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Abstract: *Workpackage WP03 of the EATS project developed two new measures of effectiveness and utility of assistive technology, respectively 1) the IPPA (Individually Prioritised Problems Assessment), intended to describe the outcomes generated by the provision of AT&S (Assistive Technology products and Services) in terms of solution to pre-identified problems and 2) EATS 6-D (EATS 6 dimensions), intended to describes changes in autonomy in daily life resulting from the adoption of such AT&S.*

Both instruments are user-centred, being designed to collect data from the direct real-life experience of the user of AT&S: in the first case (IPPA) through interview sessions carried out by trained interviewers, in the second case (EATS 6-D) by a self-administered questionnaire.

The first chapter of this document clarifies the objectives and the boundaries of the study. It also addresses the remaining open issues, that means those aspects needing further research in order to achieve a more comprehensive and thorough understanding of AT outcomes.

The second and third chapters present and describe respectively the effectiveness (IPPA) and the utility (EATS 6-D) instruments, in terms of their rationale, structure, items explanation, validity and reliability issues and administration technique.

Keywords list: *outcome measures, effectiveness, utility, assistive technology*

EXECUTIVE SUMMARY

This document presents the findings of Workpackage 3 of the EATS project. It covers the scope and the contents of deliverables D03.1 (effectiveness instrument) and D03.2 (utility instrument) as defined by the Project Programme.

Since a number of issues were found to be common to both instruments, and these are likely to be used in parallel, the solution of merging the two deliverables into a single manual was adopted as the most handy and usable for the readers. The intended audience of the document are mainly researchers, rehabilitation professionals and user groups who will use the instruments for trials.

The overall objective of EATS is the development of a methodology for comprehensive assessment of assistive technology products and services, aimed at supporting decision at policy and provision level. As a step towards such objective, the mission of this workpackage was to establish measurement instruments able to generate the data that are needed for carrying out such an assessment.

In particular, a set of two new measures was developed:

- the IPPA (Individually Prioritised Problems Assessment), intended as an *effectiveness* measure that describes the outcomes generated by the provision of Assistive Technology products and services (AT&S) in terms of solution to pre-identified problems
- the EATS 6-D (EATS 6 dimensions), intended as a *utility* measure that describes the individual perception of autonomy in daily life.

The need for carrying out separately the measurement of *effectiveness* and *utility* has been extensively substantiated by the previous EATS workpackages and the previous TIDE/CERTAIN project: they represent different domains of assessment - achievement of pre-set objectives (effectiveness) and individual perception of their value (utility) - that need to be explored in parallel in order to clearly understand and interpret the outcome.

Being addressed to so different domains, the two measures are quite different in terms of structure and administration method; however, they conform to a coherent approach and thus have a number of conceptual similarities:

- both are user-centred, being designed to collect data from the direct real-life experience of the user of AT&S: in the first case (IPPA) this is done through interview sessions carried out by trained interviewers, in the second case (EATS 6-D) by a simple self-administered questionnaire.
- both measure absolute status of present situation; however, since the objective of the measurement is not absolute status but rather *changes* in response to the adoption of AT&S, they require to be administered twice: *before* the provision, and a reasonable time *after* it.
- finally, both are concerned with outcomes at the level of individual expectations. They do not address *systemic* changes occurring in the primary network (family, helpers etc..) around the individual. The reason for neglecting (at this stage) such important aspects is the lack of consolidated knowledge on how to define and measure systemic parameters.

This deliverable builds upon the findings of the previous documents produced within the EATS project: Del 2.2 “Report of workshops” and Del 2.3 “Report on the prototype instruments”.

The first chapter of this document clarifies the objectives and the boundaries of the study. It also addresses the remaining open issues, that means those aspects needing further research in order to achieve a more comprehensive and thorough understanding of AT outcomes.

The second and third chapters present and describe respectively the effectiveness (IPPA) and the utility (EATS 6-D) instruments, in terms of their rationale, structure, items explanation, validity and reliability issues and administration technique. They also include the interview checklist for the IPPA instrument and the EATS 6 D questionnaire.

The field experimentation and the validation of the two instruments will be carried out in Workpackage 4.

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1. THE EATS INSTRUMENTS: THEORETICAL CONSIDERATIONS

1.1 Introduction

Background

Assessing outcomes of Assistive Technology products and services (AT&S) is an emerging issue on which a large debate is taking place in many Countries and at international level. The TIDE/HEART study of the European Commission pointed out areas of decision-making where outcome assessment is meaningful and important (Persson and Brodin 1993; Alastuey et al 1994). Following to that, the TIDE/CERTAIN project made a first attempt to compile assessment tools, based on methodologies initially developed for health care technology, and studied their applicability to the AT&S domain (Lorentsen and Hem 1995; Persson and Brodin 1995; Andrich and Ferrario, 1996; Van Beekum and Oortwijn 1996). Several existing instruments were tried out, but their responsiveness to AT interventions is still an issue (Andrich, Ferrario and Moi, 1998).

Many papers recently appeared in scientific journals (Assistive Technology, Fall 1997) or were presented during congresses (AAATE 97; RESNA 97) concerning the various aspects of AT outcomes, and highlighted the complexity of this domain. However, a common agreement on what has to be measured - and why - is not yet consolidated. While proving that no satisfactory instrument exists yet that addresses comprehensively this field, the CERTAIN study defined a number of key concepts that set the ground for the development of new instruments. One of them is the need for a user-centred approach; another one is the doubtfulness of estimations of the disabled person's view made on the basis of studies carried out over able-bodied populations.

Based on the above findings, the EATS project decided to concentrate on two outcome levels that, although broad in themselves, have been demonstrated to yield value in the understanding of the outcome generated by the provision of AT&S to populations of individual users. These are respectively *effectiveness* and *utility*. The need for carrying out separately the measurement of *effectiveness* and *utility* has been extensively substantiated by both CERTAIN and the previous EATS workpackages: they represent different domain of assessment - achievement of objectives (effectiveness) and individual perception of their value (utility) - that require to be explored in parallel in order to clearly understand and interpret the outcome.

Areas of assessment

The way and the extent to which outcomes have to be measured depends on the objective of assessment. EATS Deliverable 2.3 "Methodological basis for the EATS instruments" defined five levels of decision making where outcomes analysis provides useful data:

1. Technological development
2. Priorities between AT&S programmes
3. Quality assessment programmes for service providers
4. Professional guidelines in clinics and service units
5. Management of individual services

Areas 2, 3 and 4 were indicated as the focus of this study. Reliable techniques for outcome assessment are still lacking in such areas; moreover, these areas yield great societal impact in that

they directly relate with common critical problems that each Country deals with in the operation of their Service Delivery Systems for Assistive Technology;

Although all areas can benefit from effectiveness and utility assessment techniques, *area 1* - mainly product-related and thus more concerned with research and industrial aspects - and *area 5* - strictly user-related and thus more clinically oriented - will not be addressed by this study. Their importance is not underestimated. The main reason for looking at them as a lower priority is because other methods already exist for estimating outcome related to these areas (think eg. USERfit checklists applied to area 1 (USER 1997), or clinical observation applied to area 5), and it is still not completely clear how far effectiveness and utility techniques can really add to them for supporting decisions.

1.2 Objectives of the study

The IPPA and Eats 6-D instruments

The overall objective of EATS is the development of a methodology for comprehensive assessment of assistive technology products and services, aimed at supporting decision making at policy and provision level. As a step towards such objective, the aim of this workpackage was to establish a new measurement instrument able to generate the data that are needed for carrying out such assessment.

The EATS instruments address what we denote as the *effectiveness* and the *utility* levels of outcome. In particular two new instrument were developed:

- the IPPA (Individual Prioritised Problems Assessment) intended as an *effectiveness* measure that describes the outcomes generated by the provision of AT&S in terms of solution to problems identified by the user
- the EATS 6-D (EATS 6 dimensions), intended as an *utility* measure that refers to the individual perception of *autonomy* in daily life with respect to one's own priorities.

The purpose of the instruments is to detect *changes* generated by the adoption of AT&S by *populations* of AT&S users, and *measure* them by aggregating the responses provided by individual members of such populations. The ambition is to have them responsive to AT&S and not to other interventions or events that have nothing to do with AT (external events, psychological factors etc..), which in this context should be seen as *confounders*.

The need for carrying out separately the measurement of *effectiveness* and *utility* has been extensively substantiated by the previous EATS workpackages and the previous TIDE/CERTAIN project: they represent different domains of assessment - achievement of objectives (effectiveness) and individual perception of their value (utility) - that need to be explored in parallel in order to clearly understand and interpret the outcome, and discriminate possible confounders. For instance, a technology that showed low utility may suggest different interpretation depending on whether effectiveness was high (failure mainly resides with a low perceived value of achievements) or low (failure mainly resides with missed achievements).

Common features of the two instruments

Being addressed to different domains, the two instruments are quite different in terms of structure and administration method; however, they conform to a coherent approach having a number of conceptual similarities:

- both are user-centred, being designed to collect data from the direct real-life experience of the AT&S user: in the first case (IPPA) this is done through interview sessions carried out by trained interviewers, in the second case (EATS 6-D) by a simple self-administered questionnaire.
- both measure absolute status of present situation; however, since the objective of the measurement is not absolute status but rather *changes* in response to the adoption of AT&S, they require to be administered twice: *before* the provision, and a reasonable time *after* it.
- finally, both are concerned with outcomes at the level of individual expectations. They do not address *systemic* changes occurring in the primary network (family, helpers etc..) around the individual.

The reason for neglecting (at this stage) the human network around the individual is the lack of consolidated knowledge on how to define and measure systemic parameters. However, this limitation can be overcome at this stage by collecting additional backup information that helps to correctly interpret the outcomes.

Each of the two instruments is presented and described respectively in chapters 2 and 3, in terms of their 1) rationale, 2) structure, 3) items explanation, 4) validity and reliability issues, and 5) administration technique. In this chapter an overview is given of the underlying principles, that helps to understand their scope, domain of application, and cautions for use.

1.3 Outcome indicators and modifiers

What to assess

Assistive technology does not save lives nor reduce morbidity, it simply allows the disabled persons, their families and their primary networks for a more satisfactory and resourceful life. Measuring all outcomes of assistive technology is not like measuring on/off variables (like life/death, or healthy/ill etc.), these being generally very few in a process of rehabilitation and social integration. A number of inter-related factors (technical, clinical, psychological, social, environmental) are involved that make such a process extremely complex: it can be difficult to state if an observed improvement in life quality is originated by a new technical aid, a new physiotherapist, a happy event in the family, an offer for a job. Some factors may be determinant and affect the outcome substantially, others are confounders; determinants should be controlled, while the latter produce just “noise”.

Clinical assessment at the discharge from a rehabilitation centre may be not helpful enough, since it measures *efficacy* (achievement of goals in ideal use conditions and controlled environment) and not *effectiveness* (achievement in daily use context). Or, as other authors say, it checks the *capacity* (what the patient’s abilities would allow to do) rather than the *performance* (what he/she will be really able to do in daily life context). Assessing that the provision of a new wheelchair enabled the client to reach a given level of mobility, does not mean necessarily that he/she will achieve mobility in daily life (eg. due to environmental factors like the frustration of feeling observed in a wheelchair by other people); nor that he/she will experience a better quality of life because of independent mobility.

DeRuyter (1995) suggests that at least five dimensions should be investigated independently: *clinical results, functional status, quality of life, user satisfaction* and *costs*. Around these issues consensus is emerging on the idea that a user-centred approach is needed, where the ultimate outcome indicator is offered by the quality-of-life modification generated by an assistive technology programme; and any intermediate indicator should also take into account the user's preferences. This was also a finding of the CERTAIN study which - based on that assumptions - studied cost-utility techniques.

The challenge of developing measures of achievements (effectiveness) and quality of life (utility) that are *responsive to AT&S*, should first cope with a basic question: *achievements with respect to what objectives*, and *quality of life with respect to what dimension*? Any answer has advantages and drawbacks, and yields consequences on the conditions and the boundaries under which the measures are going to work or not.

The EATS choice was to assess:

- effectiveness in terms of *solution to problems that were previously identified by the user*, and
- utility in terms of *autonomy with respect to own priorities* in pre-selected domains of life.

At this stage the aim of the instruments is to offer a way to detect - with reliability and validity - the overall effect of the provision of AT&S over representative populations of AT users. Such effects are measured in terms of scores that statistically express the change detected in the individual members of such populations as a result of the adoption of AT&S.

This is a clearly user-centred approach, quite new in this area, which meets most recommendations formulated so far. However, being the outcome influenced by the *characteristics of the technology* itself, the *way it is provided*, and the *characteristics of the population receiving it*, it is important to establish the conditions under which the assessment is made.

A complex hi-tech assistive device provided according to best practice in a clinical centre of excellence, with well-structured follow-up at the user's home, good links with community care facilities and reliable technical maintenance service, may result more effective and useful than the same device provided in the community by a general practitioner who recommends such technology for the first time, has no idea of how to carry out the user training, will make no follow-up nor is prepared to support the client to cope with installation and maintenance problems. If the person depends on the device for many hours a day, this may yield higher impact on the person's life than in cases where the utilisation rate is lower, or alternative solutions are available when the device gets broken. Knowledgeable, empowered and assertive users may take the lead in the provision of their AT&S and thus have a different view of achievements and autonomy, than other peers who experience uneasiness with AT&S because of difficulties in acceptance of their disability.

Many other examples could be taken and in any of such cases a outcome study is legitimate: however, it is important to know that outcome scores may read differently from one case to another because of the experimental conditions. These should be consistent with the purpose of the study.

Critical parameters

Parameters should be established that define the measurement conditions. These relate to the choice of the *population*, the *technology* and the *environment* under study, and thus can be clustered round three categories:

- *human variables* (related to eg. disability, age, personal attitude towards disability, primary network around the individual etc.)
- *technology variables* (related to assistive devices or services provided, technical support during their life-cycle, requirements for personal assistance involved in their use, etc.)
- *social variables* (organisation of service provision, social status of users etc...).

One examples of possible experimental conditions is, for instance, a cohort of hundred young quadriplegic, getting the technology “standard electronic wheelchair”, recommended and provided by the same professional team in a centre of excellence according to the best practice, relying on good technical and clinical support in their community, showing positive attitude towards the device and living with a supporting primary network. Another example is a cohort of fifteen “severely motor disabled”, getting the technology “personal assistance and hoist for personal transfer”, recommended and prescribed by a variety of general practitioner in their various local communities, with different technical support and varied attitudes towards disability and AT. It can be argued that findings from these two cases may be hard to compare. Even more care should be taken when making comparisons across different Countries with different social provision systems and cultural attitudes. Clear choices should be made and substantiated in defining all conditions under which the instruments are administered.

The influence of this variety of *outcomes modifiers* is illustrated by a number of studies, one of them being the ongoing TELEMATICS/EUSTAT project. The focus of such study is the user’s attitude and AT knowledge, that seems to play a substantial role in shaping the user’s predisposition to accept and make the best use of AT; critical factors were found that help to facilitate empowerment of users in relation to AT. Another study (Philips and Zhao, 1993) highlighted four main reasons for early abandonment of AT like 1) failure of providers to take consumer’s opinion into account, 2) easy device procurement, 3) poor device performance and 4) changes in consumer needs or priorities: only one reason (3) is linked to the technology itself, the others are mainly linked to the provision process and environmental conditions.

Early abandonment, or lower utilisation due to environmental difficulties or dissatisfaction (“so ugly that I cannot accept living with it..”, ”it takes so much strain that I have no other energies left to do other things..”) , may seriously bias the users’ views concerning effectiveness and utility. If these events occur, the reasons for them should be analysed, and taken into account when establishing measurement conditions.

1.4. Establishing measurement conditions

It is not the task of this workpackage to design or carry out population studies based on these EATS instruments. The first study will be performed by WP04, with the specific aim of validating the instrument internationally. In this section some practical issues and some warnings are offered regarding cautions that have to be taken into account when establishing the objectives of each population study, and defining the measurement conditions accordingly. Even within each of the three categories described above (human, technology, social) it may be difficult to identify consistent descriptors. Moreover, choices in one category mutually reflect on other categories.

Population

In our context the population under study are not disabled people in general, but specifically *end-users of the concerned AT&S*. These are primarily persons with disabilities or elderly people. In some

cases these may also be family members, helpers or personal assistants whenever AT is designed as a tool for other persons of the primary network.

Such population is in itself non-homogeneous: a *standard* disabled person with standard needs and standard solutions does not exist. If at a first glance it would seem easy to identify as homogeneous the target group of a specific technology (eg. for lower limb prostheses: “people with leg amputation”), a deeper analysis would probably highlight that the effectiveness and utility of such technology highly depends on the lifestyle of its user (young man walking kilometers everyday? adult staying most of the day at home? etc..), which in turn may put different requirements of robustness and performance to the same device or even different design specifications (think eg of prostheses for children). The target group can be even more unhomogeneous when dealing with assistive devices intended for wider audiences, like eg. wheelchairs or powered-adjustable beds or adapted handles. The more the device is intended for problem solving rather than for replacing function, the more the target group will be represented by “those who experience the same problem” rather than “those who lack the same function”.

A first broad but useful categorisation can be made into four groups, sometimes with blurred boundaries between each other:

- users of AT intended to replace function (prosthetics) or support lacking function (orthotics) or relieve pain or hinder damaging tissues or organs
- users of AT intended to compensate for disabilities (assistive devices for independence)
- users of AT intended to improve environmental accessibility
- users of AT intended to support personal assistance

The more the technology moves from the first to the fourth group, the more the target group will move from *those who have similar impairments* to *those who have similar disabilities* to *those who face similar barriers* to *those whose primary network has a similar burden of assistance*.

Depending on the objectives and the extent of the study, other human factors may also need to be specified inside each group, related to eg. age, attitudes towards disability and characteristics of the primary network.

Technology

The most widespread categorisation of Assistive Technology is the ISO 9999/ EN 29999 classification of technical aids. So for a population study it may be useful to select specific clusters of such classification, or specific options within a cluster (eg. different models of electric wheelchair; different kinds of electric wheelchair; electric wheelchairs Vs scooters etc..). However, this is not the unique way to look at technology: other ways could be to look at clusters of devices provided according to the same service provision scheme, or clusters of AT programmes each composed of a mix of different technologies and services for the same purpose (eg. mobility; employment; communication etc..).

Depending on the objective of the study, technology can be looked at in a narrow sense, as a single device or a mix of devices, or in a broad sense as the mix of products, services, related human assistance and technical support that define in the whole the technical way to solve a problem. According to the second view, a technology like eg.. “mobile stairclimber” includes the device, the associated service delivery procedure, the technical maintenance over all its life-cycle, the human helper who is needed to drive the device up- and downstairs. In the field of AT a broad view is

needed: in most cases hardly the device can be separated from such context, it would simply not work, exactly like the technology “adapted taxi” would not work without taxi driver and petrol

From the end-user’s viewpoint this is especially true. The end user looks at whether the solution works or not, rather than focusing on a single device. One prompt example is personal assistance. The user may not matter whether effective solution is reached through a mix of devices, or through a well-organised personal assistance, if he/she obtains the same level of autonomy, easiness and freedom. The perception of being physically dependent on others for assistance is different from one culture to another, and also depends on the profile of personal assistance which is different in the various Countries. Thus the service “personal assistance” should be looked at as one specific type of “technology”, that like other assistive devices facilitates achievements and autonomy.

Environment

The socio-economic context in which technology is provided is another critical factor in determining the boundaries of the population study. The organisation of the service delivery system, the competence involved in the provision process and the cultural image of AT&S have an influence on the way AT&S is implemented and perceived by its users.

The more the purpose of the study moves from general issues like priorities between AT&S programmes (area 2) to specific issues like quality assessment programmes for service providers (area 3) and professional guidelines for service providers (area 4), the more selective the researcher should be with respect to the environmental conditions, being the focus of assessment moving from products to processes.

Area 2 can be somehow considered as the “entry point” for such studies, being conceptually simpler to understand and carry out. To support decisions on whether it is more effective and useful to solve a given problem with technology “A” rather than with technology “B”, it may be sufficient to measure the overall outcome of technology A provided to population X in comparison to technology B provided to a control population which is similar to population X.

Studies carried out in area 2 may also offer a baseline for area 3. Technology “A”, whose overall effectiveness and utility have been proved by an “area 2 study”, could be comparatively assessed through two different provision processes “X” and “Y”: if outcome scores of “X” are better, it can be inferred that process “X” works better than “Y”, and this is a useful indicator for service providers. Finally, by investigating the reasons why process “X” revealed better than “Y”, professional guidelines can be drawn for best practice in clinics and service units (area 3).

These are just simple examples, for the sake of understanding, of the way a study can be designed: in real life more complex approaches may be needed. However, the EATS instruments are intended to be used in all three areas, the difference being in the way how population, technology and environment are chosen, and data are processed.

Recommendations for field trials

While the mission of WP03 is to produce instruments that are supposed to be responsive to the changes generated by the implementation of AT, yielding construct and face validity, it will be the mission of WP04 to test the overall validity and reliability at international level. The ambition is that the instruments are *Country independent, culture independent and service delivery independent*.

If the population study has such a general objective (validating the EATS instruments in international context), it is important to adopt a wide concept of population (representative of the “most common user” in terms of demographics, personal attitude, culture and lifestyle), a broad concept of the technology itself (seen not as just a product, but products with all related services), and well-representative environmental conditions (the most common provision and financing procedure, the most common way the product is presented to end-user, not as it may happen only in few “centres of excellence”).

1.5 Boundaries of assessment

Strength and weakness of the instruments

Before using the EATS instruments it is important to know what they *will be able* to measure and what they *will be not able* to measure. The major issues are:

- IPPA: this technique addresses personal priorities as identified by the user before the provision of AT. This is an important advantage compared to traditional “functional independence” approaches, which generally refer to standard classifications of possible achievements that may be not meaningful for all users, and also may not reflect all achievement desired by the individual user. However, being tuned to the individual experience prior to the intervention, it tells nothing about those *unexpected* achievements that often happen after the intervention. A piece of AT changes life, opens new horizons, brings about a personal and psychological restructuring which modifies in turn personal priorities: these represent additional elements of success of AT. Some achievements may be unexpected simply because the user could not imagine them before.
- EATS 6-D: this technique is based on the EuroQol (EuroQol 1990) approach with three main modifications: a relational dimension has been added; items are expressed in terms of “performance” rather than “capacity” (“can you move about” and not “can you walk”); performance is contextualised to the person’s lifestyle (“can you move about *as you wish or need*”). Quality of life is explored with reference to the individual perception of *autonomy*. This seems a good step, but is still restricted to the individual dimension. CERTAIN stressed that not only the individual dimension should be investigated, but also at least the family / primary network dimension. Very often AT generates utility in the family (respite, relaxation etc...) that in turn reflects on the individual, and thus all utilities generated within the whole network should be measured. This aspect is not addressed by the instrument, and will be discussed in the following.

Individual Vs systemic view of outcomes

Outcomes should be observed in four domains of expectations: 1) individual 2) family or primary network, 3) professionals and 4) community (Loretsen and Hem, 1995). While it seems easy to distinguish and analyse separately the outcomes perceived by professionals and community from those experienced by the individual, it is not clear how to analyse outcomes experienced by the so-varied entity that is the primary network.

It should be observed that in some cases the members of the primary network have an influence and a role in the process of choice and use of AT. There are aspects of the individual life project that

hardly can be separated from the family life project; there may be a range of expectations originating from the relationship with the spouse, who may in turn have other needs and aspiration which are then shared with the partner. The introduction of AT in a family has an impact at various levels and it may require personal changes in other family members. It may also require modifications in the organisation of personal assistance, and thus a change in attitudes and habits of personal assistants. The same technology provided to the same person may produce different outcomes if placed in a different primary network.

Resorting to a systemic view, all the “system” composed of the individual and his or her primary network should be looked at in this analysis. Internal to the system, the role and the weight of the various members with respect to disability problems and assistive technology is different from one case to another, and can even vary in the time. There are cases in which the individual with disability is in fact the only and unique person dealing with such topics, with no influence from others; there are cases where he or she, on own choice, shares these aspects of life with others; cases where a wider group is involved; and even cases where the real end-users of AT are in fact the helpers.

What said above suggests that a comprehensive analysis of outcomes should conform to a systemic approach, and thus evaluate the overall outcome brought about in the primary network around the individual. Unfortunately, little knowledge is available on how to measure systemic outcome. That means that the more we are in the situation where it can be demonstrated that the outcome is concentrated in the individual, the more reliable will be the scores resulting from the EATS measure.

1.6 Effectiveness assessment: open issues

Problem oriented or goal oriented ?

As said before, AT is provided to individual users under a great variety of schemes throughout Europe. Some countries have implemented centralised models for AT service delivery, while others have adopted decentralised models. Some countries refer to specific lists of assistive devices, while others have a more open selection of products. Some countries have different service delivery schemes for different types of disabilities, while other countries have developed common schemes for all disabilities. In some countries, a wide range of different professions are involved in AT service provision, while in other countries only a restricted range of professions are involved. Some countries are trying to integrate AT service delivery into an holistic habilitation / rehabilitation approach for the individual person, reflecting individual prioritised goals. In other instances, AT service delivery is organised as a self-contained measure.

An instrument for assessing effectiveness should be suitable for implementation in a variety of settings. At the same time, it should reflect solutions to individual problems as they are prioritised by the individuals concerned. For such purpose two different approaches could be taken: the former would be to focus on problems to be solved in order to fulfil individual goal expectations; the latter would be to focus on goals to be achieved, and then find solutions to the obstacles that impede the achievement of them. Within the EATS project, the first approach was chosen as the most feasible. Before the provision of an assistive device, it is easier for the user to identify the problems currently experienced in daily life, than the goals that will be achieved after. However, the step does not seem too big to embark on the second approach, and thus streamline an assessment instrument that assesses outcomes of goal oriented rehabilitation procedures.

Individual prioritised activities

Traditional assessment instruments related to rehabilitation are focusing on ADL (activities of daily living) functions, which may include the ability to carry out basic tasks (such as personal hygiene, dressing, eating etc...) or the performance in various aspects of daily life (eg. walking a given distance). However, the potential of assistive technology extends also to a number of other aspects (eg. travelling, shopping, banking, participating in the school life etc.) that may yield different levels of importance for different individuals, and thus cannot be assessed in the same way for everybody. This is the basic reason for introducing the concept of "individual prioritised activities" (IPA), which offers a broader perspective than ADL (although IPA may often include ADL). On the basis of this perspective the IPPA instrument has been developed.

The IPPA also includes a problems checklist for guiding the interviewer. It would be hard to establish at this stage a closed list that encompasses any activities that may fall within individual priorities of any persons with any kind of impairment (motor, sight, hearing, cognitive). Therefore it will be useful to keep track of all the problems mentioned by interviewed people, and compare them against the IPPA checklist to see whether this can be expanded to include other most recurring problems.

In Deliverable 1 of the CERTAIN project, three dimensions of outcome were highlighted when dealing with assistive technology. These are, "activities in daily life" as prioritised by the individual persons; "inner dimension" being related to self esteem and self values, pain, content, use of energy in carrying out tasks, etc.; and "outer dimension" reflecting social network and social values, family interactions etc. When assessing outcomes of assistive technology, all these dimensions should be considered. There are also many examples of the interrelations between these dimensions. Thus we may see that even though an assistive device may solve a problem, it may not be actually used or accepted by the end user or his/her network. A device may take so much energy, so that the person has no energy left for other more meaningful tasks. Or, the device may look so dreadful, so that the end user does not want to be associated with it. Rehabilitation and provision of assistive technology can be rather complex of nature. The strategies have to be tailored to individual settings, even to settings where prioritisation issues may be difficult to settle, and to settings being dynamic of character. The strategies have to take the different dimensions of quality of life into account, due to their interrelations. The overruling strategy in any rehabilitation schemes, including AT service provision, should be goal oriented according to individual priorities.

Assessment instruments do need to reflect these characteristics of rehabilitation and provision of AT, as well as the different national frameworks for providing these services. Some of these issues will be pursued during the project life-cycle.

1.7 Utility assessment: open issues

In this paragraph some basic issues are discussed on which a number of decisions were taken in the development of the EATS instruments. A number of still unsolved aspects needing further research are also described. These will help the reader in better understanding the EATS approach and use the instrument in a proper context and with proper caution.

What dimension of Quality of life to measure?

Five dimensions of quality of life are often described in literature: 1) physical status and functional abilities, 2) psychological status and well being, 3) social interactions, 4) economic or vocational status and factors, 5) religious or spiritual status (Spilker 1996). It is apparent that AT may generate changes within any of the five domains, and that vice-versa the individual acceptance and perception of AT is influenced by the overall individual feeling in each of them. It is also apparent that *personal variables* (attitudes, education, knowledge about AT etc.), *systemic variables* (network) and *environmental variables* all have influence on the perceived changes in life quality. However, there is not yet a consolidated consensus around the specific nature of the changes that can be traced back to AT; in other words, a specific “entity” in the person’s life, that better than others is modified by AT, has never been identified in the literature so far.

In the following an attempt will be made to describe such “entity”: with respect to that, it is possible to think to a quality-of-life instrument that is responsive to AT and not to other confounders.

To understand the user’s viewpoint, first it is useful to consider that the values associated to disabling conditions highly depend on the cultural paradigms through which the rehabilitation process is looked at. The more the paradigm moves from a “medical” model (cure) to a “social” perspective, the more the attention progressively shifts from *biological health* to keywords like *well being, ability, independence, autonomy, satisfaction*.

It has been widely discussed that such “entity” has little to do with *biological health* (“death Vs perfect health”), like it would common in health care technology or environmental technology assessment. Also the domain of *functional abilities* (“full inability Vs perfect ability”), which at a first glance would appear perfectly suitable, seems insufficient from the viewpoint of AT users. A recent study observed that “paradoxically... the more free from physical limitations individuals with disabilities become, the more stuck many seemed in several important ways” (Scherer 1996). In fact *abilities* are perceived as means to achieve personal goals rather than personal objectives in themselves: setting, pursuing and achieving a personal goal seems more important than the way such goal is carried out (no matter if alone, by personal assistance, by AT etc..) or the level of physical *independence* from other people through which it is achieved.

What is said above suggests that the dimensions of *well being, autonomy* and *satisfaction* seem more interesting than others from the user’s viewpoint. Therefore all of them should be studied.

Concerning “*well being*”, CERTAIN extensively discussed the difficulty to separate AT from other “well being factors”; therefore this dimension has to be considered (instruments are already available for that) but it cannot be taken as the sole ultimate indicator. Conversely, *satisfaction* with respect the AT provided is obviously a technology-sensitive dimension and thus is an interesting indicator; however it offers a very focused perspective, as such too narrow to be seen as an *outcome* of AT.

For the purpose of this study the *autonomy* dimension is considered the most comprehensive and urgent to investigate, also due to the lack of methods to measure it. The term *autonomy* is still used with a number of different meanings in literature, and even in the field of disability (where it is often referred to, especially by users organisations) there is still some misunderstanding, it being sometimes used as a synonym of *independence*.

According to the findings of the Telematics/Eustat study (Eustat 1997), that extensively studied this concept, *autonomy* has to do with *taking control over one’s own life*, in terms of identifying and deciding on needs, setting personal goals, pursuing and achieving them. Like other dimensions of

quality of life, it may be inappropriate to describe it in absolute terms; it makes more sense to analyse *autonomy* with respect to number of specific sub-dimensions such as mobility, self care, relationship etc..., depending on what aspects are relevant to the population considered.

This approach is consistent with the findings of the World Health Organisation studies on the development of the ICIDH classification (World Health Organisation 1987). The current beta-test version of ICIDH-2 introduces a new dimension called *participation* (replacing the *handicap* dimension of ICIDH 1980) which is described in very similar term as the notion of *autonomy* offered by Eustat, and articulated in sub-dimensions such as participation in personal maintenance, participation in mobility, participation in social relationship.

Based on the above, EATS 6-D examines *autonomy* with reference to six aspects 1) mobility, 2) self-care, 3) usual activities, 4) pain/discomfort, 5) anxiety/depression and 6) relationships. The EATS 6-D structure draws upon the EuroQol 5-D instrument, and takes advantage of most of the thinking that led to the latter. However, it differs for 1) the addition of a sixth dimension (relationship), 2) the expanded notions of “mobility”, “self care” and “usual activities”, 3) the interpretation of same in terms of “autonomy” (eg. “ability to move about as I wish or need”), and 4) the consequent reformulation of items. It is therefore a *different* instrument that has to be subject to a validation procedure.

Autonomy as the ultimate outcome of AT?

Being *autonomy* a keyword in the EATS instruments, it is worth to look at this concept in more detail, based on the findings of the Eustat project (which in turn took advantage of the thoughts developed within the European Helios programme) (Eustat 1997).

The ultimate goal of assistive technology is often described in terms of social keywords like quality of life, social integration, independent living. However, these achievement should be seen as a result of a number of factors and circumstances, one of them being AT. Examples of other factors are environmental accessibility, personal assistance, social provisions, affirmative legislation (eg. anti-discrimination laws as the Americans with Disabilities Act of 1990), acceptance of diversity in the community, financial support, and so on. In the ongoing discussion around the concept of independent living, somebody argues that a person with disability who has deep knowledge of AT and full ability to make the best choice, but avails no financial mean, no funding, no public service delivery system respectful of his or her choice, very hardly could pursue a project of independent life.

On the other hand, the role played by the individual should not be underestimated in favour of just societal factors. Achievements in quality of life, social integration and self determination require the full participation of the individual person with disability, as main agent in defining his or her goals and projects, and main protagonist in carrying out actions for solution. Like a mechanic watch requires that all cogwheels be in place, but works only if the spring is loaded, likewise a “spring” is needed inside the person, that includes motivation, ability to identify and formulate needs, decision on goals, willingness to pursue projects. This “spring” will be described here with the term *autonomy*.

The concept of autonomy is not restricted to persons with full cognitive ability. Even in case of persons in the need of various kinds of support due to intellectual impairment, cognitive limitations, ageing, frailty, disease etc., they can be led to be *autonomous* with respect to their expectations (even in this case AT exists that can help achieve such goal).

The notion of autonomy has changed greatly over time and is often described very differently by various authors (Eustat 1997). The most recent definitions are relational as *ability to plan one's own life, to enter into relation with the others and, together with them, to actively participate in the construction of society* (Andrich and Porqueddu, 1990). This definition establishes a kind of equation like *autonomy = relation*, which in turn includes three types of relations: *with self*, *with others*, and *with the environment*. It is apparent that such concept applies to any persons, independently on their health or physical or mental status. An able-bodied person may be *non-autonomous* if he or she experiences difficulties in one or more domains of relation; conversely a person with severe disabilities who depends heavily on personal assistance may feel comfortable at all of the above relational levels, thus being autonomous. The onset of a disability brings about a change in life; so in order to resume a situation of *autonomy* he or she needs a *personal restructuring*, that means to build a new relation with self, with the others and with the environment.

In this view, AT - and similar supports like personal assistance - are instrumental to such goal: they are *tools for relation*. The more AT allows to take control over one's own life by building a new satisfactory relation (with self, with others, with the environment), the more it will be *useful* from the user viewpoint.

How to measure autonomy ?

One key point in measurement concerns as whether to consider the individual *alone* (as most Rehabilitation Scales do), or rather the individual *system* composed of the person plus his/her technology plus his/her human assistance. Or if you like the "person + technology" system, where the term "technology" means "the technical way to do things": sometimes a device (eg wheelchair), sometimes a mix of devices and personal assistance (eg mobile stairclimber), sometimes just personal assistance, sometimes no-technological device.

For the purpose of this study, the second approach is preferred. The technology used by the person will be considered somehow as part of the individual, inseparable from him/her being it perceived by the user in daily life as an extension of self. This approach is consistent with the concept of autonomy; is shared today by most user-organisations, that tend to describe AT and personal assistance as tools for daily life or independent living rather than stand-alone provisions; and is also adopted by the WHO/ICIDH-2 as an expression of UN Standard Rule No.4 (United Nations Assembly 1993).

According to this view, an instrument should measure "changes in autonomy" perceived by the "individual system" (person + technology), according to an intrinsically continuous rating that ranges from *full restriction* to *full autonomy*. Categorical judgement (yes/no, or other pre-defined categories) is inappropriate, since the individual expectations change from person to person (eg. "can you move about?": the answer "full autonomy" for an elderly may correspond to something very different than a young paraplegic).

EATS 6-D ratings follow this assumptions: three levels of autonomy are defined, depending on whether the individual regards himself/herself as *fully restricted*, *with restrictions*, or *fully autonomous*. Being it a non-discrete measurement based on feelings, the borderline between the three levels may be sometimes blurred: two different persons experiencing the same problem may respond differently depending on whether they feel restricted by such problem, or do not feel restricted despite recognising it exists. Such differences in interpretation are perfectly acceptable, because it is important to detect not only the problems themselves, but their perceived value.

A more in-depth decomposed approach might be developed that analyses a larger number of detailed sub-dimensions with more accurate ratings for each of them. A scenario could be for instance having sub-dimensions like “can you move about as you need or wish in your environment?” - item “at home”, with possible ratings being: 0 (not applicable), 1 (fully), 2 (with slight limitations), 3 (with moderate limitation), 4 (with severe limitations), 5 (not at all). As said above, such ratings should be given under the assumption “with the devices you have” and “with the personal assistance set-up you have”; also notice that although quite different for the respondents, for the sake of weighting the ratings “0” and “1” mean in practice exactly the same i.e. “no problem with this item”.

Possibilities for a decomposed approach were explored during the CERTAIN project. However, they were not further developed, due to the complex and cumbersome procedures of administering them.

How to calculate Quality adjusted life years ?

During the study, once more it was argued whether the utility analysis, already depicted in the CERTAIN study and in the first workpackages of EATS as the most user-centred approach, could be confirmed as suitable for this specific application. The discussion confirmed the value of this method as well established and with a solid theory behind. Successful applications are carried out with health-related QoL for health problems, while the challenge is to extend it in the field of rehabilitation, especially with AT&S in focus.

However, the utility approach brings about that, once a change in life quality is measured, one should measure how such change is maintained or develops over time, so as to allow calculation of QALYs (Quality Adjusted Life Years). Changes in functional independence and in quality of life should be observed in the medium or long term, not just at the time of provision of an assistive device. Even in case the device is successful and well accepted, they seldom remain steady over time, due to factors like the course of the pathology, changing attitudes, external circumstances. A method has to be developed for describing the evolution of such a change over the time. Within CERTAIN a possible model was hypothesised: it was called the *decay factor model*, and was associated to the notion of *clinical duration* (the period of time over which the provided AT solution yield value for the user; the *decay factor* was defined as a corrective multiplier that is needed for a more precise estimate of the utility generated by a technology over its clinical duration (Andrich, Ferrario and Moi, 1998).

In some cases the additional utility generated by a technology is steady over all its clinical duration:

$$\text{QALYs} = (\text{utility} \times \text{clinical_duration}) / \text{decay_factor}$$

in such circumstances it is possible to calculate the QALYs by just multiplying the initial utility for the number of years in which it is maintained (a *rectangular model* after the shape of the evolution diagram: the *decay factor* accounts to “1”). In other cases a linear utility loss may be expected, like eg. in the case of a self-propelled manual wheelchair provided to a person suffering from a neuromuscular disease with gradual progression, where the device gradually loses utility until becoming completely useless at the end of the clinical duration. This case (that has nothing to do with early abandonment due to inaccurate choice) can be represented by a *triangular model* (after the shape of the diagram), with a *decay factor* accounting to “2”. Other models might be developed (eg. “parabolic” with decay factor 1.5): research is needed in this area.

1.8 Conclusion

This study offers a method that, within defined boundaries, is expected to be able to detect changes in populations of AT&S users as a result of AT&S provision. The instruments should be able to discriminate populations of different severity of disability as well as sense longitudinal changes in groups of AT users. The instruments will be validated in WP4 and will be available later for population studies concerned areas 2, 3 and 4 of the list presented in the introduction.

2. IPPA: THE EFFECTIVENESS INSTRUMENT

2.1 Rationale

Introduction

IPPA (Individual Prioritised Problem Assessment) is an instrument for assessing effectiveness of assistive technology and services. It is constructed from a client centred perspective. It assesses the degree to which the use of an assistive device has actually solved the pre-identified problems it was supposed to solve. Such problems are formulated in terms of difficulty in performing certain activities. The client chooses which problems are relevant to him/her. Only effects on those problems are assessed. The impact of each of the identified problems, as perceived by the client, is measured, by multiplying the relative importance of the problem with the level of difficulty of the problem. This impact is scored both at baseline (before the client starts using the assistive technology) and at follow-up (after the client has been using the device for some time).

The instrument was developed on the basis of an existing instrument named Problem Elicitation Technique (PET), a preference questionnaire dealing with disabilities (Bakker, 1995). In its turn, PET had evolved from the McMaster Toronto Arthritis Rheumatism (MACTAR) patient preference disability questionnaire (Tugwell et al, 1987). The conceptual background of the instrument is described in chapter 1.

Structure of the instrument

The instrument should assess exactly that selection of aspects that is most relevant to the individual subject. Those aspects can relate to a variety of not health-related fields (activities of daily living, social interactions, mental well-being, intellectual development, general well-being). The aspects should be defined in terms of problems as perceived by the subject. Problems will basically be related to difficulty in performing certain activities. The measurement should assess the degree to which using assistive technology has solved each of those problems or decreased the level of difficulty.

The measurement should consist of a baseline and a follow-up assessment of the impact of problems as perceived by the user. The baseline assessment should be applied before the subject has started using the assistive technology; the follow-up assessment when the subject has gained some experience in using the assistive technology. In that way, the effectiveness of assistive technology provision as an intervention is assessed, including all factors that might be of influence (quality and accessibility of service delivery, instructions for use, social acceptance, characteristics and expectations of individual users, information, individual adaptations et cetera).

2.2 Technique

Administration method

IPPA is administered in two face-to-face interview sessions between a professional (hereinafter called “assessor”) and the client. The assessor should not be involved in the individual service delivery process if the client, but should be acquainted with such processes. It might, for example, be a colleague. In the future the instrument might also be used as a tool in the individual service delivery

process, but for the present development phase the assessment should be independent. The assessor must have knowledge of the potentials of assistive technology and the consequences of certain disabilities. Clients must be properly informed about the procedure. It is essential that they are certain that the results of the assessment will not negatively affect the service delivery process. Data must be handled as confidential.

The first session takes place before the client has started using the new assistive technology. The timing of this assessment is very critical. There must have been a first general assessment of the problems of the client, resulting in the conclusion that assistive technology might offer a solution. However, it must be before the typology of the solution: once a choice for a specific assistive device has been made, the problem assessment will probably be biased by the expectations of what the device will do, while earlier assessment might easily lead to a list of 'unrealistic' problems for which assistive technology is not a possible solution. In different countries and different service delivery systems this optimal moment for the first assessment may be different.

The second assessment takes place after the client has been using the assistive technology for an appropriate period, decided upon at the selection process. During the validation study this period will be fixed to about three months.

Both the first and second assessments consist of two steps:

At baseline

1. Identifying the problems that are most relevant to the client;
2. Scoring the impact that each of the identified problems has from the subject's point of view;

At follow-up

3. Scoring the impact of the same problems again;
4. Overall question on the degree in which using the assistive technology has fulfilled the expectations on solving the pre-identified problems.

Step1: Identifying the problems that are most relevant to the client

The client has to identify those problems that are the most relevant to him/her or that bother him/her the most and that he/she expects (or wants) to see improved by using the new assistive technology or service. The client should focus on problems related to performing activities, experienced during the last month in daily routine. Identified problems can relate to a very narrow and specific function (combing hair, turning a key, etc.) or to a more comprehensive function (preparing a meal, going shopping, et cetera). First the subject has to identify problems spontaneously, by naming all relevant problems that come to mind. When the client has named all the relevant problems he/she can think of, the interviewer reads him/her a checklist with possible problem areas, to make sure the client doesn't overlook any relevant problem. The checklist with possible problem areas is based on a list with categories of problems identified by Ankylosing Spondylitis patients and Fibromyalgia patients in a PET procedure (Bakker 1995). To this list we added transportation (which could also be considered a sub-category of mobility), housework (which could also be considered a sub-category of role activities) and safety/security. For every category we added some specific examples. We compared this list to several other categorisations of disabilities, activities or problem areas to check for completeness. If after testing the instrument we find identified problems in other problem areas, these will be added to the taxonomy.

The client should be stimulated to think of possible problem areas, but it is not necessary to push him/her to mention precisely seven problems; the aim is to identify those problems that are relevant to the client. After the client has considered the problem areas on the checklist and identified all problems that he/she finds relevant, the interviewer counts how many problems are identified. If the client identified seven or less problems, the interviewer takes an evaluation form for every identified problem. If the client identified more than seven problems, the interviewer asks the client to select the seven most relevant problems. Our choice to limit the maximum number of problems to seven is rather arbitrary. The client has to be able to identify all the really important problems. On the other hand, the number of problems should not become too big, to avoid irrelevant or non-related problems to be included. If after testing the instrument the limit of seven problems turns out to be too high or too low it will be adapted.

Step 2: Scoring the impact of each identified problem from the subject's point of view

For each of the (seven most relevant) problems, the subject is to answer two questions: 'How do you rate the importance of this problem?' and 'How do you rate the level of difficulty you have with this problem in everyday life?'. The client has to consider the importance of the problem and the level of difficulty at the time of the interview (so before he/she has started using the assistive device). The client can answer both questions by marking a point on two seven-point scales on the first interview forms.

After the interview, the interviewer can summarise the answers into an IPPA score. For each problem, the importance score (question 1) is multiplied by the difficulty score (question 2). The results are summed up and divided by the number of problems. Therefore, the maximum score is 49, the minimum score is 7. A higher IPPA score indicates that a client perceives his/her life to be more troubled by problems. A problem that scores 2 for difficulty and 6 for importance, results in the same IPPA score as a problem that scores 6 for difficulty and 2 for importance. This is consistent with the rationale of the instrument; a problem that occurs very frequently but causes little trouble when it does, will have about the same impact as a problem that occurs only occasionally but causes much trouble when it does.

Step 3: Scoring the impact of the same problems again

After the intervention, so after the client has been using the new assistive technology for a substantial period of time (during the validation phase about 3 months), the assessor asks the client to answer the question about the level of difficulty again (question 2), using the follow-up interview forms. The importance rating from the first assessment is used as weighting factor at the second assessment. This question is therefore not repeated.

The client has to answer according to his/her opinion at the time of the follow-up interview. The client is not allowed to see his/her own previous scores. New problems occurring between baseline and follow-up are not dealt with. After the follow-up interview, the interviewer calculates the IPPA score in the same way as after the baseline interview, using the importance rating from the first assessment.

Step 4: Overall question on the degree to which using AT has fulfilled the expectations

At follow-up, for each problem both client and assessor have to answer a separate question regarding the degree in which using AT has fulfilled the expectations: 'Has using the assistive device solved this problem as much as you expected it would?'. First the assessor asks the client to answer this question. Again, the client can answer by marking a spot on the answering scale on the follow-up interview forms. The scale runs from -2 to +2, equal to 'much less than expected' to 'much more than expected'. This scaling method is derived from the method used in Goal Attainment Scaling (GAS) (Kiresuk et al, 1994). The assessor answers the same question according to his/her own perspective and his/her own initial expectations, on the 'Assessor score overall question form'. Client and assessor have to answer this question separately, without discussing the scores and without seeing each others scores. The answers to these overall questions can be summarised into one 'expectation fulfilment' score, by summing up the answers and dividing them by the number of problems. This can be done for the client's answers and the assessor's answers separately.

In addition to the aforementioned questions, the client is at follow-up asked to indicate whether important changes have occurred in his/her disability, not related to the use of assistive technology (for example serious progression of disability, a new therapy programme, et cetera). For this purpose an open question is added to the assessment form.

Validity aspects

The validity of a measurement instrument is determined by the extent in which the instrument actually measures what it sets out to measure. The validity of an instrument like IPPA is hard to assess. Content validity is the extent in which the individual items or scales of a measurement instrument fully reflect the domain of content that the instrument was designed to measure. So with IPPA, content validity would be the degree in which a set of evaluation forms completed by one client, deals with those problems that are most relevant to that individual client. This could be checked by having several assessors interview the same client and comparing the forms. If differences are small, one could assume that the problems identified properly represent the whole situation. However, those parallel interviews would have to take place in a relatively short period of time. After the first interview, every other interview will be highly influenced by the previous one(s).

Criterion-related validity is hard to assess. IPPA is being developed because existing criterion measures are not satisfactory. Existing criterion measures (instruments for the assessment of disability and/or handicap like: NHP, SIP, SIP68, RAND-36, FIM, HBSH, Barthel, et cetera) are mostly health-related and consist of predetermined sets of items. They might cover certain aspects that are not relevant in an individual situation and at the same time lack other aspects that are most relevant in that specific case. We will, in the testing phase, compare IPPA outcomes with effects assessed by SIP68 (Sickness Impact Profile) and FIM (Functional Independence Measure). Both SIP68 and FIM are well documented, reliable and properly validated. They are widely (and internationally) used. Both instruments relate to a fairly wide scope that covers a great deal of the possible outcome of assistive technology. SIP68 is a questionnaire, containing 68 items with respect to a wide domain of disabilities. It is administered by the subject him- or herself. SIP68 assesses the actual performing of daily activities. It consists of six sub-scales (Somatic Autonomy, Motor Control, Mental Autonomy and Communication, Social Behaviour, Emotional Stability, Mobility Range). FIM is a questionnaire administered by a professional, which makes it a highly objective instrument. It focuses on disabilities with respect to activities of daily life. It contains 18 items with respect to care for one-self, continence, mobility, locomotion, communication and cognition.

Construct validity assesses how well a test score represents the construct (that can not be directly measured) it intends to represent, and measures what it is supposed to measure. This can be determined by checking if the conclusions that result from applying the instrument are in line with the theory on which the instrument is based. IPPA is supposed to measure the degree to which the use of assistive technology solves the problems it was supposed to solve from a user's perspective.

Responsiveness

The responsiveness of an instrument is its sensitivity to changes during a period of time. The IPPA instrument is designed to assess those problems that an individual considers most relevant. Therefore it should have a higher responsiveness than instruments that consist of predetermined items. Also, IPPA is administered by scoring on a seven-point scale (1 - 7) according to personal appreciation. This should result in a higher responsiveness than with a dichotomous scoring procedure (I am or I am not able to ..., I have or I do not have difficulty with ...).

2.3 Instructions for the interviewer for administering IPPA

Baseline-interview

Before the client starts using a new assistive device or service, the baseline interview is administered by the assessor. The timing of this assessment is very critical. There must have been a first general assessment of the problems of the client, resulting in the conclusion that assistive technology might offer a solution, but it must be before a specific solution is chosen.

The assessor should not be involved in the individual service delivery process if the client, but should be acquainted with such processes. The assessor must have knowledge of the potentials of assistive technology and the consequences of certain disabilities. Clients must be properly informed about the procedure. It is essential that they are certain that the results of the assessment will not negatively affect the service delivery process. Data must be handled as confidential.

The baseline interview consists of two steps:

1. Identifying the problems that are most relevant to the client

The assessor asks the client to identify the most important problems that he/she expects or wants to see improved. The client should focus on problems related to performing activities, experienced during the last month in daily routine. Identified problems can relate to a discrete function (combing hair, turning a key, etc.) or to a more comprehensive function (preparing a meal, going shopping, et cetera). Once the subject has finished identifying problems spontaneously, the interviewer reads him/her a checklist with possible problem areas, to make sure the client doesn't overlook any relevant problem. Clients are allowed to identify up to seven problems. The client should be stimulated to think of possible problem areas, but it is not necessary to push him/her to mention precisely seven problems; the aim is to identify those problems that are relevant to the client. If the client identified more than seven problems, the interviewer asks the client to select the seven most relevant problems.

For each of the (seven most relevant) problems that is identified by the client, the assessor takes a separate 'First interview form' and writes down a short description of the identified problem being assessed on this form and the number of the problem (1 to 7).

2. Scoring the impact of each problem from the subject's point of view

For each problem the subject is asked to do the following. First, the client is to answer question 1. (How do you rate the importance of this problem?). The client has to consider the importance of the problem at the time of the interview (so before he/she has started using the assistive device). The client can answer by circling one of the numbers on the seven-point scale (1 -7) to indicate the importance of the problem. The scale runs from 1 to 7, equal to 'of no importance at all' to 'most important'. Then, the client is to answer question 2. (How do you rate the level of difficulty you have with this problem in everyday life?), by scoring the second scale, indicating the level of difficulty of the problem (with 1 equal to 'not difficult at all' and 7 equal to 'too difficult to perform activity'). Again the client has to answer according to his/her own opinion at the time of the interview. This is done for every identified problem.

After the interview, the interviewer can summarise the answers into an IPPA score. For each problem, the importance score (question 1) is multiplied by the difficulty score (question 2). The results are summed up and divided by the number of problems. Therefore, the total IPPA score has a maximum of 49; the minimum score is 7. A higher IPPA score indicates that a client perceives his/her problems as having more impact on his/her life.

Follow-up interview

After having used the new assistive device or service for a substantial period (during the validation study a period of about three months), a second interview takes place. This follow-up assessment also consists of two steps:

1. Scoring the impact of each problem again

The assessor asks the client to answer the question about the level of difficulty for each problem again (question 2), using the follow-up interview forms. The client has to answer according to his/her opinion at the time of the follow-up interview. The client is not allowed to see his/her own previous scores. New problems occurring between baseline and follow-up are not dealt with. After the follow-up interview, the interviewer calculates the IPPA score in the same way as after the baseline interview, using the importance scores from the first assessment as a weighting factor.

2. Overall question regarding fulfilment of expectations

For each problem both client and assessor have to answer a separate question regarding the degree in which using the AT has fulfilled the expectations: 'Has using the assistive device solved this problem as much as you expected it would?'. First the assessor asks the client to answer this question. Again, the client can answer by marking a spot on the answering scale on the follow-up interview forms. The scale runs from -2 to +2, equal to "much less than expected" to "much more than expected". The assessor answers the same question according to his/her own perspective and his/her own initial expectations, on the 'Assessor score overall question form'. Client and assessor have to answer this question separately, without discussing the scores and without seeing each other's scores. The answers to these questions may be added up to a sum-score, representing the degree of 'expectation fulfilment'. The answers to these overall questions are summarised into one 'expectation fulfilment' score, by summing up the answers and dividing them by the number of problems. This is done for the client's answers and the assessor's answers separately.

In addition to the aforementioned questions, the client is at follow-up asked to indicate whether important changes have occurred in his/her disability, not related to the use of assistive technology (for example serious progression of disability, a new therapy programme, et cetera). For this purpose an open question is added to the assessment form: 'Have there been important changes in your disability, not related to the use of assistive technology?'

2.4 The IPPA Forms

Overview

Client:

Registration no.

Interviewer:

Date of first interview

Date of follow-up interview

Number of identified problems

Total IPPA score at the first interview

Total IPPA score at the follow-up interview

Effectiveness

Expectation fulfilment client

Expectation fulfilment assessor

Follow-up assessment

Complete a separate form for every identified problem.

Problem no.

Problem

How do you rate the level of difficulty you have with this problem in everyday life?
(circle the most appropriate number)

1	2	3	4	5	6	7
Not difficult at all						Too difficult to perform activity

Has using the assistive device solved this problem as much as you expected it would?
(circle the most appropriate number)

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Have there been important changes in your disability, not related to the use of assistive technology?

1	2
yes	no

If yes, please describe what has changed
.....

Assessor score overall question

Client name / no.

Has using the assistive device solved problem 1 as much as you expected it would?

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Has using the assistive device solved problem 2 as much as you expected it would?

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Has using the assistive device solved problem 3 as much as you expected it would?

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Has using the assistive device solved problem 4 as much as you expected it would?

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Has using the assistive device solved problem 5 as much as you expected it would?

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Has using the assistive device solved problem 6 as much as you expected it would?

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Has using the assistive device solved problem 7 as much as you expected it would?

-2	-1	0	+1	+2
Much less than expected	Less than expected	As expected	More than expected	Much more than expected

Examples of possible problem areas (Baseline taxonomy)

Self-care

- Shower / bathe / wash oneself
- Caring for one's teeth, hair, skin, feet
- Dress / undress
- Eat / drink
- Visit the lavatory
- Sleep and rest
- Wake up at the appointed time
- Health maintenance, e.g. take one's medicines

Mobility

- Moving around (walking, using wheelchairs or other assistive technology) indoor / outdoor
- Climb a stairs
- Get in or out of a chair
- Go to / rise from bed
- Get in or out of a car, etc.

Transportation

- By car
- By bicycle
- By public transport

Housework

- Cook / prepare a meal
- Clean / do the dishes
- Wash / maintain one's clothes
- Shop
- Lift things / pick things up
- Stoke / maintain the heating

Safety / security

- Be warned in case of fire, etc.
- Managing (lock/unlock) the outer / entrance door
- Call for help if needed

Leisure activities

- Watch TV
- Listen to radio / music
- Read newspapers/ magazines / books
- Recreation
- Gardening
- Playing
- Use a computer
- Other hobby-activities
- Sports

Role activities

- Work
- Learn / study
- Political activities

Communication

- Have conversations
- Use the telephone
- Read / write letters etc.

Social interaction

- Visit friends / family
- Participate in associations, congregations, etc.

3. EATS 6 D: the utility instrument

3.1 Rationale

Introduction

EATS 6 D is an instrument for assessing utility of assistive technology and services. Its name reflects the EATS project, and the six dimensions along which the assessment is carried out.

The instrument is constructed to measure changes in quality of life that resulted from the use of assistive devices, or of other kinds of external support for daily living like eg. personal assistance. It is not intended as a “health related” measure of quality of life in traditional sense: it focuses on the level of *autonomy* experienced by people in the context of their daily living environment.

The assessment tool of EATS 6D is a self-administered questionnaire, to be filled-in by persons with disabilities who are users of assistive technology. Respondents can be people with any kind of disabilities, unless major cognitive problems hinder a correct understanding of the questionnaire. Proxi estimates (other people that decide how to fill-in on the basis of their interpretation of the person’s view) are not recommended. Respondents who are unable to personally fill-in the questionnaire due to severe motor or communication disabilities can ask assistants (who well know their communication codes) to do it by means of an interview.

The instrument is designed to be administered twice (before and after the adoption of an AT product or service), exactly at the same times as the IPPA instrument.

Structure

EATS 6 D was developed on the basis of the EQ 5 D, a consolidated instrument for assessment of health-related Quality-of-Life (EuroQol Group, Centre for Health Policy and Law, Sanders Institute, Erasmus University Rotterdam, The Netherlands) (EuroQol Group, 1990). Although based on a similar structure and taking advantage of most of the thinking behind EQ 5 D, EATS 6 D addresses a different perspective of Quality of Life. To such end, most items have been reformulated and one more dimension has been added. It should be therefore considered a different instrument, which has still to be validated.

EATS 6-D examines *autonomy* with reference to six dimensions:

- 1) mobility
- 2) self-care
- 3) usual activities
- 4) pain/discomfort
- 5) anxiety/depression
- 6) relationships.

The main differences from the EQ 5 D are the following:

- 1) the addition of a sixth dimension (relationship)

- 2) the expanded notions of “mobility”, “self care” and “usual activities”
- 3) the interpretation of same in terms of “autonomy”
- 4) the consequent reformulation of items.

The need to reformulate each domain came to the light when experiencing EQ 5D in the field of disability during the CERTAIN project. In particular, the addition of the dimension “relationship”, intended as “quality of human relationship” rather than “quantity of relationships” (the latter being somehow covered by the EQ 5D “usual activities” domain), was the follow-up of a study that addressed the impact on quality of life generated by the autonomy to create and maintain those outer relationships that are most wished or needed (Lorentsen and Hem, 1995).

The domains of EATS 6 D are expressed in questions, with emphasis on the personal point of view, on the feeling of the domain. The formulation “... as you wish or need ...”, applied to dimensions 1, 2, 3, and 6, helps to focus the attention of the respondent on the perspective of *autonomy*.

Validation

Validation will be carried out in workpackage 4 of the EATS project, involving evaluation of *reliability* (reproducibility), *validity* (accuracy), and *responsiveness* (sensitivity to change).

The Validity issue refers to whether the instrument is measuring what it is supposed to measure. The validity is established by specifying the domain or dimensions one wishes to measure, and the expected relations between them. This can be checked by comparisons with other instruments of the same aspects of utility or status as the instrument addresses (criterion validity). Because direct measures and related instruments in this field do not exist yet, this type of validity is not relevant in the field of assistive technology. A type of validity which could be of use is *content validity*. Content validity can be measured by the extent to which the domains of the instruments are adequately represented by the items chosen. When the instrument is one measuring a hypothetical construct, the task is an on-going one. New hypotheses derived from the construct require new studies (construct validity). Similarly, if we want to use the measure with groups it was not initially validated on, we must first demonstrate that the inferences we make for them are as valid as for the original population. Finally, modifications of existing scales often require new validity studies. Life would be simple if we could establish the validity of a measure once by conducting a series of studies, and then assume that we could use that instrument under a range of circumstances and with a variety of people. Unfortunately, this is not the case. Estimates of validity, like those of reliability, are dependent upon the nature of the people being measured and, to a greater or lesser degree, the circumstances under which they are being assessed (Streiner and Norman, 1989).

Weighting

Like EQ 5 D, the score associated to each response to EATS 6 D items will be a weighted score, derived from tables resulting from weighting exercises carried out over populations. In simpler words, responses to each items will not be scored in terms of equal intervals as it would be the case of eg. 1 for “unable”, 2 for “some problems” and 3 for “no problem”, which would be hard to substantiate since there would be no evidence that the distance between “unable” and “some problems” is the same as between “some problem” and “no problem”.

The weighting exercise should identify a meaningful sample of people (reference population), ask them to estimate the value of each state with respect to other states by means of an appropriate

technique, and then statistically process the responses in such a way to obtain weighted scores (eg. 0,07 for “unable”, 0,12 for “some problem” and 0,14 for “no problem”) that summated along the six dimensions give an overall score ranging from 0 to 1. Score “0” should represent the worst situation, score “1” the best one. Since all items are considered as a whole in the weighting exercise, also the issue of unidimensionality (how to demonstrate that scores resulting from so different dimensions such as pain/discomfort and self-care can be summated along a continuum?) is intrinsically solved, it being embedded in the estimation of weights.

In EQ 5 D the TTO (time trade off) technique was applied over a population of “healthy” people to determine the tables of weights which is currently used. TTO was chosen because of its higher reliability with respect to other techniques (EuroQol Group 1990).

The drawback of TTO is the fact that such technique requires a quite large reference population, which would be hard to find out within users of assistive technology. The assumption that the problem could be solved through estimates by able-bodied people is questionable, and many doubts were raised against it (Andrich and Ferrario 1996). People who never experienced disability may tend to underestimate states of disablement, nor may they fully appreciate the utility of assistive technology when this is able to restore just a partial functioning in daily life. The EATS assumption is that weighting should be carried out with populations of AT users, and thus other techniques that allow to work with smaller population should be used.

Although in the next stages of the EATS project it is planned to further study the possibilities to use TTO, for the time being the weighting tool will be the VAS (visual analogue scale). This is a scale, visually similar to a thermometer, where the respondent marks his/her overall state just after filling-in the 6-items questionnaire. “0” corresponds to the state which is felt by the respondent as the worst imaginable (in term of restriction); “1” corresponds to the state which is felt by the respondent as the best imaginable (in term of autonomy).

The point marked on the VAS represents the individual overall weight of the respondent’s state; after a sufficient number of different questionnaires have been collected, it is possible to start calculation of the weight of the response to each item, and then refine it as more questionnaires are added to the sample. In other words the reference population will be represented by the respondents themselves.

3.2 Technique

Administration

EATS 6 D should be administered twice *to the same client*:

1. before the adoption of a new AT product or service, when the problem has been elicited and clarified, but not yet solved; and
2. a reasonable time after the product or service intended to solve such problem has been adopted, accepted by the client and in use in the daily life situation

The timing of administration is exactly the same as IPPA, so it is recommended to ask the client to fill-in the forms just after the IPPA interviews is finished.

EATS 6 D is composed of two forms.

The *first form* introduces the instrument and presents the questionnaire. This asks questions concerning six dimensions:

- *Mobility*
- *Self-care*
- *Usual activities*
- *Pain / Discomfort*
- *Anxiety / Depression*
- *Relationships*

Each of them offers three (mutually excluding) answer possibilities, listed just below the domain title. They are expressed in a sequence where the first item describes the best situation and the last one the worst. Only one answer for each domain can be given, as stressed at the top line instruction: “Please, tick one box only in each of the groups listed below”.

The *second form* contains the *Visual Analogue Scale (VAS)*, with a short introduction that explains that it is designed to express the person’s overall feeling concerning his/her autonomy at the time of administration. The VAS is a scale, drawn rather like a thermometer, leading from the “Worst imaginable state” (rated “0” - representing a feeling of full restriction) to the “Best imaginable state” (rated “100” - representing a feeling of full autonomy). The V.A.S. contains decimal numbers between 0 to 100, divided by one little dash every unity and a bigger one every five units. The respondent should to draw a line of an arrow from the sentence “Today I feel” to the point on the scale that best represents the actual state.

In filling-in both the questionnaire and the VAS, the respondent should refer to his/her current daily life situation, in his/her most usual environment, with all assistive technology and personal assistance arrangements he/she currently uses.

Dimensions

1. Mobility:

Are you able to move about as you wish or need?

“Moving about” should be considered in the most common situation experienced by the respondent, and according to the range of mobility that fits the individual expectation. Thus it is irrespective of how mobility is achieved (by walking, by car, by public transportation, by independently pushing or drive a wheelchair, by being pushed in a wheelchair by an attendant etc.) and how far the respondent actually moves.

2. Self Care:

Can you manage your personal self-care as you wish or need? (e.g. wash, dress, take care of yourself)

Examples of possible aspects of self-care are written in brackets to clarify what is meant by the term “self care”; such list is just an indication and should not be taken as exhaustive. Again, the rating is irrespective of how the self care actions are performed (without devices, with devices, with assistance etc..) and of the range of self care activities that corresponds to the respondent’s wishes or needs.

3. Usual Activities:

Can you perform your usual activities (e.g. work, study, housework, family or leisure activities) **as you wish or need?**

As above, examples of possible usual activities are written in brackets as an indication and not as an exhaustive list. Each respondents is supposed to know what he/she consider “usual” among the most important activities of daily living, with respect to the individual situation and societal role. Again, the rating is irrespective of how such usual activities are performed (without devices, with devices, with assistance etc..) and of the range of usual activities that corresponds to the respondent’s wishes or needs.

4. Pain / Discomfort: Do you ever feel pain or discomfort?

This dimension is quite similar to the fourth dimension of EQ 5 D. It asks for the individual experience of pain or discomfort in the period of life (not in the very moment) when the questionnaire is administered.

5. Anxiety / Depression: Are you ever anxious or depressed?

Again this dimension is quite similar to the fifth dimension of EQ 5 D. It asks for the individual experience of anxiety or depression in the period of life (not in the very moment) when the questionnaire is administered.

6. Relationships: Are you able to establish and maintain relationships with people as you wish or need?

The respondent may have a smaller or larger amount of contacts as part of usual activities, but that would tell little about how satisfactory such relationship are with respect to his/her expectations. In this question, social relationships are intended in terms of *quality* rather than *amount* of contacts established or maintained. They may include relationship with spouse, family members, friends, colleagues and newcomers. This dimension is intended as an indicator of the level of comfort with living in the community.

Each dimension is divided into three items following a progressive approach, whose meaning is substantially the following:

- *No problems (or so little problems that are negligible)*
- *Some problems*
- *Very severe problems*

This progression is formulated differently for each dimension. The respondent is asked to indicate which of the three statements best describes his/her personal feeling at the time the questionnaire is administered.

3.3 The EATS 6D Forms

EATS 6-D Questionnaire

Please indicate which statements best describe how you feel today, by ticking the appropriate boxes.

Please, tick only one box for each of the six questions below.

- 1 Are you able to move about as you wish or need?**
I have no problems in moving about
I have some problems in moving about
I am unable to move about

 - 2 Can you manage your personal self-care as you wish or need?**
(e.g. wash, dress, take care of yourself)
I have no problems in managing my self-care
I have some problems in managing my self-care
I am unable to manage my self-care

 - 3 Can you perform your usual activities** (e.g. work, study, housework, family or leisure activities) **as you wish or need?**
I have no problems with performing my usual activities
I have some problems with performing my usual activities
I am unable to perform my usual activities

 - 4 Do you ever feel pain or discomfort?**
I have no pain or discomfort
I have some pain or discomfort
I have extreme pain or discomfort

 - 5 Are you ever anxious or depressed?**
I am not anxious or depressed
I am moderately anxious or depressed
I am extremely anxious or depressed

 - 6 Are you able to establish and maintain relationships with people as you wish or need?**
I have no limitations in my relationships with people
I have some limitation in my relationships with people
I have severe limitations in my relationships with people
-

Thank you for answering.
Please, now turn the page and read the instructions.

Visual Analogue Scale (VAS)

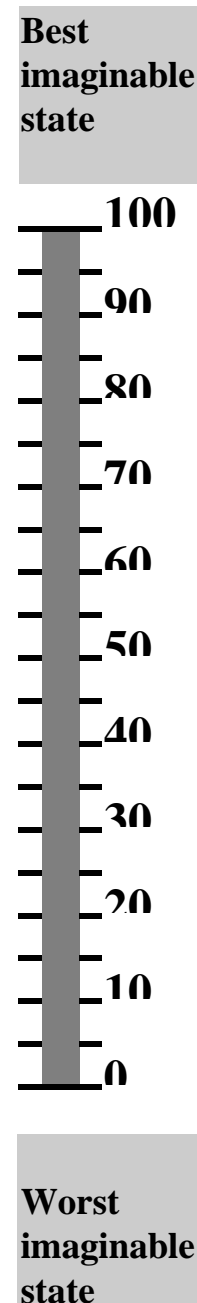
How would you rate your overall *autonomy* in this moment of your life?

With the term “autonomy”, opposite to the term “restriction”, we mean your ability to identify your needs and decide about them, to set goals and pursue them, to enter into relation with others and participate to social life as you wish or need.

You may feel in a state of full autonomy; you may not feel so autonomous as you would ideally like to be; you may feel, to a smaller or larger extent, in a state of restriction. Since the feeling of autonomy depends on individual circumstances, we ask you to express how you would you rate your state today by pointing on the following scale, similar to a thermometer, where “100” represents the best state and “0” the worst state you can imagine.

Please do this by just drawing a line from the sentence “today I feel...” to the most appropriate point in the scale.

Today I feel



4. Glossary of specific terms

Activities of daily living (ADL). Those behaviours that are fundamental to independent living, such as feeding oneself, dressing, bathing, ambulating (Luce and Elixhauser 1990).

Autonomy. Ability to take control over one's own life, in terms of identifying and deciding on needs, setting personal goals and pursuing them as needed or wished, enter into relation with others and participate in the construction of society (EUSTAT, 1998).

Benefit. The outcome of using a product or service; output; the term "consequences" may be preferred; the outcome measure in a cost-benefit analysis (Luce and Elixhauser 1990).

Benefit-cost ratio. Commonly used to describe the conclusion of a cost-benefit study. It is the ratio of the present value of benefits to the present value of costs. Given that the classification of some entities as costs or negative benefits, and benefits or negative costs, is ambiguous, the ratio can be a misleading indicator of efficiency. It is better to use the difference between the net present values rather than their ratios (Luce and Elixhauser 1990).

Capacity. Indication of what the user's abilities would potentially allow him/her to do (Marino and Cohen 1996)

Clinical duration. Period of time over which a specific assistive technology solution makes sense for the user (Andrich, Ferrario and Moi 1998).

Continuous data. Interval level data; the difference between each value is known and constant, e.g., age (Luce and Elixhauser 1990).

Control group. A characteristic of experimental studies; a group of subjects who are observed but who receive no treatment; provides the researcher with a baseline against which to measure the effect of the treatment (Luce and Elixhauser 1990).

Costs. The best alternative use value of the economic inputs that are required to achieve a certain output (Luce and Elixhauser 1990).

Cost analyses. Analyses that identify, measure, and compare the costs, or costs and benefits/outcomes, of health problems and interventions. Included are cost-of-illness, cost-minimisation, cost-effectiveness, cost-utility, and cost-benefit analysis. Among these types of analysis, the means by which costs and benefits are identified, measured, and compared vary in important ways (Luce and Elixhauser 1990).

Cost-benefit analysis. A form of socio-economic analysis in which both costs and consequences are expressed in monetary values (Luce and Elixhauser 1990).

Cost-effectiveness analysis. A form of socio-economic evaluation in which costs are measured in economic terms and at least some consequences are measured in their natural units such as lives saved or years of life saved (Luce and Elixhauser 1990).

Cost-minimisation analysis. A form of socio-economic evaluation that is appropriate when two or more alternatives have equivalent effectiveness and only their costs must be compared: analysis identifies the least costly alternative (Luce and Elixhauser 1990).

Cost-utility analysis. A form of socio-economic evaluation that measures costs in monetary terms but measures consequences in terms of their quality or utility (Luce and Elixhauser 1990).

Data. Observation on variables of interest. Data may be **Interval** (continuous; the difference between each value is known and constant, e.g., age), **Nominal** (categorical, mutually exclusive, and not ranked, e.g., marital status), **Ordinal** (categorical, mutually exclusive, and ranked, that is, one category is higher than another, e.g., socioeconomic status) (Luce and Elixhauser 1990).

Effectiveness. The extent to which the output of a product, service, or program meets its objectives as assessed under normal operating conditions (Luce and Elixhauser 1990).

Efficacy. The benefit of a technology for a given health problem under ideal, or best possible, conditions of use, e.g., as applied in a clinical trial under a strict protocol in a major medical center (Luce and Elixhauser 1990).

Efficiency. In a restrictive sense defined either as minimizing the opportunity cost of attaining a given output or as maximising the output for a given opportunity cost. The general term used by economists is known as "Pareto-efficiency". This is an allocation of resources such that it is not possible to reallocate them without imposing uncompensated losses on some individual. A variant is "potential Pareto-efficiency", where it is not possible to reallocate resources without imposing uncompensated losses on someone. It is common to see the notion of efficiency expressed at three different levels: technical efficiency, where more inputs are not used than are technically necessary to attain a given output; cost-efficiency, or cost-effectiveness, where a given output is produced using the least-cost technically efficient combination of inputs (or, conversely, output is maximised for a given level of cost); Pareto-efficiency, where output is not only technically and cost efficient but is also set at an efficient rate such that a diminution or increase would impose uncompensated losses on some individual (Luce and Elixhauser 1990).

Experimental study. A study in which subjects are randomly assigned to groups, an intervention is introduced, and the intervention's effect on the subjects is measured; ambiguity regarding cause and effect is minimized in this type of study (Luce and Elixhauser 1990).

External validity. The extent to which the results obtained from a study can be generalised to other groups (Luce and Elixhauser 1990).

Independence. Ability to do things independently, that means without the need to request help from other people (EUSTAT 1998)

Independent Living. Accessing the same opportunities and facing the same choices in every-day life that non-disabled persons take for granted (EUSTAT 1998). The term currently identifies also a movement of people: "A philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect... It means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves..." (A.Ratzka, <http://www.independentliving.org>)

Internal validity. The extent to which there is no systematic or non-random error in the data; the extent to which the results of a study are accurate for the group of patients included in the study; contrast with external validity (Luce and Elixhauser 1990).

Medical technology. The drugs, devices, and medical and surgical procedures, utilized in medical care, and organizational and support systems within which such care is delivered (Office of Technology Assessment, US Congress 1978).

Modelling. An analytical technique used to simulate processes that occur through time; often used to explain the impact of numerous independent variables on one or more dependent variables; used when experimental techniques are not feasible (Luce and Elixhauser 1990).

Performance. Indication of what the user is really able to do in his/her daily life context (Marino and Cohen 1996)

Pre-test-post-test. A one group quasi-experimental design that entails measuring a group of subjects prior to a treatment, introducing a treatment, and then comparing the response to treatment to the pre-treatment scores (Luce and Elixhauser 1990).

Prospective. A study in which data are collected during the study; a study that follows a group of patients through time with periodic evaluations (Luce and Elixhauser 1990).

Quality of life. The social, physiological, mental, intellectual, and general well-being of individuals. An index of the quality of a year of life, usually measured by a utility number and embodying the value judgments of selected judges. (QALY = quality - adjusted life - year) (Luce and Elixhauser 1990).

Reliability. The tendency of a test to result in the same score across multiple administrations; repeatability or reproducibility; the upper bounds of validity (Luce and Elixhauser 1990). A measure is reproducible if it yields the

same results when repeated in subjects whose status has not been changed. Reproducibility depends on the questionnaires characteristics, the raters, the stability of the phenomenon studied and its confounders, the sensitivity and the measurement level and distribution of data. The test-retest reliability is the most common measure, and this is often expressed in the (range) correlation between the results of the first and the second measurement.

Responsiveness: it is the ability of the questionnaire to detect important changes in states of the respondents. Responsiveness is determined by reproducibility and changeability (registration of changes in scores of subjects).

Retest reliability. A form of estimating the reliability of measurements by administering the same test to the same group of people on two occasions, and then measuring the correlation between the scores (Luce and Elixhauser 1990).

Satisfaction. Measures of the comfort and acceptability of a system to its users and other people affected by its use (International Standard ISO 9241/2.5)

Scale. A composite measure based on discrete items that measure the same construct; comprising a series of statements, questions, or words that, when scored in unison, provide a summary measure of an attitude, belief, or feeling (Luce and Elixhauser 1990).

Selection bias. A threat to the internal validity of a study that arises when there is a difference between the subjects in one group and the subjects in another; a threat to external validity when the subjects who enter the study are not representative of the population (Luce and Elixhauser 1990).

Sensitivity analysis. An analytical process that examines how results change when the values of key variables are changed (Luce and Elixhauser 1990).

Social cost or benefit. Social costs (or benefits) are the sum of private and external costs (or benefits). Social costs (or benefits) include private costs (or benefits) together with any other effects that may create costs (or benefits) for other members of the community. Social costs are all opportunity costs. Thus the social cost of a medical procedure will include its effects on households and other sectors and not just the costs that are private to a hospital or clinic. The social cost is not always the same as the financial cost (Luce and Elixhauser 1990).

Socio-economic evaluation. A group of methods that provides information about the costs and consequences of medical products and services; used to identify which of several alternatives requires the fewest resources per unit output or produces the most output for given resources (Luce and Elixhauser 1990).

Study design. The structure of the research project; includes safeguards built into sample selection and data collection that enable the researcher to address the research hypothesis and to control for extraneous effects or competing hypotheses (Luce and Elixhauser 1990).

Technical duration. Period of time over which an assistive technology solution lasts in actual use conditions before getting worn out or needing replacement (Andrich, Ferrario and Moi 1998).

Technology. A technology is any systematised practical knowledge, based on experimentation and/or scientific theory, which is embodied in productive skills, organisation, or machinery (Gendron 1977).

Technology assessment. A comprehensive form of policy research that examines the technical, economic, and social consequences of technological applications. It is especially concerned with unintended, indirect, or delayed social impacts. In health policy, the term has also come to mean any form of policy analysis concerned with medical technology, especially the evaluation of efficacy and safety. The comprehensive form of technology assessment is then termed "comprehensive technology assessment" (Luce and Elixhauser 1990).

Usability. A concept comprising the effectiveness, efficiency and satisfaction with which specific users can achieve specified goals in a particular environment (International Standard ISO 9241/2.5). The extent to which a product can be used effectively, efficiently and with satisfaction by specific users, for specified tasks in specified environments (USER 1997)

Utility. The value assigned to an outcome (Luce and Elixhauser 1990).

Utility analysis. A method of measuring health outcomes in terms of the preferences that individuals express for being in particular health states; provides a common unit in order to compare different types of outcomes (Luce and Elixhauser 1990).

Validity. The tendency of a test to measure reality accurately; accuracy; how closely data conform to reality (Luce and Elixhauser 1990).

Value. In economics usually taken as the maximum amount that an individual or group is willing to pay for a particular benefit. Marginal value is the value of marginal benefit: the maximum amount individuals are willing to pay for an increment of benefit (Luce and Elixhauser 1990).

Willingness to pay. A method of valuing indirect costs based on the value people place on health and illness; based on valuing reductions in risk of illness or death (Luce and Elixhauser 1990).

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