

“Developing a User Agenda for European Research”

Work Package 6

**Final Report from two User Workshops held in
Brussels 25-26 March and Barcelona 13-14 July
2010**

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Executive Summary

This report brings together the findings of the two FUTURAGE workshops which were delivered under Work Package 6, 'User Involvement in Research', one workshop held in Brussels (AGE Platform Europe) in March 2010 and one in Barcelona (Age UK) in July, 2010. The aims of WP6 are on page 7 and the agenda of each workshop in Annex 2.

Over the two workshops, a remarkable 79 delegates from over 20 countries attended. They included a wide range of representatives from across Europe - NGOs and older people's organisations, academic professors, industrialists, scientists, trade unions, professional associations and older people themselves.

The main outcomes of the two workshops included a general recommendation for strengthened user involvement in ageing research; the guiding principles of user involvement, including suggestions to overcome the challenges of user involvement; a prioritisation of topics for ageing research and recommendations on future ageing research.

Strengthening User Involvement

- We concluded that research on ageing should assume a prime role in providing the nations of Europe and the EU with a mandate of evidence for its policies on ageing
- Traditionally in Europe ageing research has been delivered by experts in their field such that the research agendas are expert driven and not necessarily society led; however if the end users of the research are involved in the research process the evidence is much more likely to deliver effective solutions and to be relevant to the real needs and expectations of older people
- User involvement not only has the potential to improve research quality in this field, has the potential to increase research productivity and should therefore improve knowledge transfer, including dissemination, implementation, and the development of better products and services
- In addition, market deployment of the developed products and services as well as user acceptance is facilitated because real needs and problems are addressed, so translating into cost benefits for society as a whole, as ageing becomes mainstreamed into the design of products and services. It is likely that such an approach will also contribute to the economic competitiveness of the EU
- A model of integrated user involvement is more likely to generate multi-disciplinary research which has been shown to be highly effective in providing research solutions to the challenges of an ageing Europe

- Research which engages with its user community should subsume a life course approach since ageing is now proven to take place from the earliest days of life
- One of the factors impeding the better involvement of older people in research activity is the prejudicial view that older people solely constitute a burden on society when the evidence shows that older people in fact contribute significantly in both economic and social terms
- Research that engages with its end-users is under-pinned by the European moral values of democracy, inclusiveness and equality

Recommendations

We make 9 recommendations

The principal recommendations of the workshops are as follows:

- We recommend a policy of **strengthening user involvement** in ageing research
- We recommend a number of **priority research areas** which should form the basis of research in the short-term. It is likely that issues will change considerably over the next 10-15 years
- We therefore recommend that a focus on **capacity building** is necessary so that a flexible, organic, responsive and critical mass of researchers in ageing is created
- We recommend that measures are put into place for the greater **co-ordination of ageing research in Europe** via a virtual European Institute on Ageing
- We recommend the provision of **dedicated funding** for ageing research and concluded that it is one of the critical factors in capacity building
- We recommend the inclusion of a '**user-engagement requirement for funding**' for research on ageing, an important mechanism for ensuring the involvement of users in ageing research
- We concluded that there is a **paradigm of 'user methodology'** which and recommend that it should be integrated into all EU research on ageing
- We concluded that an important element of improving user involvement in European ageing research is the work of **NGOs** and older people's organisations we recommend that DG Research should develop such support
- Finally, we recommend that DG Research should consult **other road maps**, such as BRAID and the ALLIANCE projects, so that their decisions on the ageing research road map could be informed by them.

Aims

The aims of the workshops were:

1. To identify the priorities of users of research into ageing, with reference to the priorities set by the scientific workshops
2. To identify what are the barriers and solutions to the participation of older people and other user groups in research
3. To create a lasting model of user involvement for European research on ageing as an integral part of the FUTURAGE Road Map

Context and Rationale for User Involvement Theme

Europe produces some of the most prestigious research on ageing in the world. There is a vast array of talented researchers in its universities and institutions. Their research productivity is prodigious, given the relatively low funding levels, the fragmentation and duplication of ageing research in Europe and the parsimonious levels of resources available for knowledge transfer and dissemination.

In the current economic climate, attention in Europe, as in many parts of the world, has been centred not just on the levels of funding but on public accountability. Governments and funders are increasingly examining the return on the investment of public money in research. Awards are increasingly dependent on an assessment of research impact. This parameter is notoriously difficult to define and evaluate. None-the-less it is arguable that having research in areas informed by public need, where the research agenda and even the research questions genuinely reflect the needs of society, will do much to improve the impact of research, notably the extent to which research findings contribute to beneficial change and progress in society at all levels. It is argued therefore that there is an *a priori* case for the involvement of users in research: if carried out appropriately it has the potential to improve the quality and productiveness of our research, lead to economic advantage over Europe's competitors and give much better return on scarce research resources.

Not only will there be downstream advantages in practical terms but such involvement will encapsulate our common European values of social inclusiveness, equal participation of all sectors and fairness in the distribution and utilisation of resources. No-one sector and no minority need will be neglected if research is developed through meaningful partnerships between key stakeholders and experts..

This then is the rationale for public involvement in research – no longer will the universities produce high quality research whose effect will extend no further than the book shelves of the institution's library or academic department. If Einstein produced high quality research which was of little direct relevance, then it is the research paradigm set by Pasteur to which we should aspire – high quality, prestigious and incontrovertible but simultaneously of indisputable benefit to humanity.

Philosophy and Structure of the Workshops

Although there is an increased awareness of the importance of the engagement of users in research, the extent to which user involvement has been formalised 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 order to integrate the perspectives of users 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 appointed two partners, AGE Platform Europe and AGE UK, to organise two workshops on users' involvement, where relevant stakeholders, including people representing end user's interests were invited to participate.

The workshops were organised on the principle of inclusiveness and an attempt was made to include a wide range of delegates, representing all sectors of European society. We defined 'users' very carefully as those bodies and individuals who would take up the findings of age related research in Europe and to whom such research findings would be of core interest to them, their business or their profession. Over the two workshops, a remarkable 79 delegates from over 20 countries attended. They included NGOs and older people's organisations, academic professors, industrialists, scientists, trade unions, professional associations and older people themselves.

The workshops were also conceived as an empirical evidence collecting exercise with a distinct methodology which was harmonised across both workshops so that data were collected in a coherent manner, using the same protocols. In addition, since the nature of the workshops precluded the attendance of large numbers of older people, the second workshop received data from a scientific collection of data from a much larger group of older people using a questionnaire.

The two workshops were as follows:

1. A first participative workshop, organised by AGE Platform Europe, held in Brussels on 25-26 March 2010 and
2. The second workshop, organised by AGE UK, held in Barcelona on 13-14 July 2010

The first workshop (W1) was exploratory and paved the way for continued discussion on user involvement within the project framework. Its recommendations served as a starting point for the second round of debate (Workshop 2) and in involving users in the second scientific workshops. The W1 programme was designed as follows

- A plenary session in which policy makers, researchers, industrialists and NGOs gave their perspectives on the involvement of users in ageing research

- Working group sessions on the following themes:
 - **User involvement:** How can researchers and public authorities support it?
 - **Recent experiences:** How do older people express their expectations and needs to researchers and service/product developers?
 - **Industrial best practice:** How do industries ensure that older people's expectations and needs are taken on board?
- An interactive panel discussion including the leaders of the scientific workshops which debated the issues and took questions from the floor

The second workshop (W2) developed the themes from the first workshop, continuing the identification of user priorities, looking closely at issues of knowledge transfer, refining the ideas from W1 on our model of user involvement (including removing the barriers for involvement) and drawing conclusions on the implications of our work for the Road Map. The programme was designed as follows:

- a plenary session the purpose of which was to up-date delegates who had attended the first workshop in Brussels, to brief those who were attending for the first time and to integrate the data from the expertly constituted work packages; it included presentations from authorities in their field from UAB and from important local agencies in order to embed and integrate local delegates. It included presentation of data collected from a wider group of users (Help the Aged Committees, UK)
- working group sessions – whose purpose was to collect empirically the views and issues of the delegates
- panel discussion – to bring together the rich data collected throughout the workshop and to add commentary from users including the implications for the FUTURAGE Road Map and Framework Programmes 7 and 8. Considerable time was spent discussing the structure of the Road Map and the implications for the European Framework Programme, especially in the opening plenary session and in the discussion panel at the conclusion of the workshop (details in text of document).

The agendas for the two workshops are presented in Annex 2.

Key Themes

The main outcomes of the two workshops included a general recommendation for strengthened user involvement in ageing research; the guiding principles of user involvement; concrete suggestions to overcome the challenges of user involvement; a prioritisation of topics for ageing research and deliberations on future ageing research.

Strengthening User Involvement

- Population ageing is occurring globally at an unprecedented rate and Europe has the world's oldest population. Those nations and regions who deal most successfully with this transition will have a competitive advantage: in this context, we concluded that research on ageing should assume primacy in providing the solutions and is likely to provide the nations of Europe and the EU with a mandate of evidence for its policies on ageing
- Traditionally in Europe ageing research has been delivered by experts in their field such that the research agendas are expert driven and not necessarily society led; however if the end users of the research are involved in the research process the evidence is much more likely to deliver effective solutions and to be relevant to the real needs and expectations of older people
- User involvement not only has the potential to improve research quality in this field, ensuring European age research is world-class but it also has the potential to increase research productivity, delivering data and evidence in which there is a sense of ownership. It should therefore improve knowledge transfer, including dissemination, implementation, and the development of better products and services
- In addition, market deployment of the developed products and services as well as user acceptance is facilitated because real needs and problems are addressed, so translating into cost benefits for society as a whole, as ageing becomes mainstreamed into the design of products and services. It is likely that such an approach will also contribute to the economic competitiveness of the EU
- The challenges facing an ageing population are intense and complex; we concluded that a model of integrated user involvement is more likely to generate multi-disciplinary research which has been shown to be highly effective in providing research solutions to these challenges
- Research which engages with its user community should subsume a life course approach, justified by the latest evidence indicating that ageing occurs across the life span and is not an isolated end-of-life phenomenon
- One of the factors impeding the better involvement of older people in research activity is the prejudicial view that older people solely constitute a

burden on society when the evidence shows that older people in fact contribute significantly in both economic and social terms

- Research that engages with its end-users is under-pinned by the European moral values of democracy, inclusiveness and equality because the potential users of the research outputs will inform research that is publicly funded

Guiding Principles of User Involvement in Ageing Research

The following are our collective recommendations on user involvement methodology which are intended principally for the academic community. These points are progressive and well informed. They represent a European state-of-the art position on user involvement in ageing research which is well ahead in terms of its development compared to other global regions. The following points address the major barriers to the involvement of users and their solutions.

- User involvement must not be 'tokenistic', ie a meaningful and substantial relationship should be developed between researchers and users;
- Research should not only be ethical but it should have the potential to contribute to the quality of life of older people and its impact should be evaluated;
- Efficient user participation in *all stages* of innovation and decision-making, from the outset until after the end of the research process is desirable;
- There cannot be one single model of user involvement which applies across Europe; the academic discipline, the study design, the objective of the research and other factors, such as the available resources, will also impact on the methodology of user involvement;
- User involvement is more likely to generate multi-disciplinary research which has been shown to be highly effective in providing research solutions. Involving multiple actors (i.e. caregivers, professionals, insurers, etc) is equally important;
- One of the factors impeding the better involvement of older people in research activity is the prejudicial view that older people solely constitute a burden on society when the evidence shows that older people in fact contribute significantly in both economic and social terms. Even researchers themselves sometimes ask 'why involve users' and 'non-expert', 'non-professional' knowledge is often resisted by academics. Thus, among others, it is the role of the research community and also of NGOs to change the image of older persons
- The wide range of users for any area of proposed research must be carefully identified, recognising the diversity of older people and the social context, plus the future cohorts who will become old. Restructuring smaller age-groups is considered necessary in order to respond to real-life situations. In addition, equal inclusion must be addressed: gender issues, income, social and cultural background, level of education, cognitive and

physical abilities, ethnic and geographic origin and other factors must be taken into account.

- Failing to empower users to participate efficiently may lead to inconsistent research results. Support of users may be promoted in the following ways:
 - 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 development
 - Equal participation of the most marginalised or non-mainstream groups should not be neglected; although not sufficient, national action plans for social inclusion could serve as a 'handle' for accessing these groups
 - Without disregarding rapid technological development and in order to avoid creating bigger barriers for users, older users should first learn to use existing technology effectively
 - It is of the utmost important to involve and influence the decision makers and leaders in all sectors and groups of stakeholders, so that decision making is influenced
 - Practical support, such as dedicated training, providing written material in a language they can understand, encouragement, recruiting specialists, making arrangements for accessibility etc.
 - It is necessary to deal with the anxieties of users. From the beginning they should know the ethical implications, logistic details of their involvement, what the rewards are, if any, and so on.
- We need to remedy the current poor level of communication between researchers and users by striking a balance between users' and researchers' knowledge, experience, priorities and expectations. Researchers have to be trained and educated to involve users as partners. Differences and gaps in communication may also be tackled by having the flexibility to develop methods of involving different people and non-traditional methods, eg. recruiting anthropologists/psychologists, deploying art or drama, etc
- The many different levels at which involvement may occur must be recognised – users may act as consultants; being advisors; devising the research questions or taking part. These levels depend on the type of research (development of products, expression of need, implementation of existing knowledge) but also on the method of involvement (consultation, partnership, focus groups, etc)
- Procedures for involvement must be rigorous, not only identifying the resources required but also a clear identification of the implications of involvement, for example whether there will be financial rewards for older people. Financing should not be a barrier to participation, meaning that users should not pay for their involvement and at minimum basic expenses should be covered (meals, travel and accommodation). Giving cash payments is an issue: research institutions should look for alternative solutions. The value which older people bring to research should be recognised.

- User involvement should be comprehensive and fully inclusive, and may have to involve statutory agencies; working with academics; engaging retired professionals so that groups or individuals are not excluded.

Priorities

Numerous detailed priorities for research emerged. These are iterated below carefully categorised into the FUTURAGE themes

Healthy Ageing

- Developing a theory base for user involvement and implementation science
- Defining and measuring healthy ageing
- Determinants of healthy ageing across the life course
- Healthy ageing and economic development (eg Eastern Europe)
- Inequality of access to health services
- Social engagement and participation
- Sustainability of health and care systems and pensions as the population ages
- Behavioural change
- Mental health

Social and Economic Resources

- We need to know how to improve social participation, inclusion and volunteering in the community
- Poverty, purchasing power, pensions and their sustainability are key issues
- With increased life expectancy, there will be increased living alone and we need ecological research to address this problem
- As people live longer, they will experience frailty, fear of dependence, chronic disease and dementia – all of which should be priorities for research
- We need research into services at home, how to reduce hospitalisation and how to give a voice to older people in and out of hospital
- How to improve the co-ordination between health and social care
- Research to tackle the problem of widespread ageism
- Research into intergenerational issues, the future old, migration and gender (particularly equality for older women, life after retirement and widowhood)

Environments of Ageing

- We need to research not only ageing in place but also ‘ageing places’, including integration of the meaning and value of places to the people who use them
- We need to look at those aspects of the environment which give people quality of life
- There are few studies on end-of-life environments
- We need to do more research to identify how we may meet the needs of different individuals, eg dementia vs non-dementia, in care homes

User Survey

The questionnaire survey of a small sample some 112 users (Help the Aged Committee members, median age band 65-74) revealed the most important priorities for them as follows, for each of the 3 main themes

Healthy Ageing

- Dementia
- Stroke
- Heart problems
- Maintaining physical and mental fitness
- Access to health services

Social and economic resources

- Loneliness
- Pensions
- Care giving/givers

Environments

- Community support
- Transport
- Home adaptation

Recommendations

The principal recommendations of the workshop are as follows:

- We recommend a policy of **strengthening user involvement** in ageing research. Such a policy would help to deliver more effective solutions for the challenges of an ageing Europe; produce higher quality research with greater potential for knowledge transfer and contribute to the economic competitiveness of the EU
- A number of **priorities for research** have been identified and we recommend that these areas should form the basis of research in the short-term. However, we concluded that these priorities though prescient now (and should inform our road map for ageing research) it is likely that issues will change considerably over the next 10-15 years
- We therefore recommend that a focus on **capacity building** is necessary so that a flexible, organic, responsive and critical mass of researchers in ageing is created, increasingly working across Europe and which has at its core a culture that involves users and particularly older people. This strategy would ensure that there is a measure of flexibility and would improve the identification of issues for research which are unforeseen at the present time. Measures to improve capacity are detailed in the body of the report

- We recommend that measures are put into place for the greater **co-ordination of ageing research in Europe**; there was discussion over the creation of a European Institute on Ageing Research with a view to the very successful National Institute of Ageing in the USA. We concluded that it was more important to facilitate the express functions of such an institute, rather than embody it in new physical infrastructure. These measures are detailed in the body of the report. One advantage of better co-ordination would be to bring in the countries of eastern Europe so that they can share in the developments in ageing research which exist elsewhere in the EU

- We recommend the provision of **dedicated funding** for ageing research and concluded that it is one of the critical factors in capacity building. This could be achieved via existing European programmes, by funding for co-ordinating action or by a new funding stream in future programmes, eg FP8. One of the current disadvantages of the European Funding Programmes is the inability to fund longitudinal studies

- We recommend the inclusion of a **'user-engagement requirement' for funding** for research on ageing, an important mechanism for ensuring the involvement of users in ageing research. Applicants for central funds should be asked to show that they had a substantial relationship with users, including older people, a mechanism which has worked well in some European nations where it is already used

- We concluded that there is a **paradigm of 'user methodology'** which and recommend that it should be integrated into all EU research on ageing. This paradigm includes recommendations on the process of research, the involvement mechanisms, identifying potential users and future assessments. We concluded that there would have to be variations in the paradigm to account for the cultural diversity in Europe and for the diversity in the range of users including older people

- We concluded that an important element of improving user involvement in European ageing research would be to support the **growth and development of NGOs** and older people's organisations in the EU, particularly in new and candidate countries where these developments are often fragile; we recommend that DG Research should develop such support

- Finally, we recommend that DG Research should consult **other road maps**, such as BRAID and the ALLIANCE projects, so that their decisions on the ageing research road map could be informed by them.

Annex 1: List of Participants

List of Participants – User Involvement Workshop 1 Brussels

Ser	Family name	First name	Institution
1	AGIUS	Angelo	National Association of Pensioners, Malta
2	ALBAYRAK	Sabrina	Observer
3	BAEYENS	Jean-Pierre	EUGMS
4	BARNES	Marian	University of Brighton, UK
5	BICKENBACH	Jerome	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	UAB
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	
37	WADOUX	Julia	Age Platform Europe

APOLOGIES

TOUSSAINT Olivier University of Namur

List of Participants – User Involvement Workshop 2 Barcelona

Ser	Family Name	First Name	Institution
1	Goodwin	James	Age UK
2	Harman	Tim	Age UK
3	Georgantzi	Nena	Age Platform Europe
4	Pérez-Salanova	Mercè	Institute on Aging – Universitat Autònoma de Barcelona
5	Coll Planas	Laura	Institute on Aging – Universitat Autònoma de Barcelona
6	Walker	Alan	FUTURAGE Sheffield
7	Marcellini	Fiorella	WP3: Social and Economic Resources
8	Svensson	Torbjorn	WP4: Environments of Ageing
9	Lorenzo	José Antonio	Barcelona Digital, R&D Health
10	Caminal	Montserrat	Obra Social la Caixa, Programa Gent Gran
11	Bickenbach	Jerome	Partner of COURAGE
12	Mollenkopf	Heidrun	BAGSO
13	Constantini	Bruno	FERPA
14	Mestheneos	Liz	Age Platform Europe
15	Arenas	Sergi	Universitat Autònoma de Barcelona

16	Rayner	Peter	UK NPC
17	Derks-Tai A Pin	Alvy	Netherlands
18	Cornet I Prat	Joan	Executive President TicSalut Departament de Salut Generalitat de Catalunya
19	Mas Quintana	Mercè	Older People Council Barcelona
20	Goodwin	Frank	EUROCARERS
21	Ward	Lizzie	University of Brighton United Kingdom
22	Agius	Angelo	Malta
23	Bond	Rodd	Dundalk Institute of Technology
24	Beard	John	Director of Ageing, WHO
25	Walker	Carol	Lincoln University, UK
26	Gheno	Ilenia	Age Platform
27	Sargeant	Gill	Age UK
28	Barnes	Angela	Age UK
29	Healy	Pat	Vice President National Pensioners Convention
30	Garatini	Chiara	Intel TRIL Centre, Dublin
31	Martínez	Regina	Universitat Autònoma de Barcelona
32	Elzaburu	Beñat	Universitat Autònoma de Barcelona

33	Sánchez	Andrea	Universitat Autònoma de Barcelona
34	Puig	Mireia	Universitat Autònoma de Barcelona
35	Solanes	Pilar	Departament Acció Social i Ciutadania- Generalitat de Catalunya
36	Albayrak	Sabrina	REIACTIS
37	Gómez	Gabriela del Valle	Institute on Aging – Universitat Autònoma de Barcelona
38	Domínguez Alarcón	Carmen	Universitat de Barcelona
39	Wells	Oliver	Chair of Association of British Healthcare Industry
40	Godàs Pérez	Xavier	Mayor's Office Barcelona
41	Orte	Carmen	Universitat Illes Balears
42	Ros	Assumpció	Nursing home director and president of FEATE (Federation of Entities Assisting Older Adults, NGO), SPAIN

Annex 2a: Workshop Programme – Brussel



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/Buffer 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)

Annex 2 b: Workshop Programme - Barcelona



FUTURAGE
A ROAD MAP *for* AGEING RESEARCH



FUTURAGE

Towards a model of user involvement in research Workshop 2

13-14 July 2010

Casa Convalescència, Barcelona



Institut de l'Envel·liment
UAB

The FUTURAGE project aims at consulting the most relevant stakeholders (users, researchers, public authorities, industries and 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:

- The priorities of users for research on ageing
- The continued development of a methodology of user participation in research on ageing

Day 1 – Tuesday 13 July

12.00 Registration/Bufferet Lunch (Main floor hall reception/ lunch room)

13.00 Opening plenary (room: Aula Magna)

- *Welcome* – Joan Gómez Pallarès, Vice-Rector on Research, UAB
- *Introduction* – Mercè Pérez-Salanova, UAB
- *Background to the project* – Alan Walker, Sheffield University

13.20 Stakeholders' perspectives (room: Aula Magna)

- *Summary of Workshop 1*
Liz Mestheneos, AGE Platform Europe
- *Summary of scientific workshops*
One presentation each from leaders of Work Packages 2, 3, 4, 5
WP2 Biogerontology TBC
WP3 Social and Economic Resources Fiorella Marcellini
WP4 Environments of Ageing Torbjörn Svensson
WP5 Healthy ageing James Goodwin
- *Policy perspective*
Xavier Godas Pérez, Chief of Staff, Social Action and Citizenship, Mayor's Office, Barcelona
- *The end-users perspective: issues that are important to older people*
James Goodwin, Help the Aged/Age UK

14.40 Coffee Break (garden)

15.00 Working Group Sessions – Priorities (room: Aula Magna, room 01 and room 04)

Working Group 1 User involvement priorities: Bio-gerontology Healthy Ageing Chair John Beard	Working Group 2 User involvement priorities: Social and Economic Resources Chair Fiorella Marcellini	Working Group 3 User involvement priorities: Environment and Ageing Chair Torbjörn Svensson
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16.30 Coffee Break (garden)

17.00 Working Group Sessions – Involvement (room: Aula Magna, room 01 and room 04)

Working Group 1 How to involve users: Biogerontology Healthy Ageing	Working Group 2 How to involve users: Social and Economic Resources	Working Group 3 How to involve users: Environment and Ageing
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18.30 End of first day

20.30 Leave Hotel for Welcome Dinner (Restaurant el Mirador del Palau de la Música)

Day 2 – Wednesday 14 July

9.00 Reporting from workshop sessions – Groups 1, 2, 3 (room: Aula Magna)

10.30 Coffee Break (terrace)

10.45 Discussion session and Q&A with WP leaders

Chair: James Goodwin and Mercè Pérez Salanova

12.45 Conclusion by James Goodwin – official closure by Antoni Salvà
(room: Aula Magna)

13.00 End of workshop – Lunch (lunch room)

Annex 3: Survey of UK Users – Questionnaire

FUTURAGE Questionnaire for Help the Aged Local Committees

WE wish to gather the views of Committee members, regardless of age, to input into discussion of future research priorities as part of the FUTURAGE project. By participating in this survey, you have an opportunity to influence at an international level the direction of research affecting older people, including those who are local to you.

We would be grateful if you could answer the following questions. The questionnaire should take no more than 30 minutes. The answers you provide will be anonymous and non-attributable. Any personal information will not be divulged to any external or third party. You will be informed of the results and the impact your views will have on the Futurage project.

Futurage has determined that the issues most important to older people can be divided into 4 areas:

- Biomedicine, genetics and gerontology
- Social and economic resources (social support and care)
- Environments of ageing (the physical environment)
- Healthy ageing (physical and mental health)

For each of these, listed below are the major areas of current research – please tick the appropriate box to tell us how important you think each area is for older people in general.

Biomedicine, genetics and gerontology (science of ageing)

		Very important	Important	Neutral	Unimportant	Irrelevant	Don't Know
1	Stroke						
2	Heart Problems						
3	Respiratory problems						
4	Mental decline						
5	Dementia (including Alzheimer's disease & other types of dementia)						
6	Parkinson's disease						
7	Loss of vision						
8	Loss of hearing						

9	Immunity						
10	Incontinence						
11	Bone & joint problems						
12	Cancer						
13	Why we age physically						
14	Wound healing						
15	Muscle wasting						
16	Genetic influences on ageing						

17. Please rank the top three areas that you believe are most important.

- 1.
- 2.
- 3.

18. Do you have any points you would like to make about the areas of research listed in the table above?

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Social and economic resources for ageing well

		Very important	Important	Neutral	Unimportant	Irrelevant	Don't Know
19	Pensions						
20	Loneliness/ isolation/ exclusion						
21	Elder abuse						
22	Ageism						
23	Care giving/ caregivers						
24	Poverty						
25	Gender/social class/ethnic group						

26	Changing family structure						
27	Employment						
28	Volunteering						
29	Economic contribution of older people						

30. Please rank the top three areas that you believe are most important.

- 1.
- 2.
- 3.

31. Do you have any points you would like to make about the areas of research listed in the table above?

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Environments that will help people age well

		Very important	Important	Neutral	Unimportant	Irrelevant	Don't Know
32	Care homes vs. family homes						
33	Transport						
34	Deprived neighbourhoods						
35	Crime						
36	Adaptation of the home						
37	Preventing falls						
38	Computer use						
39	Community support						

40	Rural vs. urban						
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41. Please rank the top three areas that you believe are most important.

- 1.
- 2.
- 3.

42. Do you have any points you would like to make about the areas of research listed in the table above?

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Healthy ageing

		Very important	Important	Neutral	Unimportant	Irrelevant	Don't Know
43	Diet for later age						
44	Maintaining physical fitness						
45	Maintaining mental fitness						
46	Access to health services						
47	Sleep						
48	Obesity						
49	Drugs/alcohol						

50. Please rank the top three areas that you believe are most important.

- 1.
- 2.
- 3.

51. Do you have any points you would like to make about the areas of research listed in the table above?

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52. Is there a topic or topics, not included in any of the above tables, which you think should be a high priority for research? Give your reasons for the importance of this issue.

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53. From your personal experience, and thinking of older people you know, what issues have been of most concern to them?

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54. What issues concern you most when you consider your own future as part of the older generation?

.....

Please answer some broader questions about your involvement, past and future, into research on ageing.

55. Have you personally participated in research on ageing in the past?

Yes	No

56. If yes, in what capacity? (Check all that apply.)

Conducted research projects	Member of advisory or steering group	Took part in a research project	Member of an ethics committee	Raised funds for research	Other:

57. If no, what are the reasons you have not participated? (Uninformed/unaware of opportunities, not interested, no time, etc.)

.....

58. Are you interested in participating in research on ageing?

Very interested	Interested	Neutral	Uninterested	Very uninterested

59. In what ways would you consider being a part of the research process? (Check all that apply.)

Conducting research projects	Member of advisory or steering group	Taking part in a research project	Member of an ethics committee	Raising funds for research	Other:

Please answer a few questions about you.

60. What is your age?

0-15	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85-94	95 or over

61. Are you male or female?

Male	Female

62. Are you currently... (Check all that apply)

Studying	Working part-time	Working full-time	Taking a break from work	Retired	Volunteering	Other:

Thank you for completing this survey. You will be informed of summary results and conclusions drawn.

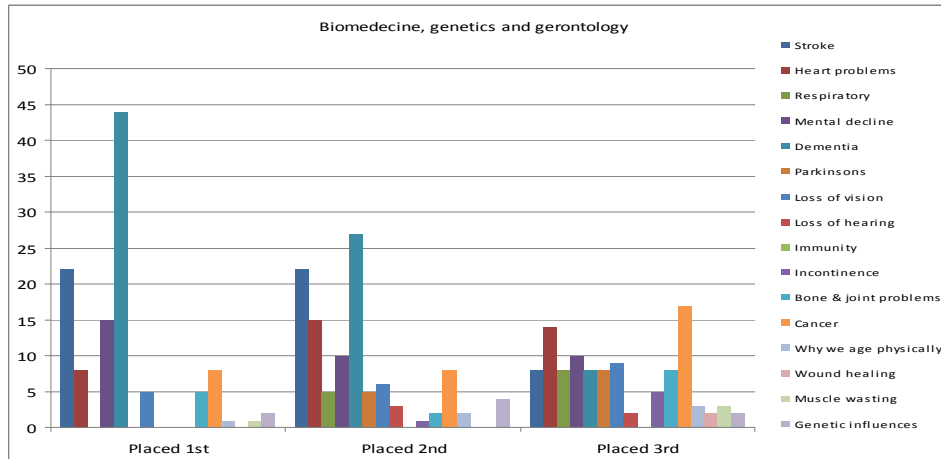
Please use the provided FREE business reply service envelope to reply

Annex 3: Survey of UK User Priorities - Results

Data prepared by Bev Stuttard (Age UK)

Biomedicine etc - results

Top 3 rankings



Top 3 weighted (1st = 3 pts, 2nd = 2 pts, 3rd = 1pt)

Dementia (194), Stroke (118), Mental decline (75)

Biomedicine, genetics and gerontology - results

- Topics which over 85% of respondents rated as important or very important
 - Dementia (99%)
 - Stroke (95%)
 - Heart problems (94%)
 - Mental decline (93%)
 - Cancer (90%)
 - Bone & joint problems (89%)
 - Loss of vision (87%)
 - Parkinson's (87%)

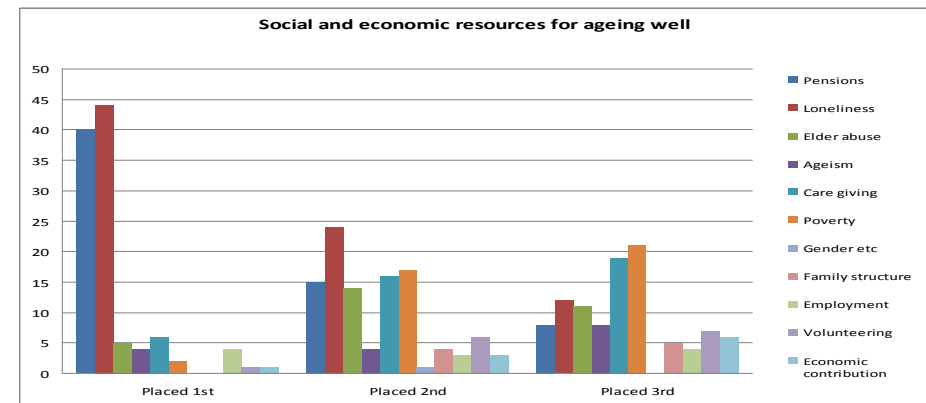
Biomedicine genetics and gerontology

Typical views on research

- As dementia is being diagnosed at an earlier age and is going to cost so much in the future, we should be researching this urgently
- Respiratory – with climate change, hotter weather will bring problems for the elderly
- Should research side effects of prescribed drugs
- Need to add diabetic problems, osteoporosis and hypertension
- There seems to be no recommended prevention for dementia and Parkinson's
- Very little is known about the genetic influences on ageing
- For personal reasons I would like to see more research on inherited heart disease
- Deafness is undervalued as a problem
- Essential that mental ability is maintained – this is the 'new cancer' and needs addressing urgently
- Loss of vision or loss of hearing can lead to isolation
- There seems to be a lot of cancer research but not much progress
- Unlike other areas a stroke can come on suddenly and without warning and results can be catastrophic – thus finding out how to reliably avoid them is very important
- I am concerned about conditions which impair life not conditions which end it

Social and economic resources - results

Top 3 rankings



Top 3 weighted (1st = 3 pts, 2nd = 2 pts, 3rd = 1pt)
Loneliness (192), Pensions (158), Care giving/givers (69)

Social and economic resources - results

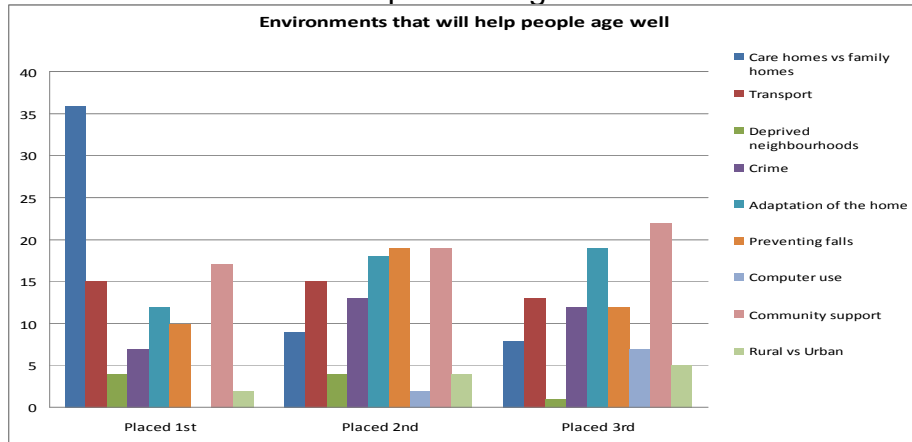
- Topics which over 85% of respondents rated as important or very important
 - Pensions (92%)
 - Loneliness (91%)

Social and economic resources Typical views on research

- Pensions and poverty bring their own problems but combined with other factors bring about loneliness and isolation
- Changing family structure – willingness of people to look after older family members
- Care homes and their activities should be researched
- Economic contribution should not be a factor – they shouldn't be working (from a younger respondent!)
- Volunteering is a route to maintaining self-respect and feeling valued
- I believe that ageism is one of the worst prejudices that we face particularly in a medical environment
- I have doubts about the benefits of research – it diverts funds and inflates the egos of those conducting the research
- Ageism is the cause of many other social and economic issues
- The care system – both in the community and residential – needs radical and urgent re-appraisal
- Ensure the research is not duplicated anywhere – limited resources need careful planning to avoid inefficiencies in overlapping research

Environments of ageing - results

Top 3 rankings



Top 3 weighted (1st = 3 pts, 2nd = 2 pts, 3rd = 1pt)

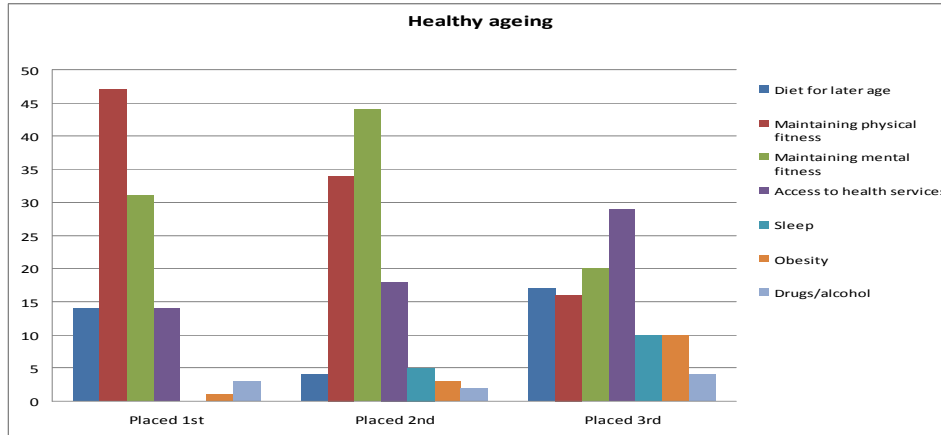
Care homes/family homes (134), Community support (111), Home adaptation (91)

Environments of ageing - results

- Topics which over 85% of respondents rated as important or very important
 - Community support (89%)
 - Transport (89%)
 - Home adaptation (87%)

Healthy ageing - results

Top 3 rankings



Top 3 weighted (1st = 3 pts, 2nd = 2 pts, 3rd = 1pt)

Maintaining physical fitness (225), Maintaining mental fitness (201), Access to health services (107)

Healthy ageing - results

- Topics which over 85% of respondents rated as important or very important
 - Maintaining physical fitness (100%)
 - Maintaining mental fitness (100%)
 - Access to health services (93%)

Healthy ageing Typical views on research

- Older people don't want to be dictated to – they are adults not babies and know what is healthy!
- Obesity/drugs/alcohol – choice should have been made earlier in life to avoid these
- There is very little research going on in these areas
- The majority of our ageing community are not given the opportunities for exercise at low cost/free sessions – this would have physical and mental benefits
- Maybe the research needs to look into the best ways of educating an older public – and providing incentives for healthier living
- Although research into diet is very important, its results must be believable. There have been far too many occasions where findings contradict each other e.g. is a glass of red wine a day good or bad for you?

Involvement in research

40% of
respondents
have already
been involved
in research

Respondents who have participated in research

Conducted research projects	5
Member of advisory or steering committee	11
Took part in a research project	11
Member of an ethics committee	4
Raised funds for research	32
Other	7
Total (counting multiple responses)	70
Total (number of people who have participated)	45

Reasons for not participating

Not interested	1
Didn't think I could be useful	4
I have never been asked	14
Unaware of opportunities	30
No time	11
Other	2
No comment	6
Total	68

Willingness to participate

- Only 6% of respondents are *disinterested* in participating in research
- 53% would participate in a research project
- 28% would raise funds for research
- 28% would be a member of an advisory committee

Summary

- The biggest concerns, and therefore the topics considered the most important to research are:
 - Maintaining physical fitness
 - Maintaining mental fitness
 - Dementia
 - Strokes
 - Loneliness and isolation
 - Pensions