EDECT Methodology

1 Introduction

In order to develop a methodology it is first of all necessary to model the processes that a user and their care network will or should go through in the provision of Assistive Technology [AT].

One way to do this is to consider what can be called the "Care Pathway" and to identify each component of that pathway.

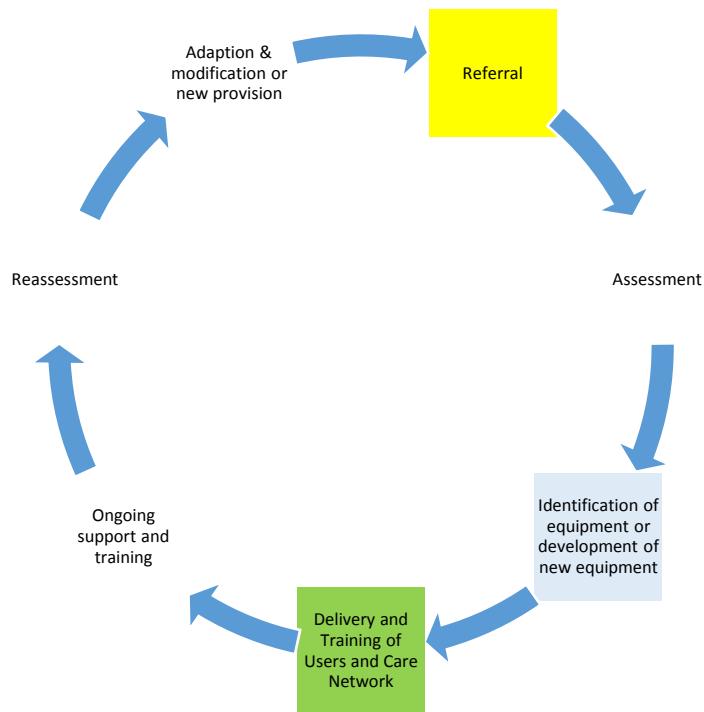A basic care pathway is shown in figure 1.

FIGURE 1 : A CARE PATHWAY FOR THE PROVISION OF ASSISTIVE TECHNOLOGY

This pathway begins with the referral of the user for provision of AT. Within that pathway there are several activities that must be robustly implemented for the ethical provision of AT.

Within the constraints of the EDECT project it was not possible to develop a methodology for all these elements.

Therefore in order to achieve the cluster goals, two activities have been selected to provide a means to systematically develop and evaluate, in an iterative fashion, the methodology for examining the effectiveness of assistive technology and its provision.

The two elements chosen were

- The Development of New AT
- Delivery of Training of the User and their Care network

Within each of these two elements only sub-elements could be chosen.

In the figure below a simplified model for the development of AT is shown.
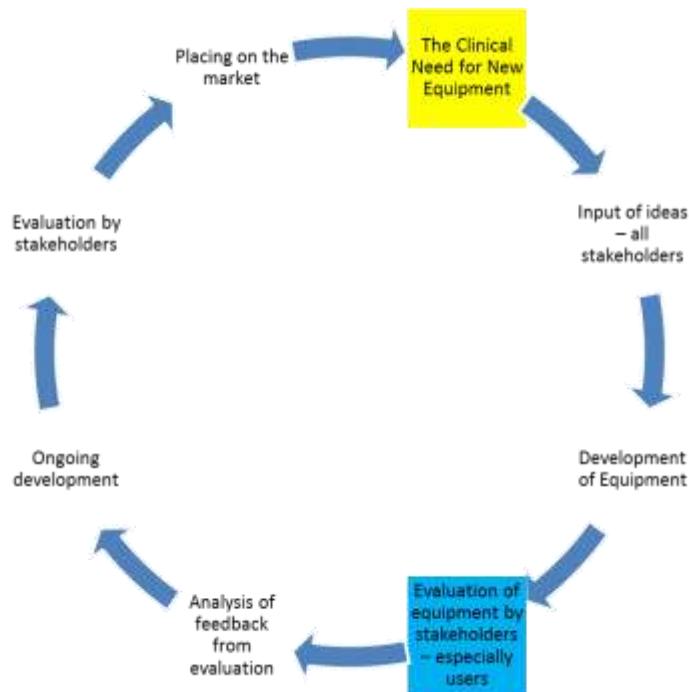

FIGURE 2: A PATHWAY FOR THE DEVELOPMENT OF AT

From within this pathway the element "Evaluation of the Equipment by Users" was selected.

For the training and long term support of users and their carers, the initial training of carers and other stakeholders [researchers, representatives of user organisations etc] was selected.

The methodology requires that stakeholders are immersed into the technology through practical evaluation organised on four Pilots (one in each country involved in the cluster: UK, NL, FR and BE).

The first activity, user input into the evaluation of a new assistive technology (a driving assistance for a powered wheelchair developed through the SYSIASS project) had, as its main objective, the improvement of the tools to be used for this 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 in the Pilot tests, it has been found from previous experience that it is necessary to develop simulation sessions. It is necessary that these sessions be as close as possible to the real life situations experienced by users.

The 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 Development of New AAT – The Powered Wheelchair (PWC) Activity

2.1 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.

2.2 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.

2.3 Methodology used

The steps followed were:

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 [driving session], 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
    a. Drive with [A] and without [B] Driving Assistance - ABABABAB
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.
10. Analysis of all the data

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

2.4 The Simulated Driving Course:

A key aspect of the methodology is that the test course developed had 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
- replicate a typical corridor, turn, doorway and lift
- define a standard test course for future trials
- easily transported to any location with a suitably sized room
- sufficiently challenging for experienced drivers so that the effect of the driving assistance system could be fully evaluated
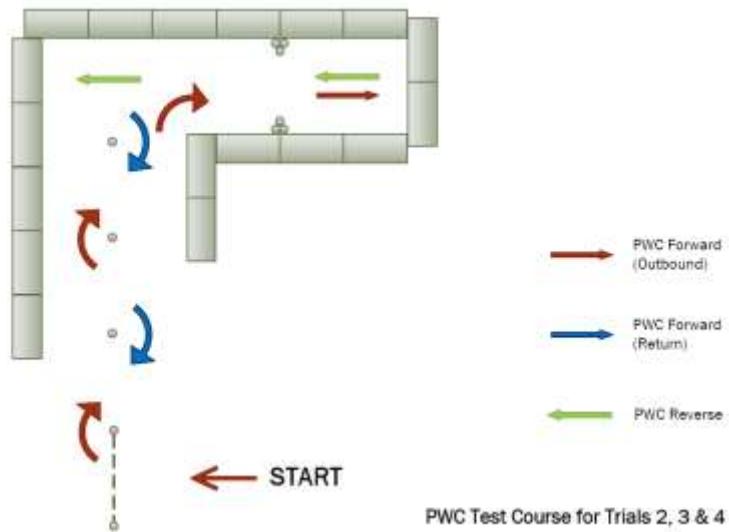
FIGURE 3: TEST COURSE DRIVING ROUTE

This course enables the user to test the chair by navigating through a slalom, turning left and right down a corridor, passing a simulated doorway, entering a space simulating a small lift and reversing the PWC back along a corridor [Fig 1.].

The participants are given a short time to familiarise themselves with driving this chair, with the driving assistance device on and off. They drive the test course several times until the run time is consistent and when they are content to start the evaluation. Initially it was thought that there may be some difficulty for some of the participants to complete the driving course.

Once the participants said that they were used to driving the chair, the route is driven four times with the Driving Assistance system on [A] and four times without the system [B] in the sequence ABABABAB.

2.5 Data recording

Before the session two questionnaires were administered. The "Pre-Session participant technical Questionnaire" explored the user experience of PWC use and their expectations for a driving assistance [DA]. The "Pre-session Ethical Questionnaire" explored the user view point on how the use of PWC in a daily life enhances and is compatible with a good care and on their feelings by being asked to participate to the tests.

The driving sessions were monitored by up to 5 observers using an "Observer Technical System Form" for recording the number of collisions, if any, the time taken to complete each run and any other observations about how the participants are driving during the tests, if any. Additionally Video recordings were made of all the runs.

During the tests a data recording system (developed within a related Interreg IVa Cross Channel project [COALAS[1]]) 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.

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[1] http://coalas-project.eu/indexen.php?p=home

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.

3 Carer Training – The Alternative and Augmentative Communication Aid (AAC) Activity

3.1 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 how the participants' empathy and insights may be developed by this training
- build a set of tools to be used in training of stakeholders
- 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

3.2 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.

3.3 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 work in pairs. In each pair one person began with the role of the caregiver and the role of the care-receiver. A script with a scenario was handed out to facilitate this role play. The session was broken into two periods of around 70 minutes each, with a break for lunch between these periods.
   1) In the first period the care-receiver has the role of someone in hospital who had lost their ability to speak and write. The care-giver has the role of an interviewer. A script with prepared questions/scenario was developed and the focus of the interview was on the evaluation of the situation and to help the care-receiver express their 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.
   2) In the second period, after the break for lunch, the participants changed roles and continued the interview.
5. *Debriefing Session:* This session included a guided discussion with the participants on their experience to collect their 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 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.

3.4   Data recording

The 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.

4   Data Analysis

The data from both activities is then analysed and correlated to look for trends in response, similarities and differences between the Pilots carried out in the four partner countries.

The feedback is then used to further refine the evaluation ad training processes and to consider how to apply this information to the other elements within the wider Care and AT development pathways.