TIDE Horizontal Activity

CERTAIN

Cost-Effective Rehabilitation Technology through Appropriate Indicators

Deliverable 3

COST OUTCOME ANALYSIS FOR ASSISTIVE TECHNOLOGY: CASE STUDIES

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Executive summary

This document presents the results of Workpackage 3 of the CERTAIN Study, carried out within the TIDE programme of the European Commission.

It builds on the findings of Workpackages 1 and 2, as reported by the following documents:

Deliverable 1: *"Critical factors and general outcomes of Assistive Technology"*
by Ø. Lorentsen and K. G. Hem
Deliverable 2: *"Prototype tool for Assistive Technology cost and utility evaluation"*
by J. Persson and H. Brodin

In Workpackage 3 a number of real life case studies of provision of assistive technology to disabled persons was investigated in order to assess the applicability of the concepts presented by the above documents. The sample was selected in such a way to include different pathologies (steady or progressive), impairments, ages, technology and social environment. Each case was described retrospectively by considering all clinical, technical and social aspects; a common structure for case reporting was developed and tested; attempts were carried out to apply concepts, methods and tools as proposed by the above documents; on the ground of such experience new methods and tools were developed and proposed.

The main findings can be summarised as follows:

1. The critical factors analysis defined in deliverable 1 are applicable to case reporting; they are useful in analysing the relationship between the initial goals, the intervention carried out and the final achievements; on the ground of them a method and a structure for case reporting was established.

2. The concepts explained in deliverable 2 for cost analysis are also applicable, and it was stressed in WP2, section 5.4.1 that fixed and variable costs has to be differently treated. In WP3 this has been further elaborated so that fixed costs can be roughly defined as the costs of the service delivery process and the variable ones are identified as the technology provided with all its economic implications. This study focused on marginal costs, and developed a simple technique that showed easily applicable to any case.

3. The existing instruments for quality of life measurement, as proposed by deliverable 2, proved quite insensitive to assistive technology. The main reason seems to lie in the fact that they are based on a health-related perspective of quality of life, and consider disability like a "unhealthy" situation: this is not realistic from the point of view of a disabled person. However, it was proved that some instruments can improve their sensitivity when reformulating their items according a more social perspective (e.g.: being in a wheelchair means being able to move, not just being unable to walk). Proposals were therefore developed and successfully tested for an improved versions of EuroQol, McMaster and IHQL.

4. Measuring changes in life quality is not enough for assistive technology assessment. Too many clinical, psychological and social factors are associated to the provision of an assistive device: methods for understanding who is actually the agent for change (the assistive device itself? the way it was proposed? the rehabilitation team? a happy event in the family? the worsening of the

pathology?) are needed. The research found that to such end not only utility (the impact on the life quality of the individual and of the family) but also effectiveness (the achievement of the goals set at the beginning of the intervention) must be measured; and that the scores produced by the scales must be interpreted in the light of the case story.

As a matter of fact, this document does not only test methods developed elsewhere, but develops a new (imperfect, but) concrete instrument (the CERTAIN Instrument) for cost-outcome analysis, including

1. a prototype method for socio-economic analysis of the consequences of disability
2. a prototype technique for measuring costs
3. a prototype technique for measuring quality-of-life.

This instrument is the development of an operational model for applying methods and techniques in real case studies.

The authors think that this instrument can be useful to both rehabilitation professional and administrators of service delivery systems.

Behind the Case Studies there are not hypothetical stories but real life. Behind Robert, Oswald, Peter, Mary, Rita, Joseph, Billy (the names are of course changed for confidentiality reason) there are real persons, their daily coping with disability, their efforts and achievements. The authors wish to thank each of them for their active co-operation in providing data, ideas and views: without such contribution this study would not have been possible.

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PART 1

COST OUTCOME ANALYSIS:

METHODS AND TOOLS RESULTING FROM THE CASE STUDIES

1. Introduction

The application of cost outcomes analysis to assistive technology is just at its start. Methods for cost analysis are not yet consolidated: however the CERTAIN project has made a substantial step forwards towards the realisation of an instrument, a systematic method, to measure costs and savings. The biggest problems still lie in the outcomes analysis: assistive technology does not save lives or reduce morbidity or remove impairments, it simply allows the disabled persons (and their families or primary networks) a more satisfactory and resourceful life.

Measuring outcomes of assistive technology is difficult as it is difficult to measure the outcomes of a social rehabilitation process. A number of 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. In the case of progressive pathologies, sometimes no change in life quality or even a worsening is observed after providing a technical aid: but again it is difficult to discriminate whether this is due to a wrong device or just to the worsening of a pathology that cannot anyway be stopped.

Moreover, measuring the outcomes just at individual level is restrictive. The family and the primary network (the people living with the disabled person, relatives, friends) represent a micro-social system that is also affected by the introduction of a technical aid. For instance, the reduction of the burden of assistance within the family brings about a change within the family "system", that reflects also on the disabled individual.

Deliverable 1 of the CERTAIN project "Critical factors and general outcomes of assistive technology" found that the outcomes should be investigated at least at four levels:

* individual goals expectations (inner relations, outer relations, domain of activities)
* family expectations
* expectations of professionals
* expectations of society (the local community or the human network around the person).

We also found that outcomes can be observed at the level of effectiveness (achievement of planned objectives, like e.g. improvement in functional independence) and at the level of utility (the personal value given to an achievement, in other terms the impact in life quality seen from the user perspective).

Deliverable 2 investigated into the utility analysis and selected instruments that seem more appropriate than others in terms of sensitivity to the impact of assistive technology on life quality. The study developed:

1. a checklist for identification of resource use
2. guidelines for the quantification of resources
3. guidelines for valuation of resources
4. guidelines for choice of instrument
5. a checklist of available instruments

In Workpackage 3 the concepts, the above developed methods and the tools were applied to real life case studies, in order to test their applicability, meaningfulness and practical usability.

The authors think the effort was worth the results. We hope that the readers of this document will find here not only a dissertation on cost-outcome concepts, but also a concrete method applicable in real life situations.

2. Method

Selection of the case studies

A number of real-life case studies of provision of assistive technology to disabled persons was selected in Italy for a retrospective study.

Name	age	period observed	pathology	impairment considered[1]	disability considered	techn ology[2]	service delivery
Robert	30	1987-92	cerebral palsy (quadriplegia)	skeletal language	behavioural communication personal care locomotion body disposition dexterity	12 18 21	Special
Oswald	45	1987-92	multiple sclerosis	skeletal	communication personal care locomotion dexterity	12 18 21	Special
Peter	53	1993 -94	spinal injury quadriplegia	skeletal	locomotion	12	Standard
Mary	15	1985-90	aphakia glaucoma blindness	visual	communication	21	Institutional
Rita	84	1989-93	amputation	skeletal	personal care locomotion	12	Institutional
Joseph	43	1986-87	spinal injury paraplegia	skeletal visceral	personal care	09	Private
Billy	8	1987-90	developmental disorder	skeletal	locomotion body disposition	12 18	Standard Private

The composition of the cohort was selected in such a way to represent different pathologies (steady or progressive), impairments, disabilities, ages, social environments, assistive technology and service delivery organisation. Some cases were selected within SIVA practice, others within external institutions so as to test the transferability of the methods developed. Four different service delivery situations are represented[3]:

[1] Impairments and disabilities specifically considered within this study. Most of these persons have also other impairments and disabilities. Here the ICIDH (International Classification of Impairment, Disabilities and Handicaps, of the World Health Organisation) terminology is used.

[2] Technology is described in terms of ISO 9999 classes

[3] Before explaining the cases a basic understanding is needed about the Italian service delivery system. The standard way to obtain partial or full funding for assistive technology in Italy is the Service Delivery procedure of the National Health

* Standard (Peter, Billy)

The disabled person interacted directly with the rehabilitation and social service of their Local Health Authorities, and had the equipment prescribed and partially funded through the National Health Service (NHS) scheme;

* Institutional (Rita, Mary)

The equipment was provided and totally funded according to the NHS scheme, but through the intermediation of the Institutions caring for them: a Geriatric Hospital (Rita) and a Vocational Centre for the Blind (Mary);

* Private (Joseph)

The disabled person directly selected and purchased the equipment;

* Special (Robert, Oswald)

  The equipment and all related services were provided within the framework of a pilot project (funded by the Lombardy Regional Government) aimed at developing innovative models of service delivery in assistive technology for persons with very severe physical disabilities. The project availed solid financial resources for purchasing any needed equipment and carrying out any adaptation under the responsibility of a unique case manager.

The practical consequence of each situation is the financial constraint. While some cases had to cope with financial limitations, the last group ("special") was the ideal situation with no need to come to compromises with funding problems. For Robert and Oswald (the most severe cases within the cohort) the primary issue was the pursuit of the best results: due to their complexity, their cases served as a primary test bed for all concepts and methods developed in the course of the study. They brought to light a lot of hidden problems and provided the largest amount of data.

Robert and Oswald represent two somehow extreme situations:

* Robert (severely disabled since his birth) went through a habilitation process: assistive technology led him to a quality of life never experienced before, with a long lasting perspective;
* Oswald (a progressive pathology was leading him from a healthy situation to a rapid physical deterioration) used assistive technology to counterbalance his quality of life deterioration, within a short-term (sometimes emergency) perspective.

Structure of the case studies

By working on the first case (Robert), a structure was gradually defined for describing in a systematic way all case studies. It is composed of the following parts:

1) Clinical background

Service (NHS), based upon a fixed list (Nomenclatore Tariffario) of types of prosthetic appliances or technical aids yearly issued by the Ministry of Health. The key actors in such procedure are:
- the authorised prescriber (always a physician with a rehabilitation medical speciality relevant to the pathology), who takes decision on the specification of the assistive technology to be provided
- the disabled person, who takes decision about the specific model or brand meeting the specification - the commercial supplier, who ensures provision and adaptation.
If the price of the selected model exceeds the price stated by the Nomenclatore Tariffario, then the person has to pay the balance. Technical aids that are not listed cannot be provided through the National Health Service and in principle have to be paid directly by the user. However, exceptions exist like:
home adaptations, where some funding is provided through the Private Housing Architectural Barriers scheme aids for the blind for school integration, where funding is provided through the Provinces
the Labour insurance scheme, that provides further benefits.

2) Case history
   * initial situation
   * action plan
   * implementation
   * final situation
   * follow up
   * evolution of functional independence (by FIM)
3) Analysis of outcome
   * contextualising the outcomes
   * characteristics of the technology provided
   * outcomes at the level of individual goals expectations
   * outcomes at the level of family and primary networks expectations
   * outcomes at the level of professionals expectations
   * outcomes at the level of societal expectations
4) Cost analysis
5) Measurement of changes in quality of life, according to
   * IHQL (Index of Health-related Quality of Life)
   * 15-D measure
   * EuroQol
   * MMHCS (McMaster Health Classification System)

The choice of the above Quality-of-life scales follows the study carried out in the previous stages of the CERTAIN project as reported in Deliverable 2.

The decision of completing the case history by resorting to a measure of functional independence stems from the need to understand how far the rehabilitation objectives set forth by the assistive technology programme are achieved. This was felt substantial before investigating on the outcomes perceived from the client side. In other words a measure of effectiveness was felt necessary before measuring the utility.

The Robert experiment

Robert was the first test bed for the case study structure. Having Robert been a SIVA client for years, most clinical and technical data were already available. To complete data collection and to fill in the quality-of-life questionnaires, many interviews were carried out with Robert and his family. The interviewer was the same person who had acted as case manager years before.

The above structure proved effective. The case history was easy to complete. FIM was found usable also in real life environment (although primarily intended for clinical observation in rehabilitation setting), despite some slight floor effects.

Describing and measuring the outcomes generated by assistive technology was a real challenge. A deep insight was needed to separate them from the outcomes generated by other kinds of interventions or events. However, the classification of critical factors proposed by Deliverable 1 was of great help for working out a free text description of the observed (by professionals) and perceived (by the client) outcomes.

Concerning cost analysis, decision was taken to clearly separate the fixed costs (the costs of the overall service delivery process of the organisation) from the marginal operating costs (the costs of the product of the service delivery, that is the technology provided with all its economic implications). Our analysis focused on marginal operating costs.

The marginal operating costs were divided in turn into two components:
* equipment-related costs (investment, fitting, maintenance)
* costs of associated human assistance.
At last, a checklist of costs and a calculation method was developed.

Filling-in the quality of life questionnaires proved quite difficult. Despite either clinical evidence or the client's opinion clearly demonstrated that assistive technology had generated a dramatic quality of life increase, each of the four quality-of-life instruments (EuroQol, 15D, IHQL and McMaster) resulted quite insensitive. In most cases they detected no changes at all. The reasons were analysed, the weak points were identified and proposals for improvement were developed.

The Robert's experiment and the insensitivity of the existing utility instruments were the main focus of a brainstorm meeting with all CERTAIN partners (Milano, 22-23 September, 1995). The main outcomes of the discussion were:
* the structure for case reporting was refined and validated
* the structure for collecting and calculating marginal costs was refined and validated
* a effectiveness measure was agreed as useful, and FIM was confirmed as a proper tool
* it was argued that CERTAIN should initiate the development of a new utility instrument - the ground for such development should be provided by IHQL, MMHCS, EuroQol.

Extention of the study

Following to the brainstorm meeting IHQL, MMHCS and EuroQol were reformulated according to a different philosophy, and named for the purpose of the study as "Certain IHQL", "Certain MMHCS" and "Certain EuroQol". Robert's case was refined, the cost analysis instrument was reformulated, and the analysis of the other cases started.

Other two cases were chosen within SIVA practice (Oswald and Joseph), the others within external Institution willing to voluntarily co-operate. The main aim of involving other Bodies was to test to which extent the methodologies and findings developed so far could be easily understood and applied in clinical practice in various environment, and by rehabilitation professionals with different background. A brainstorm meeting was held with representatives of these institutions. They were given the mission to complete the case studies within two months. During that time intensive assistance was ensured by SIVA, thus allowing a double way exchange of information and views.

The involved Bodies were:
* the Spinal Injuries Unit of the Local Health Authority 9 of Bormio and Sondalo: a major Centres in the Region of Lombardy for the rehabilitation of paraplegics and quadriplegics (the case: Peter)
* the Geriatric Department of the "Pio Albergo Trivulzio" in Milano: a leading Health Institutes for the care and the rehabilitation of the elderly (the case: Rita)
* the "David Chiossone" Vocational Institute for the Blind and Visually impaired in Genova (the case: Mary)
* the Social Services of the Local Health Authority 1 of Belluno, a community care service in the region of Veneto (the case: Billy).

All cases were processed in close co-operation with the professionals who had co-operated within the other Institutions. Within SIVA a lot of effort was devoted in organising such findings in a clear and understandable way. The final step was the reporting by producing this deliverable.

The Certain spreadsheet

In the meantime a mathematical model was developed and tested for the overall analysis of costs and outcomes to be applied to each individual case study.

The input data to the model are the following:

1. the equipment-related cost for each action carried out (e.g. provision of a wheelchair), and for the possible alternatives (e.g. maintain the status quo; transport by helpers; different technical solution; etc.)
2. the cost of associated assistance for each action implemented, and for the discarded ones
3. economic parameters (interest rate, price of assistance, paid or non-paid components etc..) to be applied to the individual case
4. functional independence and quality-of-life scores, as measured after each action through "Certain FIM", "Certain IHQL", "Certain MMHCS" and "Certain EuroQol"
5. "natural" functional independence and quality-of-life scores, as measured through the above scales by supposing that the action would not have taken place.

The model outputs two kinds of results:

⇒ analytical: cost estimates, quality-of-life changes and cost/utility ratios for each action

⇒ overall: global mobilisation of resources and quality-of-life changes for each action, and the overall outcome of the intervention (in the case of a complex intervention resulting from a sequence of actions).

The model was implemented in Microsoft Excel® and applied to each case. The results are presented in detail in the full case studies. In the following the results are summarised and discussed

3. Synthesis of the case studies

Robert

Since his birth Robert has a very severe motor and language impairment resulting from cerebral palsy. He has always been living in his family with just a marginal contact with the external world. He needs assistance round the clock for any activity of daily living, and this is provided by his parents, now elderly. His life experience is quite different from the average people of his age: he had almost no school education, nor he had the opportunity to develop assertiveness or an active attitude in coping with disability. In other words, at the time of intake he is totally dependent on his parents, either in practical or in psychological terms.

The main aim of the intervention is to decrease his dependency, to help him to take control over his life, to provide opportunities for socialisation, and to live as long as possible in his home. It is quite clear that the situation, as it is now, is unsustainable in the long run. As soon his parents' capability to assist fails (due to illness, weakening etc.) the only opportunity available for Robert would be hospitalisation or long term care in residential facilities.

The intervention is composed of a sequence of seven actions carried out over a period of three years. The technology used ranges from elevating platforms for overriding architectural barriers, to powered wheelchairs, seating systems, bathroom adaptations, hoists for personal transfer, computer-based

writing and environmental control systems. Being Robert included in a special research project, all intervention is carried out under responsibility of a unique case manager, without substantial financial limitations.

The intervention results into a substantial improvement for Robert's and his family's life. It leads him to gradually discover new life perspectives never experienced before. It really open the path to a more resourceful and comfortable way of living. At the end of the intervention, Robert still needs a degree of personal assistance, but in a way that is sustainable in the long run by his family and by the community services. He can cope with the basic daily activities in safety conditions; he communicates; he goes outdoors everyday; he has opportunity for socialisation. For the time being, catching and exploiting them is a matter of personal growth and proper social support. It is hard to think that without assistive technology Robert would have been able to live at home after his mother's death (occurred three years later), even if intensive home care would be provided.

Robert highlights four major issues:

1. When a sequence of assistive technology actions is carried out, the order of its implementation is critical and a global view must be adopted. Each piece of technology is dependent on each other, and all together contribute to the overall objective of the intervention. Errors in the sequence may lead to leakage of resources; to crises within the family or primary network; to difficulties in the client's psychological adaptation; to failures and refusals; all of them having substantial impact on the both the cost and the outcome side.

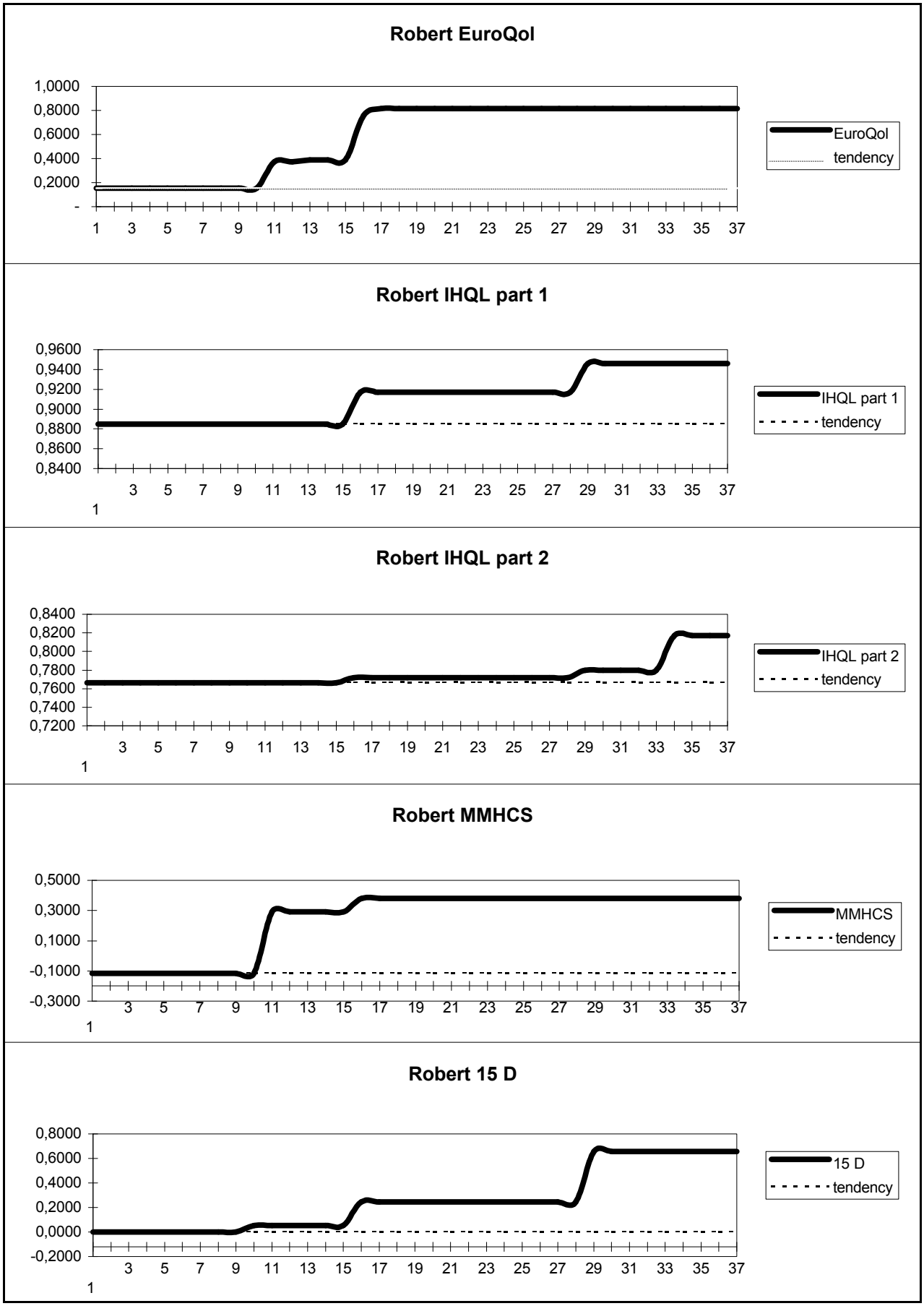
2. In cases like this, the outcomes of assistive technology should be observed in the long run. In a habilitation process (vs. re-habilitation: Robert had never experienced "normality" before), technical aids have not only a problem-solving value, but also a high training value. Each action leads Robert to discover new possibilities in life (e.g. going outdoors) he had never aimed at before. In some way each solution provided makes Robert's life more complicate, in that it raises new expectations and new limits never perceived before (in other words he discovers new handicaps). His perception of quality of life (as observed through e.g. the EuroQol) seems to decrease in the time, instead of increasing. A substantial real increase in life quality is observed in later follow-ups, sometimes years after from the conclusion of the interventions, when the personal adaptation process is concluded.

3. Due to the above, a retrospective measurement of the client's perception of changes in quality of life can be carried out only after the adaptation process is finished: first the quality of life at that time should be measured, then the client should be asked how he thinks his life would be now, if the technical aid had not been provided. This double measurement (the real situation against the supported situation) seems a reasonable solution for the time being, able to compensate for the lack of sensitivity of the utility scales. We hope that in the future new instruments will be realised so as to exactly measure the real present situation and its changes after the provision of technical devices.

4. It is not sufficient to consider only individual changes in life quality. The family and the primary network members are substantially affected by each action, so it would be more correct to measure the overall life quality changes of the social system. However, no instruments have been yet found for such a purpose.

In table 1 one can observe the QoL changes detected by the five instruments utilised. In the graphics, the time lies on the abscissa and the QoL on the ordinate. The QoL curve is shown against the tendency curve, that represents the supposed QoL without any A.T. intervention.

Table 1


Robert EuroQol
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EuroQol
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tendency

Oswald

Like Robert, Oswald was included in the same special research project, with all intervention carried out under responsibility of a unique case manager, without substantial financial limitations.

Many concepts highlighted for Robert also apply to him, but Oswald represents a somehow different situation.

The onset of multiple sclerosis when he was 32 years old, university professor, married and with grown-up children, led him to a rapid physical deterioration. His basic problem was to maintain the highest degree of independence as possible in order to be able to teach and work at the University, to limit the assistance burden for his family members, and to carry out his favourite activities.

The intervention is composed of a sequence of eleven actions carried out over a period of five years. The technology ranges from mobility aids to home adaptations, computer based communication aids and recreational equipment.

Oswald has clear expectations from life; he knows very well his pathology and the expected prognosis. He is therefore in good position to express judgement on his life quality. The main problem is that most increases in his life quality generated by a technical aid have a temporary effect, due to the concomitant deterioration of his physical conditions. In other words a technical aid that is useful now (e.g. the electronic wheelchair) gradually loses his usefulness until it becomes completely useless (e.g.: after three years the electronic wheelchair was abandoned since he could not drive it anyway, and a manual propelled one was provided). Oswald paradox is that, in some cases, after a device has been provided the utility scales detect decreases in life quality instead of the expected increases.

With respect to Robert, Oswald adds other three major issues:

1. Two time parameters should be considered for each piece of equipment:
    - *technical duration* (how long it lasts in actual use conditions before needing replacement)
    - *clinical duration* (how long it yields value before being useless).

They may be different: for Robert the clinical duration of most devices is higher than the technical duration, so they needed to be purchased again one or more times in the course of life. For Oswald, many devices last technically more than clinically, as they need to be abandoned before being worn out.

2. A model should be identified to describe how a technical aid loses its utility (gradually? suddenly? step by step?)

3. It is not sufficient to measure quality-of-life only after the provision of a technical aid. The actual change in quality of life is the difference between the score actually measured, and the measure resulting from the question: how would be my quality of life now, if I had not this device? In the following this measure will be referred as "natural".

The application of cost utility analysis to Oswald raises a challenging ethical issue:

How far is it worth spending money for assistive technology when its clinical duration is less than its technical duration?

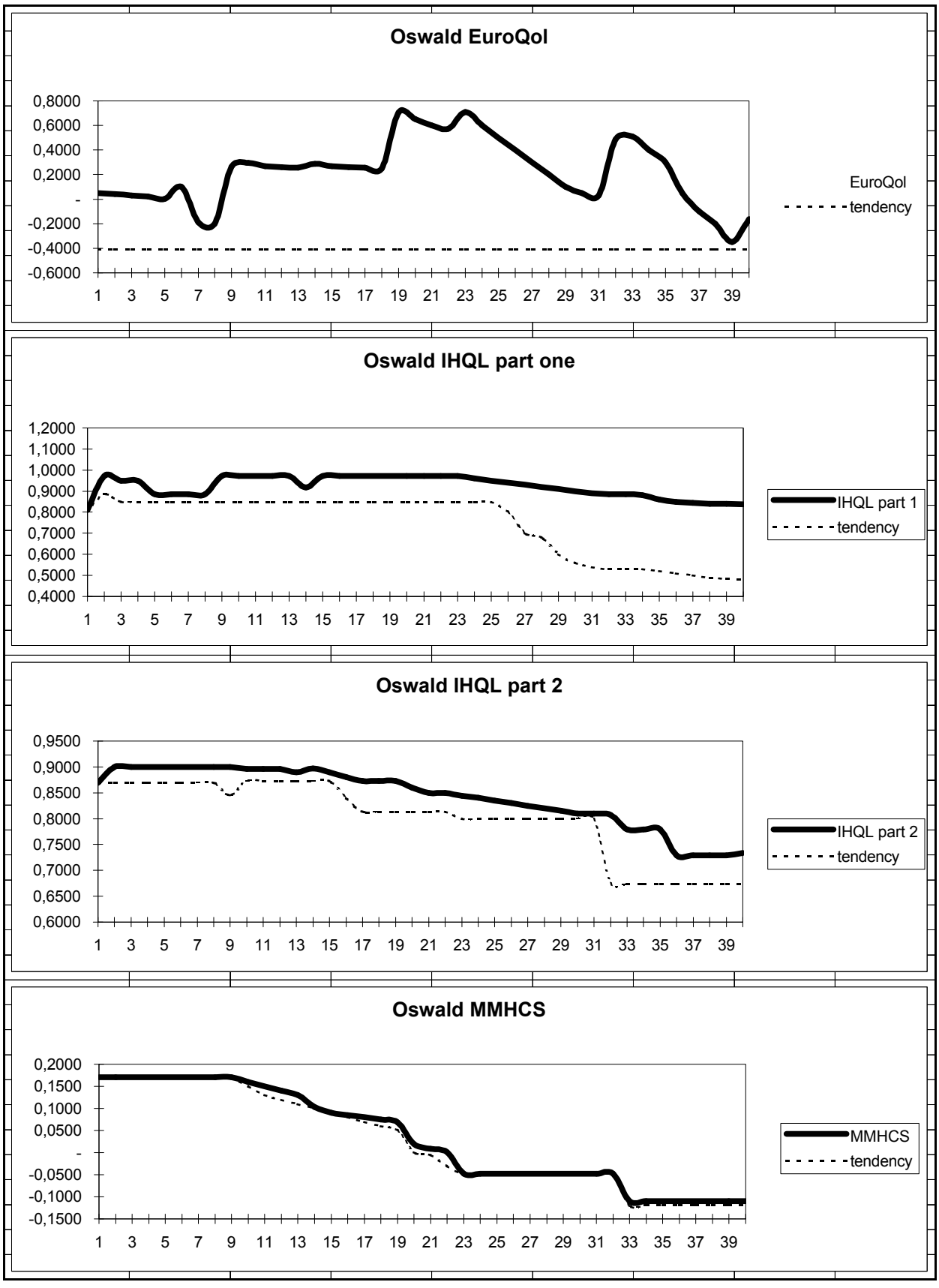
When reading the case story, both clinical observation and common sense suggest that the expenditure was extremely worth, for Oswald, for his family, for the University and for all Society. The reader is

encouraged to make his own opinion on that. The problem is how to make it evident through indexes and scores. Oswald gave a major contribution to refine the model firstly developed for Robert, and to make it sensitive to progressive disabilities.

The results of the QoL changes are depicted on table 2.

The trend of the QoL curve follows the QoL increases after each A.T. intervention and its drop towards the end of the clinical duration.
The tendency curve (the one showing the supposed QoL trend without any A. T. intervention), is not really straight but shows a decrease, because of the progressive pathology: today Oswald can adopt a new technical aid.

Table 2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Peter

The case of Peter is far simpler if compared to Robert or Oswald, but tackles one of the most classical problems in rehabilitation: the provision of a powered vs a manual wheelchair. Peter got a spinal injury C6/7 when 50 years old, resulting into quadriplegia. The problem of the wheelchair was approached in the early stage of rehabilitation, and three alternatives were considered: manual wheelchair only, powered wheelchair only, two wheelchairs (powered and manual). Being the case managed within the National Health Service, financial limitations had to be taken into account.

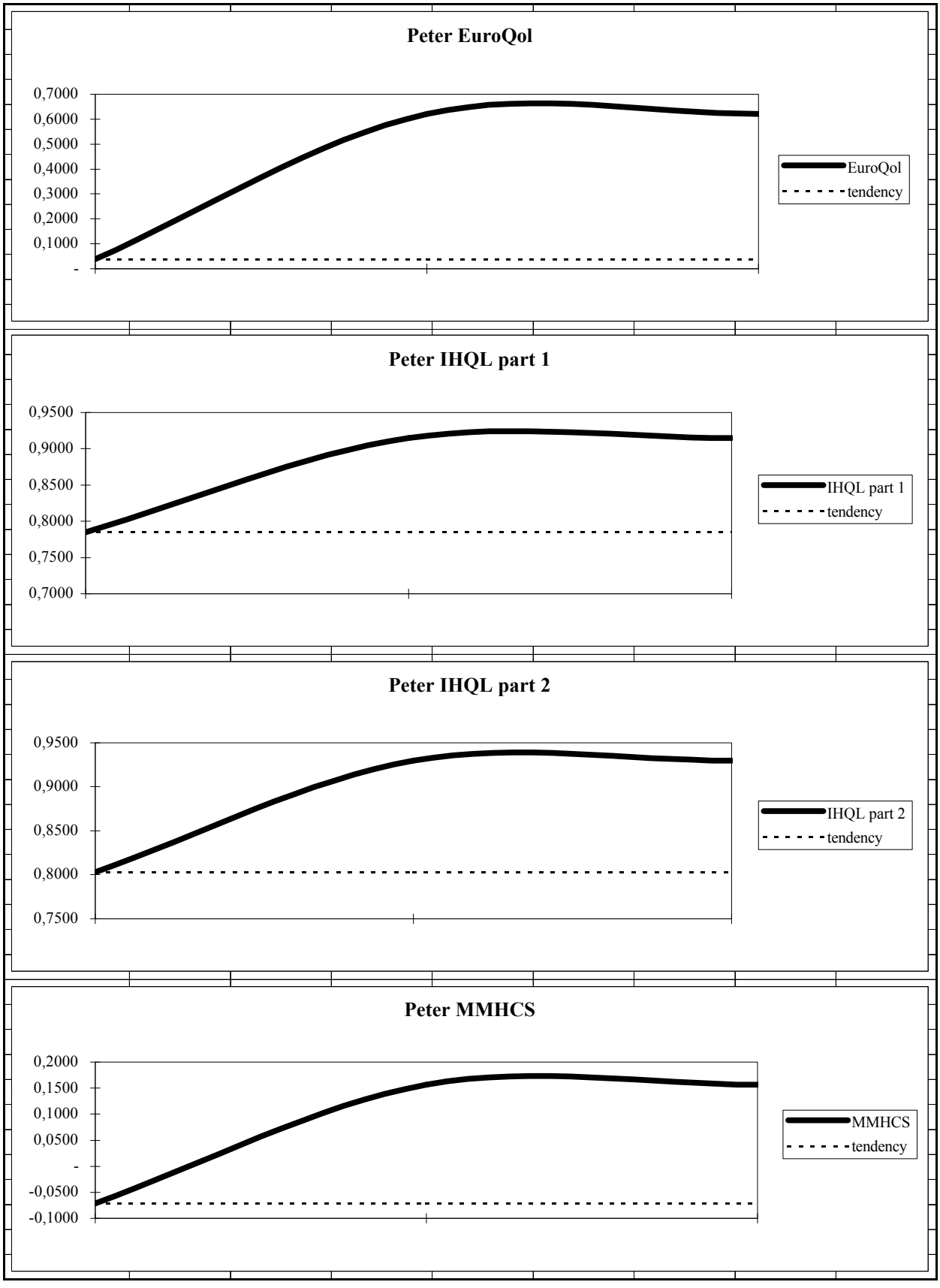
The last solution (powered and manual) was preferred as the best practice by the rehabilitation team. The clinical observation and the follow-ups confirmed the validity of such approach, that improved dramatically Peter's independence, social integration and personal satisfaction. Also the cost analysis reveals that such solution, although most expensive in terms of investment, led to substantial savings in the long run.

On the other hands, also in this case the utility scales showed little sensitivity to the difference between a manual and an electronic wheelchair. This raises another major point:

⇒ the utility scale were initially developed for non disabled people; the weighting exercise has been always carried out with able-bodied persons, who can hardly appreciate the difference between seating on a manual or a powered wheelchair (feeling of "being confined to a powered wheelchair" rather than "moving around more independently"). The ability level and the health of someone who has a permanent disability are and will be, by definition, not normal: for a proper weighting a population of disabled should be taken into account.

The changes in QoL are shown in table 3. In this case study, only one adoption of technical aid is considered, with only one QoL improvement.

Table 3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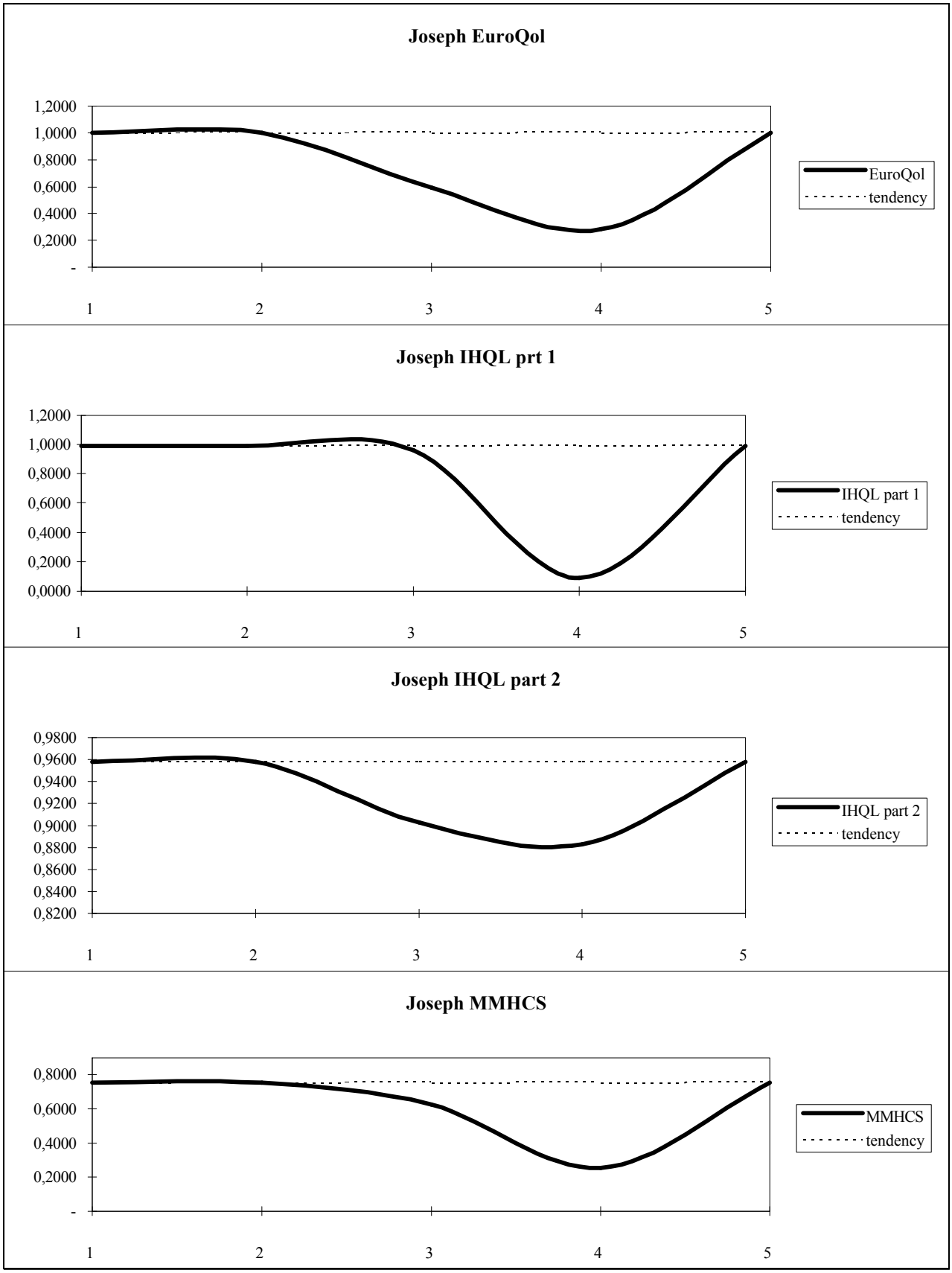
MMHCS
tendency

Joseph

Joseph focuses on simple technologies that play a key role in the life of a paraplegic. The issue is incontinence: a problem that can affect many dimensions of life (mobility, personal care etc.) if not properly managed. The comparison is made among three possible low-cost solutions, each yielding pros and cons. The costs and the outcomes of each solution, and hidden risks as well, reveal themselves in a long run analysis.

The QoL values are displayed in table 4.
The research of the most suitable technology brought about a lack of QoL, it was trough a number of unsuitable technologies before finding the optional one. Only in the last part of the intervention Joseph could recover the same quantity of QoL as in the beginning stade.

Table 4


Joseph EuroQol
1,2000
1,0000
0,8000
0,6000
0,4000
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1
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3
4
5
EuroQol
tendency
Joseph IHQL prt 1
1,2000
1,0000
0,8000
0,6000
0,4000
0,2000
0,0000
1
2
3
4
5
IHQL part 1
tendency
Joseph IHQL part 2
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0,9400
0,9200
0,9000
0,8800
0,8600
0,8400
0,8200
1
2
3
4
5
IHQL part 2
tendency
Joseph MMHCS
0,8000
0,6000
0,4000
0,2000
-
1
2
3
4
5
MMHCS
tendency

Rita

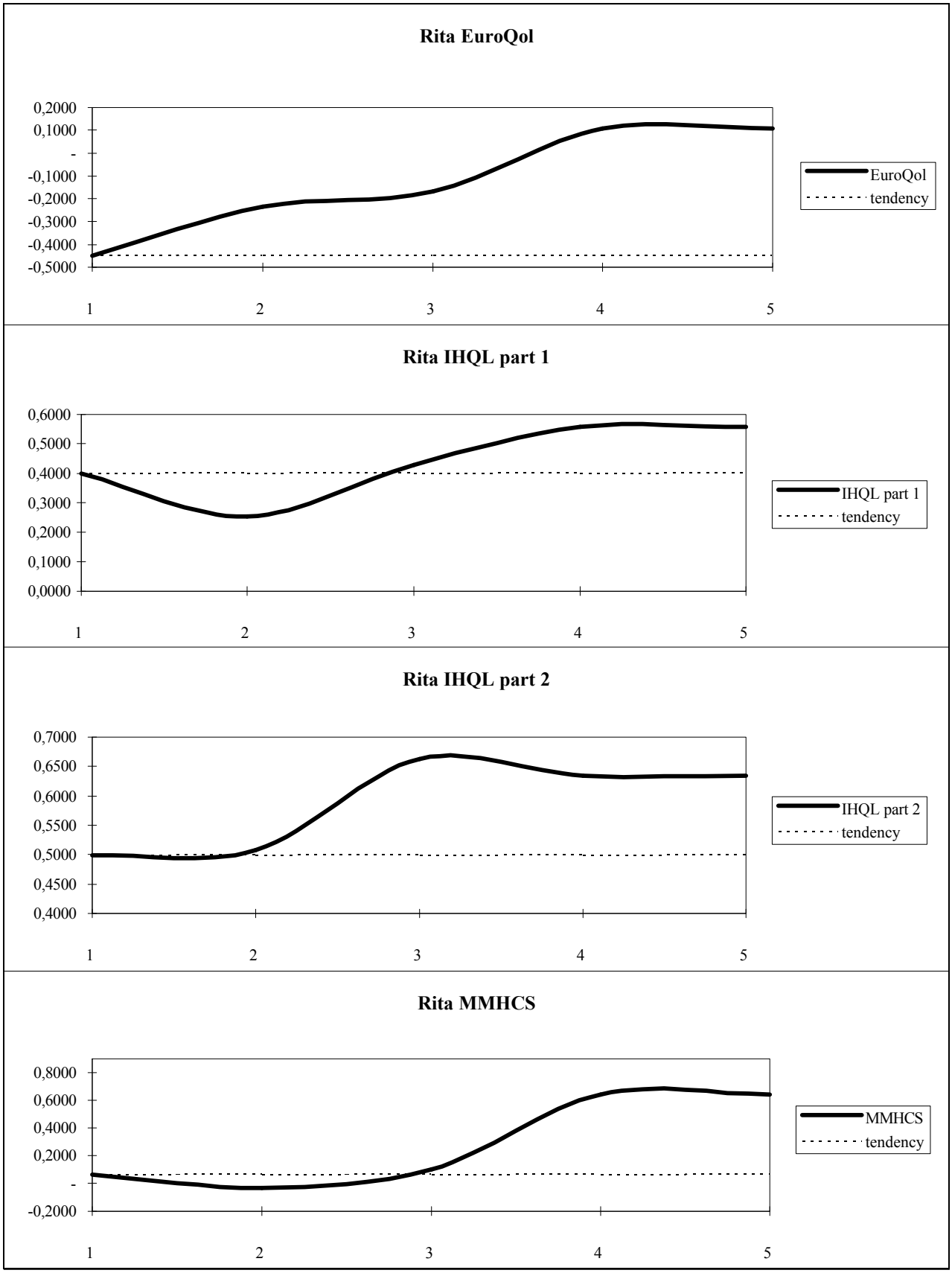
The provision of assistive technology to elderly people yields a number of critical issues. Rita is a clear example: the attempt to solve the problem of her leg amputation through a leg prosthesis failed despite the heavy investment in terms of equipment and training. On the opposite, the adaptation of a bathroom and the provision of an electronic wheelchair (a rare case in the Institution where Rita was living) at the age of 78 was successful and helped to keep higher her quality of life in her last years (she died at 81).

As for Oswald, cost utility issues may be a challenge when assistive technology has to solve a short term perspective. Many professionals show perplexity and resistance when confronted with the problem of providing high tech to old aged people (is it worthwhile? can they learn to manage a technological tool?). Resistance is sometimes even higher in sheltered facilities, where professionals are accustomed to manage everything through personal assistance.

The attitude of the professionals towards Rita was a key factor in correctly introducing her to assistive technology, providing her all associated training and support, and making it effective in her hands. The cost analysis also shows that not only a rehabilitation and human objective was achieved: the intervention produced also a remarkable saving.

In table 5 the QoL's gain is shown. Rita was loosing her QoL in a intermediate phase, as the prostheses was not suitable for her needs. Only in the further steps the QoL was increasing.

Table 5


Rita EuroQol
0,2000
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-0,1000
-0,2000
-0,3000
-0,4000
-0,5000
1
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3
4
5
EuroQol
tendency
Rita IHQL part 1
0,6000
0,5000
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0,1000
0,0000
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2
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4
5
IHQL part 1
tendency
Rita IHQL part 2
0,7000
0,6500
0,6000
0,5500
0,5000
0,4500
0,4000
1
2
3
4
5
IHQL part 2
tendency
Rita MMHCS
0,8000
0,6000
0,4000
0,2000
-
-0,2000
1
2
3
4
5
MMHCS
tendency

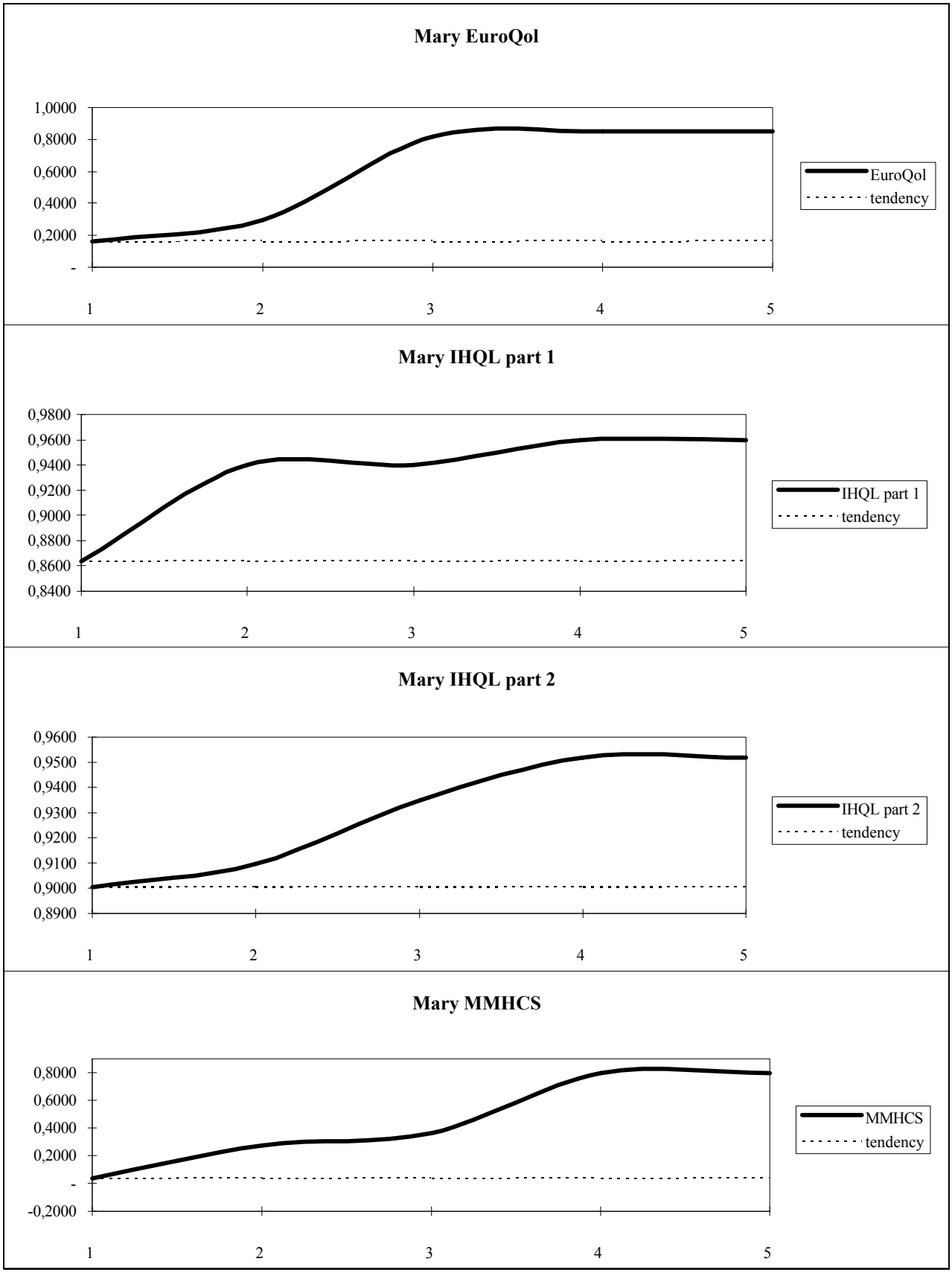
Mary

Mary is a young girl whose visual impairment turned into blindness when 8 years old. The main objective of the assistive technology programme, cared for by a specialised Centre, was to achieve independent mobility and full participation to the mainstream school. The technology used consisted of many technical aids as it is common for blind people. For the purpose of this study only the most important equipment was considered: a tactile reading machine (Optacon), a personal computer for school activity, and a long cane for mobility. For each device all possible alternatives were considered in the cost analysis.

For these kind of devices the training dimension yields a special importance, being sometimes more expensive than the device itself but necessary for making it useful. Moreover, training is often structured by validated protocols that allow to precisely define the needed resources.

In table 6 one can see the difference of QoL between the beginning and the end of the intervention.

Table 6


Mary EuroQol
1,0000
0,8000
0,6000
0,4000
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-
1
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4
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EuroQol
tendency
Mary IHQL part 1
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0,9000
0,8800
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1
2
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4
5
IHQL part 1
tendency
Mary IHQL part 2
0,9600
0,9500
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0,9300
0,9200
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4
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IHQL part 2
tendency
Mary MMHCS
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MMHCS
tendency

Billy

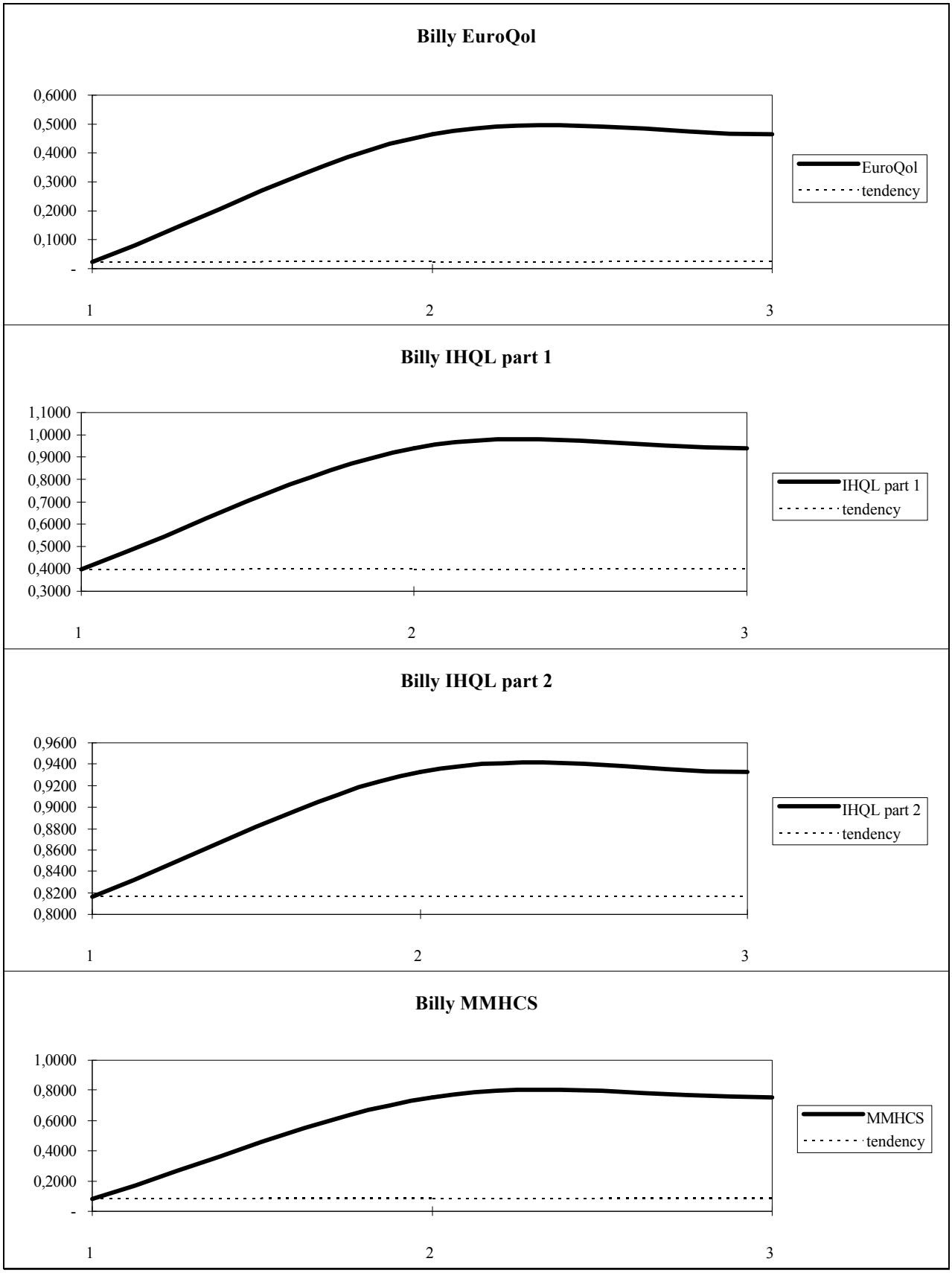
Billy is a 8 years old guy affected by a rare developmental disorder that caused nanism, inability to walk and a general difficulty to perform any movement. For years the rehabilitation programme had been mainly aimed at preparing for a hypothetical surgical solution, with the hope that walking restoration would have been possible. In the meanwhile the family support and the local community had been very active in promoting his social participation, so he was well integrated in the mainstream school and in a favourable human environment.

The perspective of undertaking surgical programmes with no certain result, with the associated burden of recurring hospitalisations far away during his childhood and youth, was confronted with the perspective of accepting the impairment and trying to ensure him a rich and resourceful life with the support of assistive technology. The second way was undertaken. To such end the major actions consisted of the provision of an electronic wheelchair for children (funded by public resources), the building of a new house completely accessible (paid by the family), and the adoption of some special furniture (paid by the school).

The new house raises an interesting issue. An accessible living environment is the baseline for any other action. It is quite difficult to estimate in the long run all outcomes of having an accessible flat. For Robert nothing could have been done if he had not moved to a more accessible flat: but for Robert the cost was easy to reckon (the difference with the rental rate of the previous flat). In the case of Billy, again the motivation to build a new house was due to his disability. But being it also his family's house, it would be incorrect to include its full cost (150.000 ecus) in the cost analysis: on the other hand it is impossible to estimate a difference between a accessible newly built house, and an inaccessible one. It may cost more or less, depending on how the architect designed it! This aspect needs further research, so it was decided to concentrate only on the problem of the special electronic wheelchair.

The QoL differences are shown in table 7.

Table 7


Billy EuroQol
0,6000
0,5000
0,4000
0,3000
0,2000
0,1000
-
1
2
3
EuroQol
tendency
Billy IHQL part 1
1,1000
1,0000
0,9000
0,8000
0,7000
0,6000
0,5000
0,4000
0,3000
1
2
3
IHQL part 1
tendency
Billy IHQL part 2
0,9600
0,9400
0,9200
0,9000
0,8800
0,8600
0,8400
0,8200
0,8000
1
2
3
IHQL part 2
tendency
Billy MMHCS
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0,6000
0,4000
0,2000
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1
2
3
MMHCS
tendency

4. Results

The results of the study can be classified as follows:

1. A structure and a method for case reporting

2. Seven representative case studies

3. A prototype instrument for cost / outcome analysis at individual level

4. A prototype instrument for effectiveness analysis

5. Three prototype Utility instruments (EuroQol based, IHQL based and McMaster based)

6. Findings of the cost outcome analysis applied to the seven case studies.

Here the basic findings are reported and discussed. For a deeper insight refer to the relevant chapters or annexes. The full case stories provide the reader with many other elements to think about.

Cost issues

The first finding is that the considered costs should be divided into two categories:
⇒ equipment related cost (investment, installation/fitting/training, maintenance)
⇒ cost of related assistance.

The former can be directly measured by monetary values, provided that no market failure exist, the latter by manhours. The conversion of assistance use into monetary values is quite complex, since at least three elements should be taken into account:
* the market value of a manhour depends on the competence required
* external helpers need a travel time for each assistance action
* when assistance is provided by family members or volunteers it is free of charge: it still yields economic value (being a resource use), but has no financial implications.

A similar concept can be applied to the equipment-related expenses. There are cases when they cost no money (e.g. donated equipment; self-done maintenance; self-done training or installation), but still are resources that yeld economic value.

Cost processing should be therefore done at two levels:
* real cost (true opportunity cost): by assigning numbers reflecting the true value of the resource
* expenditure (observed flow of money): by valuing only the resources that require financial expenses.

Real costs must be used for efficiency analysis; expenditure for finding the really needed flow of money. To calculate the difference, a profile was assigned to each case that states:
* the interest on loan (for investment costs)
* the market value for assistance level a, b and c;

* the travel time for assistants (respectively level a, b and c)
* the resources actually paid for, with the assumption that no market failure exist.

The following table shows the resources classification adopted in this study. .

Cost element	includes	excludes	unit
equipment (investment cost)	technical aids house adaptations shipping installation & setup	assessment training personalisation	ecus
training/fitting (investment cost)	personalisation training to use	related rehabilitation treatments	ecus
maintenance (running cost)	technical maintenance rentals	interest on investment	ecus
assistance level a (running cost)	personal assistance manageable by anybody	assistance not related to the purpose of the equipment	manhours
assistance level b (running cost)	personal assistance requiring strength and control	assistance not related to the purpose of the equipment	manhours
assistance level c (running cost)	personal assistance requiring professional qualification (e.g. nurse)	assistance not related to the purpose of the equipment	manhours

As said in the previous chapter, it was also found that the technical duration ($\mathbf{D_T}$) of equipment (how long it lasts in actual use conditions before needing replacement) is often different from its clinical duration ($\mathbf{D_C}$) (how long it yields value before being useless) as expressed in WP2, section 5.2.1 and 5.2.2. When the technical duration is shorter, a new item of equipment is expected to be provided after that time. When the clinical duration is shorter, the equipment becomes useless but still instalments remain to be paid.

Effectiveness issues

As said before, the interpretation of the measured utility is often difficult: it is not easy to discriminate the reasons why the individual perception of a situation changes. Does it depend on assistive technology or on other factors? It is necessary to understand whether the objectives set forth for an assistive device have been achieved, before knowing how the individual values it. The CERTAIN tool is a socio-economic measure intended for cost-effectiveness assessment, and it is important that the CERTAIN tool is not used for individual purposes but as a statistical method of comparing results from different groups of clients.

FIM, with some slight improvements, was found useful to such a purpose. This scale focuses on the domain of activities (e.g. moving around) rather than looking at how such action is reached (by walking or by riding a wheelchair). Some floor and ceiling effects were detected, but the overall sensitivity resulted far higher than the utility scales.

Utility issues

The utility scales raised four major issues:

1. The scoring systems

Being focused on health/normality concepts instead of individual goal expectations, EuroQol, IHQL and MMHCS put questions that sound sometimes as a nonsense for a disabled person. A disabled person is not "normal" for definition. For an able-bodied person the normal situation is walking, so being in a wheelchair is felt a "unhealthy" situation, no matter if powered or manual. For a quadriplegic (see i.e. Peter) the normal situation is to be sitting in a wheelchair: walking is not interesting outside the world of dreams, but sitting in a powered wheelchair makes a lot of difference in life than a manual one. For an European, Australia and New Zeland look almost the same thing, but "Aussies" (Australians) or "Kiwis" (Newzelanders) know how many hours of flight separate them from each other. When quality of life questionnaires are intended to measure the variations in the disability's world, they should put questions more relevant to the "part of the world" where the disabled look at. By focusing on the domain of activities, the FIM concept stays in that "part of the world", much more than EuroQol or IHQL or MMHCS, but looking only at the effectiveness.

2. The weighing system

Again the values provided by literature refer to weighting researches carried out on populations of able-bodied people, who have no experience of living with a disability and can hardly appreciate how life improves when a small token is added to one's independence. When using the EuroQol, IHQL and MMHCS in orthodox mode, small changes detected by the scores (if any) are virtually cancelled by the fact that the weighting value is almost the same. MMHCS is the most fuzzy in that, since the final weighting score results from a calculation that takes into account other general parameters estimated with larger approximation. A focused weighting exercise would fall outside the scope and the resources of the Certain project, so in this study the weighting values have been taken from existing literature, and linear extrapolation has been made for calculating the value to be assigned to newly created scores (since "Certain EuroQol", "Certain IHQL" and "Certain MMHCS" include some new items). This approach was useful for developing the method and getting comparable results for the purpose of this study. But of course the QALYs calculated in such a way lack scientific background: the manipulation of one scale, the modification of one item or adding some new answer possibilities to an existing item, dramatically change the complete questionnaire. This work looses the validation and the weights, but allows the calculation of some comparable scores, useful for the research purposes.

3. Calculation of Quality-Adjusted Life Years

It was found that an assistive device can never produce a quality of life increase that lasts for ever in a stable way. In other words a "rectangular model" is not realistic, as described by the following equation[4]:

$$Q_{ALY} = (q_m - q_n) * \frac{D_C}{12}$$

In real life the additional utility generated by a technical aid decreases after some time[5].

In the case of progressive pathologies it even aims to zero: after some time the device is no longer useful due to the worsening of the pathology. Even for a stable pathology, clinical experience teaches that after long time complications may arise that lessen the value of a solution that was excellent years before. The curve (how it aims at zero) has rarely been

[4] *Explanation of parameters:*

- Q_{ALY} = *quality-adjusted life years*
- q_m = *measured quality of life after provision of the assistive device*
- q_n = *natural quality of life if the device had not been provided*
- D_C = *months of clinical duration of equipment*

[5] *We name this phenomena decay, and will use the abbreviation* f_u *(utility decay factor).*

studied. However, details may be not critical in most cases, since the most important thing is to make results comparable. For the purpose of this study, in the majority of the cases, a triangular model has been adopted, being thought as a better approximation of what happens in real life (this parameter can be adjusted in the input data serie to the more suitable model depending on the pathology, the assistive device in use and some external factors):

$$Q_{ALY} = \frac{1}{f_u} * (q_m - q_n) * \frac{D_C}{12}$$

For a triangular model, f_u**= 2:** it is valid either when the clinical duration is very long (until life expectancy: a gradual linear utility loss can be assumed as physiological as the ageing process) or when it is short (e.g. the elderly Margaret or the progressively impaired Oswald: a real gradual loss was observed). For a parabolic model (stable utility for a certain time and then a rapid loss) f_u**= 1,5:,** etc.

4. The detection of quality of life changes

When used in orthodox mode, EuroQol, IHQL and MMHCS should be administered according to fixed time schedules. In our case, quality of life change should be detected between the following situations, whose timing largely depends on the individual case:

- before giving the device, assumed that the client is aware and has psychological perception of all the things he will be able to do with the device
- when the client has full control over the technical aids, that means after the adaptation process.

The first situation cannot be easily detected in a novice user of the concerned device. In most cases he or she does not know how will be life afterwards. The provision of the device and the adaptation may also require time: in the meanwhile the person may have lost (e.g. for a progressive pathology) or gained (e.g. personal growth of other items technology provided) quality of life, thus biasing the measurement of the second situation. In this study it was found that the most accurate solution is to rely on the client's capability to estimate the real value of the change. He or she knows much better than others what the device really meant for him.

5 The forgotten family

In their orthodox mode all utility instruments focus on the individual quality of life, but neglect at all the relief of the family or of the primary network. In revising the scales a special attention was deserved to this aspect, but further research is needed. On the other hands, the family dimension is quite accurately highlighted by the cost analysis: the savings in assistance resources can be a assumed as a good indicator of family relief.

Application to the case stories

For **Robert** the series of seven actions carried out over a period of three years brought about in the whole ("for the lifetime") a mobilisation of 126,988 ECUs due to the equipment-related resources (68,904 for equipment, 14,475 for training/fitting and 43,609 for maintenance), and a saving of 77,040 manhours of active assistance during the whole life (composed by a saving of 63,360 assistance A and 13,680 assistance B). By pricing the latter at market values the real change in resource use is a saving of 191,405 ecus, that is the difference between the absolute real cost of having left him at the borders of society and the absolute real cost mobilised to get Robert's achievement through assistive technologies. The financial saving is 111,199 ecus. The reason why the financial saving is less than the real one is that all level A assistance is not an expenditure but is provided free of charge by the family and the primary network. Also, it is important to stress the fact that in this case the global intervention allowed to eliminate the whole burden of assistance B (13,680 manhours) since assistive technology restricted

the assistance burden to just level A. That means that the burden of assistance still exists, but is manageable in the long run in a climate of family comfort and with no financial burden.

The numerical measure of the outcome can be measured in 44 points increase in functional independence (Certain FIM), and a QALY gain of 7.17 (Certain EuroQol) or 0.625 (Certain IHQL 1) or 0.492 (Certain IHQL 2) or 4.374 (Certain MMHCS), or 5.7385 (Certain 15D). By dividing the life span additional cost by the additional QALYs gained, a cost/utility ratio is obtained. The QALY figures may look disappointing when compared with the tremendous achievements described in the case story; this depends on the lack of sensibility of the utility instruments, that need to be further improved.

However, the balance expenditure / savings is quite accurate, and the outcome measures show a trend. What is missing for a complete comparison is the estimate of the costs that society would have incurred if no intervention had been made: Robert situation would not have remained stable despite the stable pathology, due to the environmental deterioration (long term hospitalisation).

In Robert's case each action builds upon the solutions carried out in the previous actions, some of them being so closely linked to each other. For instance action d (adjustable chair for transferring to the shower) is a consequence to action c (rebuilding the bathroom): a monthly-equivalent investment of 32 ecus (29 for equipment, 3 for maintenance) allows to avoid any external assistance, since the hygiene management in the rebuilt bathroom had resulted to require 1 manhour of expensive level B assistance. The saving is clear in this case, as it is for action g (the ceiling lift). In action g the saving is further exploited by the fact that all assistance has been moved from level B to level A. Action d seems to give no contribution to functional independence (in fact only the burden of assistance has changed); but EuroQol and MMHCS detects one of the highest QALYs while IHQL is insensitive. The weighting weakness of the utility scales is shown by the fact that for action g, IHQL marks the highest change, while EuroQol and MMHCS think nothing has happened.

The method allows to make clear comparisons between the implication of different valid alternatives. This has been made for the cost analysis. For some actions (b, d) the selected solution resulted also the most economically convenient. For some other the difference is irrelevant, for some other the selected solution is even the more expensive. A more expensive solution is motivated by two factors: the estimated better impact on life quality, or the possibility to prepare the ground for further actions. Action c (rebuilding the bathroom) is an example: the solution is more expensive (theoretically 300 ecu/month against 237 of adapting the bathroom or even 68 of carrying out personal hygiene in the bedroom). Surprisingly, just a small increase in functional independence is detected, and no gain in QALY at all. But action d is possible only after action c has been completed: here a remarkable saving is observed, against an impressive number of QALYs.

The comparison among alternatives raises another issue. Let us take action b (going upstairs) as an example. The chosen solution was the elevating platform, but the case manager reported that the wished solution had been the elevator. Unfortunately it was not possible to get the technical permissions for building an external elevator. With the stairclimber Robert started to go outdoors once everyday, so the comparison is made with other alternatives by assuming that he would go outdoors once everyday. Maybe with an elevator his outings would be more frequent, and with just helpers more seldom, thus changing the resulting cost. However, to make alternative comparable an assumption must be made, and the most reasonable is to answer the question: "How much would other alternatives cost in order to reach the same objectives as with the adopted solution ?"

This way to interpret the cost / outcome tables applies to any other case.

Let us look for instance at **Oswald**. A sequence of eleven actions carried out over a period of five years brought about in the whole a mobilisation of 42,123 ecus (34,353 for equipment, 3,248 for fitting/training and 4,522 for maintenance), and a saving of some 11,391 manhours of assistance (7,271 assistance A and 4,120 assistance B). Since assistance level A is provided by the family or by students,

the expenditure profile is somehow like Robert. Therefore the total balance is a financial saving of 98,509 ecus (against a real saving of some 226,498 ecus), that is the actual saving resulting for adding quality to life instead of leaving Oswald to cope with the physiological deterioration due to multiple sclerosis.

By looking at the tables, the effect of Oswald's progressive disability is shown by the absolute FIM and quality of life (EuroQol etc.) rates: sometimes they decrease as time goes on. After action C the FIM rate was 85 and IHQL 0,9710. After action D FIM reported 77 and IHQL 0,9170. It seems that action D generated a step down in life quality. This is not true: if the action would not have taken place, at that time FIM would report 72 as natural value, and IHQL 0,8110. A positive difference of 0,106 exist, that generates:

$$Q_{ALY} = \frac{1}{2}(q_m - q_n) * \frac{D_C}{12} = \frac{1}{2} * \left[(0{,}9170) - (0{,}8110)\right] * \frac{60}{12} = 0{,}265$$

The same applies when moving from action F to action G (provision of a automated bed, after an electronic wheelchair was provided four months before): MMHCS reports a fall from 0,0685 to -0,0475 (minus: as felt "worse than death"). However, without automated bed the natural quality of life would be -0,0490, so the device brought about a positive result of 0,00606 QALYs.

Rita is another case where assistive technology is provided within a short-term perspective. That is due to the short life expectancy, that in fact proved true. However, the intervention was very cost effective. It brought about a mobilization of 10,159 ecus (8,500 equipment, 1,000 training, 659 maintenance) but saved a lot of manhours of paid assistance thus leading to an actual saving of 68,664 ecus. A good result was gained in terms of individual quality of life (e.g. 0.3459 QALYs measured by Certain EuroQol). A positive outcome obtained through saving money: a very nice result in the mind of an administrator! Nevertheless, still many professionals argue if providing sophisticated technology to the elderly is worthwhile. An important component of the saving is the prosthetic leg. But the detected QALYs are small (Certain EuroQol: 0,026) or even negative (IHQL: -0,0181), thus highlighting a negative impact on the quality of life. This is confirmed by the case story: the prosthetic was retrospectively judged a mistake, since it accelerated deterioration and generated depression. The lesson learned is that not everything that makes saving is good!

In comparison to the above, **Peter** raises a simple but important problem: the selection of the couple manual/electronic wheelchair against other cheaper solutions. In this area the scales show higher sensitivity than before. The analysis shows that a overall mobilisation of 14,460 ecus is needed (10,840 equipment, 1,084 training and 2,536 maintenance) against a good result in term of QALYs. Certain EuroQol is the most sensitive and detects a cost utility ratio of 3,318.

Joseph achieves a satisfactory management of incontinence through a overall expenditure of some 9,024 ecus. No quality of life change is detected by the scale between the initial and final situations, but the comparison among alternatives show that other solutions, although similar in terms of money disburse, would deteriorate the quality of life by exposing to medical complications. Joseph is the only case where it was possible to measure the quality of life that would have been obtained through alternative solutions. In fact the client had the opportunity to try each type of incontinence system for a period, before achieving the final choice.

Mary offers examples of technical aids with high training value, also involving a substantial training investment: the long cane has a very cheap cost that we sum with the training needed to get the solution working achieving a total costs of 380 ecus. For its 6 months of clinical validity it allows a theoretical saving of 518 ecus/month, against an expected cost of some 1,167 ecus/month if the same degree of mobility would be achieved with the help of an accompanying persons. But the long term advantage of the long cane lays in its being a tool for learning independent mobility: after 6 months the device is not

required any longer (Mary goes around independently), while helpers or other technical aids would be needed all the life long. The overall cost/outcome analysis highlights how small was the mobilisation of resources against the impressive achievement obtained in Mary's independence and school integration (even if the utility scales are poorly sensitive to that).

Billy shows that the high purchasing cost of the technology yields a saving in the long run: the compared alternatives show a high investment of 36,618 ecus (22,583 ecus of equipment, 1,355 of training and 12,680 of maintenance) with a parallel assistance saving of 8,680 hours (7,000 of assistance A and 1,680 assistance B).

5. Conclusions

This study confirms that a technique for carrying out cost / outcome analysis is possible. It has been done for the case studies. It is applicable to other cases. It gives useful data at analytical level (comparison among valid alternatives for solving a problem) and at aggregate level (globality of intervention, with relationship among components). It keeps into account not only individual aspects, but also family issues like the assistance burden.

While the cost analysis method, although open to refinements, is already quite mature and usable as it is, effectiveness and utility analysis are still at their beginning. To really understand the outcomes of applying assistive technology, it is absolutely necessary to resort to a detailed free text description: the scales in themselves provide just quick feelings. In no case this cost/outcome model should be used as the sole criterion to evaluate the appropriateness of the cost efficiency of an intervention.

Therefore suggestions are given here, in order to help further developments that are needed in this area.

1. Cost analysis has been limited so far to marginal operating costs. To calculate real opportunity costs, the resources used in the assesment and selection process should also be included; techniques to achieve that should be developed.

2. An effectiveness analysis instrument is needed, so as to check to what extent the desired operational objectives are achieved in real life. FIM seems tuned in the right approach. It could serve as the basis for achieving a proper instrument.

3. A new utility instrument is needed, based on the findings of the Certain project. Its items should be based on individual goals expectations that are commonly felt among disabled persons, and the scores be weighted with a population that includes disabled people.

The method developed in this document is prepared to accept further developments along the above lines.

Annexes to Part 1

Annex A

The Cost / Outcome Instrument

This cost / outcome instrument is intended to measure:
⇒ marginal costs
⇒ effectiveness
⇒ utility
generated by the provision of assistive technology to solve a disability problem. It allows to obtain either analytical data (cost, effectiveness and utility generated by each possible solution) or global data (cost, effectiveness and utility generated by a complex assistive technology programme composed of a sequence of actions distributed over a given time).

The term **marginal costs** indicates the resources directly related to the technology provided. They include:
- the equipment provided (devices, adaptations, methods etc.)
- the service delivery aspects directly involved by the technology provided (fitting, training)
- the human resources (personal assistance) required to maintain the adopted solution.

The first two items can be easily described in monetary values; the third are better described in terms of human time (e.g. manhours), and its conversion into monetary values depends on a number of social and environmental parameters.

Effectiveness refers to the achievement of the objectives, either for each solution or the global intervention; **utility** refers to the impact on the client in term of changes in life quality.

Using the instrument requires that the analysis be carried out step by step, according to a scheme similar to the case history structure. At each step all possible alternatives are described, so as to compare the involved resources and the estimated outcomes. A global perspective is adopted, with no distinction being made between the various cost bearers (family, Municipality, Region etc.).

The resources sharing between payers is outside the scope of the study: it requires a further level of analysis, being it much dependent on the Country and sometimes also on the individual situation. However, the "expenditure profile " to be filled in under the heading "general input parameters" allows such a kind of simulation. For instance, when there is a resource sharing between the client and a public agency, the instrument can be filled-in twice according to different expenditure profiles, thus obtaining separately the financial implications for both.

General input parameters

name	unit	abbr.	definition
			Economic parameters
investment	%	i_i	annual interest rate on a bank loan, used to calculate the fixed

costs discount rate			instalments to be paid off and used to discount the investment costs
running costs discount rate	%	$\mathbf{i_r}$	annual interest rate, used to discount the running costs
assistance A	ECUs/h	$\mathbf{p_a}$	current price (ecus) of one hour of assistance "level A" (manageable by anybody)
travel time A	minutes / action	$\mathbf{o_a}$	time needed for an external helper to travel forth and back each time he/she has to provide a "level A" assistance action
assistance B	ECUs/h	$\mathbf{p_b}$	current price (ecus) of one hour of assistance "level B" (not manageable by anybody: requiring strenght and control)
travel time B	minutes / action	$\mathbf{o_b}$	time needed for an external helper to travel forth and back each time he/she has to provide a "level B" assistance action
assistance C	ECUs/h	$\mathbf{p_c}$	current price (ecus) of one hour of assistance "level C" (not manageable by anybody: requiring professional qualification)
travel time C	minutes / action	$\mathbf{o_c}$	time needed for an external helper to travel forth and back each time he/she has to provide a "level C" assistance action

Expenditure profile

equipment	%	$\mathbf{f_e}$	states which percentage of this cost is actually paid for by the actor considered (in this study always the client and/or the family)
fitting	%	$\mathbf{f_f}$	states which percentage of this cost is actually paid for by the actor considered (in this study always the client and/or the family)
maintenance	%	$\mathbf{f_m}$	states which percentage of this cost is actually paid for by the actor considered (in this study always the client and/or the family)
assistance a	%	$\mathbf{f_{aa}}$	states which percentage of this cost is actually paid for by the actor considered (in this study always the client and/or the family)
assistance b	%	$\mathbf{f_{ab}}$	states which percentage of this cost is actually paid for by the actor considered (in this study always the client and/or the family)
assistance c	%	$\mathbf{f_{ac}}$	states which percentage of this cost is actually paid for by the actor considered (in this study always the client and/or the family)

Input data

Estimate of resources

utility decay factor		$\mathbf{f_u}$	number that describes how the utility of the technical solution decreases in the time until aiming at zero at the end of the clinical duration. Depending on circumstances such decrease may follow: ⇒ a rectangular model ($\mathbf{f_u = 1}$): utility is fully retained until the end of the clinical duration ⇒ a triangular model ($\mathbf{f_u = 2}$): a gradual linear utility loss until becoming null ⇒ a parabolic model ($\mathbf{f_u = 1.5}$): utility is almost fully retained for a substantial percentage of the clinical duration, than falls down rapidly

clinical duration	months	$\mathbf{D_C}$	how long the technical solution is expected to be useful to the user. This may depend on the life expectancy, on the training value of the equipment (e.g. a device temporarily used for rehabilitation purposes), on the changing conditions resulting from growth (e.g. a seating system for a child who is growing) or pathology (e.g. a progressive diseased that make the device useless after a while)
completed	months	**T**	how many months after the beginning of the intervention the technical solution is in operation
FIM	score	**e**	aggregated score resulting from the FIM scale, as modified in the Certain project (see annex B). The measured value should refer after the implementation of the technical solution. The natural value (corresponding to the column "before" of the spreadsheet) is estimated: it refers to how would be at the same time functional independence, if the device had not been provided.
QoL	score	**q**	aggregated weighted score resulting from a Quality of Life scale. In the Certain project four instruments have been adopted with modifications: EuroQol, IHQL (part 1 and 2), MMHCS.
equipment	ECUs	$\mathbf{c_{ie}}$	investment or purchase cost of the equipment
technical duration	months	$\mathbf{D_T}$	how long the equipment is expected to last in proper use conditions before needing replacement
fitting / training	ECUs	$\mathbf{c_{if}}$	investment cost for getting the equipment in operation and its user properly trained to use it
maintenance	ecu/year	$\mathbf{c_{my}}$	annual cost of maintenance of the equipment
assistance A	minutes / action	$\mathbf{a_a}$	active time required by each "level A" assistance action. It answers the question: "how long should my helper(s) stay with me to complete the concerned task (e.g.: loading me onto a stairclimber, taking me downstairs and unloading) ? "
assistance B	minutes / action	$\mathbf{a_b}$	active time required by each "level B" assistance action. It answers the question: "how long should my helper(s) stay with me to complete the concerned task (e.g.: loading me onto a stairclimber, taking me downstairs and unloading) ? "
assistance C	minutes / action	$\mathbf{a_c}$	active time required by each "level C" assistance action. It answers the question: "how long should my helper(s) stay with me to complete the concerned task (e.g.: loading me onto a stairclimber, taking me downstairs and unloading) ? "
actions a	actions / month	$\mathbf{n_a}$	number of times that assistance A is required each month
actions b	actions / month	$\mathbf{n_b}$	number of times that assistance B is required each month
action c	actions / month	$\mathbf{n_c}$	number of times that assistance C is required each month

Intermediate data

Monthly sharing of resources

equipment	ECUs / month	$\mathbf{c_e}$	equivalent monthly cost of the equipment investment. It is the equivalent to a fixed instalment to be paid off monthly to a bank for a period corresponding to the amortisation period. In this model the amortisation period is assumed to be the same as the technical duration. If the clinical duration is longer than the technical duration, the equipment needs to be purchased N times, at the same conditions of the first time (purchase cost

			of the equipment, annual interest rate on bank loans and technical duration): $$N = integer\frac{D_{C\,-\,1}}{D_T} + 1$$ "Integer" stands for truncation of decimals: that means that when $\mathbf{D_C<D_T}$, or $\mathbf{D_C = D_T}$, **N=1** (the equipment is purchased once); when $\mathbf{D_T < D_C< 2*D_T}$, **N=2** (the equipment needs to be purchased twice,) and so on. $$c_e = \frac{c_{ie}}{\sum_{t=1}^{D_T}\frac{1}{\left(1+\frac{i_i}{12}\right)^t}}$$
fitting/training	ECUs / month	$\mathbf{c_f}$	equivalent monthly cost of the fitting / training investment associated to the equipment. N is calculated as above $$c_f = \frac{c_{if}}{\sum_{t=1}^{D_T}\frac{1}{\left(1+\frac{i_r}{12}\right)^t}}$$
maintenance	ECUs / month	$\mathbf{c_m}$	equivalent monthly cost of maintenance: $$c_m = \frac{c_{my}}{12}$$
assistance A active time	manhours / month	$\mathbf{h_a}$	net monthly amount of manhours (level A) $$h_a = \frac{a_a * n_a}{60}$$
assistance B active time	manhours / month	$\mathbf{h_b}$	net monthly amount of manhours (level B) $$h_b = \frac{a_b * n_b}{60}$$
assistance C active time	manhours / month	$\mathbf{h_c}$	net monthly amount of manhours (level C) $$h_c = \frac{a_c * n_c}{60}$$
			Estimated monthly value
absolute real cost (monthly cost)	ECUS / month	$\mathbf{c_t}$	monthly real cost, by assuming that all equipment and assistance expenses are paid. Assistance cost includes travel time. Defining the monthly cost of assistance type i (i = a, b, c) as $c_i = \frac{(a_i + o_i)}{60} * n_i * p_i$, is: $$c_t = c_e + c_f + c_m + c_a + c_b + c_c$$
absolute expenditure (monthly expenditure)	ECUS / month	$\mathbf{c_o}$	monthly financial expense of money. Calculated as above, but applying also the "expenditure profile": $$c_o = c_e * f_e + c_f * f_f + c_m * f_m + c_a * f_{aa} + c_b * f_{ab} + c_c * f_{ac}$$
relative real cost	ECUS / month	$\mathbf{k_t}$	difference between the absolute real cost with and without the solution $$k_t = c_{t(with.\,solution)} - c_{t(without.\,solution)}$$
relative expenditure	ECUS / month	$\mathbf{k_o}$	difference between the absolute expenditure with and without the solution $$k_o = c_{o(with.\,solution)} - c_{o(without.\,solution)}$$

Output Data

			Present value of additional costs
equipment	ECUS	$\mathbf{K_e}$	additional amount of equipment resources needed for the concerned technical solution. Defining the absolute amount of these resources as $C_e = \sum_{t=1}^{N*D_T} \frac{c_e}{\left(1+\frac{i_i}{12}\right)^t}$ $K_e = C_{e\ (\text{with solution})} - C_{e\ (\text{without solution})}$
fitting/training	ECUS	$\mathbf{K_f}$	additional amount of training resources needed for the concerned technical solution. Defining the absolute amount of these resources as: $C_f = \sum_{t=1}^{N*D_T} \frac{c_f}{\left(1+\frac{i_i}{12}\right)^t}$; $K_f = C_{f\ (\text{with solution})} - C_{f\ (\text{without solution})}$
maintenance	ECUS	$\mathbf{K_m}$	additional amount of maintenance resources needed for the concerned technical solution. Defining the absolute amount of these resources as $C_m = \sum_{t=1}^{D_C} \frac{c_m}{\left(1+\frac{i_r}{12}\right)^t}$ $K_m = C_{m\ (\text{with solution})} - C_{m\ (\text{without solution})}$
assistance A	ECUS	$\mathbf{K_a}$	additional amount of assistance A involved by the technical solution. Defining the absolute amount of these resources as $C_a = \sum_{t=1}^{D_C} \frac{c_a}{\left(1+\frac{i_r}{12}\right)^t}$ $K_a = C_{a\ (\text{with solution})} - C_{a\ (\text{without solution})}$
assistance B	ECUS	$\mathbf{K_b}$	additional amount of assistance B involved by the technical solution. Defining: $C_b = \sum_{t=1}^{D_C} \frac{c_b}{\left(1+\frac{i_r}{12}\right)^t}$; $K_b = C_{b\ (\text{with solution})} - C_{b\ (\text{without solution})}$
assistance C	ECUS	$\mathbf{K_c}$	additional amount of assistance C involved by the technical solution. Defining: $C_c = \sum_{t=1}^{D_C} \frac{c_c}{\left(1+\frac{i_r}{12}\right)^t}$; $K_c = C_{c\ (\text{with solution})} - C_{c\ (\text{without solution})}$

		Cost indicators	
absolute real cost	ECUS	**ARC**	real value of resources involved by the technical solution $ARC = C_e + C_f + C_m + C_a + C_b + C_c$
absolute expenditure	ECUS	**AE**	financial value of resources involved by the technical solution $AE = C_e * f_e + C_f * f_f + C_m * f_m + C_a * f_{aa} + C_b * f_{ab} + C_c * f_{ac}$
relative real cost (lifespan cost)	ECUS	**RRC**	relative real cost of the technical solution, compared to not having adopted it $RRC = ARC(_{with.solution}) - ARC(_{without.solution})$
relative expenditure (lifespan expenditure)	ECUS	**RE**	relative expenditure, compared to not having adopted it $RE = AE(_{with.solution}) - AE(_{without.solution})$
		Impact on Quality of Life	
additional QALYs	QALYs	**Q**	Additional quality-adjusted life years generated by the technical solution $Q_{ALY} = \frac{1}{f_u} * (q_m - q_n) * \frac{D_C}{12}$
		Cost/Utility ratio	
cost/utility ratio	ECUs / QALY	$\mathbf{R_{cost}}$	Ratio between the additional lifespan real cost (RRC) and the additional quality-adjusted life years (Q) generated by the technical solution. It represents the cost of each additional QALY gained. The ratio is meaningful only in case additional QALYs are actually achieved. In other words, the ratio yields a numerical value only when Q>0. A negative ratio means that additional QALYs have been reached through a saving of reasources.

The CERTAIN Spreadsheet

The following table shows the results of an application of this model in Microsoft Excel® environment.

CASE: BILLY		**ACTION A: WHEELCHAIR**			
INPUT DATA		**before**	**CUSTOM. EL.**	**manual**	**stand. electr.**
Investment costs discount rate	*%*	*15*	*15*	*15*	*15*
Current costs discount rate	*%*	*5*	*5*	*5*	*5*
Estimated technical duration	months	240	60	60	60
Estimated clinical validity	months	240	240	240	240
Equipment	ECUs		12500	1500	4500
- % paid	%		100	100	100
Training/Fitting	ECUs		750	500	300
- % paid	%		100	100	100
Maintenance	ECUs/year		2500	75	150
- % paid	%		100	100	100
Assistance level A:					
- actions per month	act./mon.	90	50	90	50
- active time per action	min./act.	20	1	20	1
- travel time per action	min./act.	40	40	40	40
- cost per hour	ECUs/hour	5	5	5	5
- % paid	%	0	0	0	0
Assistance level B:					
- actions per month	act./mon.	90	30	90	90
- active time per action	min./act.	5	1	5	10
- travel time per action	min./act.	40	40	40	40
- cost per hour	ECUs/hour	10	10	10	10
- % paid	%	100	100	100	100
Assistance level C:					
- actions per month	act./mon.				
- active time per action	min./act.				
- travel time per action	min./act.				
- cost per hour	ECUs/hour				
- % paid	%				
Effectiveness analysis:					
Certain-FIM	scores	74	85		
Utility analysis:					
Certain-Euroqol	scores	0,0219	0,4630		
Certain-IHQL I	scores	0,3990	0,9400		
Certain-IHQL II	scores	0,8161	0,9331		
Certain-MMHCS	scores	0,0840	0,7559		
15-D	scores				
Utility decay factor	1; 1,5; 2	2	2		
MONTHLY COSTS					
Equipment	ECUs	0	294	35	106
Training	ECUs	0	18	12	7
Maintenance	ECUs	0	208	6	13
Assistance A	manh./month	30	1	30	1
Assistance B	manh./month	8	1	8	15
Assistance C	manh./month	0	0	0	0
monthly cost	ECUs	1125	895	1178	1046
monthly expenditure	ECUs	675	725	728	875
OUTPUT DATA					
ADDITIONAL COSTS (Pr.Val.)					
Equipment	ECUs	-	22.583	2.710	8.130
Training	ECUs	-	1.355	903	542
Maintenance	ECUs	-	31.699	951	1.902
Assistance A	manhours	-	-7.000	0	-7.000
Assistance B	manhours	-	-1.680	0	1.800
Assistance C	manhours	-	0	0	0
life span cost	ECUs	-	-58.353	4.564	-20.491
life span expenditure	ECUs	-	-15.876	4.564	21.986
ADDITIONAL FUN.INDEPENDENCE					
Certain-FIM			11	0	0
ADDITIONAL UTILITY					
Certain-Euroqol	QALYs	-	4,4110		
Certain-IHQL I	QALYs	-	5,4100		
Certain-IHQL II	QALYs	-	1,1700		
Certain-MMHCS	QALYs	-	6,7190		
15-D	QALYs	-			
COST/UTILITY RATIO					
Certain-Euroqol	ECUs/QALY		-13.229		
Certain-IHQL I	ECUs/QALY		-10.786		
Certain-IHQL II	ECUs/QALY		-49.874		
Certain-MMHCS	ECUs/QALY		-8.685		
15-D	ECUs/QALY				

ANNEX B:

The FIM-based Effectiveness Instrument

During the project, we used different type of questionnaire to test and evaluate the differences and the improvements in functional independence. The most useful one, for our purposes, seems to be the FIM[6], Functional Independence Measure.

It was developed to try to measure the independence that can be achieved in the course of a rehabilitation treatment. It is based on a questionnaire that provides scores for each item and an overall aggregated score resulting from the sum of the individual item scores.

Some little problem were encountered in using the questionnaire with the case studies, as it is developed to measure great improvements or lacks in daily life activities. On the other hand, it is developed to check only the personal capacities of performing activities, avoiding to consider the needs or savings in the assistance operations.

Following these considerations, we tried to use the "standard" FIM in the study with our clients, but we thought also useful try to expand the meaning or the value attribute to one dimension, in order to facilitate the global sensitivity of the tool.

Improvement in functional independence

Each action performed had an impact on the functional independence in each case study.

Here an attempt follows to use the standard version of the FIM, in the case of Robert.
Some sensitivity can be noted in the results, and these improvements can be described by the following table.

		0	a	b	c	d	e	f	g
Self-care	eating	1							
	grooming	1							
	bathing	1			2				

[6] *Functional Independence Measure: Copyright 1992 - The Research Foundation of the State University of New York. Each score refers to a well defined level of independence (described in its handbook) that can be summarised as follows:*

No Helper	*independence*	*7*	*complete independence (timely, safely)*
		6	*modified independence (device)*
With Helper	*modified dependence*	*5*	*supervision*
		4	*minimal assistance (subject = 75%)*
		3	*moderate assistance (subject = 50%)*
	complete dependence	*2*	*maximal assistance (subject = 25%)*
		1	*total assistance (subject = 0%)*

	dressing-upper body	1							
	dressing-lower body	1							
	toileting	1							
sphincter control	bladder management	7							
	bowel management	7							
mobility	bed-chair-wheelchair	1							
	toilet	1							
	tub, shower	1							
locomotion	walk or wheelchair	1					6		
	stairs	1							
communication	comprehension	7							
	expression (non-verbal)	5						6	
social cognition	social interaction	7							
	problem solving	1					3	7	
	memory	7							
total		**52**	**52**	**52**	**53**	**53**	**60**	**65**	**65**

Sensitivity of FIM to assistive technology

Self care
Very hardly a quadriplegic person can manage self care without complete help by an assistant. Therefore the scores are almost always "1". In the proposed case, the exception is "bathing" where the client was able to do part of the job ("2") after the bathroom was adapted with proper placement of the shower. That happened because a spastic quadriplegic normally has a potential for level 2, but such potential was locked before by an unsuitable environment. The scale fails to reveal the real improvement observed in the "eating" dimension: after the provision of the wheelchair/seating system Robert is able to independently approach the dining table and keep the head in a favourable position for the assistant who feeds him. The effort required is substantially reduced: the assistance does no longer need to stay in fatiguing positions and to have one hand hold Robert's head. Moreover, Robert is able to better see the food and look at the assistant, thus improving communication.

Sphincter control
The absence of incontinence ("7": full control of sphincters) does not mean that Robert is independent in the urine and evacuation function, since he needs complete assistance for transferring to the toilet for using the bedpan or the urine bottle. The situation has substantially improved after the bathroom adaptation and the provision of the commode chair, but the scale is unable to detect such improvement. A further improvement occurred after the installation of the lift, allowing more frequent transfers and therefore a more regular planning of evacuation.

Mobility
No improvement is detected since Robert still requires complete assistance despite the adoption of the ceiling-mounted lift. In real life a substantial improvement occurred, in that very small effort is now required to the assistant for transferring Robert between the bed and the wheelchair, or from the wheelchair to the commode chair. Before the lift was installed, two expert persons were needed for each transfer, with a lot of effort and some risk of falling down. Now Robert feels free to ask for transfer more times a day, even with non expert assistants.

Locomotion

The improvement involved by the wheelchair is clearly detected. On the other hands, the scale fails to reveal the substantial reduction of assistance offered by the stair climbers: since Robert still requires complete assistance in boarding the platform and controlling the switches, FIM always assigns level "1". Before the stair climbers, three young and strong persons were needed for taking Robert up- and downstairs, now one person is quite enough and no effort is required at all. That also means that Robert feels free to decide himself when to go outdoors and where.

Communication
Robert cannot speak, but is fully able to develop concepts and has developed a highly expressive non-verbal communication code. The problems in understanding his messages lies mainly in the novice listeners, while family members or friends find almost no difficulty. Hence level "5 - non-verbal". The computer based communication system allows a better independence ("6 - non-verbal") since extends the understanding of his messages to anybody else. Moreover, now Robert can write and phone: but this last aspect is not detected by the scale.

Cognition
In principle Robert has no problems in relating with people ("7"): the problem at the beginning was how to meet people without going outdoors or phoning!
Also for problem solving Robert had a full potential, but before the wheelchair and the communication system he had no means to bring to a solution independently the problems he wanted to solve. For example, one day his mother found herself locked in the terrace, and only owing to the wheelchair Robert was able to move to the door and open it. In this case FIM was able to detect the change.

Improving FIM sensitivity to assistive technology

FIM is designed around the concept of individual functional independence, as most of the effectiveness scales used in rehabilitation. For severe disabled persons who (like Robert) will always require some personal assistance, floor effects appear in some dimensions (eating, mobility, stairs). In other words only the individual improvements of the "patient" are considered, not the overall improvements of the primary group (in this case, the family, and the primary assistance network).

The assistive technology implemented with Robert can be clustered round three groups:
* devices improving personal independence (wheelchair, communication system)
* devices reducing assistance (stair climber, lift, shower chair)
* environmental improvements (accessible flat, bathroom adaptations).

FIM looks quite sensitive to individual improvements brought about by the first group; but it does not look sensitive enough either to other groups or to the side effects of the first group.

In general, we think of the possibility of transforming the meaning of a question so as to detect a change also when the improvement is not really of the disabled person, but also of the "group of persons living with him/her". Starting from this point of view, we can consider the "assistance improvements" when using a special hoist, or a stair climber. In Robert's case, he would be never able to transfer by himself from the bed to the wheelchair, but the adoption of the hoist had a big impact on the whole family: not a time gain, as the time spent was comparable, but a fatigue saving. In a second view, now Robert can exit also when his mother is not at home, helped by a friend or the father.
Again, the mother now can relax herself a little more than before, because she has not to plan everything for his son. This consideration is valid also considering the environmental improvements, e.g. the communication system or the alarm system.
We tried to follow those considerations during the compilation of the "social" FIM scale.

If a "social" view of independence (of the primary group) is adopted instead of a pure individual view, the "modified" FIM seems to be more sensitive to all kinds of assistive technology, specially by taking into account the reduction of the assistance load.

Taking in mind those considerations, we ticked the answer in the second attempt of use of the FIM scale. The sensitivity seems improved. The method can be reproduced considering not only the independence gain of the client, but also the fatigue savings of the persons living with the disabled.

Annex C

General remarks on the examined utility questionnaires

In general, we think that the examined scales were designed for healthy persons, or to measure one person's health.

All the questionnaires seem:

1. to be not sensitive enough to the improvements in disabled persons' independence
2. to ignore the possibility of moving around using a wheelchair or a walking device
3. to ignore the possibility of working or maintaining a social network, when completely quadriplegic, specially if lying in bed
4. to forget the possible use of technical devices, except (in one case) for spectacles and hearing aids.
5. to focus the attention on the health state
6. the items formulation seems to ignore the problems connected with the disability or the lack of function of disabled persons.

In filling in the items, we faced interpretation difficulties of the mobility problems sentences starting from the point of view of one disabled person, without the use of the legs, sitted on a wheelchair: when asking for mobility, almost all the scales interpret this word as "walk", normally walk by the use of the legs. We think that the possibility to expand the meaning to "move around, move about, move between one place to another" will allow a person with moving difficulties, but independent by the use of the wheelchair, to state: "I'm independent, I can move around by myself".

During the weighting attempt with the scales, they seemed quite unsensitive to our purposes. Then we made an extra work, we tried to expand the meaning of some sentence, or the answering possibilities, in order to modify the global sensitivity. On the other hand, we were also artificially modifing some weight value, owing to the changes of some item formulation, or introducing new weights for each new answering possibility, by mathematical extrapolations. It is clear that such alteration leads to artificial measurements that are useful just for simulation, so as to achieve the calculation of utility / cost ratios. We are really conscious that the scientific rigour has been lost, but only doing so, we could achieve a simulation of the utility / cost ratio.

ANNEX D:

The 15 D-based Utility Instrument

We tried to analyse the different questions displayed in the 15 D scale and to focus them in the case studies elaborated: most of the items seem to have problems connected with the disability or the lack of function of disabled persons.

1. Mobility

1 • *I am able to* ***walk normally*** *(without difficulty) indoors, outdoors and on stairs.*

We would like to ask:

1 ***• I am able to move around (without difficulties) indoors, outdoors and on stairs.***

Transforming the sentence, level one can be ticked by a person sitted on a wheelchair and with a stair climber or a lift to go along the stairs.

2 ***• I am able to move around without difficulty indoors, but outdoors and/or on stairs I have slight problems.***

Answer 2 can be used by a person sitted on a wheelchair, with a stair climber or a lift manoeuvred by an attendant.

3 ***• I am able to move around without help indoors, but outdoors and/or on stairs only with considerable difficulty or with help from others.***

Answer 3 could be ticked by a quadriplegic person able to move indoors and outdoors by an electronic wheelchair, who needs slight help for manoeuvring it and an assistant to control the stair climber or the lift

4 ***• I am able to move around indoors and/or outdoors only with help from others.***

Answer 4 can describe a quadriplegic person sitted on a manual wheelchair that he/she cannot control

5 ***• I am unable to move around or completely bedridden***

Answer 5 can describe a quadriplegic person, sitted on an electronic wheelchair that he/she cannot control owing to the joystick control problems, or a completely bedridden disable person.

2. Visual

Answer 4 and 5 consider only the possibility of **walking** about. We propose to expand the meaning to "**move around**".

4 • *I cannot read papers or TV text either with glasses or wit hout, but I can see enough to walk about without a guidance.*

4 ***• I cannot read papers or TV text either with glasses or without, but I can see enough to move around without a guidance.***

5 • *I cannot see enough to walk about without a guide. i.e. I am a lmost or completely blind.*

5 ***• I cannot see enough to move around without a guide, i.e. I am almost or completely blind.***

3. Hearing
4. Breathing
5. Sleeping
6. Eating
No relevant comments

7. Speech
The subject of the question is the **verbal language**, the possibility of speak by the voice, avoiding to consider all the possibilities of alternative languages: gestures, signing, mimics, closed questions, communicators, synthesisers. Only in the last question one can read the word *gesture*, but intended as the ***worst condition*** where a person cannot make him/herself understood but by the use of gestures. One has to consider only minor difficulties of the sound articulation with the scope of communication.

8. Elimination
Here the continence function is considered, avoiding the possibility of the use *of any kind of assistive devices* to control it: urine diverters, urine collectors, diaper and pads.

1 • ***My bladder and bowel work normally and without problems***
2 • ***I have slight problems with my bladder and/or bowel function, or I need a continence device, but I am independent in wearing or using it.***
3 • ***I have marked problems with my bladder and/or bowel function, or I need a continence device and slight assistance in wearing or using it.***
4 • ***I have serious prob lems with my bladder and/or bowel function, or I need a continence device and total assistance in wearing or using it.***
5 • ***I have no control over my bladder and/or bowel function.***

9. Usual activities
It is quite difficult to think about the usual activities of a quadriplegic person always managed by others, by the mother, the assistant, the therapist. Robert, for example, in the first survey, has no personal activities, as he always is looked after and cured for the 100% of the time. His usual activities can be described as eating, sleeping, waiting for a friend's visit or the therapist's session. How can he answer when the question concerns the usual activities? or more, the previously usual activities? Robert was born spastic, he never sperimented a "normal and previous" life. He always had severe movement impairments. He never lived a "normal" life.
Perhaps we can cover this gap with the possibility of a positive answer:

1 • *I am able to perform my usual activities (... ...) without difficulty.*
1 • ***I am able to perform better than before my usual activities, or I am able to perform more today than yesterday***

2 • *I am able to perform my usual activities slight less effectively or with minor difficulty.*
2 • ***I am able to perform my usual activities (... ...) without difficulty.***

3 • *I am able to perform my usual activities much less effectively, with considerable difficulty, or not completely.*
3 • ***I am able to perform my usual activities less effectively or with difficulty or not completely***

4 • *I can only manage a small proportion of my previously usual activities*
4 • ***I have severe difficulties to manage activities***

5 • *I am unable to manage any of my previously usual activities.*
5 • ***I am totally unable to manage activities***

10. Mental function

We think that the 4th and the 5th answer are not proprially intended for an autocompilation:

4 • *I have great difficulties in thinking clearly and logically, or my memory is seriously impaired.*

5 • *I am permanently confused and disoriented in pl ace and time.*

11. Discomfort and symptoms

The sentences (except the first) are difficult to interpretate (and then to answer), because quite everybody in our society can state to bear some physical discomfort or symptoms.
Perhaps the item can result more comprehensive if correlated to a temporal quantity.

2 • ***Sometimes, during my normal day, I bear physical discomfort or symptoms, but it lasts no more than 15 minutes.***

3 • ***Sometimes, during my normal day, I bear physical discomfort or symptoms, but it lasts no more than one hour.***

4 • ***Often, during my normal day, I bear physical discomfort or symptoms.***

5 • ***I have unbearable physical discomfort or symptoms all day long, e.g. pain, ache, nausea, itching, etc.***

12 Depression

The sentences (except the first) are difficult to interpretate (and then to answer), because quite everybody in our society can state to feel sometimes sad, melancholic or depressed.
Perhaps the item can result more comprehensive if correlated to a temporal quantity.

2 • ***Sometimes, during my normal day, If eel sad, melancholic or depressed, but it lasts no more than 15 minutes.***

3 • ***Sometimes, during my normal day, I feel sad, melancholic or depressed, but it lasts no more than one hour.***

4 • ***Often, during my normal day, I feel sad, melancholic or depressed.***

5 • ***All day long I feel extremely sad, melancholic or depressed.***

13. Distress

The sentences (except the first) are difficult to interpretate (and then to answer), because quite everybody in our society can state to feel some anxiety, stress, or to be nervous.
Perhaps the sentences can result more comprehensive if correlated to a temporal quantity.

2 • ***Sometimes, during my normal day, If eel anxious, stressed or nervous, but it lasts no more than 15 minutes.***

3 • ***Sometimes, during my normal day, If eel anxious, stressed or nervous, but it lasts no more than one hour.***

4 • ***Often, during my normal day, I feel anxious, stressed or nervous.***

5 • ***All day long I feel extremely anxious, stressed or nervous.***

14. Vitality

The sentences (except the first) are difficult to interpretate (and then to answer), because quite everybody in our society can state to feel sometimes weary, tired or fleeble.
Perhaps the item can result more comprehensive if correlated to a temporal quantity.

2 • ***Sometimes, during my normal day, I feel weary, tired or fleeble, but it lasts no more than 15 minutes.***

3 • ***Sometimes, during my normal day, I feel weary, fired or fleeble, but it lasts no more than one hour.***

4 • ***Often, during my normal day, I feel weary, tired or fleeble.***

5 • ***All day long I feel extremely weary, tired or fleeble.***

15. Sexual activity

It is quite difficult for an always managed by old parents person try to achieve an independence for his sexual life. The protection of the mother is really a double strength chain between them. And then, how can Robert live his personal sexual life? Hissing to a girl in the street? or following her to drink a cola in a pub? Yes, but the mother will push the wheelchair!

5 • ***My state of dependence makes sexual activities impossible***

In the following table, one can observe the weighing attempt with the connected relative lack of sensitivity of the standard 15 D questionnaire filled in by Robert during the project.

	0	a	b	c	d	e	f	g	'94	'95
mobility	5									5
vision	1									1
hearing	1									1
breathing	1									1
sleeping	1									1
eating	4									4
speech	5									5
elimination	1									1
usual activities	5									5
mental function	1									1
discomfort	1									1
depression	1									1
distress	1									1
vitality	1									1
sexual activity	1									1
weigh	2.0018									2.0018

Certain l5 D ***(Modified version of the 15 D questionnaire in order to try to improve its sensitivity.)***

1. Mobility

1 • I am able to move around (without difficulties) indoors, outdoors and on stairs.
2 • I am able to move around without difficulty indoors, but outdoors and/or on stairs I have slight difficulties.
3 • I am able to move around without help indoors, but ou tdoors and/or on stairs only with considerable difficulty or with help from others.
4 • I am able to move around indoors and/or outdoors only with help from others.
5 • I am unable to move about or completely bedridden

2. Vision

1 • I see normally, i. e. I can read newspapers and TV text without difficulty (with or without glasses
2 • I can read papers and/or TV text with slight difficulty (with or without glasses).
3 • I can read papers and/or TV text with considerable difficulty (with or without g lasses).
4 • I cannot read papers or TV text either with glasses or without, but I can see enough to move around without guidance.
5 • I cannot see enough to move around without a guide, i.e. I am almost or completely blind.

3. Hearing

1 • I can hea r normally, i.e. normal speech (with or without a hearing aid).
2 • I hear normal speech with a little difficulty (with or without a hearing aid).
3 • I hear normal speech with considerable difficulty; in conversation I need voices to be louder than normal (with or without a hearing aid).
4 • I hear even loud voices poorly; I am almost deaf (with or without a hearing aid).
5 • I am completely deaf.

4. Breathing

1 • I am able to breath normally, i.e. with no shortness of breath or other breathing difficulty.
2 • I have shortness of breath during heavy work or sports, or when briskly on flat ground or slightly uphill. OR I have to facilitate my breathing by the use of some drugs.
3 • I have shortness of breath when walking on flat ground at the same speed as others my age. OR At certain intervals I use breathing devices
4 • I get shortness of breath even after light activity, e.g. washing or dressing myself. OR I need the use of breathing devices almost all the time.
5 • I have breath difficul ties almost all the time, even when resting. OR I live only connected to a breathing device.

5. Sleeping

1 • I am able to sleep normally, i.e. I have no problems with sleeping.
2 • I have slight problems with sleeping, e.g. difficulty in falling aslee p, or sometimes waking at night.
3 • I have moderate problems with sleeping, e.g. disturbed sleep, or feeling I have not slept enough.
4 • I have great problems with sleeping, e.g. having to use sleeping pills often or routinely, or usually waking at night and/or too early in the morning.
5 • I suffer severe sleeplessness, e.g. sleep is almost impossible even with full use of sleeping pills, or staying awake most of the night.

6. Eating

1 • I am able to eat normally, i.e. with no help from others.
2 • I am able to eat by myself with minor difficulty (e.g. slowly, clumsily, shakily, or with special appliances).

3 • I need some help from another person in eating.
4 • I am unable to eat by myself at all, so I must be fed by another person.
5 • I am un able to eat at all, so I am fed either by tube or intravenously.

7. Communication

1 • I am able to communicate in a comprehensive manner, clearly, audibly and fluently (using or not a communication device).
2 • I have slight communication difficulties, e.g. my communication is not completely comprehensive to all the persons I meet (using or not a communication device).
3 • I can make myself understood, even if with severe difficulties or by mean of a prolonged amount of time (using or not a communication device).
4 • I can only communicate to persons who very well know my communication (using or not a communication device).
5 • The majority of the persons have severe difficulties in understanding my communication (using or not a communication device).

8. Elimination

1 • My bladder and bowel work normally and without problems
2 • I have slight problems with my bladder and/or bowel function, OR I need a continence device, but I am independent in wearing or using it.
3 • I have marked problems with my bladder and/or bowel function, OR I need a continence device and slight assistance in wearing or using it.
4 • I have serious problems with my bladder and/or bowel function, OR I need a continence device and total assistance in wearing or using it.
5 • I have no control over my bladder and/or bowel function.

9. Usual activities

1 • I am able to perform better than some time ago my usual activities, or today I am able to perform more activities than some time ago
2 • I am able to perform my usual act ivities (e.g. employment studying, housework, freetime activities) without difficulty.
3 • I am able to perform my usual activities less effectively or with difficulty or not completely
4 • I have severe difficulties to manage activities
5 • I am totall y unable to manage activities

10. Mental function

1 • I am able to think clearly and logically, and my memory functions well.
2 • I have slight difficulties in thinking clearly and logically, or my memory sometimes fails me.
3 • I have marked difficult ies in thinking clearly and logically, or my memory is somewhat impaired.
4 • I have great difficulties in thinking clearly and logically, or my memory is seriously impaired.
5 • I am permanently confused and disoriented in place and time.

11. Discomfort and symptoms

1 • I have no physical discomfort or symptoms, e.g. pain, ache, nausea, itching, etc.
2 • Sometimes, during my normal day, I bear physical discomfort or symptoms, but it lasts no more than 15 minutes.
3 • Sometimes, during my normal day, I bear physical discomfort or symptoms, but it lasts no more than one hour.
4 • Often, during my normal day, I bear physical discomfort or symptoms.
5 • I have unbearable physical discomfort or symptoms all day long, e.g. pain, ache, nausea, itching, etc.

12. Depression

1 • I do not feel at all sad, melancholic or depressed.
2 • Sometimes, during my normal day, I feel sad, melancholic or depressed, but it lasts no more than 15 minutes.
3 • Sometimes, during my normal day, I feel sad, melancholic or de pressed, but it lasts no more than one hour.
4 • Often, during my normal day, I feel sad, melancholic or depressed.
5 • All day long I feel extremely sad, melancholic or depressed.

13. Distress

1 • I do not feel at all anxious, stressed or nervous.
2 • Sometimes, during my normal day, I feel anxious, stressed or nervous, but it lasts no more than 15 minutes.
3 • Sometimes, during my normal day, I feel anxious, stressed or nervous, but it lasts no more than one hour.
4 • Often, during my normal day, I feel anxious, stressed or nervous.
5 • All day long I feel extremely anxious, stressed or nervous.

14. Vitality

1 • I feel healthy and energic.
2 • Sometimes, during my normal day, I feel weary, tired or fleeble, but it lasts no more than 15 minutes.
3 • Sometimes, during my normal day, I feel weary, tired or fleeble, but it lasts no more than one hour.
4 • Often, during my normal day, I feel weary, tired or fleeble.
5 • All day long I feel extremely weary, tired or fleeble.

15. Sexual activity

1 • My state has no adverse effect on my sexual activity.
2 • My state has slight effect on my sexual activity.
3 • My state has a considerable effect on my sexual activity.
4 • My state makes sexual activity almost impossible.
5 • My state makes sexu al activity impossible.

ANNEX E:

The EuroQol-based Utility Instrument

It seems a scale specially developed for adult persons, become disabled after living normally a period of their life.
It is quite simple and graphic, but seems rather superficial: it never explore the real causes or reasons of some little changes one can live in his/her life.

1. Mobility
The title asks for the mobility possibilities, but in the following lines one can note the presence of the word "*walking about*". We think that the expression can be changed into "***moving around***", so as to allow to tick the box also to a person moving in a manual or electronic wheelchair.

2. Self-care
In this section we have two different questions: in the first one is asked if there is some problems with ***self-care***, as far as we can understand, *washing, dressing, undressing, using the bathroom*, etc.
In the second and third questions, one has to restrict and confine the field only to *wash and dress*.
Perhaps *evacuation* problems can be fitted inside this part, but this activity is not nominated.

3. Usual activities (e.g. work, study, housework, family or leisure activities)
It is quite difficult to think about the usual activities of a quadriplegic person always managed by others, by the mother, the assistant, the therapist. Robert, for example, in the first survey, has no personal activities, as he is always looked after and cured for the 100% of the time. His usual activities can be described as eating, sleeping, waiting for a friend's visit or the therapist's session.
How can he answer when asked about the usual activities?

4. Pain/Discomfort
The first sentence is quite clear: *I have no pain or discomfort*.
The second can wide the answer possibilities, because today almost all the people we meet can answer they are sometimes suffering "*moderate*" pain or discomfort in some manner.
The third one has the possibility to confuse the term "*extreme*": perhaps the word "***unbearable***" would limit the interpretations.
We think useful add to the questions a temporal connection:

2. ***• Sometimes I bear pain or discomfort, but it lasts no more than one hour each day***
3. ***• I have unbearable pain or discomfort all day long***

5. Anxiety/depression
The first sentence is quite clear: *I am not anxious or depressed*.
The second can wide the answer possibilities, because today almost all the people we meet can answer they are sometimes suffering "*moderate*" anxiety or depression in some manner. The third one has the possibility to confuse the term "*extremely*": perhaps the word "***always***" can limit the interpretations.

One is then asked to compare the actual level of life with the one lived in the past year. We think that this comparision is very important and useful.
The rilevation regards the word "***health***": I have to compare an objective status and not a sensation of living much the same or better/worse than one year ago.

Perhaps it can be different if we transform the sentence into:

Compared with my overall state over the past 12 months, today I feel:
better
much the same
worse

The thermometer scale can help people to place him/herself in an exact position and to visualise it.
Normally people positioning him/herself in a scale, make a comparison between the personal life situation and something else. The sentences avoid to mention every referent to other situations, or groups, or dates, but in this manner is not really clear which kind of paragon everybody is using.
We think of the necessity of a referent to a temporal indication (Today my state is 70 compared with yesterday, or one year ago, when I was only 50).
Second, we need a comparision with the group I belong to: I feel myself 70, but the majority of the people living my same situation are at 100, or 40. Only with this referent I can assume that today I live in a standard or better or worse situation.
Third: the best and worse imaginable health state are referred to a person living my own situation or to a "normal" one? It can be really different if I have to consider my personal state or the "normality". And in this case, which is the worst imaginable state I can imagine? Have I to consider and compare my situation in an absolute or relative manner?

After those considerations, we can transform the sentences as follows:

To help people say how good or bad a state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine for a person living your situation is marked by 100 and the worse state you can imagine for a person living your situation is marked by 0.

We would like you to indicate on this scale how good or bad is your own state today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your current state is.

In the bottom part of the page, we would like to add another sentence:
We would now like you to tell us where you can position the majority of the persons belonging to the group you are member of. Please circle the point on the scale which indicates where the group of persons you are member of, can be placed in your opinion.

On page seven, we think that the sentences are really clear, but, we would like to know if our interpretation is the correct one or not.
We would like you to tell us how good or bad you feel the state 'dead' is compared with being in the other states for one year
We interpret this sentence as the request of **indicating the state where one should prefer to die instead of continuing to live, the state and the position where a person looses his/her personal living dignity.**

In the following table, one can observe the weighing attempt with the connected relative lack of sensitivity of the standard EuroQol questionnaire filled in by Robert during the project

	0	a	b	c	d	e	f	g	‘94	‘95
mobility	3									3
self-care	3									3
usual activities	1									1
pain / discomfort	1									1
anxiety / depression	1									1

weigh	0.122									0.122

Questionnaire

We are trying to find out
what people think about his/her state.

We are going to describe a few states
that people can be in.
We want you to indicate how good or bad each
of these states would be for a person like you.

There are no right or wrong answers.

Here we are interested only
in your personal view.

But first of all we would like you to indicate
(on the next page)
your own state of today.

By placing a tick in one box in each group below, please indicate which statements best describe your own state of today, compared with the one you lived in the past month.

Mobility	*Today I can move around than one month ago*	*better* □	*same* □	*worse* □

I have no problems in moving around □
I have some problems in moving around □
I am unable to move around by myself □

Self-care	*Today I can manage my self care than one month ago*	*better* □	*same* □	*worse* □

I have no problems in managing my self-care □
I have some problems in managing my self-care □
I am unable to care for myself □

Usual activities (e.g. work, study, housework, family or leisure activities)	*Today I can perform my usual activities better than one month ago*	□	*same* □	*worse* □

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 □

Pain / Discomfort	*Today I bear pain/discomfort than one month ago*	*less* □	*same* □	*more* □

I never bear pain or discomfort during my normal day □
Sometimes I bear pain or discomfort, but it lasts no more than one hour each day □
I have unbearable pain or discomfort all day long □

Anxiety/Depression	*Today I feel anxious/depressed than one month ago*	*less* □	*same* □	*more* □

I never feel anxious or depressed □
Sometimes I feel anxious or depressed, but it lasts no more than one hour each day □
I always feel anxious or depressed □

Compared with my general state over the past 12 months, today I feel:

Better □
Much the same □
Worse □

To help people say how good or bad a state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine for a person living your situation is marked by 100 and the worse state you can imagine for a person living your situation is marked by 0

We would like you to indicate on this scale how good or bad is your own state today, in your opinion, compared with the one you have lived in the past month. Please do this by drawing a line from the two sentences below to whichever point on the scale indicates how good or bad your current state is, compared with the one you lived in the past month

Best imaginable state

100
95
90
85
80
75
70
65
60
Your own stato today ------> 55
50
45
Your own state one month ago -------> 40
35
30
25
20
15
10
5
0

We would now like you to tell us where you can position the majority of the persons belonging to the group you are member of. Please cirlce the point on the scale which indicates where the group of persons you are member of, can be placed in your opinion.

Worse imaginable state

Using this modified questionnaire, we have found some sensitivity more than before.
We had modified also the weighing system, using as a base the published work:
The University of York
The measurement and valuation of Health: a chronicle By Alan Williams
Discussion paper 136
This work was written during the June 1995, by the Centre for Health Economics in the University of York.

In the weighting measurement, we have not modified any of the previous weights. In the questionnaire we have only inserted one independent item: the valuation of a better or worse state, more or less difficulties.

We have tried to dimension and to assign a weigh to this modification test, using the same formula one can read in page 45 of the mentioned work, transformed into a three dimension code one can find in the following table

	coefficient	improvement	same situation	increased difficulties
		coeff * 1.1	coeff * 1	coeff * 0,9
Constant	0.081	0.081	0.081	0.081
Mobility				
level 2	0.069	0.0759	0.069	0.0621
level 3	0.314	0.3454	0.314	0.2826
Self-care				
level 2	0.104	0.1144	0.104	0.0936
level 3	0.214	0.2354	0.214	0.1926
Usual activity				
level 2	0.036	0.0396	0.036	0.0324
level 3	0.094	0.1034	0.094	0.0846
Pain / discomfort				
level 2	0.123	0.1353	0.123	0.1107
level 3	0.386	0.4246	0.386	0.3474
Anxiety /depression				
level 2	0.071	0.0781	0.071	0.0639
level 3	0.236	0.2596	0.236	0.2124
N3	0.269	0.269	0.269	0.269

ANNEX F:

The IHQL-based Utility Instrument

All the questions are referred to the last week, with a temporal comparing situation. Perhaps this amount of time is not really sufficient for appreciating some changes in the QoL.

We think IHQL is a relatively complete scale and not really simple to fill in, as it is quite long. It will take approximately 20 minutes to read all the questions, understand them and then answer doing best.

IHQL part one
1. HEALTH RELATED QUALITY OF LIFE
Has your state of health caused any impairment in your life in the past week?
The first question addresses only to a negative state. Impairment means something less than the week ago. But we think a person can also improve his/her state and consequently the QoL.
We would like to change the sentence into:
Has your state caused any modification in your life in the past week?
In this manner we would accept also a positive answer.

2. DISABILITY
Here is described in the last part the situation of a disable person *confined to a wheelchair* that he/she can control by him/herself, in a position very closed to the *Confined to bed* one. The description immediately over the wheelchair describes the impossibility of undertaking any paid employment. We think e.g. that a person sitted on a wheelchair can work, can perform a lot of different jobs. Housewives can be able to manage the house work, not only simple tasks. We would like to change the term disability into difficulty: difficulty to perform simple or complicated tasks during the "normal" daily life.

3. DISCOMFORT
4. DISTRESS
No relevant comments

IHQL part two

It is divided into four sections: disability, discomfort, distress and fulfilment

1. DISABILITY
Here the disability concept is explored more in detail, but in the sense of activities and specific sensations one can feel during his/her normal daily life.
Everywhere, we face with the impossibility of stating that our condition is better today compared with the one lived in the last week.
The expressed question is very clear: "..... any disability you may have had in the past week".
The following items ask about our ability to manage by yourself during daily life, but without considering any improvement: ***Today I feel (or I live) better than a week ago.***

a. Self-care
no more comments

b. Mobility
The sentence asks about *general mobility*, the answer transforms the meaning into *walk* and *travel*. We think that a person sitted on a wheelchair can *move around* also *without using the legs.*

c. Physical disability
In this sentence it is not clear if the physical disability one has lived in the past week can be the same of the one lived in the last year or if it is needed some change.
In Robert's case, for example, he was born with a severe disability, with a severe paralysis: shall he tick No, some or severe?
On a second hand, the term Physical disability are not correct in their meaning referred to the following sentences: we would like to translate them into **Motor impairment**

We think possible to change the sentence from:
Have you had any physical disability from any of the following in the past year? into:
Have you had any modification in your motor impairment from any of the following in the past year?
In this manner I can answer about an improvement, a positive modification of my conditions.

d. Staying away from home for treatment
No relevant comments

e. Consciousness
f. Thinking
g. Body functions
h. Medicines/Drugs/Substances
i. Sensory loss
Also in this sections we think of the importance of a positive answer: I improved my conditions in the last week.

1. Transmissibility
It is necessary to understand if the risk is a new one or if it is an already known one.

m. Occupational, social and family roles
Also in this section we think of the importance of a positive answer: I improved my conditions in the last week.

2. DISCOMFORT
No relevant comments

3. DISTRESS

a. Mood
b. Distressing treatment
No relevant comments

c. Social network
Here the possibility of social interactions is considered, by mean of personal meeting, telephone, letter. Also in this sections we think of the importance of a positive answer: I improved my general condition in the last week.

d. Communication
The communication items may appear sufficient, as they include also ***non verbal expression***. But, it has to be clear that the non-verbal expression or gesture is utilised with communicative purposes, not only as a corollarium of the real communication.

Also in this sections we think of the importance of a positive answer: I improved my communication in the last week.

e. Intimacy
f. Sexual function
g. Fulfilment
h. Attitude
No relevant comments

i. Perceived prognosis
It is the only item where one can be really positive, looking for the possibility of being cured.

In the following table, one can observe the weighing attempt with the connected relative lack of sensitivity of the standard IHQL questionnaire filled in by Robert during the project

		0	a	b	c	d	e	f	g	'94	'95
HRQL		1									1
Disability		6									6
Discomfort		1									1
Distress		1									1
weigh part one		**0.885**									**0.885**
Disability											
self care	wash	2									2
	dress	2									2
	feed	2									2
mobility	walk	3									3
	travel	3									3
physical disability	paralysis	2									2
	amputation										
	weakness										
	involontary movements	2									2
	tremor										
	stiffneess										
stayng away											
consciousness	unconscious										
	other										
thinking	memory										
	concentration										
	confusion										
	disorientation										
body function	bowel										
	bladder										
	dependent										
	transplant										
medicine / drugs / substances	prescribed	1									1
	mind affecting										
	addictive										
sensory loss	sight	1									1
	hearing										
	taste										

	smell										
	touch	2									2
trasmissibility	infection										
	inherition										
occupational / social / family	main										
	other										
	financial	4									4
	social										
	family	4									4
Discomfort											
pain physical discomfort	slight										
	moderate										
	severe										
	agonizing										
symptoms	breath										
	disfigurement										
	fatigue										
	appetite										
	eating										
	nausea										
	sleep										
Distress											
mood	depressed										
	anxious										
	elated										
distressing treatment		1									1
social network	face to face										
	telephone	1						0			
	written	1						0			
contacts	supportive	1									1
	non supportive	3									3
	hostile	3									3
	demanding	1					2				2
	needed	3									3
health professionals		1									1
communication	speech	4									4
	writing	4						1			1
	non verbal	3									3
intimacy	yes / no	2									2
	warm										
	confiding										
	listening										
	depend										
sexual function	yes/no	2									2
	loss interest										
	loss enjoyment										
	inhability to perform										
Fulfilment											
fulfilment	blamed	1									1
	stigmatized	1									1

	socially unacceptable	1									1
	loss of meaning	1									1
	dissaatisfied with life	1									1
	bored	1									1
	frustrated	1									1
	a burden to others	3									2
	loss of ambition	1									1
you understand		1									1
informed		2									1
attitude	fighting										
	resenting										
	accepting resignation	1									
	accepting positively										1
	hopeless										
	denying										
	guilty										
	punished										
	disappointed										
prognosis		3									2
weigh part two		**0.2320**									**0.2166**

Certain IHQL *(Modified version of the IHQL questionnaire in order to try to improve its sensitivity.)*

INSTRUCTIONS
Read each question carefully and answer by putting a tick in the position which best describes how things have been for you. Please, answer all questions.

HEALTH RELATED QUALITY OF LIFE:
Has your state caused any modification in your life in the past week?
Yes 0 No 0
If yes, which kind of modification?

	better	much the same	worst	extremely worst
today I feel				

DISABILITY
Which level of difficulty best describes the way things have been for you in the past week?

Today I feel **less 0** **same 0** **more 0** difficulties than the last week

1 I have no difficulties at all
2 I can perform everything I want like a week ago
3 Slight difficulties which interfere with social life
4 Severe social difficulties or slight impairment to perform heavy works
5 Severe limitation in performing works or tasks
6 Unable to undertake any paid employment
7 Unable to manage myself
8 Unconscious

DISCOMFORT
Which level of discomfort best describes the way things have been for you in the past week?

1. no discomfort
2. slight discomfort
3. moderate discomfort
4. severe discomfort
5. extreme discomfort

DISTRESS
Which level of distress best describes the way things have been for you in the past week?

1. no distress
2. slight distress
3. moderate distress
4. severe distress
5. extremely distressed or actively suicidal

1. DISABILITY
In this section we ask more detailed questions about any disability you may have had in the past week.

SELF-CARE
In the past week have you been able to care for yourself in the following ways?

	by myself	cope by myself, using special devices	only with assistance, with or without special devices	not at all
wash				
dress				
feed				

MOBILITY
In the past week has your mobility been restricted in any of the following ways?

	by yourself	by yourself with some difficulties	by yourself but only if assisted by another person	totally unable
moving around				
travel e.g. by car or public transportation				

MOTOR IMPAIRMENT

Have you had any motor impairment resulting from any of the following in the past week?

	less impairments	no alterations	some	severe
paralysis				
amputation				
weakness				
involuntary movements				
tremor				
stiffness				

STAYING AWAY FROM HOME FOR TREATMENT

In the past week have you had to stay away from home for health treatment in any of the following places?

	yes	no
General hospital		
Psychiatric unit in general hospital		
Mental hospital		
Intensive care unit		
Hospice		
Hostel or other (specify)		

CONSCIOUSNESS

In the past week has your level of consciousness been impaired in any of the following ways?
Have you...?

	never	sometimes	all the time
been unconscious			
had any other impairment of consciousness			

THINKING

In the past week have you had any of the following problems with your ability to think?

	mild	moderate	severe	extreme
memory loss				
loss of concentration				

		some	severe
confusion			
disorientation	in time		
	in place		
	in person		

Tick here if NO 0

BODY FUNCTIONS

In the past week have you been ....?

		yes, continuously	yes, intermittently	yes, but I've solved the problem by the use of special devices	no
incontinent	bowel				
	bladder				

Are you .....?

		yes, continuously	yes, intermittently	no
dependent on a machine for body functions	inside body			
	outside body			
transplant dependent			\\\\\\\\\\\\\\\\\\\\\\\\	

MEDICINES

In the past week have you been reliant on any medicines/drugs/substances that are...?

	yes, same quantity	more	less	no
Prescribed				
Mind affecting				
Addictive				

SENSORY LOSS

Have any of your senses been modified in the past week? .

		partial loss - corrected	partial loss - uncorrected	complete loss	no
sight	more				
	same				
	less				
hearing	more				
	same				
	less				
taste	more				
	same				
	less				
smell	more				
	same				
	less				
touch	more				
	same				
	less				

TRANSMISSIBILITY

Do you have a condition which could be either infectious to other or inherited by your children? If yes, how much have you been concerned about this in the past week?

	not at all	slightly	moderately	extremely
Risk of infecting others				
Risk of your children inheriting your condition				

OCCUPATIONAL, SOCIAL AND FAMILY ROLES

In the past week has your state modified your ability to perform any of the following roles?
If yes, please indicate ...

	no	mildly	moderately	severely	totally
main occupation e.g. work, house work, study					
other occupation(s) e.g. part time job, house work					

financial: providing income I financial resources					
social: social activities, recreation, hobbies, holidays					
family: family responsibilities & / or caring for dependants.					

2 DISCOMFORT

In this section we ask about any discomfort you may have had in the past week.

PAIN / PHYSICAL DISCOMFORT

Have you had any pain/physical discomfort in the past week?
If yes, please indicate

	occasionally	frequently	almost all the time	no
slight				
moderate				
severe				
agonising				

SYMPTOMS

Have you had any of the following symptoms in the paste week?

	some	severe	no
breathlessness			
disfigurement			
fatigue, lack of energy			
poor appetite			

		yes	no
eating disturbance	overeating		
	bingeing		
	self-starving		
nausea and vomiting	nausea		
	vomiting		
sleep disturbance	too much sleep		
	sleeping but not rested		
	difficulty in onset		
	interrupted sleep		
	waking early - not sleeping again		

3. DISTRESS

In this section we ask about distressing feelings and experiences, your relationships with other people and your personal sense of fulfilment.

MOOD

Have you had any problem with your mood in the past week? If yes, please indicate ...

	mildly	moderately	severely	extremely	no
depressed					
anxious					
elated for no reason (maniacal, hugh)					

DISTRESSING TREATMENT

In the past week has your state required you to have treatment which has been distressing to you?
if yes, ...

	mild	moderate	severe	extreme	no
amount of distress due to treatment					

SOCIAL NETWORK

In the past week have you had problems with the following types of contact with people?

	yes	no
face to face		
telephone		
written letter		

In the past week how much of your contacts with people have been.. ?

	a lot	a few	none
supportive			
non-supportive			
hostile			
demanding			
of a type that makes you feel needed			

How many of your contacts with people this week were with ...?

	none	a few	most
health professionals or social service workers (as opposite to family or friends)			

COMMUNICATION

In the past week has your state modified your ability to communicate with people in any of the following ways?

		mild	moderate	severe	extremely	no
verbal communication	more					
	same					
	less					
writing	more					
	same					
	less					
Non-verbal expressions or gestures (absent or abnormal)	more					
	same					
	less					

INTIMACY

Do you have a close relationship? YES 0 NO 0

If yes, would you describe this relationship as ... ?

	yes	no
warm		
confiding		
listening		
one you can depend on		

SEXUAL FUNCTION

Does sex feature in your life? YES 0 NO 0

If yes, has the condition of your state affected your sex life in the past week?

Have you had problems with ... ? .

	less	some	severe	no
loss of interest				
loss of enjoyment				
inability to perform				

FULFILMENT

Here we explore aspects of life fulfilment which may be affected by the condition of your state.
Do you feel?

	no	less	partially	a lot
blamed				
stigmatised				
socially unacceptable				
loss of meaning				
dissatisfied with life				
bored				
frustrated				
a burden to others				
loss of ambition				

Do you feel ... ?

	yes	partly	no
that you understand your state			
that you have been informed about your state			

ATTITUDE

What has your attitude towards the condition of your state been in the past week?
Has it been ... ?

	tick if yes
fighting	
resenting	
accepting with resignation	
positively accepting	
hopeless	
denying	
guilty	
justly punished	
disappointed	

PERCEIVED PROGNOSIS

How do you view the way your condition will be in the future? Do you see it as ...?

cured	improved	the same	worse	fatal

Weighing attempt **(rules adopted to weigh the new dimensions of the modified version of the IHQL questionnaire).**

To weigh this questionnaire, we have used the WP2, between page 61 and 69. The first page has no changes at all: only the real meaning of the *DISABILITY* sentences are modified somewhere, but maintaining the same weigh as before. In the other pages, one will find the new weigh in the new position in the table, all other weighs are the same as before.

HEALTH RELATED QUALITY OF LIFE:
Has your state caused any modification in your life in the past week?

Yes 0 No 0

If yes, which kind of modification?

	better	much the same	worst	extremely worst
today I feel				

DISABILITY
Which level of difficulty best describes the way things have been for you in the past week?

Today I feel **less 0** **same 0** **more 0** difficulties than the last week

1 I have no difficulties at all
2 I can perform everything I want like a week ago
3 Slight difficulties which interfere with social life
4 Severe social difficulties or slight impairment to perform heavy works
5 Severe limitation in performing works or tasks
6 Unable to undertake any paid employment
7 Unable to manage myself
8 Unconscious

DISCOMFORT
Which level of discomfort best describes the way things have been for you in the past week?

1. no discomfort
2. slight discomfort
3. moderate discomfort
4. severe discomfort
5. extreme discomfort

DISTRESS
Which level of distress best describes the way things have been for you in the past week?

1. no distress
2. slight distress
3. moderate distress
4. severe distress
5. extremely distressed or actively suicidal

1. DISABILITY

In this section we ask more detailed questions about any disability you may have had in the past week.

SELF-CARE
In the past week have you been able to care for yourself in the following ways?

	by myself	cope by myself, using special devices	only with assistance, with or without special devices	not at all
wash	0.0	0.0023		
dress	0.0	0.0018		
feed	0.0	0.0028		

[SELF-CARE wash (2=0.0062) (1=0.0038)
by myself (=0.0000)
by myself using special devices: the ratio between 2 and 1 standard position is 0.0062/0.0038=1.63
we assume the same ratio between the position 1 and the new one: 0.0038* 1.63=0.0023]

MOBILITY

In the past week has your mobility been restricted in any of the following ways?

	by yourself	by yourself with some difficulties	by yourself but only if assisted by another person	totally unable
moving around	0.0			
travel e.g. by car or public transportation	0.0			

MOTOR IMPAIRMENT

Have you had any motor impairment resulting from any of the following in the past week?

	less impairments	no alterations	some	severe
paralysis	-0.0020	0.0		
amputation	-0.0021	0.0		
weakness	-0.0011	0.0		
involuntary movements	-0.0015	0.0		
tremor	-0.0012	0.0		
stiffness	-0.0010	0.0		

STAYING AWAY FROM HOME FOR TREATMENT

In the past week have you had to stay away from home for health treatment in any of the following places?

	yes	no
General hospital		
Psychiatric unit in general hospital		
Mental hospital		
Intensive care unit		
Hospice		
Hostel or other (specify)		

CONSCIOUSNESS

In the past week has your level of consciousness been impaired in any of the following ways?
Have you...?

	never	sometimes	all the time
been unconscious			
had any other impairment of consciousness			

THINKING

In the past week have you had any of the following problems with your ability to think?

	mild	moderate	severe	extreme
memory loss				
loss of concentration				

		some	severe
confusion			
disorientation	in time		

	in place		
	in person		

Tick here if NO 0

BODY FUNCTIONS

In the past week have you been ....?

		yes, continuously	yes, intermittently	yes, but I've solved the problem by the use of special devices	no
incontinent	bowel			0.0025 (ratio 1.46)	0.0
	bladder			0.0017 (rato 1.62)	0.0

Are you .....?

		yes, continuously	yes, intermittently	no
dependent on a machine for body functions	inside body			
	outside body			
transplant dependent			\\\\\\\\\\\\\\\\\\\\\\\\	

MEDICINES

In the past week have you been reliant on any medicines/drugs/substances that are...?

	yes, same quantity	more	less	no
Prescribed		0.0042 (0.0028 + ½ * 0.0028)	0.0014 (0.0028 - ½ * 0.0028)	
Mind affecting		0.0100 (0.0067 + ½ * 0.0067)	0.0033 (0.0067 - ½ * 0.0067)	
Addictive		0.0090 (0.0061 + ½ * 0.0061)	0.0030 (0.0061 - ½ * 0.0061)	

SENSORY LOSS

Have any of your senses been modified in the past week? .

		partial loss - corrected	partial loss - uncorrected	complete loss	no
sight	more	0.0022 (0.0015+1/2*0.0015)	0.0053	0.0099	
	same	0.0015			
	less	0.0007 (0.0015 + ½ * 0.0015	0.0017	0.0033	
hearing	more	0.0022	0.0050	0.0090	
	same				
	less	0.0007	0.0016	0.0030	
taste	more	0.0011	0.0024	0.0051	
	same				
	less	0.0004	0.0008	0.0017	
smell	more	0.0070	0.0021	0.0045	
	same				
	less	0.0002	0.0007	0.005	
touch	more	0.0012	0.0027	0.0045	
	same				
	less	0.0004	0.00089	0.0015	

TRANSMISSIBILITY

Do you have a condition which could be either infectious to other or inherited by your children? If yes, how much have you been concerned about this in the past week?

	not at all	slightly	moderately	extremely
Risk of infecting others				
Risk of your children inheriting your condition				

OCCUPATIONAL, SOCIAL AND FAMILY ROLES

In the past week has your state modified your ability to perform any of the following roles?
If yes, please indicate ...

	no	mildly	moderately	severely	totally
main occupation e.g. work, house work, study					
other occupation(s) e.g. part time job, house work					
financial: providing income I financial resources					
social: social activities, recreation, hobbies, holidays					
family: family responsibilities & / or caring for dependants.					

2 DISCOMFORT

In this section we ask about any discomfort you may have had in the past week.

PAIN / PHYSICAL DISCOMFORT

Have you had any pain/physical discomfort in the past week?
If yes, please indicate

	occasionally	frequently	almost all the time	no
slight				
moderate				
severe				
agonising				

SYMPTOMS

Have you had any of the following symptoms in the paste week?

	some	severe	no
breathlessness			
disfigurement			
fatigue, lack of energy			
poor appetite			

		yes	no
eating disturbance	overeating		
	bingeing		
	self-starving		
nausea and vomiting	nausea		
	vomiting		
sleep disturbance	too much sleep		
	sleeping but not rested		
	difficulty in onset		
	interrupted sleep		

	waking early - not sleeping again		

3. DISTRESS

In this section we ask about distressing feelings and experiences, your relationships with other people and your personal sense of fulfilment.

MOOD

Have you had any problem with your mood in the past week? If yes, please indicate ...

	mildly	moderately	severely	extremely	no
depressed					
anxious					
elated for no reason (maniacal, hugh)					

DISTRESSING TREATMENT

In the past week has your state required you to have treatment which has been distressing to you?
if yes, ...

	mild	moderate	severe	extreme	no
amount of distress due to treatment					

SOCIAL NETWORK

In the past week have you had problems with the following types of contact with people?

	yes	no
face to face		
telephone		
written letter		

In the past week how much of your contacts with people have been.. ?

	a lot	a few	none
supportive			
non-supportive			
hostile			
demanding			
of a type that makes you feel needed			

How many of your contacts with people this week were with ...?

	none	a few	most
health professionals or social service workers (as opposite to family or friends)			

COMMUNICATION

In the past week has your state modified your ability to communicate with people in any of the following ways?

		mild	moderate	severe	extremely	no
verbal communication	more	0.0052 (0.0035 + ½ * 0.0035	0.0108	0.0170	0.0202	
	same	0.0035				
	less	0.0017	0.0036	0.0056	0.0067	
writing	more	0.0025	0.0055	0.0090	0.0123	
	same					
	less	0.0008	0.0018	0.0030	0.0041	

Non-verbal expressions or gestures (absent or abnormal)	more	0.0040	0.0084	0.0127	0.0160	
	same					
	less	0.0013	0.0028	0.0042	0.0054	

INTIMACY

Do you have a close relationship? YES 0 NO 0

If yes, would you describe this relationship as ... ?

	yes	no
warm		
confiding		
listening		
one you can depend on		

SEXUAL FUNCTION

Does sex feature in your life? YES 0 NO 0

If yes, has the condition of your state affected your sex life in the past week?

Have you had problems with ... ? .

	less	some	severe	no
loss of interest	0.0016 (ratio 2.46)			
loss of enjoyment	0.0022 (ratio 2.26)			
inability to perform	0.0037 (ratio 1.87)			

FULFILMENT

Here we explore aspects of life fulfilment which may be affected by the condition of your state.

Do you feel?

	no	less	partially	a lot
blamed		0.0016 (ratio 2.00)		
stigmatised		0.0020 (ratio 1.75)		
socially unacceptable		0.0022 (ratio 1.75)		
loss of meaning		0.0025 (ratio 1.82)		
dissatisfied with life		0.0024 (ratio 1.79)		
bored		0.0010 (ratio 2.36)		
frustrated		0.0017 (ratio 1.94)		
a burden to others		0.0032 (ratio 1.66)		
loss of ambition		0.0022 (ratio 1.86)		

Do you feel ... ?

	yes	partly	no
that you understand your state			
that you have been informed about your state			

ATTITUDE

What has your attitude towards the condition of your state been in the past week?

Has it been ... ?

	tick if yes
fighting	
resenting	
accepting with resignation	
positively accepting	

hopeless	
denying	
guilty	
justly punished	
disappointed	

PERCEIVED PROGNOSIS

How do you view the way your condition will be in the future? Do you see it as ...?

cured	improved	the same	worse	fatal

ANNEX G:

The MMHCS-based Utility Instrument

McMaster has no temporal referents at all. It displays the questions only in the present time. It seems to explore only the present condition.

Standard MMHCS

* The first question ask about the "run" possibilities. If we try to change the word into “cover”, we gain the possibility of a positive answer also for all the persons living sitted on a wheelchair, even if it is an electronic one.
We suggest to change from
1. Today are you physically able to run a short distance, say 300 feet, if you are in hurry?
into:
1. Today are you able to quickly cover a short distance, say 300 feet, if you are in hurry ?

* The second question allows only two answer possibilities: *Difficulty, No difficulty* We suggest to spread this answer into four categories:
I'm independent
I'm independent, but with the help of assistive devices
I need assistive devices and assistance from other people
I'm totally dependent from an assistant

Secondly, we suggest to change at least two of the sentences:
a. cover as far as a mile
b. cover the distance between two different flats

We think the following table can summarise our expansion intent.

	I'm independent	I'm independent but need aids	I need aids and assistance	I’m totally dependent
cover one mile distance				
cover the distance existing between two flats				
stand up and sit down				
feed				
undress				
wash				
shop				
cook				
housework				
clean floors				

* Sport

Here we can face a strange situation: a person cannot "walk" by him/herself around, but can practice sports, like swimming, hockey, golf and so forth. This question has no wheelchair limitations. And then I cannot walk by myself, but I can play golf sitted on a wheelchair.

* Also in this question the authors used the word "walk". We prefer to change into "move around".

At present, are you able to move around out of doors by yourself ? (also when the weather is bad ?)

1) What is the farthest you can ***move around*** by yourself?
   - one mile or more
   - less than 1 mile, more than 30 feet
   - less than 30 feet

2) Are you able to move around by yourself?
   - between rooms
   - only within a room
   - 6 can't move around at all

From question 5. till to the end we have no relevant suggestions.

In the following table, one can observe the weighing attempt with the connected relative lack of sensitivity of the standard MMHCS questionnaire filled in by Robert during the project

			0	a	b	c	d	e	f	g	'94
run distance			1								1
walking			1								1
climbing			1								1
standing up											
feeding			1								1
undressing			1								1
washing			1								1
shopping			1								1
cooking			1								1
dusting			1								1
cleaning floors			1								1
sports			1								1
walk out of doors	no		1								1
		are you able to walk by yourself?	6								6
	yes										
		what is the farthest you can walk by yourself?									
bus			2								2
car			2								2
driving a car			2								2
wear glasses	no	newsprint									
		headacke									
	yes	newsprint	1								1
		headacke	1								1
wear hearing aid	no	conversation	1								1
		television	1								1
	yes	conversation									

		television									
10			1								3
11			1								3
12			2								2
13			3								4
14			3								3
15			5								3
16			1								1
17			3								2
18			3								3
19			3								4
20			1								1
21			2								2
22			3								2
23			3								4
24			3								3
25			3								4
26			4								4
27			4								4
health			1								1
things			1								1
spending life			2								2
physical			3								2
social			3								2
emotional			2								2
working	yes										
	no		6								6
television			4								4
social	church		2								2
	relative's home		1								1
	other										
visit	relative		2								2
	friend		2								2
	religious		2								2
	social agency		1								2
phone			2								2
used telephone	friend		1								2
	religious		1								1
	social agency		1								2
called by telephone			1								2
holiday			10								3
separation			1								1
divorce			1								1
welfare			1								1
trouble with friends			1								1
retired			1								1
other											
weigh			-0.11519						-0.11519		

CERTAIN MMHCS *(Modified version of the MMHCS questionnaire in order to try to improve its sensitivity.)*

Section A: Physical function items

1. Today are you able to quickly cover a short distance, say 300 feet, if you are in hurry?

1. no 2. yes

2. To day do you have any physical difficulty at all with

	I'm independent	I'm independent but need aids	I need aids and assistance	I'm totally dependent
cover one mile disatance				
cover the distance existing between two flats				
stand up nd sit down				
feed				
undress				
wash				
shop				
cook				
housework				
clean floors				

3. Today are you physically able to take part in any sports or exercise regularly?

1. no 2. yes

4. At present, are you able to move around out of doors by yourself? (also when the weather is bad?)

a. What is the farthest you can move around by yourself?

1 one mile or more
2 less than 1 mile, more 30 feet
3 less than 30 feet

b. Are you able to move around by yourself?

4 between rooms
5 only within a room
6 can't move around at all

5. Today do you have any physical difficulty at all travelling by bus whenever necessary?

1. no 2. yes

6. Today do you have any physical difficulty at all travelling by car whenever necessary?

1. no 2. yes

7. Today do you have any physical difficulty at all driving a car by yourself?

1. no 2. yes

8. Do you wear glasses?

2. yes

1. no

a. Do you have any trouble seeing ordinary newsprint when you wear your glasses?

1. never
2. sometimes
3. always

c. Do you have any trouble seeing ordinary newsprint?

1. never
2. sometimes
3. always

b. Do you have a headache after watching television or reading when you wear your glasses?

1. never
2. sometimes
3. always

d. Do you have a headache after watching television or reading?

1. never
2. sometimes
3. always

9. Do you wear a hearing aid?

2. yes

1. no

a. Do you have trouble hearing in a normal conversation with several other persons when you wear your hearing aid?

1. never
2. sometimes
3. always

c. Do you have trouble hearing in a normal conversation with several other persons?

1. never
2. sometimes
3. always

b. Do you have trouble hearing the radio or television when you wear your hearing aid?

1. never
2. sometimes
3. always

d. Do you have trouble hearing the radio or television

1. never
2. sometimes
3. always

Section B:

Emotional function items

Often people's state affects the way they feel about life. For these next questions, please circle the choice that is closest to the way you feel about each statement.

If you strongly agree, circle 1
If you agree, circle 2
If you are neutral, circle 3
If you disagree, circle 4
If you strongly disagree, circle 5

		agree				disagree
10	I sometimes feel that my life is not very useful	1	2	3	4	5
11	Everyone should have someone in his life hose happiness means as much to him as his own	1	2	3	4	5
12	I am a useful person to have around	1	2	3	4	5
13	I am inclined to feel that I'm a failure	1	2	3	4	5
14	Many people are unhappy because they do not know what they want out of life	1	2	3	4	5
15	In a society where almost everyone is out for himself, people soon come to distrust each other	1	2	3	4	5
16	I am a quick thinker	1	2	3	4	5
17	Some people feel that they run their lives pretty much the way they want to and this is the case with me	1	2	3	4	5
18	There are many people who don't know what to do with their lives	1	2	3	4	5
19	Most people don't realise how much their lives are controlled by plots hatched in secret by others	1	2	3	4	5

20	People feel affectionate towards me	1	2	3	4	5
21	I would say I nearly always finish things once I start them	1	2	3	4	5
22	When I make plans ahead, I usually get to carry out things the way I expected	1	2	3	4	5
23	I think most married people lead trapped (frustrated or miserable) lives	1	2	3	4	5
24	It's hardly fair to bring children into the world the way things look for the future	1	2	3	4	5
25	Some people feel as if other people push them around a good bit, and I feel this way too	1	2	3	4	5
26	I am usually alert	1	2	3	4	5
27	Nowadays a person has to live pretty much for today and let tomorrow take care for itself	1	2	3	4	5

Section C:
Social function items

This section contains some questions on general state and on your social activities.

28. How would you say your state is today?
    1. very good
    2. pretty good
    3. not too good

29. Taking all things together, how would you say things are today? you are..
    1. happy
    2. pretty happy
    3. not very happy

30. In general, how satisfying do you find the way you're spending your life today?
    1. completely satisfying
    2. pretty satisfying
    3. not very satisfying

31. How would you say your physical functioning is today (we mean the ability to move around, see, hear and talk)
    1. good
    2. good to fair
    3. fair
    4. fair to poor
    5. poor

32. How would you say your social functioning is today? (we mean your ability to work, to have friends, and to get along with your family)
    1. good
    2. good to fair
    3. fair
    4. fair to poor
    5. poor

33. How would you say your emotional functioning is today? (We mean your ability to remain in good spirits most of the time and to be usually happy and satisfied with your life)
    1. good

2. good to fair
3. fair
4. fair to poor
5. poor

34 Are you presently working on a job for wages, either full- or part-time?

1. yes --->go to Q. 35
2. no ---- Are you presently
   - on vacation
   - on a sick leave
   - retired
   - a student
   - a housewife
   - other (please specify) _____

35. How much time, in a one-week period, do you usually spend watching television?

1. none
2. less than three hours a week
3. less than one hour a day
4. more than two hours a day

36. Which of the following describe your usual social and recreational activities?

* going to church
  - no
  - yes
* going to a relative's home
  - no
  - yes
* any other activities? (please specify)

37. Has anyone visited you in the last week?

* a relative
  - no
  - yes
* a friend
  - no
  - yes
* a religious group member
  - no
  - yes
* a social agency representative
  - no
  - yes

38. Do you have a telephone?

1. no ----> go to Q. 41
2. yes

39. Have you used your telephone in the last week to call

* a friend
  - no
  - yes
* a religious group member

no
yes

* a social agency representative
no
yes

40. Have you been called in the last week by a social agency representative?
1. no
2. yes

41. How long has it been since you last had a holiday? (Write in number '0' if presently in holidays)
months _____ OR _____ years

42. During the last year, have any of the following things happened to you?
* separation from your spouse?
no
yes
* divorce?
no
yes
* going on welfare during the last year?
no
yes
* trouble getting along with friends/relatives during the last year?
no
yes
* retired from work during the last year?
no
yes
* some other problem or change in your life? (please specify)
_____

The weighing instrument has not really changed. We have utilised, as basis, the WP2, between page 78 and page 80, with the formula utility = 1.42 (ml * m2 * m3 * m4) - 0.42