

FUTURAGE

A ROAD MAP *for* AGEING RESEARCH

“Towards a model of user involvement in research” **Work Package 6**

**Report from the 1st Scientific Workshop
held in Brussels, Belgium on the 25-26 March 2010**

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List of abbreviations:

AAL	Ambient Assisted Living
ANBO	Association for Older People in the Netherlands
BAGSO	<i>Bundesarbeitsgemeinschaft der Senioren-Organisationen</i> (German Federation of Organization of Older People)
CIP	Competitiveness and Innovation Programme
DG INFSO	Directorate General – Information Society and Media
EC	European Commission
EU	European Union
EUGMS	European Union Geriatric Medicine Society
EUROCARERS	European Association Working for Carers
FERPA	European Federation of retired and Older Persons
FP7	Seventh Framework Programme
INRCA	<i>Istituto Nazionale Riposo E Cura Anziani</i> (Italian National Institute for Older People's Care)
NPC	National Pensioners Convention
NGO	Non Governmental Organization
NOPO	Nordic Older People's Organisation
R&D	Research and Development
REIACTIS	<i>Réseau d'Etude Internationale sur l'Âge, la Citoyenneté et l'Intégration</i> (International Study network on Age, Citizenship and Integration)
WP	Work Package

1 Executive Summary

The overall objective of the FUTURAGE project, a two-year project funded by the European FP7, is to create the definitive Road Map for ageing research in Europe for the next 10-15 years.

Drawing on experts and specialists from Europe and beyond, the road map will represent the most extensive consultation ever conducted in this field and identify the main priorities on ageing and health from a multi-disciplinary perspective.

This report presents the main outcomes of the first workshop dedicated to “user involvement” with the title “**Towards a model of user involvement in research**”.

The report’s structure highlights the goals, the key presentations and themes the workshop addressed. The main issue of “user involvement” has a dedicated chapter that stresses methodologies, challenges and barriers that concern this topic most.

The involvement of some of the most relevant stakeholders in the field of research, representatives from the world of industry, academies and research centres, together with older people organizations active at national and European level, has assured a high quality debate, whose valuable outcomes are hereby presented.

In line with its main goal, this first workshop, organized by AGE Platform Europe with the support of AGE UK and the cooperation of the FUTURAGE Coordinator and work-package leaders, will pave the way for the next discussion on user involvement within the project framework.

As a matter of fact the recommendations described below will serve as a starting point for the second round of debates that AGE UK will coordinate with AGE Platform Europe on users’ involvement in research.

This report reflects its authors' views and the comments of the workshop’s participant, as registered during the meeting. The European Commission is not liable for the information contained therein.

2 Aims And Objectives And Structure Of The Workshop

The 1st workshop on user involvement in the framework of the FUTURAGE project was organized by AGE Platform Europe with the support of AGE UK – UK, with the main aims of:

- Identifying what are the barriers and solutions to the participation of older people and other user groups in research
- Creating a lasting model of user involvement for European (ageing) research
- Integrating user perspectives, especially those of older people, into the process of generating the definitive Road Map
- Ensuring that the Road Map represents both the priorities of scientists and those of final users

In order to effectively cope with all issues and goals foreseen, the key part of this participative workshop was held in working groups that tried to generate prompt responses.

Central attention was paid to the construction of a methodology for user involvement in research, focusing on the following themes:

- **User involvement:** How can researchers and public authorities support it?
- **Industrial best practice:** How do industries ensure that older people's expectations and needs are taken on board?
- **Recent experiences:** How do older people express their expectations and needs to researchers and service/product developers?

For answering these questions, participants were asked to focus not only on the theory and methods of user involvement and the relationship between research, policy and practice, but also on more practically-oriented inputs on experiences and good practices in user engagement.

3 Summary Of Presentations And Workshop Discussion

Opening Plenary

After the formal opening of *Anne-Sophie Parent*, AGE Platform Europe Director, Dr. *James Goodwin* (AGE UK) provided an overview of the FUTURAGE project, explaining its objective, its structure and its link with previous and current research projects in this area.

He underlined his main concerns, such as the needs to

- have a common language in order to bring together the different disciplines which consist the FUTURAGE project;
- look at existing state-of-the-art in ageing research;
- consider a life-course approach;
- maintain both an interdisciplinary and multidisciplinary perspective;
- encourage activity and participation;
- examine inequalities of ageing and
- coordinate ageing research in Europe.

Stakeholder's perspectives

During the plenary session *Paul Timmers* (Head of Unit ICT for Inclusion, DG INFSO, European Commission), *Fiorella Marcellini* (INRCA), *Simon Roberts* (Intel) and *Heidrun Mollenkopf* (BAGSO) presented the stakeholders' perspectives on user involvement, namely the EU, the research, the industry and the user approach.

While agreeing on the need to define new models for user involvement in research, the four speakers agreed that there is no single solution that works in every situation. On the contrary, the selection of users, of the methodology and kind of involvement depends on various factors, such as the type and the objective of the research.

They further emphasized that a wider vision should be adopted; implementing the life-course approach, involving multiple actors and engaging researchers from different disciplines were the most commonly agreed recommendations.

Besides, there was a consensus about the complexity of the concept of "users", arguing for the importance of recognizing that they are not a homogenous group. Ethical concerns should also be tackled and last but not least, they all called for user involvement at all stages, from forming research questions to giving feedback on research results.

- **The European Perspective:** *Paul Timmers* (Head of Unit ICT for Inclusion, DG INFSO, European Commission) presented the work of the EC in this field and outlined the main challenges for ageing research and user involvement. He presented the "ICT and Ageing Well" Action Plan as well as the FP7, the AAL and the CIP Programmes aiming to improve quality of life, create opportunities for growth and innovation, raise awareness and address barriers in this area. While acknowledging the importance of user participation, he called for comprehensive methodologies for user involvement in research. In this perspective, questions like how users are reacting in the process and at which stage they should be involved should be addressed. A multi-actor approach where user involvement is envisaged at all stages was also suggested. Ethical guidance and measurements of impact

and quality of life are equally important. Moreover, as an example of a wider perspective on users, the life-course approach was considered to be very relevant.

- **The research perspective:** *Fiorella Marcellini*, (Italian National Institute on Ageing) focused on the complex definition of users and the various methodologies for their involvement depending on the discipline and the study design. She suggested that users should be consulted at all phases of the research, from the preliminary stage until after the end of the research, paying particular attention to the need for better dissemination of the research results at national, local and EU level. Ethics and monitoring by user organizations should also be addressed, while personal contact with the users was deemed essential. She further called for a multi-actor research perspective involving caregivers, professionals and stakeholders.
- **The industrial perspective:** *Simon Roberts* (Intel) presented users consultation in the process of development of services and products as a moral commitment and as recognition, that failing to involve users, one might fail in his/her ambitions. Moreover, the term 'user', like the concept of 'consumer', might have a flattening connotation, disregarding the heterogeneity of users and the complexity of this issue. While literature has generated a huge number of methodologies for user involvement, the participatory approach is the most appropriate in order to create and share ideas depending on the user group and the objectives pursued. Drawing from an example in the field of transport, Simon Roberts, encouraged service developers to engage users beyond the research phase and to look at them as systems and not as individuals or types of people. He further made a distinction between specific and neutral or mainstream technology.
- **The end-user perspective:** *Heidrun Mollenkopf* (BAGSO) reflected upon what the meanings of an ageing society are, and how it is experienced by older people in their everyday life. Common challenges include community participation, social isolation, mobility, access to services and information, security and care provision. While the potential of new technologies is largely acknowledged, they should not create additional barriers, especially since it is usually the younger, healthier and wealthier people who benefit from them. Questions like what do 'user' and 'user involvement' mean, who, how and to what extent should be involved were also raised. The diversity of older people should be put at the forefront, as well as to intensify research on future ageing generations who might have different characteristics. The approach - largely dependent upon the benefits of involving users and the nature of the research - should be interdisciplinary, engaging older people in the whole process, without disregarding the need for appropriate training both for users and researchers/developers.

The Working Group Sessions

Due to the relevant outcomes of the break-out sessions for the topic of User Involvement and in relation to the Key Themes of the workshop, the related chapters (5 and 6 respectively) summarize the presentation of the Working Group Sessions.

Presentation of WPs

The 2nd day was devoted to the sum up of all discussions raised in the break-out sessions and to the presentation of the state of the art by the different FUTURAGE WP leaders. *James Goodwin* (AGE UK, UK) explained that the objective of these presentations and round of questions was to reach interaction between researchers and users at an early stage; to avoid thinking in isolation; to have better transfer of knowledge and to influence research thinking and the sequence of workshops.

He further transmitted the apologies of *Olivier Toussaint* (University of Namur, BE), leader of WP2 on Biogerontology, who could not attend the meeting and gave the floor to the other WP leaders.

WP3 Social and Economic Resources

Fiorella Marcellini (INRCA, IT) presented the developments in WP3 on Social and Economic resources: she pointed out the goals of the working groups organised by INRCA, as the Ancona workshop aimed at creating a coherent framework for research findings on the socio-economic resources of later life, identifying any new research topics and priorities likely to emerge in the future (in the next 10-15 years).

37 leading European scientists attended the Workshop and gathered in 4 thematic working groups whose outcomes can be summarized as follows:

Working group 1: older people as caregivers

This group raised a number of questions related to the identifications of carers, care arrangements and care contents (also taking into account the interaction between professional and informal care), the analysis of the relationship between the carer and care recipient in a family setting, the investigation on the influence of care giving on work life, the rewards and costs of caring, community structures and city patterns facilitating caring, till a general discussion on public policies and management on care.

Working group 2: dependent older people

This group underlined some issues, e.g. the need of better understandings of dependency and independence, the socio-cultural values that underlie them and the impact of new technologies on enabling the usage of the capacities by dependent older people. Besides the group highlighted the need to explore the understandings of quality of home and residential care (migrant care workers may, for example, have a different take on what constitutes quality of care than care workers from the ethnic majority), as well as the need to identify the factors that affect good quality of home and residential care.

Working group 3: older people as a socio-economic resource for society

Working Group 3 discussed on the activities at the labour market, asking whether the fact of working longer, affects the financial crisis; activities within the family: intergenerational relations, effects of changing family structures? Learning/teaching: new media, lifelong learning; Volunteering/active citizenship: changing character and economic value of activities; Activities of everyday life: consumption, media use, time use.

Working group 4: socio-economic needs of older people

Social integration: Touching also on fields like ageism and discrimination, media representation and social solidarity mechanism; Income maintenance and pension system developments, analysis of consumptions patterns over the life course, the topic of vulnerability: e.g. Elder abuse and neglect, living arrangements of different social groups, the accumulation of life-long disadvantages including disabled elders; the field of cultural definitions, religion and spirituality development was discussed as well.

WP4 Environments of Ageing

Torbjorn Svensson (Lund University, SE) reported on behalf of WP 4 on Environments of Ageing, stressing the relevance of the understanding the interrelations between ageing persons and their physical-social surroundings (home environments; out-of-home environments, technology and products), the relationship between the environment and the ageing outcomes, the connections with a set of disciplines all contributing to the understanding of person-environmental relationships (e.g., architecture, psychology, transport, occupational therapy, epidemiology, sociology), to link such issues with the ageing of our societies and with current and future societal challenges at large.

Differently from other workshops, the Lund one (June 2010) will involve young scholars in all of these issues from the beginning, on the basis of a rather general set of topics (issues of theory, method and implementation), building on the experience of the Heidelberg workshop where 37 scholars (including young scholars from Austria, Finland, Germany, Holland, Italy, Japan, Latvia, Lithuania, Spain, Sweden, UK, U.S.A) took part. Participants represent a wide range of disciplines (architecture, engineering, epidemiology, geriatric medicine, health sciences, occupational therapy, psychology, sociology, transport research).

As underlined in occasion of other debates, to invest more into the communication of the interplay of the physical-social-technical environment as been stressed (societies still mostly think in terms of "persons" / personal characteristics).

Other important aspects keep to the link of local diversity with country diversity and use a person-environment perspective to better understand such diversity, the cultural ones included.

Through this broad research path, the WP leader aims at drafting a Preliminary Roadmap on Environments and Ageing at the end of 2010.

WP5 Healthy Ageing and Wellbeing

Carol Jagger (University of Newcastle, UK) outlined the results of the first Scientific Workshop on Healthy Ageing, in the framework of the 5th WP. The meeting, held in Newcastle, 15-16th March 2010, aimed at identifying research priorities and plans related to healthy ageing and well-being, by agreeing the scope of healthy ageing and well-being for the purposes of European research; clarifying the relationship between this stream and the other three scientific ones; creating a coherent framework for research findings; identifying any new research topics likely to emerge in the foreseeable future; determining the key research priorities in this field for the next 10-15 years.

This workshop highlighted some *overarching issues*, namely the assumption that Europe is a basic comparative natural population laboratory; the ability to extend and integrate biological, social, economic aspects of ageing; the need to build capacity/knowledge/infrastructure in countries that have little experience in ageing research. Besides some general points for break-out groups have been discussed and must be kept in mind: it is important to understand the dimensions of healthy ageing, to boost research to underpin comparative measures to monitor healthy ageing including indicators of socio-economic status functioning, multi-morbidity, social engagement, to model links between disease and functioning over the life course and how these will play out in future, to depict trends in health of young old and relationship with different exits from labour market, pensions, SES and cultural expectations.

This workshop also highlighted the main reasons behind these needs: the academic world (and the society as a whole, served by the academic outcomes and results) wants to:

- Understand the huge variation in healthy life expectancy between European countries as a basis for planning for the ageing population including organisation of services
- Assess personal and societal burden of ageing and its social gradient of in different countries.

Thanks to this focus on each workshop, planned or already organized, it has been possible to realize the lack of real users involvement in those meetings. This issue has thus been taken into account to improve the coming-up events linked to the project.

An overview on the user involvement in research and within the FUTURAGE project follows in the next chapter. The main themes of discussion and of future actions are then separately highlighted in the dedicated chapters.

4 User Involvement In The FUTURAGE Project

Although there is an increased awareness of the importance of the engagement of users in research, the extent to which user involvement has been formalized within European programmes varies greatly.

The need for a society-driven research has been acknowledged by the FUTURAGE project as an added value both for users and researchers. Meanwhile, such a coordinating activity should strengthen the effectiveness of research expenditure and the relationship between research and policy and practice.

In the view of integrating user's perspectives in the production of the Road Map, to discuss the role of users in real research priorities and to contribute to the development of a methodology of user participation for future research, the FUTURAGE project has appointed two partners, AGE Platform Europe and AGE UK, to organize two workshops on users' involvement, where relevant stakeholders, including people representing end user's interests are invited to participate:

1. A first participative workshop, entitled "Towards a model of user involvement in research", which this report refers to and
2. A second workshop, organized by AGE UK, planned for July 13th - 14th 2010.

User involvement: the outcomes of the break-out sessions

As core of the workshop, the involvement of users and the participatory approach have been put in place thanks to the break-out session: participants were divided in 3 groups, each one focusing on different perspectives of user involvement.

The 3 external experts, *Marian Barnes* (Brighton University), *Merce Perez-Salanova* (University of Barcelona) and *Jean Philippe Viriot-Durandal* (REIACTIS) served as moderators for the 3 working groups, composed as follows:

<p>Session 1</p> <p>USER INVOLVEMENT:</p> <p><u>How can researchers and public authorities support it?</u></p>	<p>MODERATEUR: Marian Barnes</p> <p>RAPPORTEUR: Rodd Bond</p> <p>Fiorella Marcellini</p> <p>Frank Goodwin</p> <p>Ilenia Gheno</p> <p>Jean Pierre Baeyens</p> <p>Jerome Bickenbach</p> <p>Josine Van't Klooster</p> <p>Lino Agius</p> <p>Pat Healy</p> <p>Siana Karsheva</p> <p>Torbjorn Svensson</p>
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<p>Session 2</p> <p>INDUSTRIAL BEST PRACTICE:</p> <p><u>How do industries ensure older people's expectations and needs are taken on board?</u></p>	<p>MODERATEUR: Merce Perez Salanova</p> <p>RAPPORTEUR: Peter Rayner</p> <p>Ben Sluijkhuis</p> <p>Bruno Constantini</p> <p>Cecile Courmont</p> <p>James Goodwin</p> <p>Mario Romao</p> <p>Paivikki Kuoppakangas</p> <p>Paul Timmers</p>
<p>Session 3</p> <p>RECENT EXPERIENCES:</p> <p><u>How do older people express their expectations and needs to researchers and services/product developers?</u></p>	<p>MODERATEUR: Jean Philippe Viviot-Durandal</p> <p>RAPPORTEUR: Liz Mestheneos</p> <p>Alvy Derks</p> <p>Carol Jagger</p> <p>Heidrun Mollenkopf</p> <p>Julia Wadoux</p> <p>Laura Coll Planas</p> <p>Simon Roberts</p> <p>Tim Harman</p> <p>Tor Kristian Ronnberg</p>

Although the 3 working groups looked into the question of user involvement from different perspectives (research and public authorities; industry; users) there were some **overarching issues** identified by all groups.

- **Issue:** There was wide consensus about the **need to identify** who are the users and to interpret this term broadly; the adopted interpretation is particularly important in order to avoid excluding marginalized groups or treating completely different situations in the same way. In this context, restructuring age groups, approaching less accessible users and engaging carers, professionals, stakeholders and other actors was considered essential. In addition, all groups were in favour of an interdisciplinary approach involving different areas of research.

Contribution to the solution: Participants underlined the benefits of user involvement for researchers, users and the society in general. They further recognized the increasing influence of older people in the market, in the sense that in the near future industries and researchers would not be able to ignore them; however the lack of a unified voice and effective representativeness was also noted. In that sense, the groups considered that it is necessary influencing policy makers, industries and industries. Without doubt, **older people's organizations will be asked to play an important role in this direction.**

- **Issue:** The groups further agreed that a single methodology for user involvement would be ineffective. While defining different levels of participation and complexity,

participants accepted that the strategy to be followed depends largely on the objective of the research.

Contribution to the solution: User participation at all stages was stressed throughout the workshop, while the 3 groups also tried to define how early involvement can be achieved in practice. Overcoming barriers in this sense means empowering people to use their own voice, by helping them understand technology and other services and encouraging them to express their needs. Furthermore, researchers should observe patterns of living, in order to appreciate older people's needs. In practice that would mean recruiting experts (i.e. anthropologists) and engaging in a dialogue with the users.

- Issue: **Funding conditions** were a principal concern;

Contribution to the solution: local authorities were seen as increasingly important actors in research but at the same time the need to better link European research with the local, national and regional level was considered essential. Exchange of good practices should also be encouraged.

In order to better express the outcomes of each session, a presentation dedicated follows herein.

4.1 Session 1. USER INVOLVEMENT:

How can researchers and public authorities support it?

The central issues tackled by the first working group were how the research question is defined and how it is funded, mainly at the national, local and regional level.

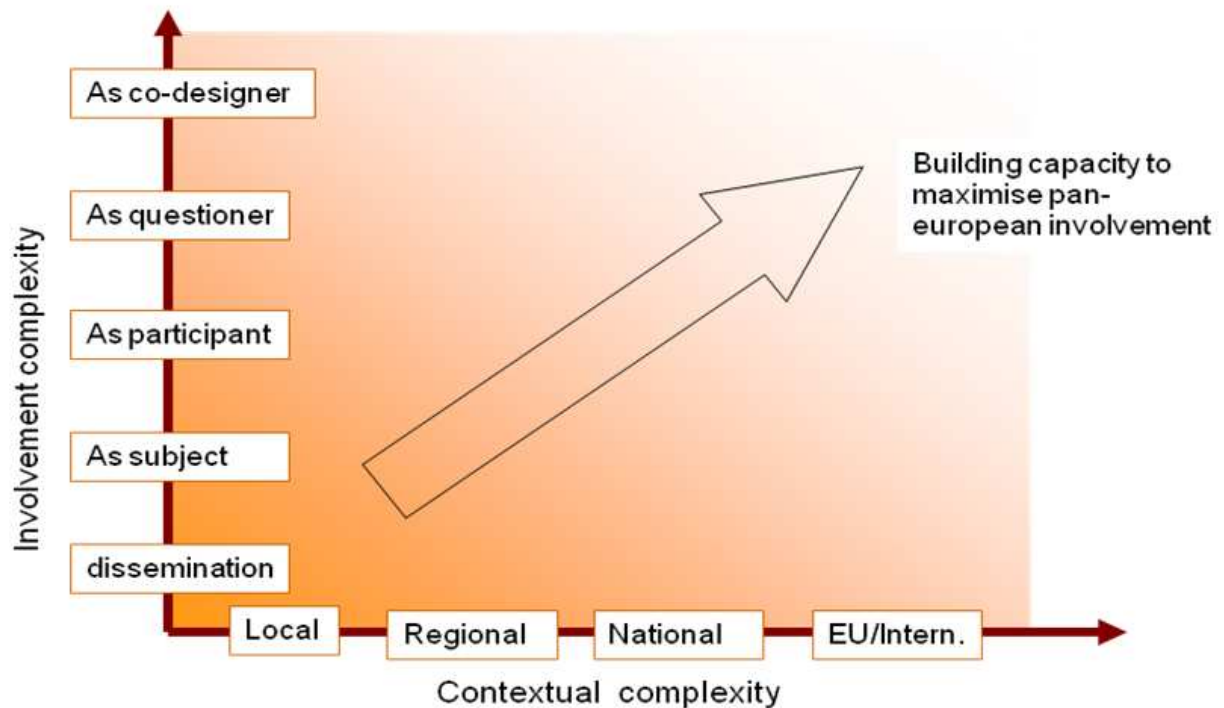
Rodd Bond (Dundalk Institute of Technology, IE) outlined the principal considerations and suggestions on how researchers and public authorities can support user involvement.

He mentioned that often the NGO voice is excluded from debates if not conforming to current orthodoxies. Moreover, encouraging older people to work together with formal researchers as well as including less accessible groups (i.e. isolated, rural, and vulnerable) were seen as important challenges.

The group acknowledged two types of complexity in user participation, namely involvement and contextual complexity.

1. Involvement depicts different levels of participation, clearly showing that older people should not only come to validate the research question; they might as well become **framers of the research**. This change of role of older users from subjects of research, to active participants and further on to co-designers of research, requires observation and ethnographic work, as well as a long-term dialogue between older people and researchers. Moreover, a process of reconceptualising ageing, shifting from the stereotype of burden to bounty of ageing and recognizing the informal economic contribution of this age group was considered essential.
2. The contextual complexity as shown in the image below only refers to aspects of space, but other dimensions could be addressed as well. Questions relating to funding were also raised, mainly concerning the variations at national and regional level and the limited budgets attributed to applied R&D. The UK example of user involvement as a pre-requisite for funding opportunities came up in the discussion as a good practice in this field.

Diagram 1: User Involvement



Source: Rodd Bond

The main recommendations issued by this group were the following:

- The **involvement** of older people as researchers in universities could become reality by giving access to research resources and networks to retired professors and by endorsing skills retention programmes.
- Create a new **funding** model, by encouraging R&D capacity-building at the local level through voucher system, in order to tackle the difficulty faced by NGOs to work on tight budgets for the development of research proposals. Funding must be allowed with preferences to projects really involving older people.
- Research should follow emerging policy shifts, such as the extension of the anti-discrimination regulation.
- **Intergenerational awareness** should be promoted, through cross-generation participation in research as well as other events (i.e. EU day on intergenerational solidarity).
- Strengthening the **role of public authorities**, as funders, co-researchers and extended subjects, is essential.
- The EU should develop a coordinating function, in the view of avoiding duplication, maximizing share of knowledge and recognizing a longitudinal dimension in research (European Institute on Ageing or Network of National Centers and Experts)

- The proper **media coverage** and media involvement must be sought, as the first way to raise awareness and to inform the general public and especially older people.

4.2 Session 2. INDUSTRIAL BEST PRACTICE:

How do industries ensure older people's expectations and needs are taken on board?

Peter Rayner (NPC, UK) expressed the second group's doubts on whether older people's needs and expectations are in practice taken on board by industries and service providers.

A first point raised concerned the term "industry", both in terms of what type of industry does it refer to (i.e. service, engineering) but also making a distinction between those who really try to take into account people's concerns and others who appear to be doing it only for their public image.

A central point of discussion was acknowledging that convincing industries to invest in end users services, could not be driven by a mere intellectual joy and philanthropy. In other words, the group agreed that product and service developers would not examine older people's needs unless it represented a real business opportunity for them. To do that, industries would need to employ anthropologists that would be able to tackle these issues.

They further argued that without any doubt baby-boomers already provide a market and with the rise of life-expectancy this market will become even larger. However, the group also realized that the most appropriate business plan would be one that would see into innovation as a benefit for society as a whole.

In addition, the second group tackled gender issues, recognizing not only the increased participation of women in the labour force but also the fact that sometimes the loss of their partner might result in an immediate loss of resources for older women.

The group's main recommendations were the following:

- **Mainstream** solutions, instead of specific technologies addressed to older users, should be developed.
- Public-private funding partnership, with the participation of NGOs, should be promoted, as a means to ensure decent research, which is not led by profit-making forces only. Carers, insurers, builders and other relevant **actors** should also be engaged in the process.
- In order to achieve a change of attitude in industry, **influencing at the top level** is of foremost importance.
- Without disregarding the rapid technological development and in order to avoid creating bigger barriers for users, older users should first learn to use **existing technology** effectively. Moreover, simple should be preferred to sophisticated solutions. Imposed technology should respect the fine line between inclusion, exclusion and intrusion.
- **Gender issues** should be part of the discussion on older user's concerns as well as paying attention to other differences within older people (i.e. the younger old, the healthy old, the working old, etc).

- Organizations, industries and public authorities should explore ways to raise awareness of older people's needs (i.e. **age-friendly** campaigns or listings or logos).

4.3 Session 3. RECENT EXPERIENCES:

How do older people express their expectations and needs to researchers and services/product developers?

Liz Mestheneos (AGE Platform Europe, EU) presented the outcomes of the discussion held in working group 3, which focused on how older people express their needs and expectations.

She started by stressing the need to influence policy makers and delineated different types of research, depending on its focus: development of commercial products and services, evaluation of services, expression of new and old needs, etc.

The group recognized difficulties that older people face in being heard; for instance, researchers may not listen or not allow them to formulate research questions. Furthermore, some research clearly excludes older people (i.e. commercial research for over 65-70) or puts everyone over a certain age in the same pot. Ms. Mestheneos, underlined that a target group comprising people aged 65+ cannot share the same difficulties or expectations and should be treated differently. Recognizing that investing in user-involvement and empowering people is a time consuming process, the question of cost-effectiveness inevitably came up. The group shared the opinion that observing older people's patterns of living and involving users in setting up questions would allow researchers to come up with better insights and results.

Moreover the group realized that although older people have created a new market force, they do not yet have a **unified voice as consumers** in the EU that would allow them to express their difficulties more consistently and for service and products providers to take them more seriously. The group further noticed the value of professionals, not as representatives of older people but as a useful resource, granting access to others, leading opinions or animating others for example. Additionally, they noted that the different political and cultural settings in the various countries influence significantly the capacity of organizations in representing older people.

Bearing in mind the above considerations, the suggestions of the third group were the following:

- There is an urgent need for the Commission and others to deconstruct **statistics** in smaller age categories than 65+.
- In order to create users' research agendas, empowering people with necessary "tools" for effective **participation** and observing their difficulties are deemed equally necessary.
- **Equal** participation of the most marginalized or non-mainstream groups should not be neglected; although not sufficient, the national action plans for social inclusion could serve as a handle for accessing these groups.
- Depending on the research, a variety of strategies should be undertaken: qualitative, quantitative, focus groups, observation, etc.
- Personal experience is a valuable tool; engaging older experts (i.e. engineers) in research should be promoted.

- Exchange of good practices on user involvement with other industrial countries (i.e. Japan, US) should be encouraged.
- **Media** is a useful resource to raise awareness on how older citizens can benefit from research and inform them on opportunities and technological developments.

The reactions from the floor endorsed the conclusions of the 3 working groups, paying particular attention to the need to redefine age groups; involve multiple actors and different research disciplines and empowering older people to be able to fight their own corner. Moreover, *Marian Barnes* (Brighton University, UK) insisted that researchers have to realize that working without involving people is inconsistent. She further called for a better link with older people's organizations in order both to enable people to participate in research but also to influence government policies. *Simon Roberts* (Intel, EU) and *Carol Jagger* (University of Newcastle, UK) argued for embedding ageing research into other disciplines as a means to raise awareness or extend the influence of the ageing agenda to other areas of study that might otherwise ignore it. Last, *Fiorella Marcellini* (Italian National Institute on Ageing) stressed the need for a better articulation between European and national level and exchange of good practices.

5 Key Themes

Although the 3 groups looked into the question of user involvement from different perspectives (research and public authorities; industry; users) there were some **overarching issues** identified by all groups.

Defining end users: categorization, representativeness and approach matter

There was wide consensus about the need to identify who are the users and to interpret this term broadly; the adopted interpretation is particularly important in order to avoid excluding marginalized groups or treating completely different situations in the same way. In this context, restructuring age groups, approaching less accessible users and engaging carers, professionals, stakeholders and other actors was considered essential. In addition, all groups were in favour of an interdisciplinary approach involving different areas of research.

Some ideas include:

- Older people's involvement as researchers in universities, by giving access to research resources and networks to retired professors and endorsing skills retention programmes.
- Personal experience is a valuable tool; engaging older experts (i.e. engineers) in research should be promoted.
- There is an urgent need for the Commission and others to deconstruct statistics in smaller age categories than 65+.

Catalyzing a recommendation regarding the importance of engaging users in research

Participants underlined the benefits of user involvement for researchers, users and the society in general. They further recognized the increasing influence of older people in the market, in the sense that in the near future industries and researchers would not be able to ignore them; however the lack of a unified voice and effective representativeness was also noted. In that sense, the groups considered that influencing policy makers, industries and industries is necessary. Without doubt, older people's organizations will be asked to play an important role in this direction.

The participants further agreed that:

- Organizations, industries and public authorities should explore ways to raise awareness of older people's needs (i.e. age-friendly campaigns or listings)
- Mainstream solutions, instead of specific technologies addressed to older users, should be developed and simple solutions should be preferred to the more sophisticated ones.
- Gender issues should be part of the discussion on older user's concerns as well as paying attention to other differences within older people (i.e. the younger old, the healthy old, the working old, etc).

Presenting different methods and levels of user involvement

The groups further agreed that a single methodology for user involvement would be ineffective. While defining different levels of participation and complexity, participants accepted that the strategy to be followed depends largely on the objective of the research. Researchers may choose among qualitative or quantitative analysis, focus groups, observation, etc. The main idea that came out of the discussion in the groups was:

- Older people should not only come to validate the research question; their role should be gradually enhanced: from subjects of research, to active participants and further on to framers of the question and co-designers of research.

Discussing directions and opportunities for strengthening the role of users in research

While user participation at all stages was stressed throughout the workshop, the 3 groups also tried to define how early involvement can be achieved in practice. Overcoming barriers in this sense means empowering people to use their own voice, by helping them understand technology and other services and encouraging them to express their needs. Furthermore, researchers should observe patterns of living, in order to appreciate older people's needs. Researchers should also be active on the spot and apply a hand on the concreteness of their research issues through a direct contact with older people and research targets in general. This also means to recruit experts with the right profile (i.e. anthropologists) and to engage a creative dialogue with the users.

Recruitment and support of users could be promoted in the following ways:

- Imposed technology should respect the fine line between inclusion, exclusion and intrusion.
- Media is a useful resource to raise awareness on how older citizens can benefit from research and inform them on opportunities and technological developments.
- Equal participation of the most marginalized or non-mainstream groups should not be neglected; although not sufficient, the national action plans for social inclusion could serve as a handle for accessing these groups.
- Without disregarding the rapid technological development and in order to avoid creating bigger barriers for users, older users should first learn to use existing technology effectively.
- Involving and influencing top levels of all stakeholders concerned is of utmost importance, as dealing with single department cannot guarantee the right degree of effectiveness.
- The role of environment cannot be neglected, but it must be taken into consideration not as an obstacle and a concern, but like an issue we can work on.

Developing funding opportunities and coordinating mechanisms

Funding conditions were a principal concern; local authorities were seen as increasingly important actors in research but at the same time the need to better link European research with the local, national and regional level was considered essential. Exchange of good practices should also be encouraged.

Participants proposed:

- A new funding model, by encouraging R&D capacity-building at the local level through a voucher system, in order to tackle the difficulty faced by NGOs to work on tight budgets for the development of research proposals. R&D budgets should be designed to include users instead of subject matter experts.
- Public-private funding partnership, with the participation of NGOs, should be promoted, as a means to ensure decent research, which is not led by profit-making forces only.
- Strengthening the role of public authorities, as funders, co-researchers and extended subjects, is essential.
- The EU should develop a coordinating function, in the view of avoiding duplication, maximizing share of knowledge and recognizing a longitudinal dimension in research.
- Implications of R&D at different levels – local, regional, EU- should be addressed.
- Exchange of good practices on user involvement with other industrial countries (i.e. Japan, US) should be encouraged.

Lacking issues

Despite the good quality of topics and discussions, the workshop missed to tackle some issues, *Liz Mestheneos* (AGE Platform Europe, EU) summarized as:

- The project should bear in mind the marginalized and the isolated people.
- FUTURAGE could be more effective with the media because this is what older people, politics and politicians listen to.
- The viability of pensions' schemes should also be taken into account in this research framework, at least for the WP concerned, as this is a concern of both individual and governments. The project could have a look of what other projects are doing with this extent and possibility link this issue to the wealth creation and wealth distribution, to discuss what role older people can play.
- In relation to WP3 it should be stressed that health care costs are a concern for older people and the viability of health care system could be more stressed within the project.
- Besides, given the role of FUTURAGE in providing inputs at policy level, the issue of care costs and care workers could be addressed to relevant stakeholders for policy recommendations and solutions.

The following chapter, dedicated to the some additional comments on relevant issues, provides an inside into the discussions and highlights the interactions as well as the connections between the most important topics raised during the workshop, in the light of the general project framework and project's goals.

6 Commentary On Important Issues

Some cross-cutting issues rose during the workshop, especially as comments to the break-out session. The participated discussion from the floor stressed some relevant issues that affect also the general project framework and that can be usefully linked to the project's goals as well. That's why those comments and analysis are part of this seventh chapter, dedicate to other commentaries on important topics.

User involvement in previous and future FUTURAGE workshops

James Goodwin (AGE UK, UK) and *Marian Barnes* (Brighton University, UK) questioned partners on whether users were involved in the first round of scientific workshops and on how they were planning to involve them to put the research agenda forward. The WP leaders responded that only experts participated in them but expressed their wish to invite representatives of user organizations in the second workshops.

With this regard and for such a reason, the Brussels' workshop (and the Barcelona one that will follow) are particularly important.

Link with other projects

Since various projects aiming to produce **roadmaps** in areas related to ageing came up during the discussion (i.e. BRAID, PREVE, AALIANCE etc.) participants acknowledged the need to make a link between projects that have a parallel horizon with FUTURAGE and others who have already resulted in the definition of some research priorities. In other words, there were concerns that FUTURAGE might be "reinventing the wheel" and furthermore that existing knowledge is not equally distributed among all parties.

Heidrun Mollenkopf (BAGSO) suggested the creation of a **common pool of knowledge**, both at national and European level. *Torbjorn Svensson* explained the advantages of the establishment of a European Institute on Ageing. In his opinion this institute would work as a clearing house, without being in charge of funding and of the conducted research, but keeping track of the produced knowledge; it would make possible to have a 'roadmap of roadmaps' and disseminate research findings in different corners of Europe while also facilitating longitudinal research and supporting new scholars. *Carol Jagger* (University of Newcastle) argued back that a European Institute would deflect money, taking the attention away from the national perspective. In her point of view a network of national centres, that keep an eye on what happens at national level and feed into the European research area might be a better model.

Defining users' priority areas: some missing issues

Angelo Agius (National Association of Pensioners, MT) suggested looking at chronic conditions besides dementia, such as loss of sight or hearing and implicating these patients and their carers in the production of the roadmap. *Carol Jagger* (University of Newcastle, UK) pointed out that singling out diseases in research is insufficient. Attention was also drawn to **frailty** in old age.

Peter Rayner (NPC, UK) expressed fear that in some areas like mobility, there is a bulk of knowledge but **measures** to address the problems are missing. *Torbjorn Svensson*

admitted that there should be increased attention given to implementation of existing knowledge and this is one of the priorities defined in FUTURAGE workshops.

Marian Barnes (Brighton University, UK) endorsed the focus in the relationship aspect, as it is fundamental to the experience of well being and further proposed to create measures for relations with people, the environment and ideas. Besides, **unhealthy ageing** should also be better monitored and analysed. *Carol Jagger* (University of Newcastle, UK) also added that quality of sleep is another important area not mentioned in the workshops.

Rodd Bond (Dundalk Institute of Technology, IE) insisted on the need to interpret the concept of **environment** in a wider sense; besides being a prosthetic challenging of ageing, it should be seen as something that we age and engage with. Moreover, he explained that end of life should be re-conceptualized and dying in dignity should also be addressed in research.

Liz Mestheneos (AGE Platform Europe, UK) underlined mental health as one of the most important components of healthy ageing. She further added that what was missing from the presentations is the user's perspective with regard to the **viability of pension** schemes and health care systems. In her view, wealth creation, wealth distribution and the role older people can play in that are important topics and the researchers should consider ways to make policy recommendations on this subject. The WP leaders clarified that these were indeed areas that were taken into consideration and agreed that the user perspective of this issues should be enhanced.

Heidrun Mollenkopf (BAGSO, DE) indicated that the life course perspective should be emphasized in all the different topics (i.e. pensions). *Carol Jagger* (University of Newcastle) further clarified that longitudinal studies are enormously expensive and inhere the danger to see only into things that can change in early life, neglecting factors that may have an impact at later life as well.

Overarching topics in all research streams

Heidrun Mollenkopf (BAGSO) gave examples of areas where there is an inevitable overlapping of topics among the different scientific themes (i.e. social relations, health, housing, economic resources and well being are interlinked), stressing the need to find linkages between the several issues (and related research).

Transfer of knowledge and dissemination

Rodd Bond (Dundalk Institute of Technology, IE) affirmed that research should not be made for knowledge's sake; dissemination enabling to drive change is crucial in this respect. Establishing contacts with professionals and users organizations at the national level is deemed essential.

7 Recommendations

The objective of this first workshop was to provide concrete recommendations to feed into the final report for the Roadmap, as well as to influence the research thinking.

Partners and participants agreed on exploring ways to bring users in the discussion of the scientific workshops and also ask researchers to examine barriers and methods to involve users in their projects, as highlighted in the previous chapters.

Nevertheless the present report aims at synthesizing the most relevant recommendations that the next Barcelona workshop and the FUTURAGE Consortium could take into consideration for the project's purposes.

Participants concluded in some recommendations regarding user involvement within the FUTURAGE scientific streams, the research priorities, the transfer of knowledge at the practical level and the linking with other European or national projects to avoid duplication and achieve better results.

The main recommendations were the following:

- Users should be invited in future FUTURAGE scientific workshops: "it is not about definition of roles, but of dialogue" (*Marian Barnes*, Brighton University).
With this regard, the project could help calling on peer-to-peer involvement.
- It is important to take into account that a big part of older population is not included in research and it has no means to be really involved, as it does not belong to any association and they are not represented; research and the Road Map building should try to cope with this challenge.
- The users' recommendations should feed back into the scientific work: "older people are us, it is us we are thinking about" (*Marian Barnes*, Brighton University).
- Partners should explore ways to make links with other relevant European projects and in a long-term perspective a centralizing mechanism for research in ageing should be envisaged.
- Dissemination of research results should be emphasized in order to drive change and an increased involvement of medias should be envisaged for both awareness raising and for informing the wider audience, older people and general users included.
- A better exchange and transfer of knowledge should be sought, both at top level and intermediate ones, thus helping avoiding research on overlapping issues and to take advantage of the existing good practices.
- With this regard it could be relevant to talk to the European Institutions, namely the European Commission: besides the need of knowledge transfer and dissemination, the European Research Programmes should be more focused on involvement and not only in evaluating.

8 Evaluation Report

A workshop evaluation form was included in each participant kit. A total of 24 completed forms were returned, from a total registration of about 34 people (organizers not included), representing a 71% rate of return. With ratings varying from very good to satisfactory, participants appear to have been satisfied with the overall organization and implementation of the workshop.

Working methodology

- Participants found the discussion held in working groups valuable; it was suggested that such round tables are very useful, especially due to the different expertise of the participants involved and the opportunity for informal discussions to continue during and after the workshop.
- The majority further considered that a list of participants with contact details should be distributed in the delegate's package. The organizers plan to circulate this list, together with the presentations made during the workshop, after receiving the permission of participants, via email.
- Some concerns were expressed however about whether the working group discussions could be better structured in the future. Although participants were given a background note before the workshop, some of them felt that they were missing clear guidance with regard to the objectives pursued during the discussion. Moreover, about 50% of the respondents were unsure whether the aims of the event were fulfilled.
- The stakeholders' presentations were very well received as well; the main weakness was that little time was allotted for adequate discussion of the broad topics presented by the speakers.
- **Future involvement:** Interestingly, a number of participants clearly stated their wish to be involved in future relevant meetings (although an explicit question on this subject was not a part of the questionnaire).

Suggestions for the next workshop

- In terms of the suggestions for the next workshop, it should be noted that the simultaneous interpretation was considered as contributing to making the workshop more inclusive. Moreover it was suggested that the report of this meeting should be distributed to participants before the next workshop in Barcelona.
- A suggestion for future events is to ask for participants' permission to distribute their contact details before the meeting (for example in the registration form) in order to be able to include this list in the participants kits.

We are pleased to report that the general consensus is that, in spite of the comments noted above, the workshop was a worthwhile experience for all participants.

Annex 1 List Of Participants

Ser	Name	Role
1	AGIUS Angelo	National Association of Pensioners, Malta
2	ALBAYRAK Sabrina	Observer
3	BAEYENS Jean-Pierre	EUGMS
4	BARNES Marian	FUTURAGE, external expert
5	BICKENBACH Jerome	Partner of COURAGE project
6	BOND Rodd	Dundalk Institute of Technology
7	COLL PLANAS Laura	Universitat Autònoma de Barcelona
8	CONSTANTINI Bruno	FERPA
9	COURMONT Cécile	Fondation Bonduelle
10	CRAIG Juliet	FUTURAGE
11	DERKS Alvy	Older Women's Network Europe, NL
12	GHENO Ilenia	AGE PLATFORM EUROPE
13	GOODWIN Frank	EUROCARERS
14	GOODWIN James	AGE UK
15	HARMAN Tim	AGE UK
16	HEALY Pat	NPC, UK
17	JAGGER Carol	WP5: Healthy Ageing and Wellbeing
18	KARSHEVA Siana	Bulgarian Red Cross
19	KUOPPAKANGAS Paivikki	University of Turku
20	MARCELLINI Fiorella	WP3: Social And Economic Resources
21	MAWATA Augusta Anata	Observer – University Paris Descartes
22	McCARTHY Kevin	DG Research, EC
23	MESTHENEOS Liz	AGE, 50+ Greece

24	MOLLENKOPF Heidrun	BAGSO
25	MOREL Karine	Observer
26	PARENT Anne-Sophie	AGE PLATFORM EUROPE
27	PEREZ-SALANOVA Merce	FUTURAGE, external expert
28	RAYNER Peter	NPC, UK
29	ROBERTS Simon	Intel
30	ROMAO Mário	Intel
31	RONNBERG Tor Kristian	NOPO
32	SLUIJKHUIS Ben	ANBO
33	SVENSSON Torbjörn	WP4: Environments of Ageing
34	TIMMERS Paul	DG INFSO
35	VAN'T KLOOSTER Josine	Universitair Medisch Centrum Groningen
36	VIRIOT DURANDAL Jean-Philippe	FUTURAGE, external expert
37	WADOUX Julia	AGE PLATFORM EUROPE
APOLOGIES		
	TOUSSAINT Olivier	University of Namur

Annex 2 Workshop Programme



FUTURAGE WP.6 Workshop 1

**Towards a model of
user involvement in research**

25th –26th March 2010

Thon Hotel Brussels City Center

The “*FUTURAGE: A Roadmap for Ageing Research*” project aims at consulting the most relevant stakeholders (users, researchers, public authorities, industries, carers and informal carers) in the field of ageing research, with the main goal of defining a definitive roadmap for relevant research in Europe for the 10-15 years to come.

This participative workshop mainly focuses on:

- Users involvement: barriers and solutions
- The development of a stakeholders oriented mechanism for users’ involvement in the EU research agenda

Day 1 – Thursday, March 25

12.00 Registration/Bufferet Lunch (Cap Nord Hall)

13.00 Opening plenary (Bergen Hall)

Welcome and introduction – Anne-Sophie Parent, AGE Platform Europe

Background to the project – James Goodwin, Help the Aged

13.15 Stakeholders’ perspectives (Bergen Hall)

- *The EU perspective*
Paul Timmers, Head of Unit ICT for Inclusion, DG INFSO, European Commission
- *The research perspective*
Fiorella Marcellini, INRCA (Italian National Institute on Ageing)

- *The industry perspective*
Simon Roberts, Product Research and Innovation, Digital Health Group, Intel Corp.
- *The end-users perspective*
Heidrun Mollenkopf, BAGSO (Federal Association of Senior Citizens Organizations - Germany)

14.30 Coffee Break (Foyer A)

14.45 Working group sessions

Session1	Session2	Session3
<p><i>User involvement:</i></p> <p><i>How researchers and public authorities can support it?</i></p>	<p><i>Industrial best practice:</i></p> <p><i>How do industries ensure older people's expectations and needs are taken on board?</i></p>	<p><i>Recent experiences:</i></p> <p><i>How do older people express their expectations and needs to researchers and services/product developers?</i></p>

16.15 Coffee Break (Foyer A)

16.30 Working group sessions continue

17.45 End of first day session

19.30 Welcome dinner (Restaurant nearby)

**

Day 2 – Friday, March 26

9.00 Reporting from workshop sessions (Bergen Hall) *by Rapporteurs*

10.30 Coffee Break (Foyer A)

10.45 Presentation of state-of-play of WP and questions from the WP leaders

Chaired by Anne-Sophie Parent, AGE

12.45 Conclusion - official close (Bergen Hall) *by James Goodwin, Help the Aged*

13.00 End of the workshop - Lunch (Cap Nord Hall)

Annex 3 Workshop Evaluation Questionnaire

1. Overall, how do you rate the event?

Very good	Good	Satisfactory	Poor	Very poor

Event activities

2) How useful were:

	Very good	Good	Satisfactory	Poor	Very poor
The introduction and scene setting					
The guest speakers					
The structure and contents of the break-out/working groups/workshops					
The delegate packs					

Administrative arrangements

3) How satisfied were you:

	Very good	Good	Satisfactory	Poor	Very poor
With the booking process and pre-event organisation?					
With the organisation of the day?					
With the venue and facilities?					
With the arrangements and quality of the catering?					
With the additional activities organised, eg: lectures, tours (if appropriate)					

4. Were the aims of the event

	Yes	No	Unsure
Clear?			
Fulfilled?			

5) If any, what were the main strengths of the event? Which parts of the event were most useful for you?

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6) If any, what were the main weaknesses of the event? Which parts of the event were of little or no use to you?

7) Do you have any comments or suggestions?