



Report of the Users Involvement in Ageing Research Workshop

22nd November 2006

Held at Regents Park Hotel, Carburton Street, London



Sixth Framework Programme, ERA-NET/1/CA-SSA No. 510177

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SECTION 1

EXECUTIVE SUMMARY OF FORUM RECOMMENDATIONS

1.1 Sustaining a dialogue between funders, researchers and end users of research

Participants identified various ways of sustaining a dialogue between funders, researchers and end users of research:

- Funders can successfully set conditions in their funding application criteria to stimulate dialogue.
- Researchers and end users should be encouraged to approach projects with open and objective minds.
- Researchers should receive training on approaches to involve end users of research.
- Funders, researchers and end users should establish common goals.
- Stakeholders should develop a collaborative culture.
- Researchers need to communicate the user involvement methods that they use and research findings clearly.
- A centralised body comprising of politicians, researchers and end users could be established to guide people on end user involvement. ERA-AGE could become the centralized co-coordinator for research, becoming the broker to promote the initiative in participating countries.

1.2 Factors which have affected the process of involving end users in research

- Involving older people in the research process ('older people as researchers') helps researchers to identify the right questions.
- An effective communication process and good project management are essential to involving end users and producing positive project outcomes.
- Mutual appreciation of stakeholders expertise and experience is essential
- End user organisations should be actively involved in disseminating research findings.
- It is crucial to involve organisations which represent older people such as Help the Aged, UK, in research processes.

- A lack of information exists on end user involvement.
- End user involvement can be very expensive and it is sometimes difficult to obtain a budget for involving end users in research.
- End users and researchers often have different objectives. This may deter (i) end users from participating in the research and (ii) researchers from inviting end users to participate.
- Social barriers language, culture, religion and educational background may hinder the process of involving users.

1.3 Ensuring that research proposals are informed by older people

Participants suggested a number of ways to ensure that older people inform research proposals:

- The involvement of end users may be a condition/criterion for obtaining funding.
- The provision of a methodological guide and training to inform good practice in knowledge transfer.
- Ensure that research is on the agenda for organisations for older people including non-governmental organisations (NGOs).
- Retired researchers may be involved to establish a link between older people and current researchers.
- The views of users may be used to influence the direction of research rather than methodological issues since these decisions tend to require specific expertise.
- Older people should be given the opportunity to assist in the development of proposals.

1.4 Good practice principles guiding user involvement in ageing research

- Funding organisations should advocate the principle of involving older people in the research process within their funding call's eligibility criteria.
- Develop clear criteria for recruiting and involving end users.
- Negotiate and agree mutual expectations from the outset.
- Develop good communication and dissemination strategies to involve and accommodate all stakeholders.

- Ensure that ethical issues are explored and appropriate actions taken.
- Provide training on good practice principles in involvement (including ethical guidelines and responsibilities) to researchers and, when appropriate, end users.
- Ensure that older people benefit from participation in research.
- Involve older people during all stages of research if possible.

SECTION 2

PROGRAMME

- Opening Plenary, Professor Alan Walker, University of Sheffield (UK)
- Welcome and introductions to ERA-AGE – Professor Alan Walker, University of Sheffield (UK)
- Presentations:
 - 'Advantages and barriers to user's Involvement in Research' by Isabel Borges (Information and Policy Officer, AGE, Belgium)
 - 'Public Involvement in NHS public health and social care research' by Nick Partridge (Chief Executive and Chair of INVOLVE, UK)
 - 'Active Involvement of patient/clients in agenda setting on health research' by Dr J.E.W Broerse (Associate Professor, ATHENA, The Netherlands)
 - 'Empowering senior citizens in research: A multilevel implication' by Dr Viriot Jean Philippe Durandal (University of Franche-Comte, France)
 - 'Introduction to the European Research Area on Ageing' by Professor Alan Walker (University of Sheffield, UK)
- Working groups on end user involvement in research

Working groups:

 - Sustaining dialogue between funders, researchers and end users on research development and knowledge transfer
 - Barriers to involving end users in research
 - Good practice between users
 - Good practice principles to guide user involvement in ERA-AGE research
- Closing Plenary

SECTION 3

AIMS AND OBJECTIVES OF THE EUROPEAN FORUM MEETING

The Aim of the Meeting:

To identify principles of good practice from different European countries to enable ERA-AGE partners and other funders of ageing research to better involve **end-users** in research. The workshop built upon the FORUM recommendations on user involvement and by sharing experience among partners, developed these recommendations in more detail. Good practice principles will subsequently form the basis for developing potential transnational collaboration in this field.

The objectives of the Meeting:

1. To present some good practice models of end user involvement in research (via presentations)
2. To draw upon the experience of ERA-AGE partners and others to identify and critically appraise a range of European models of end users involvement in research (via workshop)
3. To achieve an agreement on the principles that should guide good practice in the involvement of end users in ageing research (via workshop).

SECTION 4

SUMMARY OF PRESENTATIONS

4.1 Advantages and barriers to user's involvement in research

Isabel Borges

Information and Policy Officer, AGE, Belgium

AGE- the European Older People's Platform believes that user's involvement in research is indispensable:

- To improve the quality of services in Health and Social care
- Public Transport
- Information and Communication Technology products

There are strong reasons to involve users groups, especially representative organisations to improve the quality of life of citizens, individually and collectively.

- The European Commission has in recent years been in the forefront of requesting the **active involvement of user representative organisations in EU Research** project proposals.
- AGE has had a **positive experience** regarding the involvement of its organisation in research projects at EU level such as:

Eurofamcare: "Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage" was a European project funded under the 5th Framework programme for research.

<http://www.uke.uni-hamburg.de/extern/eurofamcare/>

AGE:

- drafted a report which analysed how the policies developed at EU level can impact on the situation of family carers;
- helped developing a European charter for family carers;
- disseminated the results of the project at the European level;
- Collaborated with the various research institutions involved in the project giving input on the subject from an older people's perspective.

Uniaccess: Promotion of accessibility in public transport is a project funded under the Sixth Framework Programme for Research. Its goal is to promote and support the networking and coordination of research and innovation activities in the field of universal design of accessibility systems for public transport.

<http://w3.euve.org/uniaccess/index.asp>

AGE:

- Represents the views of older people;
- Disseminates the results of the projects;
- The involvement of users organisations such as AGE and other disability organisations has raised interest of the Organisation for Economic Co-operation and Development (OECD); European Parliamentarians, various Directorate Generals from the European Commission (DG Employment, Social Affairs and Equal Opportunities; DG Transport and Energy, and DG Research), industry (Siemens, Fiat), operators, cities and others, to the subject of universal accessibility. The successful workshop and final conference at the Committee of the Regions at the beginning of this month evidenced this.

Healthy Ageing

- The project builds upon the existing work of “Proven Strategies to improve Older People’s Health - Eurolinkage report for the European Commission” (1999) and will provide EU organisations and Member States with a framework in which to:
 - Collect knowledge about health promotion activities for health in later life.
 - Review and analyse existing data on older people’s health.
 - Facilitate and develop further healthy ageing partnerships.
 - Provide a network for the exchange of best practice on healthy ageing between Member States. <http://www.healthyageing.nu/>

AGE:

- The project has produced an evidence-based report
- Currently drafting recommendations for an integrated EU approach to ageing and health, with an emphasis on prevention measures for people from the age of 50.

Importance of User's Involvement in Research at EU Level

- Over the years there has been a growing political and research interest in user involvement.
 - This approach to involve users in the research process “reflects the democratic approach to participation (...) being able to improve the quality of their lives; being able to influence decision making and an overall redistribution of power”
- For AGE, user involvement in research means:
 - Building a strong partnership a “collaboration” which describes the process in which various parties share information and work together to advance their causes simultaneously.
- AGE was successful in ensuring that user's involvement will be better promoted in the 7th Framework Research Programme in particular, for the Science in Society programme from DG Research. The Directorate General for Information, Society and Media has also asked AGE to take part in the e-Inclusion stakeholder group to represent the voice of the users in access to Information society and have consulted us to develop the priorities for FP7 within this area of work.

What Are The Advantages Of User Involvement In The Research Process?

- Identification of research relevant to users, definition and prioritisation of users needs.
- User involvement from the very beginning of the research process to get things right and to provide effective services. This is essential to ensure the outcome meets the identified needs.
- Exchange of ideas and dissemination of relevant information that can be used by the various actors and distributed through the various communication channels.
- Establishment of research priorities, setting the agenda.
- Develop new research, concepts and ideas and accelerate the acceptance of new policies, products, processes and services by end users.
- Interpretation of the practical implications of the research findings.
- Raise the profile of research and encourage the use of users in the research process.

- Mutual motivation and achievable targets in the research process.
- Reduce the gap between academic research and actual practice.
- Gain new experience experiences and skills.
- Have direct ownership of the research project.
- Better quality and solid research.
- Attracting funds and recognition of their organisation.
- Etc.

What Are The Barriers To User Involvement In The Research Process?

- Collaboration with users is not always seen as a priority. It comes down on the list of priorities of researchers.
- The role of the users is sometimes not clearly defined in the research process.
- Research findings are not accessible to or understandable by users. When the information is not presented in the language of the user, it is unlikely that a consensus and adoption will occur.
- The research process does not address or properly articulate a problem as perceived by the end user. Quite often this occurs because the potential end user does not have an active role in the problem definition.
- When the involvement of users does occur it is often in the latest phases of the research process for example in the development or at the implementation process when products and services do not satisfy user's needs and they have to be refitted and readjusted. This takes more time and money.
- Funding user's involvement might be a problem especially when representative user's organisations are non-profit making, as are older people's organisations.
- Researchers and users may have different opinions on how the research money should be prioritised or what and how should it be measured
- Difficulty in sustaining long term relationships with end user organisations to become and remain involved.
- Objectivity, neutrality, validity of the research may be put in to question. Is this type of research real "science"?

- Opinions of end users are sometimes not feasible because of legal, institutional, financial or other constraints.
- End users often have difficulty expressing their views in a way that is usable for researchers; representative NGO's have to build capacity to express user's needs in a coordinated way.
- Etc.

Conclusion

No matter what the advantages and barriers of end user organisations in the research process both parties have to make sure that one does not annul the other.

Both have their own research objectives and interests but both can work together to achieve **common goals**.

“Democratic approaches to involvement in research face the same barriers and inequalities that democratic approaches to participation have faced more generally. These much be challenged and more support given to such research approaches (...)”

4.2 Public Involvement in NHS public health and social care research

Nick Partridge

Chief Executive and Chair of INVOLVE (UK)

INVOLVE

- National advisory group funded by the Department of Health
- Aims to promote active involvement of the public in research and development in the NHS, public health and social care
- If research reflects the needs and views of the public, it is more likely to produce results that can be used to improve health and social care services

What do we mean by the public?

- Patients and potential patients
- Informal (unpaid) carers
- Parents / guardians
- Users of health and social care services
- Disabled people
- Potential recipients of health promotion programmes
- Groups asking for research because they believe they have been exposed to potentially harmful substances or products
- Organisations that represent people who use services

What do we mean by active involvement?

- Where research is carried out 'with' or 'by' the public, rather than 'to' 'about' or 'for' them

e.g. Involvement through membership of advisory groups, commenting on patient information leaflets, as user researchers undertaking research

Key Activities of INVOLVE

- Raising awareness and providing guidance on public involvement
- Sharing knowledge and experiences about public involvement
- Influencing policy and practice

Raising Awareness and Providing Guidance

Examples:

- Briefing notes for researchers
- Guidance for the public on getting involved
- Guidance on involvement in research commissioning
- Guidance on payments to the public

Sharing Knowledge and Experience

Examples:

- Newsletter and website www.invo.org.uk
- Discussion forum
- Workshops and conferences
- Database of training providers
- Database of research projects involving the public

Influencing Policy and Practice

Examples:

- Working with Department of Health research commissioners
- Working with UK Clinical Research Collaboration and UK Clinical Research Networks

- Working with NHS Trusts
- Ethical review of research

Why Should Older People Be Involved In Research?

- Older people have a right to be involved
- Involvement can improve the quality of research
 - relevance of research
 - acceptability of research to research participants

How Can Older People Contribute to Research?

- Highlight issues of importance from a public perspective
- Identify outcome measures which reflect concerns of older people
- Advise on research design and methods from a public perspective
- Advise on information provided to research participants
- Assist in communication of findings

Who Should Be Involved?

- Avoid tokenism
- Consider diversity of involvement
- Public perspective

How Should People Be Involved?

- Involvement early in the process
- Allow plenty of time for involvement
- Be clear about expectations (from both researchers and public)
- Jointly agree roles and responsibilities

- Importance of keeping people fully informed

Resources and Funding

- Training, and support for public
- Training and support for researchers
- Budget for involvement
 - payment for expenses
 - payment for involvement
 - costs of providing support

4.3 Participative strategies in health research: Active Involvement of patients / users in agenda setting

Dr J.E.W Broerse

Associate Professor, ATHENA (The Netherlands)

Research System (1)

- Research system is supply driven
- Decision-making on health research –from research programming to evaluation– is currently domain of small elite of qualified academics and pharmaceutical industry

Persistent Problems

The research system

- Favours disciplinary approaches (over interdisciplinary ones)
- Is disease oriented (rather than focused on integral approaches)
- Is intervention oriented (rather than supporting individual responsibility or addressing implementation problems)
- Is universalist (rather than responsive to individual needs)

Problem-Oriented Research System

- Pleas for switch from a supply-driven towards a more problem-oriented research system
- Need for application of participative strategies including relevant stakeholders, such as patients
 - in research agenda setting
 - as reviewers of proposals
 - in research design
 - as researchers
 - in dissemination of research results

Interactive Approach Of Athena Institute (1)

- Principles
 - Active involvement of users throughout process
 - Conducive social conditions
 - Inclusion of experiential knowledge
 - Attention for plurality and diversity
 - Enhancement of learning processes
 - Dialogue between different stakeholders
 - Flexible (and emergent) research design

- Various roles of researchers

Guidelines: Five Phases

1. Preparation
2. Consultation
3. Integration
4. Programming
5. Implementation

Rich toolkit of research methods and techniques

Example of interactive research agenda setting

The case of the Dutch Burns Foundation

But also: Asthma Foundation (2004)
Diabetes Foundation (2006)
ZonMW (mental disability) (2006)
RGO (medical biotech) (2005)

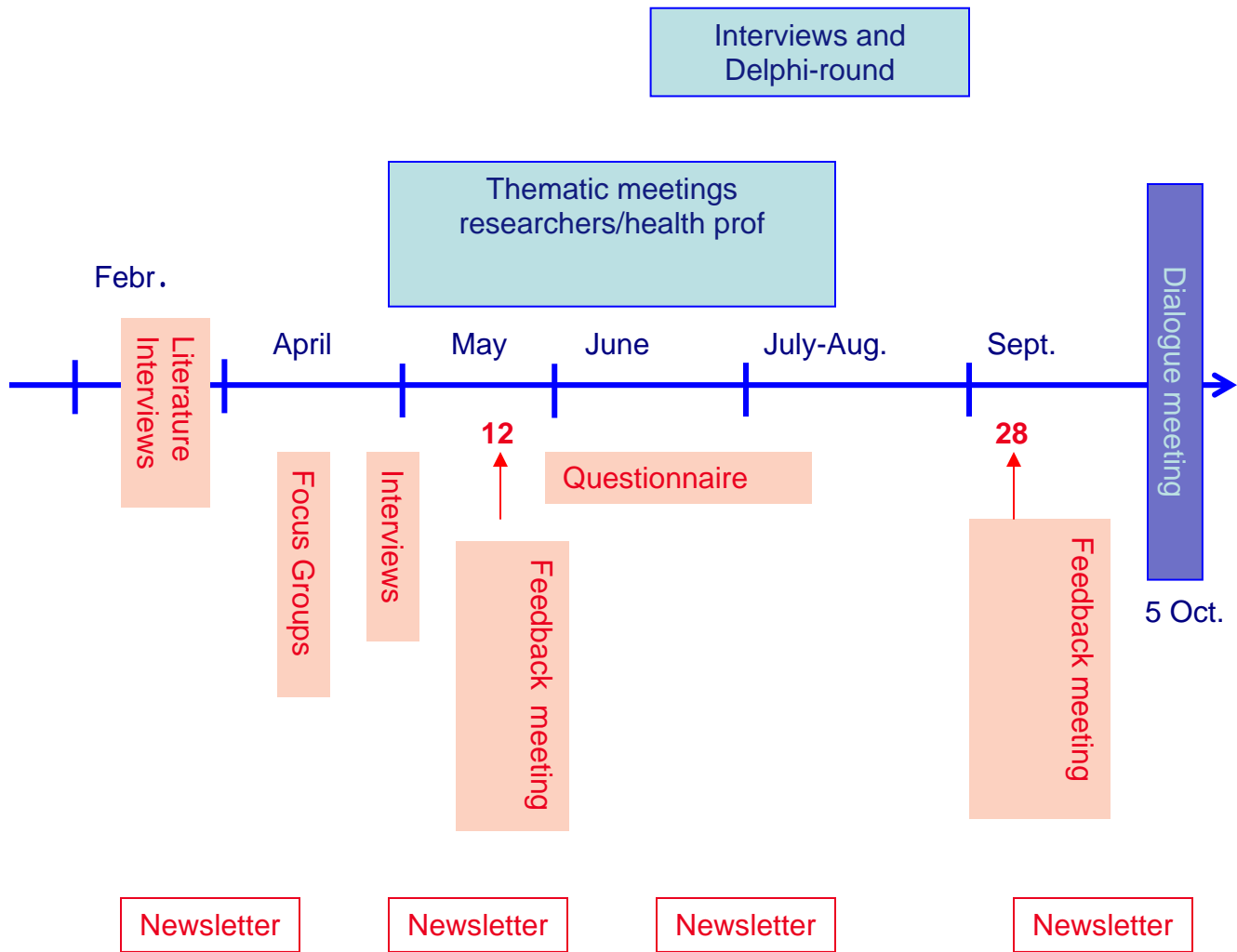
Not only research also health policy in general
(MoH - use of pharmaceuticals -2004-05)
In other sectors: agriculture (since the 90s)

BhURN Project

Phases:

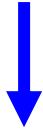
1. Preparation: exploration of relevant issues through literature study interviews, actor chart
2. Consultation: priority lists per actor group through focus groups, feedback meetings, questionnaire, interviews, Delphi round, argumentation tree.
3. Integration: broadly supported priority list through dialogue meeting
→ report as advise to NBS
4. Programming: advise as input for development research program 2007-2011

Bhurn Project – diagram 1

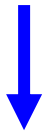


Priority List People with Burns

Literature & interviews

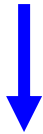


Focus groups (5 groups) → 37 participants



Feedback meeting (2 groups)

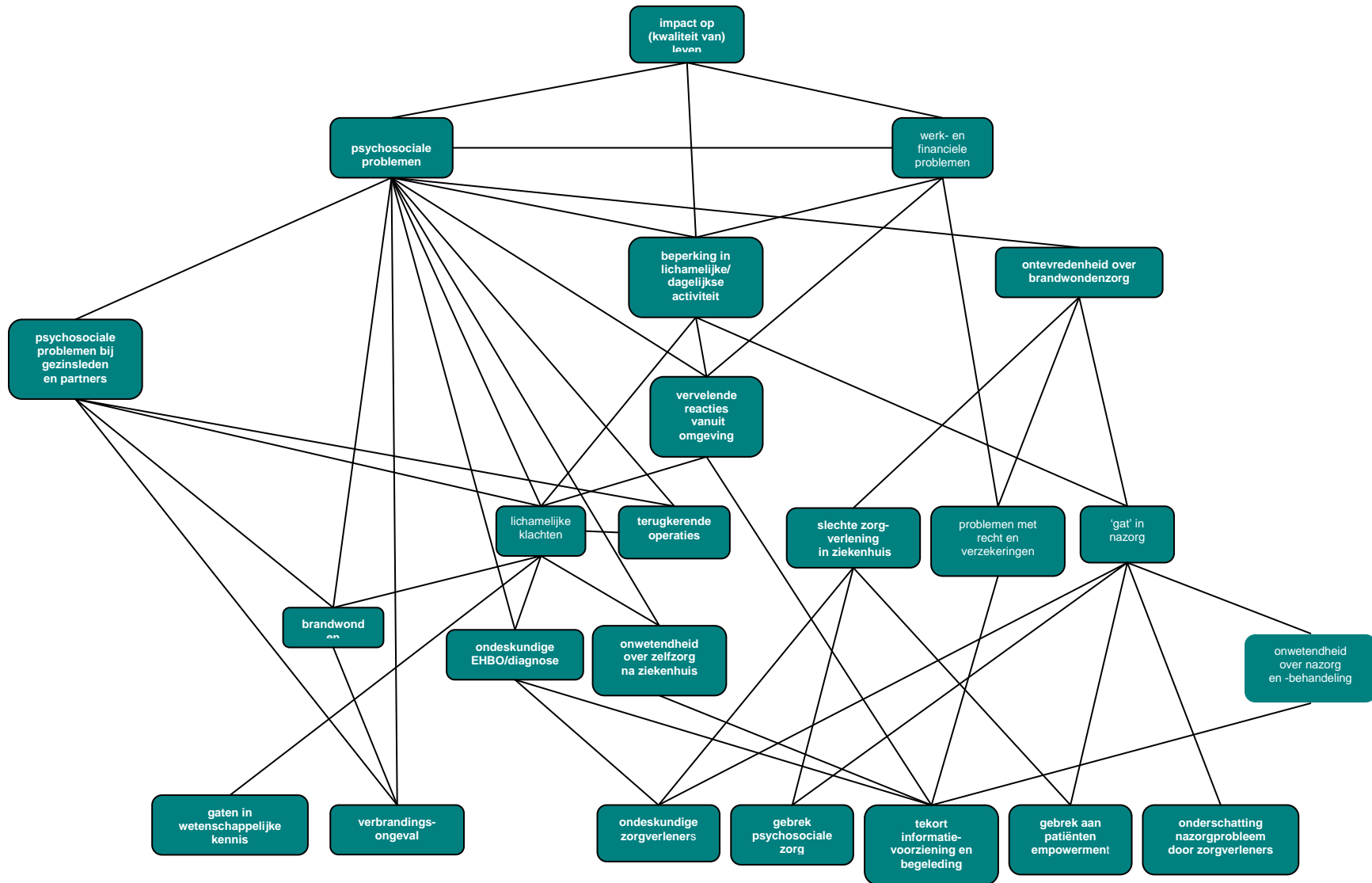
Questionnaire (912) → 224



Feedback meeting

15 topics







Problem Tree



Questionnaire

- Part I: general characteristics
- Part II: prioritise research topics and themes
- Part III: evaluative questions

- 10 themes → top 4
- Each theme comprises 6 topics (60 total)
 - per theme top 3

  	D
 	F
	C

Based on literature, focus groups and feedback meetings

Prioritisation of research

	Research Themes	Money Bags	Share in top 15
1	Treatment of burn wounds and scars	481	3
2	Skin and scars	394	3
3	Burn care in hospitals	307	2
4	Psycho-social problems of people with burns	286	2
5	Supervision and 'after care' in hospital	248	2
6	Psycho-social problems of close relatives	116	1
7	Participation in society	98	1
8	First Aid	78	1
9	Information supply	76	0
10	Other Physical problems	67	0
		2151	

Theme top 10

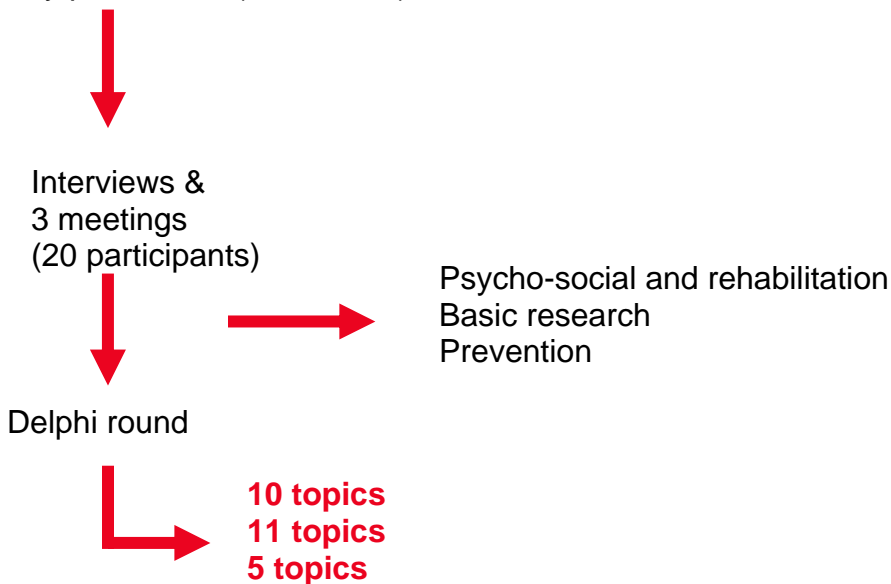


Top 15 patient agenda

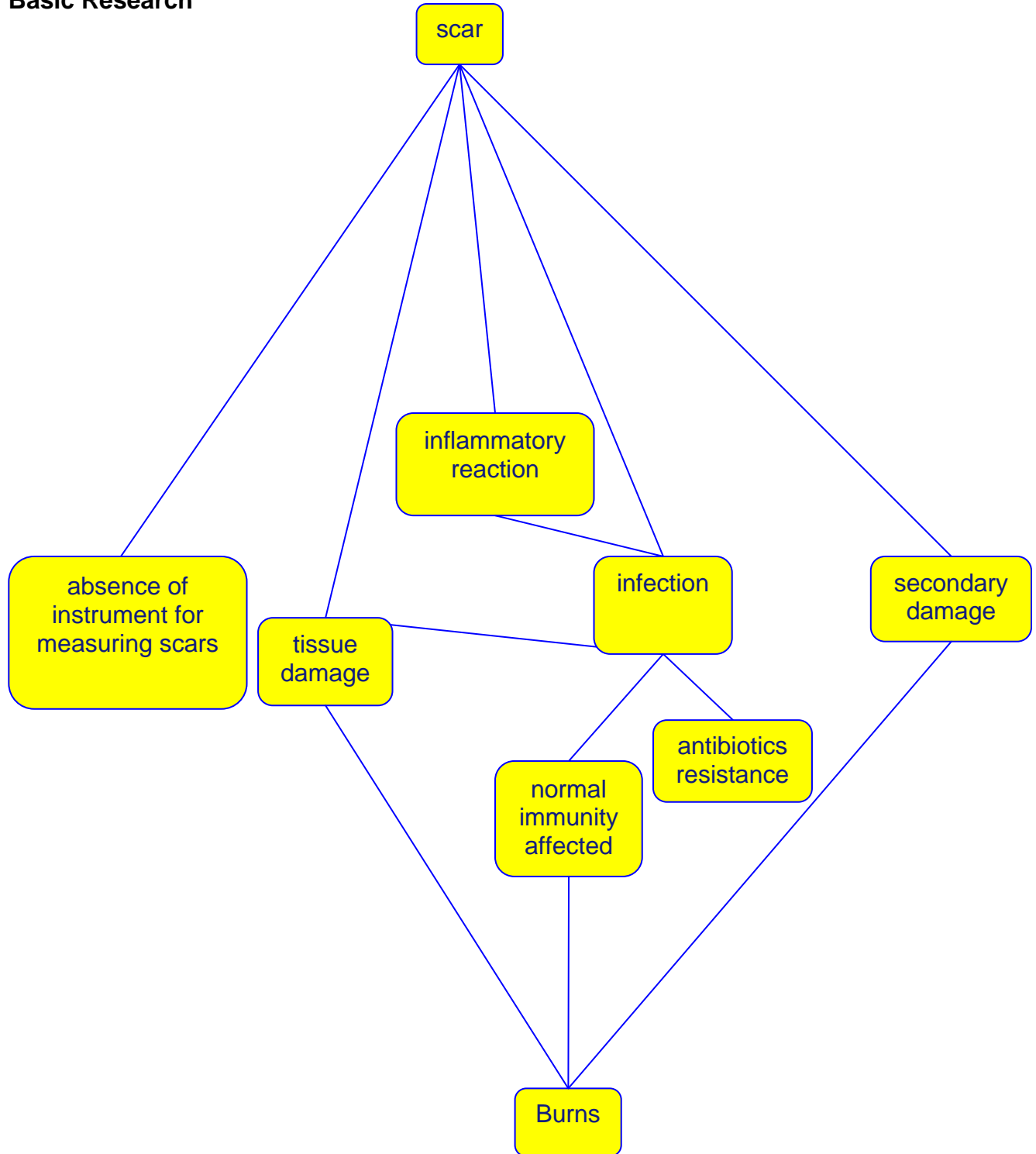
Example:
 $481 \text{ bags} / 2151 \text{ bags} \times 15 = 3,354$
 $\rightarrow 3 \text{ topics in top 15}$

Priority Lists Professionals

Policy plan VSBN (2004-2008)



Basic Research



Intermediate Conclusion

- Topics mentioned by people with burns are broad
 - only lack of attention for prevention
 - Topics of professionals give more detailed 'picture' of part of topics mentioned by people with burns
- Good foundation for dialogue meeting

Dialogue Meeting

- 30 participants: 15 people with burns and 15 professionals
- Discussion of 4 priority lists (differences, similarities, 'blind spots')
- Integration into one list with 7 themes and 41 research topics
- Prioritization of integrated list
 - 7 themes placed in order
 - selection of top 10 of research topics

Conclusion

- Result: Broad research agenda for burns
- Each stakeholder group had own priorities
 - People with burns: itching and oedema
 - Professionals: prevention and evidence-based treatment protocols
- Patients were able to set research priorities
 - They prioritized biomedical research topics highest
 - Attention for long-term research
 - Input of new research topic (itching and oedema)

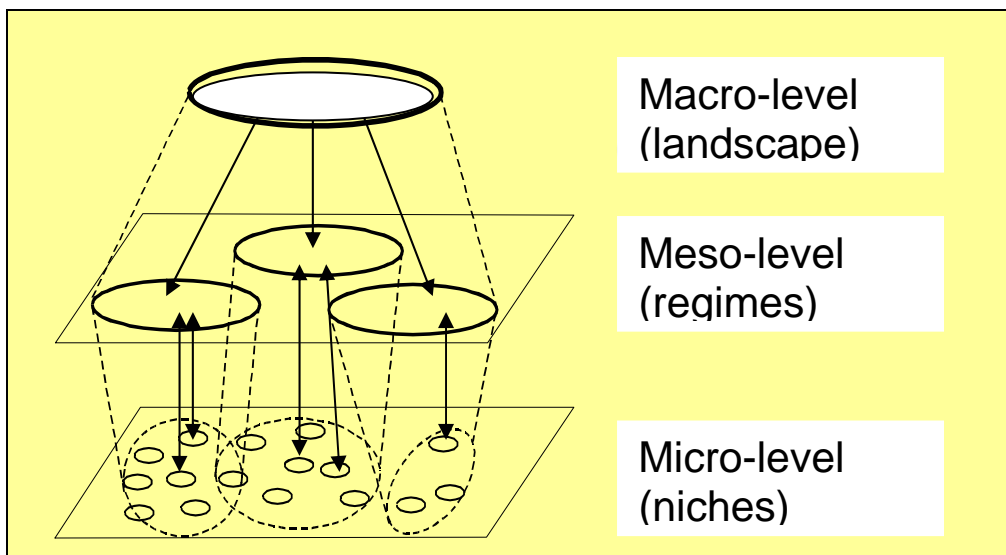
Barriers to Involvement (1)

- Switch from a supply-driven towards a more problem-oriented research system is not easy
- It requires:
 - Different way of thinking and acting of current dominant actors (scientists, industry, donors)
 - Involvement of 'new' actors (e.g. patients and health professionals), who possess relevant knowledge of problem context --> change in power relations

→ A system innovation

Barriers to Involvement (2)

- Macro level trends:
 - Democratisation of science
 - Patient empowerment
- Micro level trends:
 - Individual actors experiment with involvement of patients, e.g. ZonMw, charity funds, patient organisations, RGO
- Current initiatives isolated and short term, not always effective → obstacles at micro level and at regime level



Barriers at Niche Level

- Lack of 'proven' effective methodologies
 - Many initiatives not thoroughly evaluated
 - Exchange of experience hardly occurs
 - Few 'best practice' models
- Competencies of 'practitioners'
 - Required new roles and skills for researchers not taught in universities
 - New practitioners often need to reinvent the wheel

Barriers at Regime Level (1)

- Lack of sense of urgency
 - No considered surplus value in participation of users (substantive / instrumental / normative)
 - Fear for delay and complication of decision making
- Dominant structures and procedures
 - Financing structure dominated by scientists
 - Appraisal procedures based on scientific criteria
 - No additional means for patient involvement

Barriers at Regime Level (2)

- Characteristics research community:
 - Strong specialization in monodisciplines
 - Importance of scientific achievement and publications
 - Importance of scientific autonomy and curiosity
 - Low valuation of 'experiential' knowledge
- Characteristics patient community:
 - Limited will to participate
 - Lack of scientific knowledge
 - Limited ability of objectification and abstraction
 - Lack of self-confidence and empowerment
 - Internalization of medical rationality

4.4 Empowering senior citizens in research: A multilevel implication

Dr Viriot Jen-Philippe Durandal

University of Franche-Comte (France)

Context

- 70's and participative democracy.
- Creation in 1973 of the first University of the Third age by Pierre Vellas in Toulouse (France)
- Massive development of seniors' organization (*Aînés ruraux*, *FNAR*, *UFR*, *CFR* ...)
- Development of coordinations between senior clubs (*Offices des retraités*) mostly backed by public subsidies
- Massive investment for the development of universities over the national territory (70's, 80's)
- socio-demographic trends (increase of the longevity and of the socio economic status of senior citizens)
- But no national programmes to foster participation like the *BGOP* in Great Britain.

The University of the Third Age as a Field of Investigation and Research

- Research was one of the pillars of the University of the Third age according to its founder Pierre Vellas. (Pierre Vellas, *La recherche et les Université du Troisième âge*, *Gérontologie et société*, n°55, Decembre 1990)
- International association of the Third Age **in the 80'** : 1984 Xist Congress of AIUTA and the report of 1986 entitled "recherche pour et avec les personnes âgées (Research for and with the older persons.
- **In the 90's** : in 1990 the scientific board of AIUTA in Hull (Canada) has drafted a program to support the development of research within AIUTA

Multifactoral Aspects of the Success

- The successful stories are mostly the result of a conjunction of individual factors (senior citizens motivation), in a structural and cultural positive context (support of the university and local authorities).

Field 1

Research Out Of The Ageing Field

Research in local history and heritage

Data collecting on recent periods of history:

Interviews of elderly persons by researchers or seniors for a testimony of the past and heritage building through living memory (Vellas 90, Pennec forthcoming)

Field 2

Research On Ageing Processes

- Study on the biological and medical aspects of ageing
 - Psychological and physical impairment between 50 and 80 (UTA Toulouse)
- Study on social aspects of ageing
 - Situations in the life cycle*
 - Grand-parent-hood (Caradec V. 98)
 - Retirement (University of Nancy)
- *Social processes toward societies*
 - Discrimination, stereotypes, Intergenerational gaps ...
 - Legislation toward retired persons and frail elderly (UTA, FIAPA 2006)

Fields: *physiology, medicine, biology, psychology, social sciences, law...*

Partners: *UTA Toulouse with Sanofi and 300 seniors, University Lille III, University Nancy II, Office nancéen des personnes âgées (office of retired persons, Nancy)*

Field 3

Research on Programs and Activities Toward Older People

- Measure the effects of programs like cerebral activation, physical training, preparation for retirement ...
- The assessment of the efficiency of such programs helps to adapt and improve them. Senior organizations and organizations dedicated to them can monitor their activities with the scientific support of researchers. (FFRS, UTA Toulouse)

Fields: *physiology, cardiology, biology, neurology, psychology, social sciences ...*

Partners: *French Federation for the promotion of sports toward older persons (Fédération Française de la Retraite sportive), UTA, University of Nancy II/ office nancéen des retraités*

Field 4

Research on Programs and Activities of Seniors Citizens Toward Other Populations

- Analyze their own situation as benevolent service providers to others :

= > Evaluation of support programs to children with reading difficulties and assessment of the efficiency of after schools programs (Le borgne & Pennec 1996, Pennec 1999)

Fields: **Social sciences**

Partners: *University of Occidental Britany/ Academic Workshop in Sociology, Office of retired persons, Brest*

Field 5

Environment, Living Conditions

- Housing, Transportation

=> UTA Toulouse, « Housing, urbanism and ageing », in cooperation with UTA Geneva, 1985

=>Villeneuve d'Asq, UTL/ CCAS/ ARPET : 20 years later (Gardey & alii, 2005)

- Other topics

Fields: **Social sciences, law ...**

Partners: *UTA, local authorities.*

Field 6

Research on Senior as Citizens, Beneficiaries of Public Policies and Service Users

- Evolution of retirement and income (FNAR, Paris), critics on the calculation of consuming power,... (Viriot Durandal, 2003)
- Research commission: Commission d'Etude, de Recherche et de Mission (CERM) within FNAR and CFR. Work in sub-commissions (Income, Health, Pensions...), but weak research capacity

- The national council of retired and older persons* has called for the creation of a consultation body to access to /and/ provide expertise to senior citizens' groups in order to propose public policy alternatives. (CES, 2001)

* = The national consultation board presided by the Minister of Social affairs, and composed of the 16 most representative national organizations of senior citizens.

Expertise and Citizenship in a Knowledge Based Society

- Research to analyze, understand and become aware of their own situation as individuals experiencing ageing processes
- But also ... as members of a social group or sub-groups (Raynes 2004, Viriot Durandal 2003 & 2004, ...) to encourage a shift from a micro and individual experience to a macro and collective perspective on ageing ... including a sens of right and duties and citizenship
- Research and knowledge dissemination are considered as resources for senior citizens to assess the situation, make it visible, and prepare propositions to change their environment at the macro as well as at the micro level.

Dissemination 1

Association Du Chemin Des Auteurs En Gérontologie Sociale

- Network of 16 towns in 4 french speaking countries :France, Belgium, Quebec (Can), Switzerland
- Since 2001, 21 tours for a total 52 meetings
- With seniors citizens groups
- With practitioners, professionals and public decision makers
- In 2006 14 researchers.

BEAULIEU Marie

Professeur titulaire, Université de Sherbrooke
 Responsable de la Maîtrise en gérontologie, Université de Sherbrooke
 Chercheur senior, Centre de recherche sur le vieillissement, Institut universitaire de gériatrie de Sherbrooke

CHARPENTIER Michèle

Professeur, Université du Québec à Montréal (UQAM)
Chercheur, LAREPPS (Laboratoire de recherche sur les pratiques et politiques sociales) et
équipe VIES (Vieillesse, exclusions sociales et solidarités)

VEZINA Jean

Professeur, Université de Laval
Directeur de l'Institut sur le vieillissement et la participation sociale des aînés

GUILLEMARD Anne-Marie

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Dissemination 2

Cahiers De La Fiapa

- 2 volumes on "senior citizens' power and influence in the political, economic and social fields"
 - Volume 1 : Political power and influence, Cahiers de la FIAPA, Paris, 2002-2003
 - Volume 2 : Economic and Social influence, Cahiers de la FIAPA, Paris, 2004-2005
- 45 contributions
- 23 countries
- 50% of the global population
- Dissemination of research on empowerment in Spain, France, Great-Britain, Equator, Chile, etc....
- Translation in French, English and now Spanish with the support of Spanish government.

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4.5 Introduction to the European Research Area on Ageing

Professor Alan Walker

University of Sheffield (UK)

Agenda

- FORUM : ERA-AGE Forerunner
- The European Research Area on Ageing

Coordinating European Research In Ageing



<http://www.shef.ac.uk/ageingresearch>

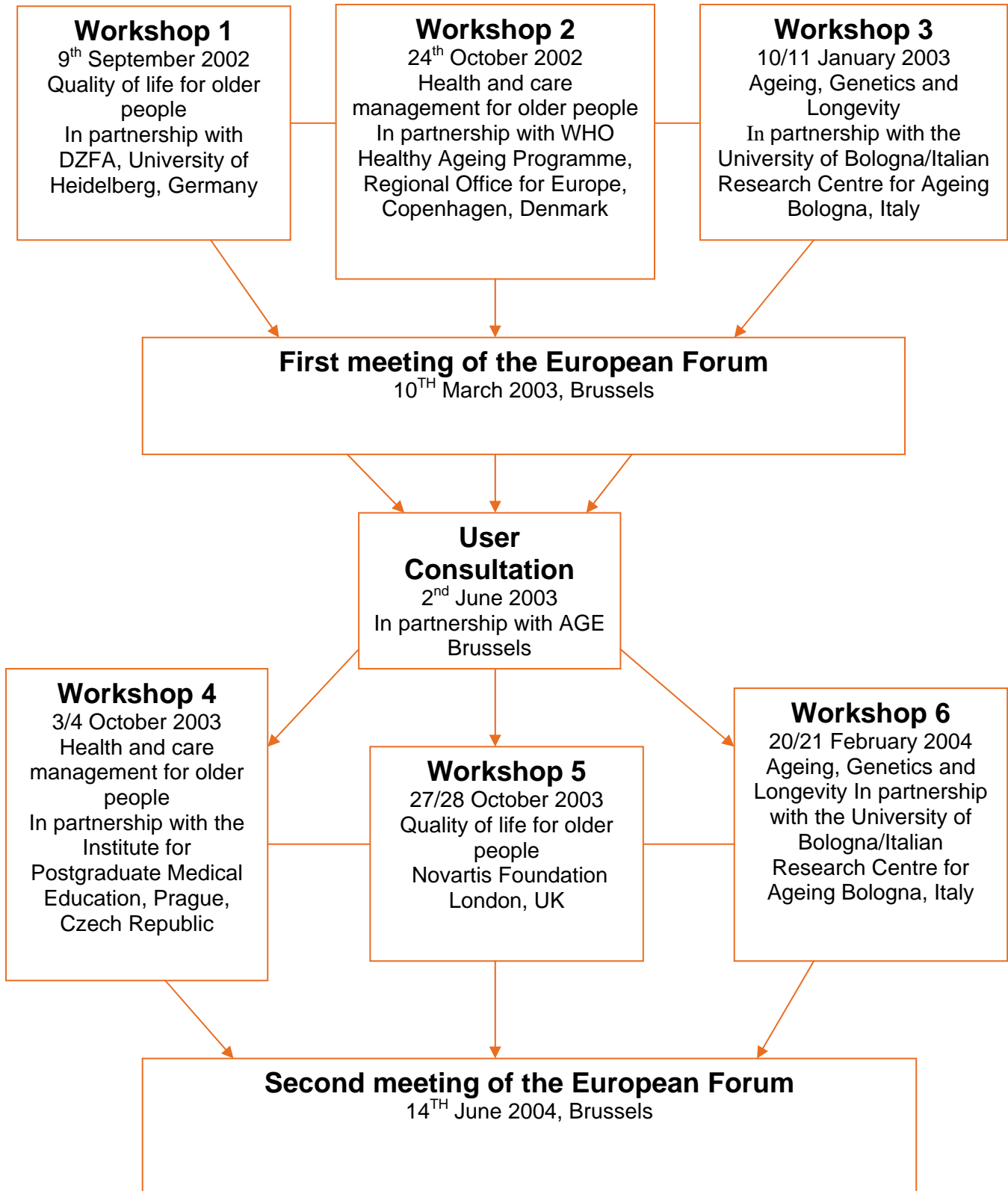
Realising The Benefits Of Ageing Research

FORUM Objectives:

- To promote European co-operation in ageing research
- To develop synergies between national and international programmes
- To improve channels of communication
- To stimulate interdisciplinary research

- To promote improved public awareness

EUROPEAN FORUM ON POPULATION AGEING RESEARCH: TIMELINE OF EVENTS



FORUM PRIORITY RECOMMENDATIONS – TOP 5

- Use recommendations to plan FP7
- Establish a European Institute on Ageing
- Work together to develop European and interdisciplinary collaboration
- Commitment to user involvement
- Attract and support new researchers

EUROPEAN RESEARCH AREA IN AGEING (ERA-AGE)



www.shef.ac.uk/era-age

Partner Countries:

Austria, Finland, France, Germany, Israel, Italy, Luxembourg, Netherlands, Norway, Romania, Sweden, UK (coordinator)

Associate Partner Countries:

Latvia, Spain

Objectives

- To facilitate coordination of existing ageing research programmes
- To promote interdisciplinary research activities between countries
- To share good practice in coordination and management of ageing programmes
- To support the production of European priorities for ageing research programmes
- To help break down the barriers between ageing research programmes and policy and practice

RECOMMENDATIONS FROM THE QUALITY OF LIFE WORKSHOP

Research Priorities

- New comparative studies within the old and new Member States
- New methodological approaches for longitudinal surveys
- Intergenerational research
- Individual and societal changes in the second half of the life course
- Involvement of older people in research
- Policy and practice orientated research
- Interdisciplinary approaches to all research topics

SECTION 5

WORKING GROUP THEMES AND RECOMMENDATIONS

Participants of the meeting were organised into four working groups, each group had a chair and a note-taker.

- Group 1** - **Chaired by Gerda Geyer - Austria**
note-taker Elizabeth Hanson – Sweden
- Group 2** - **Chaired by James Goodwin - UK**
note-taker Anu Nuutinen - Finland
- Group 3** - **Chaired by Martin Barth - Germany**
note-taker Isabel Borges - Belgium
- Group 4** - **Chaired by Jacqueline Broerse - Netherlands**
note-taker Eithne Carey - Ireland

5.1 Working Group Questions

Participants were asked to discuss the following questions and the outcomes of the discussions were presented to the closing plenary.

1. How can we sustain a dialogue between funders, researchers and end users of research on:
 - (a) how research should be carried out?
 - (b) how we can learn from and use research to improve quality of life in old age?
2. What has helped and what has hindered the process of involving end users in any research with which you have been associated?
3. How do we ensure that research proposals are informed by older people?
4. What three good practice principles should guide user involvement in ageing research?

5.2 Summary of the working group recommendations

5.2.1 How can we sustain a dialogue between funders, researchers and end users of research on:

- a. how research should be carried out?
- b. how we can learn from and use research to improve quality of life in old age?

Working groups provided general feedback on sustaining a dialogue between funders, researchers and end users in research rather than making a distinction between parts 'a.' and 'b'. Some groups felt it necessary to define end users. Groups collectively identified end users as:

- older people
- policy makers utilising research for policy development
- funders commissioning research and
- all people who have a vested interest in research
- industry such as pharmaceutical companies, nutrition, and information technology.

The following key issues were identified as important in sustaining a dialogue between funders, researchers and end users of research:

- Funders can successfully set conditions in funding call criteria to stimulate dialogue between researchers and end users. However, it is important to establish a budget to encourage dialogue.
- Researchers and end users may have pre-conceived ideas about research outcomes. It is very important to encourage all stakeholders to approach research projects with open and objective minds.
- Researchers should receive training on approaches to involve end users in research.
- Researchers should be encouraged to provide clear communication on the user involvement methods that they use and their subsequent research findings.
- Important research findings should be disseminated in a way in that can be understood by lay people. For example, language proofing is used in Ireland where end users "translate" texts in order to make them understandable to lay people. Language proofing helps to reduce the gap between scientific knowledge and public understanding. The practice of using different media and quotes from older people may make information more understandable.
- A centralised body comprising of politicians, researchers and end users could be established to guide people in end user involvement in research. ERA-AGE could become the centralized co-coordinator for research, becoming the broker to promote the initiative in participating countries.

- It is important to build a collaborative culture. All stakeholders need to recognise the benefits that can be gained and the issues that may arise from end user involvement. It is a challenge to develop common understandings and goals among different stakeholders with different agendas.
- Regular meetings and communication between all stakeholders is essential, particularly in regard to research focusing on life style, quality of life that involves people from different backgrounds and cultures who may have diverse views.
- It is important for stakeholders to establish common goals. End users should identify research priorities; there is a need to use a bottom up approach. Older people must have a say in research topics. In Norway, for example, older people have identified food and quality of life in old age as research topics that should be given priority. Governments should also play a role in prioritising research. All stakeholders' opinions must be respected. Older people should be empowered to speak out about their needs.
- End users often take part in the research process in the absence of financial rewards. Some older people take part in order to give something back to their own community for example. However, it is important to avoid taking voluntary participation for granted. From the outset, there is a need to consider whether financial incentives should be provided to end user participants.

Other considerations:

- The focus of research may determine the extent to which user involvement principles may be applied.
- Private funders, such as pharmaceutical industries, often establish their own research priorities. Consequently, the level of power may vary considerably among various stakeholder groups involved in the research process.
- The status of end users can change. In Israel, for example, older people became policy makers in Israel's Older People's Party. End users may potentially become powerful partners.
- Older people's confidence may increase by participating in the research process. In Torino, Italy, for example, the municipality established a board of older people to provide their views on various topics such as social care and transport. The municipality's approach has had a noticeable impact leading to positive changes within the local community.
- Workshop participants generally agreed that many end users are interested in knowing more about research. Research should be more focused on the needs of end users including those of healthy older people and carers and not only on the sick old.

5.2.2 What has helped and what has hindered the process of involving end users in any research with which you have been associated?

Workshop participants identified a number of issues that may assist and/or hinder the process of involving end users in research:

- Involving older people in the research process ('older people as researchers') helps researchers to identify the right questions. Good practice can be identified in Italy, Finland and the Czech Republic. In Italy, for example, each city requires an advisory council. They develop guidelines with older people for older people. Older people help to frame the research questions. In Finland, some researchers and university institutions receive more money when they involve end users.
- There are many ways of involving end users in the research process from consultation to deeper engagement strategies such as the development of citizen's juries and the development and delivery of participatory workshops. It is necessary to identify the most appropriate approaches for the research in question.
- The extent to which end users are involved in research processes may differ among fields of research such as biological research. It is easier to involve end users in research projects that have concrete aims such as the development of guidelines or a device. End user involvement is possible with abstract/theoretical topics although the process may be time consuming.
- Good project management and effective communication processes are essential to involving end users and producing positive project outcomes. It is helpful to convert written and verbal information containing academic language into user-friendly texts or speak for lay people for example.
- It is essential to overcome hierarchical problems. Researchers may feel that they are controlled and criticised by end users; end users might feel that researchers are more powerful because of their knowledge. In the UK empowerment workshops have been designed to improve the rhetorical skills and the self-assertiveness of end users. It is useful to give older people a training to voice their concerns. An appreciation of mutual stakeholders' expertise and/or experience should be recognised from the outset.
- End user organisations should be actively involved in disseminating research results. Older people may gain a sense of ownership by being involved in the dissemination of research. Shared ownership of the process may enrich the process and reap positive outcomes for all stakeholders.
- It is crucial to involve organisations which represent older people such as Help the Aged, UK, in research processes.
- It should be recognised that older people are not a homogeneous group. Stakeholders ought to consider ageism and negative images of older people when communicating findings.

- All stakeholders should be given the opportunity to learn from the research that they are involved in. People working in the public sector should learn from working methods employed in industry and the private sector for example.
- From the outset, identify key research topics that are likely to be funded. Currently more funding is available for disease-oriented research than for open-ended ageing research for example.
- There is a lack of information relating to end user involvement. Government funding research initiatives are sometimes unknown to older people's organisations and similarly, governments sometimes lack knowledge on appropriate end user organisations to be involved. Governments may be reluctant to include end users in their enterprises in the absence of this knowledge.
- End user involvement can be very expensive and it is sometimes difficult to obtain a budget for involving end users in research (especially if end users are to be paid).
- End users and researchers often have different objectives. This may deter (i) end users from participating in the research process and (ii) researchers from inviting end users to participate. End users may feel that they are being used and/or feel they have not got anything worth contributing and/or feel that they are not "clever" enough. Other groups such as caregivers may not have sufficient time to assist the research process due to their caring commitments.
- Social barriers such as language, culture, religion, and educational background may hinder the process of involving users. In addition, issues may arise when researchers feel that they have been forced into involving end users due to funding mechanisms for example.
- Difficulties are sometimes encountered in regard to involving end users at an early stage of the research process. Approaches to encourage early involvement need to be communicated and encouraged.

5.2.3 How do we ensure that research proposals are informed by older people?

Participants identified various approaches to ensure older people inform research proposals:

- The involvement of end users could be made a condition/criterion for obtaining funding. Some funding calls specify this already.
- A methodological guide may be required to inform good practice in knowledge transfer. Newly established and less experienced researchers may require training which focuses on appropriate approaches to involve end users.
- It is important to ensure that research is on the agenda for older people's organisations such as NGOs since they can use research findings to lobby governments.
- Retired researchers may be involved to establish a link between older people and current researchers.
- The views of older people may be used to influence the direction of research rather than decisions concerning methodology. There is a need to recognise that decisions concerning methodological approaches often need specific expertise.
- Older people should have the opportunity to be involved in the development of proposals.
- It is crucial to identify appropriate older people to take part in research processes. Retired politicians are unlikely to represent people from grass roots for example.
- In epidemiological studies, older people/end users may inform the way in which scientists design their questions. Clinical research should be informed by the end users by obtaining feedback from patients for example.

5.2.4 What three good practice principles should guide user involvement in ageing research?

Working groups identified the following good practice principles:

- Funding organisations should endorse the principle of involving end users in the research process within their funding call eligibility criteria.
- Develop clear criteria for recruiting and involving end users. For example, the role of end users in advisory boards should be clarified.
- From the outset, negotiate and agree mutual expectations, roles and necessary support during the research process. Conflict between researchers, end users, NGOs etc may be avoided by establishing agreed expectations (common understandings) from the outset. It is insufficient to invite end users to participate in a project in the absence of planning.

- Develop good communication strategies to accommodate all stakeholders. A good communication strategy will ensure that end users have the opportunity to inform the research process and that researchers clearly communicate research outcomes. The two way process will help to reduce the knowledge gap between researchers and relevant stakeholders.
- Develop a good dissemination strategy and involve all key stakeholders. An inclusive dissemination strategy will engender a feeling of shared ownership and responsibility. Research findings are more likely to reach a wider audience by using a shared ownership dissemination approach.
- Ensure that ethical issues are explored and appropriate actions are taken. The involvement of end users, particularly vulnerable older people, often raises ethical issues. It is the responsibility of funders and researchers to take appropriate actions. For example, some research proposals may require approval from university or local ethics committees.
- Researchers and, when appropriate, end users should receive user involvement good practice training. Innovative practices may be developed such as mobility opportunities to enable researchers to learn from expert institutions in processes of user involvement while developing their research. In France researchers, for example, can take six-months leave, paid by the government, to work with NGOs in order to broaden their experience in carrying out research.
- Older people should benefit from participation in research. Incentives may be considered to encourage older people to participate.
- Older people should be involved during all stages of research if possible.
- Research ideas should be explored with relevant end users during the planning stage of research.
- Diversity among, and the context of working with, end user groups should be given careful consideration by all stakeholders.

Appendix A

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Many thanks to workshop participants for their contribution to the findings of this report

Appendix B

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Appendix C

GLOSSARY OF DEFINED ACRONYMS

AGE	-	European Older Peoples' Platform
AHRC	-	Arts and Humanities Research Council
AIUTA	-	Association Internationale des Universités du Troisième Age
BBSRC	-	Biotechnology and Biological Sciences
BGOP	-	Better Government for Older People
CES	-	Economic and Social Council of the Republic of France
CFR	-	La Confédération Nationale des Retraités
DG	-	Directorate General
EPSRC	-	Engineering and Physical Sciences Research Council
ERA	-	European Research Area
ERA-AGE	-	European Research Area in Ageing
ESRC	-	Economic and Social Research Council
EUROFAMCARE	-	Services for Supporting Family Carers of Elderly People in Europe
FIAPA	-	Fédération Internationale Des Associations De Personnes Agées
FLARE	-	Future leaders of Ageing research in Europe
FNAR	-	la Fédération Nationale des Associations de Retraités
FP6	-	Framework Programme 6
FP7	-	Framework Programme 7
GO	-	Growing Older Programme
INVOLVE	-	Promoting public involvement in NHS, public health and social care research
LAREPPS	-	laboratoire de recherche sur les pratiques et politiques sociales
MOH	-	Ministry of Health
MRC	-	Medical Research Council
NCAR	-	National Collaboration on Ageing Research

NDA	-	New Dynamics of Ageing
NGO	-	Non Governmental Organisation
NHS	-	National Health Service
OECD	-	Organisation for Economic Co-operation and Development Research Council
RGO	-	Council for Health Research
UFR	-	l'Union Française des Retraités
UQAM	-	Universit� du Quebec a Montreal
UTA	-	University of the Third Age
VIES	-	Vieillissement, exclusions sociales et solidarit�
ZonMW	-	The Netherlands Organisation for Health Research and Development