The research perspective for the users’ involvement

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Analyzing the research perspective

Issues to consider for the users’ involvement:

- Definition of User
- Needs and resources of the users
- Stakeholders and authorities
- Methodology (such as different ways of involvement)
The users represent the target population of the research.

They are the subjects of the study design.

The people who will receive benefit from the intervention.

The individuals who report needs to be satisfied.

• The definition of ‘user’ is complex and opens the discussion at many levels.
• There is the need of closing the gap between science and society.
• The methodology concepts have to be strictly linked with the human aspects, such as needs, characteristics of the users and social organization.
• It is essential to create an “alliance” between older people and researchers.
Users: Who are they? (2)

On the basis of the objectives, the users could be:

- The End Users: whose needs are investigated. They received the primary benefits from the intervention.

- The Caregivers: who take care of older people. They have the full knowledge of the end user’s condition.

- Professionals: who operate constantly with the end users.
When involve them?

Involving older people in the research process helps the researcher in identifying the right questions.

The users should be involved in different phases of the research:

- Preliminary phase – to draw out the needs of the target population and of the context.
- During the process of the research - to get feed-back and to guarantee the adherence of the study to the real needs of the end users.
- At the end of the research – to disseminate the results to them or to verify the effect and benefits of the intervention.

The perspective of users may influence the direction of the research.

End users and researches should approach projects with open minds.
How to study them?

Different methods could be used, depending on the discipline and on the study design:

<table>
<thead>
<tr>
<th>Subject</th>
<th>Methods</th>
<th>Open Issues</th>
</tr>
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<tbody>
<tr>
<td>Medicine</td>
<td>RCT, trials with medicines</td>
<td>Ethics, few frail people in the studies</td>
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<tr>
<td>Biology</td>
<td>blood sampling</td>
<td>DNA (Ethics)</td>
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<tr>
<td>Psycho-social</td>
<td>focus group, tests</td>
<td>Generalization of data</td>
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<tr>
<td>Socio-economic</td>
<td>questionnaires, market analysis</td>
<td>Society changes, elderly of the future</td>
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<tr>
<td>Technology</td>
<td>pilot studies with prototype, user centred design methods</td>
<td>Privacy, too small samples</td>
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Horizontal Issue: Age segmentation – Which age has to be considered in the research study?

For the validity of the research, it is crucial to find the instruments and the theories that really measure the chosen outcome, considering the characteristics of the specific discipline.
Where involve them?

The first contact with the end users is a crucial issue for their involvement in the research process

A deep knowledge of the social organization and of the local context is required, to find key places in which recruiting end-users, such as:
- NGO, Church
- Recreational/Cultural organizations
- Centres devoted to the care and the assistance
- Residential areas in which end-users are mostly presented
- Random sampling from devoted databases

From our experience, elderly, who are mostly active in social and cultural activities or associations, are often glad of being involved. This confirms the positive effect of social inclusion also towards the research.
How to involve them?

There are different ways for involving elderly: the most important issue is to give attention to the subjects and don’t make them feeling just as the target group of the study.

The end-users should be reached through:
- advertisement in public meetings
- local TV, radio
- newspapers and magazines
- presentation in elderly associations

Strategies that should be used:
- informative letter
- phone interviews
Communicate the results to the Users

Communicating the results is an essential step in any research study: currently the value of the research is partially lost due to inadequate dissemination activities.

Transferring knowledge is a key issue.

- The importance of a **Target Centered Communication**
- Accessible language (Keep your message clear and simple without technical words, using the national language)
- Use examples to make complex information understandable
- Provide handouts
- Draw pictures
Focus on Ethics

The ethical aspects represent an issue to be considered in many disciplines:

- **Medicine** - informed consent, clinical trials with drugs...
- **Biology** - collection of blood sampling and their storage, DNA, genetics...
- **Psycho-social science** – informed consent, privacy issues
- **ICT** - trials with new technology; intrusiveness, safety, privacy (in case of monitoring system)...

The study on Ethics should allow the right involvement of the elderly and of the other actors in the research, giving the assurance of respecting their condition and opinions and most of all, their dignity.
The European Project HAPPY AGEING (AAL-2008-1), is coordinated by INRCA and involves five European countries (IT, NL, SP, UK, HU) and seven international partners in the development of a new assistive device for elderly people.

The main objectives of the project are:

- to prevent the incidence of chronic conditions and to manage such conditions when present, supporting independent living in old age;
- to develop and integrate a customizable system matching the demand for technology by the elderly with current market supply;
- to directly involve the end-user in all phases, assessing the user’s expectations and needs, assuring user acceptance of the new system.

The device will be composed of three main modules, that will be integrated:

- Lifestyle monitor
- Personal assistant
- Navigation assistant
Example of user’s involvement in ICT research phases

From: www.adrianchong.com
The End-Users were involved in different phases of the project:

**WP1-Task 1.1 - “Elderly independent living frame definition”:**
- to collect data on end-users condition and attitude towards technology
- to investigate the factors that influence the choice of using an ICT device
- to involve directly the end-users in the device requirements

Desk research + achieved experience on the field + Focus group with End-Users

- development of a Protocol of questionnaires (End-user condition, end-user perspective on the device, demand and cost information)
- contact with local organizations for elderly and municipalities

A sample of 180 subjects (104 females, 76 males) was recruited in NL; IT; HU (Mean age=75.72; SD=6.6)
WP1-Task 1.4 - “Institutions role investigation”:

- to get an overview of private and public health/social systems of each countries
- to understand the role of policy-stakeholders as driver and/or barrier to innovation in the context of elderly independent living

Focus Groups were carried out in IT, NL, HU, with relevant stakeholders, based on the following themes:

- general impression on the device
- welfare system, reimbursement mechanism and spending capacity
- technology acceptance by the elderly and ethical questions

Participants in Italy were:

- Person in charge of Social Services for elderly of the Municipality
- Coordinator of Social Services of a Consortium of Municipalities
- Expert of Epidemiology and Prevention Health Unit of Ancona
- Rehabilitation Therapist of Rehabilitation Unit of INRCA Hospital
- Person in charge of Alarm System for elderly of the Municipality
- Person in charge of Pensioners Organization
- Four people in charge of Voluntary Organizations for elderly home assistance
WP1-Task 1.5 – “Requirements analysis for a consistent architecture”

- Availability of a complete document matching users expectations/needs to the existing market frame.
- Elderly users, ageing experts, psychologists and designers described the required functionalities of the overall device.

A document were prepared, that contains the desiderable characteristics for the promotion of the usability

i.e.: list of activities that elderly want to be supported by the device:

- Remind me to take medicines (64%)
- Remind me if a food is out of date (57%)
- Indicate the time spent in inactivity (48%)

i.e.: ergonomics dimensions:

- What about a wrist watch as portable HAPPY AGEING device?
- What about a pendant as portable HAPPY AGEING device?
- What about a mobile phone as portable HAPPY AGEING device?
**WP4 - “Lifestyle Monitor”, WP5 – “Navigation Assistant”, WP6-“Personal Assistant”**

These WPs are focused on the design, development and validation of the three modules of the HAPPY AGEING system.

- A sample of 10 end-users will be involved in each of them, in a continuous feedback to get a satisfactory usability and accessibility and a high matching to users' expectation (rapid prototyping).

- The objective is to demonstrate the validity of the three modules directly on elderly people application.

**WP7-“HAPPY AGEING Field Trial”**

This WP is focused on the validation of the developed prototype system in the real life environment. The system will be tested in dedicated sites by the elderly, their families and/or informal or formal carers, at home.
Recommendations for involving users

- Research has to take account of multiple perspectives including older person, carer, professional, system and policy.
- Ageing is a complex phenomenon, that differs between population groups and across countries.
- End users should be included in all the phase of the research, especially at the beginning.
- More and appropriate dissemination: the results of research should be communicated to end users. More time and funds for that are needed.
- New methods has to be implemented, such as user centered design, devoted to maintain a strictly link between the objectives of the research and the condition of the users.
- Particular attention has to be given to Ethics.
Thank you for your attention!!!

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