all the participants to be a real life situation. But despite this we can conclude that by simulation the awareness, insights and empathy of the participants for users and carers undoubtedly grow: more insight in the limits, frustrations and other feelings that disabled people must have in real daily life events, more empathy, more attention for support and understanding... It was suggested that the collaboration with real service users in the test could enhance this experiential learning process, as well as gaining a long-term-effect.

An important issue with completing the questionnaires, which was observed, was the recognition that the cognitive ability, or effect of the user's condition, on memory and comprehension needs to be taken into account. How to do this will be a matter for further research.

The EDECT team also had to manipulate a lot of documents and different versions of each one. In the context where different partners from different countries and institutions were involved, each one with their own security policy, sharing documents using free tools as Google Drive or Dropbox was found to be impossible. Therefore ensuring that all partners use and work on the latest version of the documents was a real challenge.

Cultural differences in responding to questionnaires and giving more extended feedback needs to be investigated. This was a major discovery which has come out of the EDECT cluster pilot trials. Interviews with participants from across the region gave varied brevity in their answers, which may have been due to cultural difference in communication styles. For example, the Flemish participants did not seem to be so open to give further comments, were more reserved, or in explaining their answers; a simple yes or no was often enough in their opinion.

Translation of the wording and meaning between cultures and languages has been a major hurdle for the EDECT team to overcome. It may be easy to simply translate a word but the actual local meaning may be very different, for example in English to reverse a vehicle means to drive the vehicle backwards, as we discovered this can translate to turn round and go back in Dutch!

The EDECT partners have worked together to deal with all the challenges expeditiously, valuable lessons have been learned and all the partners will leave the cluster with far greater understanding of developing assistive technologies across different cultures.

5.3 What still need to be improved?

Participant feedback made it clear that there was a need to reduce the number of questionnaires; this they reported would help reduce the load on the participants. Therefore



both the ethical and technical questionnaires should be combined to be the “Pre-session Participant Questionnaire” and the “Post-Session Participant Questionnaire”.

The NASA TLX questionnaire is not straightforward to understand and to apply, although the questions were modified to make them easier to understand it was still not clear whether the current analysis is reliable because of this lack of clarity. The wording and communication of the questions will have to be investigated in future research.

The participants need to be given longer to familiarise with the PWC and with the driving assistance system. Thirty or so minutes with explanation and demonstration of how the new assistance technology works should be sufficient. Then the participant can familiarise with the test course.

The methodology and script used in the AAC activity needs to be adapted for every individual’s needs and situation of the participants who will be involved in the future pilots.



6 Future work

The test carried out in the four pilots organised by the EDECT cluster team gave useful feedback from the 40 participants on how the co-production method could be practically implemented for developing, testing, giving on-going support and training the users of assistive technologies and their carers. It also highlighted the importance of involving various stakeholders in the process.

Useful methodology and tools have been designed and tested during the cluster period.

Based on these results and the experience gained by the cluster team, some partners will apply this methodology as they continue to design assistive technology and appropriate long term training by involving all the stakeholders. The collaboration of stakeholders from different countries gives more opportunity to develop technology and training that take into account the cultural differences and needs across the countries. The co-production approach will improve the quality of technology and will ensure a better acceptability and positive outcome and will increase the delivery of innovation.

Development of training which make stakeholders more aware of the needs of the user, the methodology developed in EDECT of the immersion in the simulation activity needs to be extended.

These different ways should be explored under a new project, EDUCAT, proposed to be funded by the Interreg VA 2 Seas Programme.