



DEVELOPING INDICATORS AND IMPACT ASSESSMENT METHODOLOGIES ON ICT FOR AGEING WELL

Exploratory Workshop

Brussels, 19 October 2009
Borschette Centre

Workshop results and major findings

Contents

1. Executive Summary	3
2. Introduction	4
3. Practical indicators for impact assessment.....	4
3.1 Indicators for Quality of Life Improvements	5
3.2 Indicators and methodologies for economic impact	11
4. Specific challenges for indicators and impact assessment methodologies	14
5. Conclusions	16
6. Next Steps	18

1. Executive Summary

The emerging demographic change towards an ageing population is introducing drastic changes in our society. We therefore need to find ways to motivate and assist older people to stay active for longer in the labour market, to prevent social isolation and promote societal inclusion and finally to help people stay independent for as long as possible.

There have been numerous experiments and smaller scale pilot projects developing and testing Independent living, telecare and telehealth solutions. A challenge is however still **to strengthen measurement of the anticipated improved quality of life for the users and socio-economic benefits for the care systems** in a scientifically acceptable way. Solid evidence on common indicators and statistically significant impact measurement methodologies are essential to convince policy makers and industry to invest further in wide deployment and uptake of solutions.

The scale and frequency of trials is now increasing due to the large interest in the ageing well domain. There is thus a strong need to align even more the individual projects' approaches, to set up mechanisms for best practice exchange on indicators and methodologies employed in order to advance comprehensiveness and ensure comparability of evidence collected to be used for meaningful policy and investment decisions.

The purpose of this workshop has been therefore to bring together relevant representatives of ongoing or planned major trials in this field, who shared knowledge and contributed with practical experience with a view to defining good practice and recommendations for the future. A major contribution came from participants in the pilot projects for ageing well launched under the European Commission's CIP ICT Policy Support Programme.

In terms of outcomes, an initial set of possible common indicators stemming from the ongoing projects and pilots work was analysed; ground-rules for constructing statistically significant impact measurement methodologies in this field were discussed and initial recommendations and guidelines for comparable future impact measurements arose from an interactive brainstorming and discussion amongst the participants.

The results are to be further taken up by a follow-up work in a form of a repository of existing relevant documents to serve as background for further discussions and intensified and structured best practice exchange. The purpose is **to develop a common framework for arriving at solid and comparable evidence to facilitate policy decisions and further investment for wide deployment and uptake of solutions.**

Overall the exchange confirmed the relevance of the topic - detailed results of the workshop have been captured in this report, to be published and widely disseminated as part of the Commissions' ICT for Ageing Well action plan.

2. Introduction

In the context of the CIP ICT-Policy Support Programme and the emerging pilot projects on ICT for Ageing Well, the workshop has focused on exchanging information about experience and practice in developing relevant indicators and possible reliable measurement methodologies.

The workshop methodological approach was based on a set of initial presentations, that set the scene, followed by a brainstorming ('tour de table') for each of the participants who expressed their opinion, shared current practices and arrived at indications on possible common guidelines / scenarios.

Pilots on the ground with corresponding indicators and methodologies focused on **quality of life indicators** for ageing people and informal carers and on **economic indicators**, measuring costs and efficiency gains for actors along the whole value chain.

Measuring socio-economic impact of ICT for Ageing Well products and services was discussed based on an exchange of views and practices on exemplary cases and approaches used so far, trying (1) to identify the advantages and shortcomings of current methodologies and indicators and (2) to establish general principles in selecting and further developing methodologies and indicators that ensure statistically meaningful results, comparability, use scenarios etc.

The discussion on next steps aimed to figure out what kind of further cooperation and support would be expected related to this topic, not only in terms of other events but most of all on setting up of a practitioners' community and forum on ePractice.

3. Practical indicators for impact assessment

A growing body of evidence shows that independent living, telecare and telehealth solutions provide multiple benefits for the elderly and social care system; however these benefits have to be properly documented in order to determine the overall impact of ICT solutions. To this end identification and consistent application of **outcomes**, reliable **indicators** and **measurement tools** are necessary. Reliable indicators would document the changes in status attributable to ICT interventions, and how status changed over time following implementation of such solutions. Well chosen indicators could stimulate change and encourage future investment, identifying transferable technologically appropriate and culturally sensitive ICT solutions that could be implemented when and where similar problems are observed.

Within the context of the workshop particular attention was given to **outcome indicators** (and corresponding measurement tools); here outcome indicators are understood as parameters desired to assess in order to determine if an ICT intervention has had a result or visible effect. Examples of such indicators are quality of life, quality of care, etc.

Many pilot projects are currently underway, both under the CIP ICT-Policy Support Programme as well as on a national level using a variety of methodologies and indicators to capture and demonstrate the benefits that arise from ICT mediated solutions. The first part of the workshop focussed therefore on the identification, presentation and discussion of the main practical indicators for impact assessment considered by the various projects and initiatives represented at the event.

3.1 *Indicators for Quality of Life Improvements*

One of the aims of ICT solutions in the context of ageing well is to help improve the quality of life and perspectives of being able to live independently and healthily in real-life situations.

However, improvements in quality of life are difficult to measure and showing the effectiveness of ICT based solutions on its basis may prove problematic without careful operationalization of the concept. Quality of life consists of both objectively measurable conditions and subjective aspects of good life. It's an individual's understanding of her life situation with respect to her values and cultural context, as well as in relation to her goals, expectations and concerns. Person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment are seen as essential dimensions or prime determinants of subjective quality of life.¹ The role of ICT solutions is to mediate the relationships between these predictors and the concept of quality of life in order to improve the latter.

An overview of the instruments for assessing the quality of life improvements employed by the projects presented at the workshop reveals how the term was operationally² conceptualized. A short presentation and methodological approaches of each project are described.

1. PERSONA project aims to develop integrated solutions, i.e. Ambient Assisted Living Services for social inclusion, support in daily life activities, early risk detection, personal protection from health and environmental risks, support in mobility and displacements within neighbourhood for elderly persons.

The improvements in quality of life due to ICT intervention are measured against the functional level of the end user ability to **perform activities of daily living (ADL)** (i.e. dressing, shopping, cleaning or visit friends) instead of being dependent of public or private services. Moving away from the “elderly as fragile and weak” approach, the project focuses on resources old people or persons with functional disabilities need in order to carry out day to day activities.

The project relies on the ICF (**International Classification of Functioning, Disability and Health**)³ as frame of reference and **SF-36v2** survey as supporting tool in order to:

- develop a universal methodology to describe and measure end users improvements or decline in health functions & well-being
- review and test the methodology and the assessment tools during the trial
- evaluate if the methodology can establish a generic approach to measure benefits of technological interventions in health & social care

¹ WHOQOL Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL). Springer Netherlands 2004; 2(2).

² For the purpose of this report an operational definition is one that denotes specific quality of life factors measured in the selected projects: e.g.: physical and psychological functioning, social functioning, independence etc.

³ World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO, 2001

The International Classification of Functioning, Disability and Health (ICF) systemizes the overall elements of citizen's functional ability: Body Structure/Function, Activity and Participation. Additionally, it considers the contextual factors (surroundings) and personal factors as components that can enhance or limit functional ability, depending on how the citizen experiences limitations (i.e. due to possible weakness, illness and/or handicap). The interaction of ICF concepts is illustrated below (Figure1). The advantages of ICF rely on its focus on the consequences of disease, disability and impairment, the comprehensive view of the user assessment and widely acceptance among social care and health professionals.

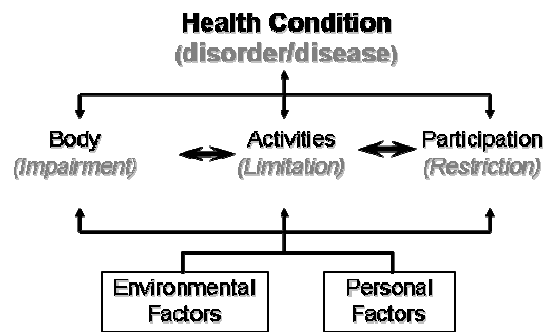


Figure 1. Interaction of ICF concepts

Based on the ICF framework the project has developed the so-called '*ICF Persona version*' along the following lines:

1. Activity – **Professional evaluation** (individual's functional ability, consequences of weakness, illness and/or handicap)
2. Participation - **Everyday Living** (citizen's everyday life)
3. Body - **Health condition** (physical function depreciation, any problem with bodily functions)
4. Environment and Personal factors - **Contextual factors** (citizen's home and citizen's capacity to master things)

The PERSONA project measures **Activity** based on functional levels (level of limitations) and comprises the following categories: eat; drink; take a bath; wash; nurse the body; get dressed and undressed; use the toilet; move around own accommodation; shop daily necessities; cook; clean; wash linen; go outside; use public transportation; move; prevent diseases or deterioration in functional ability; secure continuity in activities of daily life.

Participation is operationalized as citizens' everyday living and it is focused on the experienced limitations, wishes and priorities. Participation level (data on activities, monitoring level of performance and relevance) is measured against the following categories: work/education; contact to family and friends; interest/hobbies; meals; personal hygiene; daily housekeeping; maintenance of house & garden; shopping; mobility.

Body - Since offering health services to the users is not the main aim of the project, a basic classification of the citizen's health condition was considered sufficient. The ICD-10 (International Statistical Classification of Diseases and Related Health Problems) is used for assessing this element in the '*ICF Persona version*'.

Contextual factors documentation has been limited to contain the overall expressions about the *Home's interior design* and *Personal factors*.

- The first category includes an assessment of the degree of limitation/compatibility that home's interior design may introduce in the citizen's ability to complete the activities: the entrance conditions to the home (from in the home to the outside); the kitchen's design; the living room's design; the bedroom's design; the toilet and bathroom's design.
- Personal factors are understood as 'capacity to master things'. The capacity to master things expresses which resources (capacity) the citizen has in relation to ability to act when unprepared situations occur in which the citizen does not necessarily know how he should react. In 'ICF Persona version' an overall registration of whether a citizen's mastering capacity is relatively low, middle or high. The expression is related to the Professional Evaluation and is connected to a specific decision.

Short Form 36 (SF-36v2) is a self-report survey with 36 questions that assess the general health status measuring domains of physical functioning, role limitations-physical, bodily pain, general health, vitality, social functioning, role limitations-emotional, mental health. It has been recognized as one of the most widely used instruments for the measurement of health related quality of life (HRQOL). It provides scores for each of the eight health domains, psychometrically-based physical component summary (PCS) and mental component summary (MCS) scores. It is a generic measure, as opposed to one that targets a specific age, disease, or treatment group. Accordingly, the SF-36 has proven useful in surveys of general and specific populations, comparing the relative burden of diseases, and in differentiating the health benefits produced by a wide range of different treatments.

SF-36 survey is used in PERSONA project as a supporting method for defining the user profile. A preference-based utility index, called the SF-6D, is also available to help understand economic benefits. It is available in more than 110 languages.

2. DREAMING project aims to assess the impact of health and environment monitoring, alarm handling and purpose-designed videoconferencing on elderly people. One of the objectives is to improve the **quality of life** of elderly people by extending their independent life even when they live alone, by providing a level of safety equivalent or better than that enjoyed in elderly homes.

The project uses Controlled Randomised Trial method in order to demonstrate that ICT, if properly tuned to the specific needs of the elderly, can have positive impact on a number of relevant indicators. The trial framework includes a single trial protocol for 6 trial sites, discussed and agreed by clinicians from each of them. The same technological platform has been adopted by all the 6 trial sites. The trial set-ups were adapted to the organisation in place in each of them. A standard care has been provided to the Control Group documented in the protocols.

Quality of life: Listed among the **primary outcomes** of the project **health related quality of life (HRQOL)** is assessed by SF-36 questionnaire, at the beginning, midterm and the end of trial period.

3. Long Lasting Memories (LLM) regards the market validation of an integrated ICT platform which combines mental exercises against cognitive deterioration with physical activity in the framework of an advanced ambient assisted living environment. By combining cognitive exercises and physical activity LLM delivers an effective countermeasure against age-related cognitive decline, reducing chances of mild dementia or Alzheimer's disease appearance.

LLM project uses a **Randomized Controlled Trial** research design. Testing is focused on elderly volunteers who are screened and monitored throughout the course of the trials to provide high quality data and feedback to help improve the LLM solution. The service is targeted at three categories of end-users (testing participants): people living at home, people in day care centres and hospitalized people.

In the context of quality of life improvements the project identifies primary and secondary health related outcomes. The measurement will capture:

- Improvements of *experimental group* in standardized cognitive function and cognitive/motor activity in daily living relative to *control groups*. (primary outcome, neuro-psychological testing)
- Changes in abnormal brain waves that correlate with mild cognitive decline and dementia (using MEG-Konstanz or EEG).
- **Quality of life** is measured relative to improvement in cognitive, motor and social function indices and autonomy. Personal interviews and caregiver or relative answers are developed in order to identify additional changes in the above mentioned categories.

4. ISISEMD - The aim is to provide a pilot of innovative intelligent set of scalable services that will support the independent living of elderly people in general and in particular the group of elderly with cognitive problems or mild dementia and at the same time to support the formal and informal caregivers in their daily interaction with the elderly. The project addresses the needs of three target end-user groups - elderly, formal and informal caregivers.

Quality of life rating scales and indicators for all three target groups were developed:

- 1) Rating scales for the primary end-users - elderly with mild dementia (*see Table 1*)
 - Cognitive functioning for patients (**MoCA/MMSE**)
 - **Katz's Scale** for activities of daily living (ADL) and **Lawton and Brody's scales** for instrumental activities of daily living (IADL)
 - Quality of Life (QOL) of patient with mild dementia - **Quality of Life – Alzheimer's disease (QOL-AD, Logsdon scale)**
- 2) Rating scales for the secondary end-users, informal caregivers (*see Table 2*)
 - Quality of Life (QOL) of informal caregiver - **Scale of Quality of Life of Care-Givers (SQLC, Glozman scale)**
 - Burden of care - **Zarit Burden Interview (ZBI)**
 - For formal caregivers – QOL will not be measured; only user acceptance and satisfaction with the ICT services will be measured, based on **specifically designed ISISEMD questionnaire**

Table 1. Quality of life predictors and measurement tools for elderly persons with mild dementia (primary end-users)

QoL dimensions	Predictors (determinants)	Measurement tools
Level of cognitive functioning	Cognitive domains of executive function, Visuo-spatial function, New learning, Attention and concentration, Abstraction, Memory, Language, Conceptual thinking, Calculations and Orientation.	MMSE - Mini-mental State Examination scale MoCA – Montreal Cognitive Assessment scale
Activities of Daily Living (ADL)	Bathing, dressing and undressing, eating, transferring from bed to chair, voluntarily control urinary and fecal discharge, using the toilet, walking.	Katz's Activities of Daily Living Scale
Instrumental Activities of Daily Living (IADL)	Light housework, taking medication, shopping for groceries and cloths, using the telephone, care of others, care of pets, child rearing, communication device use, community mobility, financial management, safety procedure and emergency responses.	Lawton and Brody's Scales

A specific conceptualization of Quality of Life of people with dementia is develop by **Logsdon – Quality of Life Alzheimer's Disease Scale (QoL-AD)**; here, the following QoL domains and predictors are subject to assessment: Physical and mental health (physical status, memory, energy, mood); Social contact (family, friends); Attachment (marriage); Enjoyment of activities (leisure); Ability to contribute (being useful); Financial situation.

Table 2. Quality of life predictors and measurement tools for informal caregivers (secondary end-users)

QoL Predictors (determinants)	Measurement tools
Professional activity, social and leisure, responsibilities of the caregiver to help the patient in everyday living	Glozman Quality of Life for Caregivers Scale (SQLC)
Emotional strain, level of frustration, fulfilment, caregiver uncertainty, social and financial support, physical domains	Zarit Burden Interview (ZBI) for the measurement of caregiver burden/stress.

Additional aspects to be considered that may improve the quality of life of groups, patients and caregivers alike, as a result of an ICT intervention: perception of safety; level of user satisfaction with the ICT solution/service offered, access to extra services and care not offered with traditional public care.

5. CAALYX-MV project (to start in 2010) objective is to widely validate an innovative and efficient ICT based solution focused on improving the elder’s quality of life by prolonging the time they can stay safer, autonomous and independently at home, by monitoring and controlling their social and health status and providing them with some tools and services to support their daily home activities in terms of comfort, security, energy efficiency and communications. CAALYX-MV system consists of a wearable light device able to measure specific vital signs of the elderly, as well as to detect falls and to communicate autonomously in real time with his/her caregiver and/or the 112 Emergency Service in case of an emergency.

The project will employ a *pre/post methodology (before and after)* in order to measure project impact. To this end a **baseline** will be established by recording the health and social care services costs undertaken by a sample of at least 40 users over a 3 month period without using the CAALYX-MV. At the midterm after a trial of 6 months using CAALYX-MV, the expectation is to reach an increased interest in using tele-monitoring systems by all the actors involved; at the end of the project, after the third trial, the expectation should at least reach a reduced number of visits to the doctor or care centres and 85% users acceptance.

Indicators as users' satisfaction, number of visits face-to-face, quality of life improvements due to home security will be taken into account in order to measure and compare the rates before and after the project implementation of the pilots.

6. T-SENIORITY aims to improve the quality of life of elderly people through an ICT innovative solution based in digital inclusion through TV.

T-Seniority is a set of integrated e-care services addressed to elders and info-marginalised audiences and their informal carers (families, neighbours, etc.). Its main target is a “user-centric” integration of services delivered through TV, especially assistance programmes (including trans-borders services) for disadvantaged social groups. It aims to cover a diverse range of care needs in a wide range of services modalities (home care, tele-assistance, mobile telecom services, tele-alarms, nursing services...).

T-Seniority services are accessed by TV, the most widely available and preferred channel by info-marginalised sectors.

The real added value of the project results in its ability to address two main issues of concern at European level relative to the risk of exclusion (the so called 'key success factors'):

- Availability: People disadvantaged due to lack of geographical coverage
- Accessibility:
 - ✓ People with disabilities such as visual, audio, speech, cognitive or mobility related impairments
 - ✓ People who are lacking ICT skills.

Aging Well – A US perspective: *Within the scope of the workshop, current developments in the field of ICT for Ageing Well in the US were discussed with a view to identify common ground for future exchange of knowledge between researchers and practitioners in the field of measurement methodologies and indicators.*

Discussions on aging well in the US are inevitably linked to the current Reform of the US Health Care System. Here, a great deal of emphasis is placed on preventing medical errors and addressing cost explosion problems with the reimbursement system.

Exploring opportunities to pursue EU –US synergisms should start with the acknowledgement of common problems that both sides have to address: a similar increase in the aging population and related issues (e.g. cost of care for older adults).

From the US perspective main problems associated with ageing that constitute a focus of current research refer to:

- Functional decline
- Falls
- Chronic diseases
- Depression
- Caregiver burden

As decline in function and occurrence of disease that marks the aging process are addressed through various interventions, outcome measures to assess the effectiveness/efficacy of these interventions are necessary. Traditional outcome measures are survey-based and include the **SF-36** (widely used in the US), the Health Related Quality of Life (HRQOL), **EuroQoL Group 5-Dimension Self-Report Questionnaire (EQ-5D)**, mainly used in Europe – United Kingdom 36% and Continental Europe 42% - in order to measure health related quality of life⁴, and the **Health Utility Index (HUI)**⁵, mostly used in Canada. Further information can be found at <http://www.euroqol.org/> and <http://www.medal.org/visitor/www/inactive/ch1.aspx>

More recently, attempts have been made to minimize the time necessary to administer these survey-based measures by relying on methods based on the item-response theory (Late Life Function and Disability Instrument). However all these methods suffer from perception and recollection bias.

Opportunities for US-EU cooperation are to be found in developing standards and interoperability, coordination of study design, sharing research platforms (common devices, data-sets and algorithms) and exchange of best practices in the field.

3.2 Indicators and methodologies for economic impact

The economic impact or the 'savings' that can be attributed to various ICT led interventions are of considerable interest to both policy makers and industry. Wide deployment and uptake of ICT solutions are based in part on expectations of reducing costs, controlling resource allocation, improving service quality. The second part of the workshop focussed on the identification, presentation and discussion of the main practical indicators for **economic** impact and cost analysis considered by the various projects represented at the event.

1. CIP DREAMING aims to provide a documented *return-on-investment (RoI)* by comparing the costs associated to the provision of services with savings in other areas of health and social care. Unlike traditional return-on-investment models, in health care, benefits are frequently gained from cost avoidance rather than from revenue enhancement activities.

The project distinguishes between two categories of **clinical/economic indicators** (cash and time releasing):

4 EQ-5D is a standardised instrument used as a measure of health outcome developed by a network of researchers, originally from seven centres in England, Finland, the Netherlands, Norway and Sweden. The result was a single index value for health status with potential for use in health care evaluation.

5 The HUI measurement system is a generic, preference-scored, comprehensive system for measuring health status, health-related quality of life, and producing utility scores.

Primary

- Number of hospitalizations
- Number of permanent transfers to elderly homes

Secondary

- Time to permanent transfer to elderly homes
- Total and average length of stay in hospital
- Number of consultations with GPs
- Number of consultations with specialists
- Number of home visits by nurses
- Number of home visits by social operators
- Number of ambulance transports
- Number of accesses to emergency rooms
- Number of falls
- Number of femur fractures
- HbA1c change over time (participants with diabetes only)
- Survival

2. ISISEMD relies on Cost Utility Analysis (CUA) to determine whether the proposed solution is cost-effective. *Cost Utility Analysis* allows comparison across different health programs and policies by using a common unit of measure: **money/QUALYs gained**, where QUALY represents quality adjusted life years.

CUA provides a more complete analysis of total benefits than simple cost-benefit analysis (it takes into account the quality of life of an individual); the ability to compare directly the monetary cost of different health outcomes makes it attractive to decision-maker. However the method presents several shortcomings: it does not take into account the 'spillovers' such as the quality of life improvement of informal caregivers and consequently indirect benefits - possibility for the caregiver to work more hours; reduced stress and depression symptoms; reduced rates of morbidity among them; improved physical and mental health.

3. Long Lasting Memories – Besides health (mentioned in part 1.1) the following outcomes for determining project impact are subject to assessment:

a) Technology and Usability

- Number of technical support calls
- Comparison of log-files and system responses
- End-user satisfaction levels regarding usability of the technology (interviews / questionnaires)
- End-user satisfaction levels regarding form factor attractiveness (interviews / questionnaires)

b) Marketability

- Technical staff (minimum skills level) able to effectively install the system without additional training.
- Reported technical problems addressed on a timely basis.
- End-users level of satisfaction with the use of and results from the solution
- Solution deployment delivered in a range of different elder care environments.

4. COMMONWELL aims to support independent living of older people and those with long-term conditions. The integrated services are to support the effective management of chronic disease, and to address issues which affect independence, such as reduced agility, vision or hearing. The results of evaluating the pilot operation will be used to extend service provision and promote the wider uptake of this model of care across Europe.

An integrated list of core health and well-being objectives is to be developed, with two initial targets being:

- Reduce admissions to hospital for selected long-term conditions by 10% over three years
- Reduce admissions to older people's care homes by 5% a year.

5. CLEAR project proposes the implementation of e-rehabilitation services allowing patients to extend part of the rehabilitation treatment at home/kiosk (or at the point of their need) under the supervision of a rehab team. Project's purpose is to implement and validate sustainable clinical models for the management of chronic diseases, at low cost; additionally improvements in the quality of life of impaired people by programs of maintenance of their functional abilities are expected.

The Health Technology Assessment (HTA)⁶ process implemented in CLEAR project provides for the evaluation of 24 sectors that arise from considering 8 possible HTA dimensions (clinical impact, organizational impact, ethical and social issues, risk management, evidence based information, quality perception, security, privacy) within 3 possible HTA fields (protocols, technical assessment, service assessment). The sectors under evaluation are vastly heterogeneous and require the definition of widely applicable procedures and survey tools.

To this end a methodology which identifies the collection of structured background information and the distribution of dedicated checklists as tools applicable to all sectors was developed. In this way HTA user will be able to act on those aspects that the evaluation has identified as the most critical making efforts on them to gain success for the service.

The Consortium intends to standardize a procedure, starting from user needs and evaluation needs in order to apply HTA within EU projects.

⁶ HTA is a systematic, broad-ranging evaluation of the implications of using technologies within a particular health care-system. HTA summarizes information about the medical, social, medical and ethical issues related to the use of a health technology in order to determine the benefits and costs for the health –care system, thus informing policy decisions.

4. Specific challenges for indicators and impact assessment methodologies on ICT for ageing well

Using the case studies as a springboard for conversation, workshop participants discussed methodological and operational challenges facing the field.

1. Methodology

The review of project presentations revealed that the preferred methodology for collecting evidence of ICT solutions impact is randomised controlled trials (RCT). There was a common understanding among participants that RCT provides robust results in the assessment of efficacy of ICT interventions however several problems that deserve further attention were identified:

Attribution problem: Although RCT is a 'golden standard' for the assessment of new treatment efficacy it could be less appropriate and lose validity when used to assess changes in individual quality of life and system of care delivery generated by the ICT solutions. The reason is the difficulty in separating the changes attributable to the interventions being studied and those that are the result of other influences. It is therefore important to make sure that extraneous factors are comparable or controlled between groups and thereby provide evidence that ICT solution makes an independent contribution to the outcome.

Attrition problem was also mentioned by the workshop participants as causing bias estimates of ICT intervention effect on subjects in RCT and restricting the generalizability of results. Although there is no strategy to fully eliminate the attrition bias in RCTs, some 'countermeasures' are possible in order to reduce the rate of participants' drop-outs. The record of drop-outs is also relevant as the attrition rate could be an indicator of user (dis)satisfaction with the proposed ICT solution.

Linked to the attrition problem are the **selection/eligibility criteria** of trial subjects which have to be clearly specified. Most of the cases use volunteers (also for ethical reasons) or physician referrals, however the information about refusal rates at point of initial referral are not always record. Thus, it is not possible to discount selection bias in favour of those likely to be positive about ICT interventions.

Cost versus sample size: In order to have statistical power RCTs must be run with a significant number of subjects otherwise the observed differences even if real do not reach significance with small groups. However this could be expensive as it requires a lot of time and subjects.

2. Quality of Life as generic outcome indicator

There is general agreement that quality of life requires a comprehensive assessment, meaning that measurement should not be limited to physical and functional capacities alone. Physical health and day-to-day functioning, psychological well-being, social relationships and environment should be taken into account when determining the impact of ICT on Quality of Life. Health status, safety, independence, loneliness, anxiety, relationships with family members these are only a few examples of quality of life predictors that ICT may have an impact on. However there are several problems associated with the measurement and improvement of quality of life that ICT brings about:

One of them is the so-called '*response shift*' problem, in fact the lack of sensitivity to what caused the change (it is similar to attribution problem) and the shifting internal standard by which quality of life is judged. Furthermore workshop participants expressed their concerns relative to the sensitiveness of some measurement tools currently employed by the projects such as SF-36 which measures all general indicators while ICT intervention (e.g. telecare services offered) will make direct impact only on some of them.

The workshop participants also agreed to the necessity of measuring the quality of life concept both objectively (clinical results) and *subjectively* (users' feedback); the latter however raises further problems due to the subjective judgments of quality of life made by people involved in trials: for example users' expectations influence appraised quality of life; also individuals may feel constrained because of courtesy or intimidation from actually expressing their views while taking the survey. The intimidation is more likely if the person is in vulnerable health and perceives himself or herself as dependent on care providers.

3. Economic impact

Some of the projects recognized a lack of assessment methodologies for the economic impact with particular reference to informal carers and families. Further analysis is necessary in order to identify the costs and benefits both at individual and systemic level: e.g. user time surveys for informal carers could give an account on the number of hours spent by an informal caregiver and indirectly on their quality of life; systemic indicators can be further developed such as the cost of underemployment due to caregiving represented by the gap between full-time and involuntary part-time work, measured in hours and multiplied by the average real wage rate (here gender implications are also relevant as women are recognized as the main informal care providers) or in the case of domestic workers the number of unpaid hours spent on elderly care multiplied by the average hourly earning of household domestic workers.

Other obstacles relating to the economic impact assessment of ICT interventions on the whole care system are due to difficulties in quantifying the costs generated by organizational change as a result of the adoption of ICT solutions by organizations (telecare). Possible modeling methodologies for care system (economic modeling) could be envisaged.

More transparency on the economic reporting is also needed. The costs reported by projects varied so that comparison of the reported savings is difficult. The costs reporting must be done wherever possible as a comparison with conventional care alternatives in order to convince stakeholders of the benefits of ICT interventions.

4. Practical problems

- Some of the measurement methodologies and tests are relatively new – they have not been in use among the public care providers;
- Many measurement instruments require translation in local languages and have to be standardized for each country (this requires a separate study to customize them including a suitable number of persons done by professionals in elderly care, dementia or Alzheimer associations);
- Many of them, because of their sensitive nature for each person, must be administered by care-provider personnel, specially trained to apply these tools so that the validity of results is not affected.

5. Conclusions

From the work and approaches presented there is a clear necessity to urgently bring coherence and comparability in view to develop reliable, replicable and scalable Indicators and Impact Assessment Methodologies on ICT for Ageing Well.

Such data will help address the imminent demographic change challenges (reversing age pyramid with the often related increased incidence of disabilities in the population, mounting public spending on pensions/health/long-term care with falling tax revenue from the shrinking working age population, declining dependency ratios, shortfall of qualified human resources particularly in care sector) in terms of the role ICT can play in bringing efficiencies and new opportunities into these sectors.

The workshop has contributed to clarifying the scope and any possible shortcomings (in terms of their applicability to constructing 'macro' level indicators and methodologies) of current approaches, indicators as well as assessment methodologies used by several current projects in the field. Moving forward in developing and implementing indicators and impact assessment methodologies on ICT for Ageing Well will call for answers to several issues:

1. Specifying what is being evaluated: an overview of the intended outcomes mentioned by the projects identified four main categories by which the impact of ICT solutions for ageing well has been measured:

- Quality: quality of life
- Access: the extent to which clients face barriers to using ICT equipment
- Acceptability/Satisfaction: extent to which (self-reported) needs of the client group are met, and
- Cost: the economic value of interventions.

A conceptual framework for the impact assessment of ICT interventions could be build around these outcomes and their corresponding indicators. (see Table 3)

2. Multi-actor evaluation: a comprehensive assessment requires the analysis of impact, costs and benefits for all the actors along the value chain. During the workshop was evident that that distinguishing between the needs of elderly, carers and families/informal carers is an essential step. It also became more obvious how some aspects are **actually marginally addressed by current projects, in particular those related to families and informal carers impact assessment.**

Demographic Change – a Challenge

- 80+ population will double until 2050; 60+ increase from 20% in 2000 to 29% in 2025;
- 21% of 50+ population in Europe has severe vision/hearing/dexterity problems;
- today 4 working people for 1 retired; in 2050 2 working for 1 retired;
- costs of pensions/health/long-term care to go up by 4-8 % of GDP by 2025;
- critical shortfall of care staff in Europe.

Ageing Well with ICT – an Opportunity

- smart homes market will triple between 2005 and 2020;
- early patient discharge by tele-health will contribute reducing cost by 1,5 B€p.a.;
- tele-care at home is expected to empower elderly and provide efficiency gains of 25% (UK).

3. Identifying indicators and selection criteria: criteria for the selection of a set of key common outcome indicators and measurement tools could be implemented. Possible criteria: the importance of what is being measured in terms of the impact on outcome; the scientific soundness of the measure, reliability and validity;⁷ the relevance of the indicator for accelerating take-up and reimbursement (downstream deployment); the feasibility of obtaining internationally comparable data for the indicator and its associated measure: e.g. Quality of life indicator developed by WHO and its corresponding measurement tool WHOQOL -100 (and its shorter versions - WHOQOL – BREF), SF -36 and ICF classification, EQ-5D.

4. Data collection

Statistically significant impact measurement methodologies would help delivering comparable results. However, a lack of available, reliable **national statistical indicators** that could facilitate comparison at international level was highlighted as hindering emergence of such reliable, common metrics. Data mining over a larger data repository would bring higher statistical relevance to the rather fragmented evidence from the initiatives and projects so far.

Table 3. Indicative Matrix for assessing the socio-economic impact of ICT for Ageing Well solutions

OUTCOME	INDICATOR	MEASURE	TOOL
1. Quality	- Quality of Life - Quality of Care	- Health Status (Physical and Mental)	SF -36, WHOQOL BREF
2. Cost	- Reduced Number of Hospitalization	
3. Access			
4. Acceptability/Satisfaction			

Within each category an indicative set of common indicators can be agreed upon based on the general selection criteria mentioned above.

The Matrix should also be able to provide relevant data at each actor level along the value-chain: individual (users, formal and informal carers), market, care system.

LEVEL and CATEGORY	INDIVIDUAL	MARKET	CARE SYSTEM
1. Quality	- Quality of Life	-	- Quality of Care
2. Cost	- Cost of the ICT solution supported by the individual (% monthly household income paid for ICT service)	- Cost of the technical solution	- Implementation Cost - Personnel training cost
3. Access			
4. Acceptability/Satisfaction			

⁷ Eduard Kelley and Jeremy Hurst, Health Care Quality Indicator (HCQI) Project, Conceptual Framework Paper, OECD, March 2006

6. Next Steps

Development of best practice on indicators and methodologies related to ICT for Ageing Well deserves further effort – with case studies accompanying the theoretical work. In terms of methodologies for instance ICF and SF-36 could represent viable starting platforms, although they need further refinement to be suitable for post-assessment of running services.

Practices (tools, methodologies) available from the various ongoing types of projects should be brought together to develop a practical tool-box for the constituency – enabling replication and upscaling.

One of the final questions was how to make collaboration in the field concrete and fruitful. Amongst the immediately implementable ideas the following were recommended.

- All CIP assessment deliverables are and will be of a public nature, facilitating networking and sharing of knowledge and practice.
- An ePractice forum will be set-up, as a place to exchange further views, approaches, documentation, with the aim to reach a structured and shared set of indicators and assessment methodologies, ensuring reliability and comparability of assessments at EU level. The Forum will be found at <http://www.epractice.eu/community/ageingimpact>
- It was agreed that a working group on best practice in suitable indicators and a working group on best practice on measurement methodologies should be established as soon as possible, with active involvement of relevant projects and initiatives across Europe and beyond.
- The possible launch of a specific CIP support activity could also be considered in the future, based also on the effective interest arising from the constituency and the success and findings deriving from the Forum activity.

Annexes:

Background documents

List of participants

Background documents

They can be downloaded at

http://ec.europa.eu/information_society/activities/einclusion/policy/ageing/assessment_workshop_09/index_en.htm

- Persona project – ICF User Assessment Evaluation Methodologies
- NHS, Department of Health:
 - Whole Systems Demonstrators - An Overview of Telecare and Telehealth
 - Whole Systems Demonstrators - Participants Questionnaires

List of participants

Name	Organisation / Project
Ingo Meyer	Empirica Gesellschaft für Kommunikations / Commonwell CIP project
Claus Nielsen	Delta A/S / Dreaming CIP project
Wendy Moreno	Moviquity / CAALYX CIP Project
Mar O'Neill	Malta EPA
Kjeld Olesen	Aalborg / ISISEMD CIP project
Karina Skov Lisberg	North Denmark EU Office
Miguel Alborg	IDI EIKON / T-Seniority CIP Project
Marco d'Angelantonio	HiMsa / Dreaming Project
Panagiotis Bamidis	Aristotle University of Thessaloniki / Long Lasting Memories CIP project
Paolo Bonato	Partner Healthcare, US
Filomena Carriera	InCasa CIP Project
Hasse Petersen	Region of Southern Denmark, Brussels Office
Mauro Grigioni	Istituto Superiore della Sanità / CLEAR CIP Project
Mette Thiim	The fund for labour saving technologies
Silas Olsson	AAL Association
Alberto Bonetti	Rapporteur
Peter Wintlev Jensen	EC - ICT for Inclusion
Katarzyna Balucka-Debska	EC - ICT for Inclusion