



Report of the Quality of Life Workshop

1st December 2005

Held at the Holiday Inn Hotel, London



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

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ERA AGE

**European
Research
Area in
Ageing**

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 - c) *List of the Steering Committee Members*

EXECUTIVE SUMMARY OF THE RECOMMENDATIONS FROM THE WORKSHOP

Priority Topics for an Ageing Research Programme in Quality of Life

- The importance of an interdisciplinary perspective in ageing research was emphasised and the single discipline approach was rejected.
- Subjective views on ageing and older people as well as the involvement of users of health and social care systems should be at centre of research.
- More longitudinal studies are needed but methodological issues such as choosing the right cohort and sequence need to be addressed. By choosing two measurement points during a seven year period scientists should be eligible to obtain funding from the EC framework funds.
- New comparative studies are needed on the quality of life of older people within the old Member States and the new Member States.
- There is a need for more inter-generational research and research on care systems, both formal and informal, as well as more studies on the risks of social inclusion and exclusion.
- Research should be focused on individual and societal changes in the second half of the lifecourse, including retirement and transition from work to retirement.

Learning from Good Practices

- Sources such as cross-sectional data should be further extended and enriched with longitudinal data, biographical data and lifecourse information and be used to develop a European Longitudinal Survey.
- Good practices at the national level across Europe should be sourced and effectively disseminated.
- Research findings require translation into policy and practice. Research results should inform new policies and serve as the basis for the further development of research.
- There is a lack of funding resources for the translation of research results into practice.
- There is an urgent need for coordination at the European level to ensure that the outcomes of research are widely disseminated to the general public and policy makers.

Fundamental Priorities for European Collaboration

- There is an urgent need to strategically coordinate research activities in the ageing field at the European level.
- Firm structures need to be urgently developed to facilitate cross-national research, workshops, training and capacity building for future generations of researchers in the ageing field.
- Strategies for the interdisciplinary career development of young scholars need to be developed in order to retain new talent.
- An appropriate institution such as a virtual European centre or a data house is needed to coordinate ageing research at the European level and to facilitate European collaboration.
- Incentives for network building are needed to bring together all stakeholders of ageing research.
- National Forums of Ageing Research should be established within countries in order to facilitate collaboration.

Possible Avenues for Ageing Research in Framework Programme Seven

- Strategies for successful applications under broader themes in Framework Programme Seven should be developed and new funding niches for ageing research should be sought.
- Ageing research has been given a low priority in the Framework Programme Seven, therefore it needs to be lobbied for at the European Commission. NGO's across Europe should approach the European Parliament stressing the importance of ageing research for society and national governments.
- Supportive evidence of research results should be provided to demonstrate the necessity of the continuity of ageing research.
- A three pillar approach should be developed:
 - Strengthen the credibility of gerontology to national governments.
 - Integrate ageing research with policy research relevant to ageing.
 - Develop Interventions promoting quality of life in later life.

PROGRAMME

Opening Plenary

Welcome and introductions
by the Chair:

- **Professor Ariela Lowenstein**, (The University of Haifa, Israel)

Presentation on ERA-AGE

- **Professor Alan Walker**, (University of Sheffield, UK)

Presentations on Quality of Life

- Factors Related to Quality of Life in a Comparative Cross-national Perspective - **Professor Ariela Lowenstein**, (University of Haifa, Israel)
- Quality of Life of the Elderly in Spain-**Professor Rocio Fernandez-Ballesteros**, (Autonoma University of Madrid, Spain)
- European Ageing Research on Environmental Resources and Quality of Life: Needs and Avenues to go- **Professor Hans–Werner Wahl**, (DZFA, Germany)
- Care-related Quality of Life - **Professor Marja Vaarama**, (University of Lapland and Stakes, Finland)

Working Groups

- Developing European Scientific Collaboration

Closing Plenary

Feedback from the working groups and discussions of the key issues for future scientific collaboration in the quality of life field.

AIMS OF THE QUALITY OF LIFE WORKSHOP

The second phase of the ERA-AGE project comprises a series of scientific workshops which are designed to identify research gaps and long term priorities in the ageing research field and to form a platform for future transnational collaboration.

This was the first scientific workshop focusing on 'The Quality of Life in Old Age', building on the scientific recommendations that emerged from the Forum project in this field of research. The aims of this workshop were to develop these recommendations in detail and use them as a basis for developing potential transnational collaboration in the quality of life field.

The meeting brought together 47 scientists from 17 European countries, the majority of whom also participated in the Forum project.

The morning sessions focused on presentations on quality of life issues in old age and these were followed by working group discussions in the afternoon. The recommendations of these working groups were presented in the closing plenary. The outcomes of the workshop will also be presented to the research funders and policy makers at the fourth European Forum meeting in 2007.

Before the meeting the participants were asked to provide a one page summary on their current research activities undertaken in their countries. This was developed into a background document for the working groups.

The next scientific workshop on Health and Social Care will be held in Bucharest, Romania, on 19th of June 2006. This will be followed by the scientific workshop on Demography, Longevity and Genetics in Innsbruck, Austria on 1st of December 2006.

SUMMARY OF PRESENTATIONS

Research Priorities on Quality of Life: From FORUM to ERA-AGE

Professor Alan Walker
University of Sheffield, UK

- The European Research Area in Ageing
- FORUM Research Priorities
- Tasks for Today

The European Research Area in Ageing (ERA-AGE) 2004 – 2008

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

Methods:

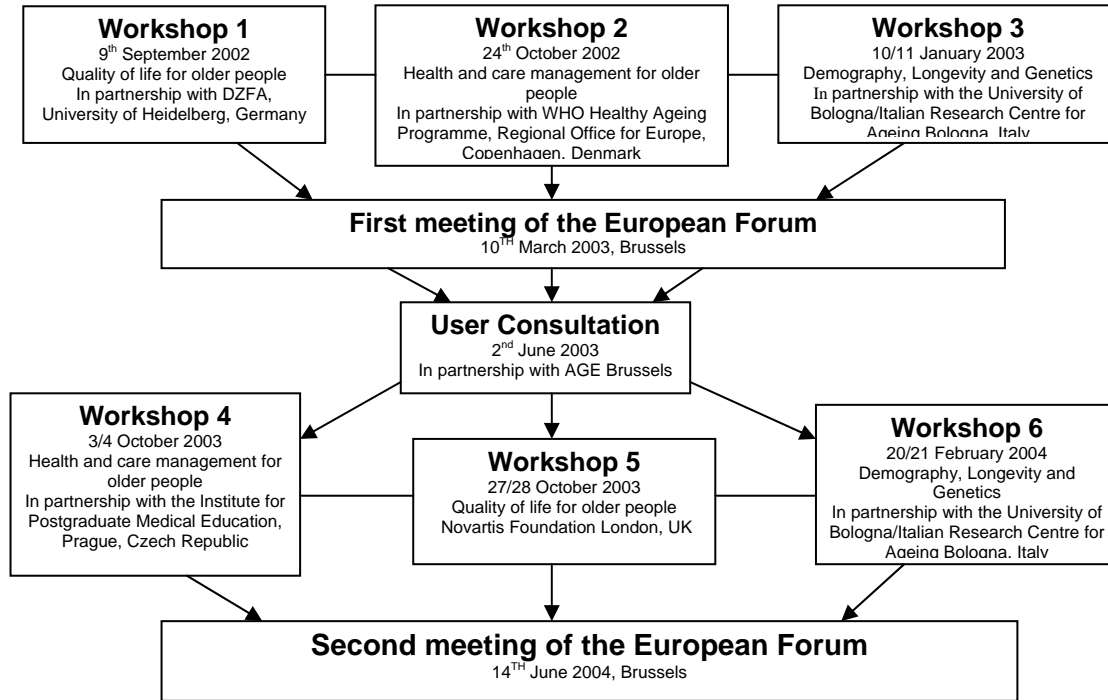
- Systematic exchange of information and good practice
eg. Databases, workshops
- Strategic activities
eg. European Forum, expert meetings
- Joint activities
eg. Website links, open calls for research
- Transnational collaboration
eg. Draft cooperation agreement

Ensuring a key role for scientists

Workshops on quality of life; health and social care; and demography longevity, and genetics.

European Forum on Population Ageing

Research: Timeline of Events



Priority Recommendations from Scientists and Research Users

- Topic specific
- Research and methodological approaches
- European collaboration
- Interdisciplinary collaboration
- User Involvement
- Policy

**European Forum on Population Ageing Research:
Knowledge Gaps and Research Priorities**

	INSTRUMENTS	STRUCTURAL LIMITATIONS	METHODOLOGICAL ISSUES	RESEARCH PRIORITIES
Quality Of Life	<p>1) Consensus on how to understand measure and define Quality of Life - both standardised and culture specific.</p> <p>2) Predictors of active ageing</p> <p>3) Assess environmental measures to understand how to improve the lives of older people.</p>	<p>1) Developing gerontology researcher capacity in quantitative and financial expertise .</p> <p>2) Health issues have taken priority to the detriment of other aspects.</p>	<p>1) Biographical and older person centred perspectives.</p> <p>2) Involving older people in research.</p> <p>3) Theoretical development that integrates findings across the domains of Quality of Life.</p> <p>4) Examination of societal level as well as the individual – including provision, providers and recipients.</p> <p>5) Targeting of research on 50-67 year olds – ‘tomorrow’s older people’.</p>	<p>1) Data on wealth and goods in kind and Individual as a unit as well as household.</p> <p>2) Little is known about the causal factors of Inequalities between countries and social groups.</p> <p>3) How income needs and perceptions of older People change as they age.</p> <p>4) Investigate expectations and normative belief Systems of older people.</p> <p>5) Investigate cross-cultural definitions of Quality of Life.</p>
Health And Social Care Management	<p>1) More effective quality assurance of e-health and e-care services.</p> <p>2) All interventions should be tested amongst the ‘oldest old’.</p>	<p>1) Expand research beyond the dominant perspectives and the limitations created by commercial priorities.</p> <p>2) Fund more research into non-medical interventions.</p>	<p>1) Methodologies need to keep up with the rapid evolution of knowledge – i.e technology, modelling, representativeness, culture.</p> <p>2) User involvement is underdeveloped and under-utilised. Need for more flexibility and clarity about how and why to involve users.</p>	<p>1) What e-health and e-care services are available, what services do older people want & how do these Services interact with others?</p> <p>2) How to get people on low income and with low education to use these services – greater accessibility.</p> <p>3) Extensive European longitudinal study that begins by reviewing existing longitudinal studies and their methodologies and variables.</p>
Demography Longevity And Genetics	<p>1) No international standard co-morbidity index</p> <p>2) How to measure and define health and frailty in the oldest old is controversial.</p>	<p>1) The challenge is how to identify bridges between disciplines and integrate their understandings of longevity and ageing</p>	<p>1) Nonagenarians are under-researched in longevity studies.</p> <p>2) Co-ordinated approach regarding what biological samples and data should be gathered. Statistics should help define this.</p>	<p>1) Better define the phenotype ‘longevity’ from a biochemical and physiological perspective.</p> <p>2) Investigate relationship between diseases and Longevity to define which genes to study.</p> <p>3) Focus on what happens before mortality, why people survive with co-morbidity and what can be Changed by what interventions.</p> <p>4) Researchers should try to answer: a) can we attain A robust common measure of individual biographical frailty? b) Can we use this measure to identify genetic, lifestyle, psychological, social and environmental Factors that influence the onset of critical frailty?</p>

FORUM Research Priorities

Cross-cutting Themes:

- Policy and system orientated research
- Research on diversity and difference
- Research on environments of ageing
- Interventions
- Life course and transitions
- Care and carers
- Agency of older people

Forum Research Priorities

Quality of Life:

- Tomorrow's older people
- Comparative research
- Monitoring quality of life in the new Member States
- Longitudinal surveys
- Clarification of key concepts
- Involvement of older people

Research Priorities on Quality of Life: From FORUM to ERA-AGE

Tasks for Today:

- Scrutinise FORUM recommendations
- Replace, revise, endorse
- Prioritise topics
- Identify good practice
- Make recommendations

Working Group Questions

1. What priorities should a research programme on ageing address in the field of quality of life?
 - What should be the main priority topics? Please list five topics maximum.
 - Are there any of these research topics that should be addressed by a single disciplinary perspective?
 - From a scientific perspective what are the key priorities in terms of research infrastructure and cooperation at European level?
2. Can you identify any examples of good practice in interdisciplinary and European collaboration that can be useful models to use and learn from?
3. What kind of support should a European programme provide to facilitate both interdisciplinary and European collaboration?
4. How can we address the fact that ageing has received such a low priority in Framework Programme 7?

**Factors Related to Quality of Life in Cross-National Perspective:
Evidence from the OASIS Project**
Professor Ariela Lowenstein
Center for Research & Study of Ageing - University of Haifa, Israel

Old Age and Autonomy:

The Role of Service Systems and Intergenerational Family Solidarity

The Partnership

Norway	NOVA – Norwegian Social Research, Oslo
Germany	DZA – The German Center of Gerontology, Berlin
England	Keele University – School of Social Relations
Spain	University of the Basque Country, Bilbao – Faculty of Sociology
Israel	The Center for the Research and Study of Ageing, University of Haifa
ESHEL	The Association for the Planning and Development of Services for the Aged in Israel, Jerusalem

Intergenerational family relations and Quality of Life

A basic question is: Does the well-being and quality of life of older parents depend on the quality of their intergenerational family relations with their adult children? Lawton, *Silverstein and Bengtson (1994)* argue, “Each dimension of family relations is interconnected with the others in ways that affect the well-being of both generations”.

Intergenerational relationships are one of the most important elements that influence Quality of Life. It is viewed as an important component, especially for successful coping and social integration in old age (*McChesney & Bengtson, 1988; Silverstein & Bengtson, 1991*), and it contributes to Quality of Life of the individual throughout his/her life course (*Roberts & Bengtson, 1988; Rossi & Rossi, 1990*).

Studies of the effects of family solidarity on coping with situations of crisis have revealed that higher family solidarity contributes to better adjustment in crisis like widowhood or immigration (*Silverstein & Bengtson, 1991; Katz & Lowenstein, 1999*).

The focus of this presentation is, thus, on the links between family relations and older parents' Quality of Life in a comparative cross-national perspective. To our knowledge, there exist only few cross-national studies on these topics.

Research comparing two countries or more on inter-generational relations exists, but without relating it to well-being and Quality of Life (*Bengtson & Martin, 2001; Silverstein, Burholt, Wenger & Bengtson, 1998*). In order to fill the above gap, our study dealt both with ‘cross-cultural’, ‘cross-national’ comparisons of countries belonging to different and/or similar ‘family cultures’ and welfare regimes.

Well-Being and Quality of Life

Measures of subjective well-being and quality of life can be useful in assessing the need for certain policies, and in measuring the outcomes of policy interventions. Consideration of these indicators is particularly warranted due to the growing evidence that subjective well-being is a desirable goal for nations in that it produces beneficial societal outcomes (*Lyubomirsky, King, & Diener, 2005*).

Quality of life – Definition

- Quality of life usually refers to the degree to which a person’s life is desirable versus undesirable, often with an emphasis on external components, such as environmental factors and income. In contrast to subjective well-being, which is based on subjective experience, quality of life is often expressed as more “objective” and describes the circumstances of a person’s life rather than his or her reaction to those circumstances.
- However, some scholars define quality of life more broadly, to include not only the quality of life circumstances, but also the person’s perceptions, thoughts, feelings, and reactions to those circumstances.

Quality of Life - Concepts and Instruments

Concept	Scale / Instrument
Cognitive assessment General indicator	WHO Quality of Life Life Satisfaction WHO Quality of Life-bref Subjective Quality of Life
Cognitive assessment Specific assessment scales	WHO Quality of Life-bref Physical Health WHO Quality of Life-bref Psychological Health WHO Quality of Life-bref Social Relationships WHO Quality of Life-bref Environment
Mental status	PANAS Positive Affect PANAS Negative Affect

Quality of Life - Means and standard deviations of the scale

Subjective physical health

Country	Age Group 25-49			Age Group 50-74			Age Group 75+		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Norway <i>Mean</i>	17,0	16,5	16,7	16,2	15,3	15,8	14,6	13,8	14,1
<i>SD</i>	2,2	2,6	2,5	2,9	3,1	3,0	3,1	3,4	3,3
England <i>Mean</i>	16,3	16,1	16,2	14,6	14,5	14,6	13,5	12,8	13,0
<i>SD</i>	3,2	3,1	3,1	3,8	3,7	3,7	3,5	3,8	3,7
Germany <i>Mean</i>	17,9	17,3	17,6	16,6	16,1	16,3	14,6	14,1	14,2
<i>SD</i>	2,2	2,3	2,3	2,5	2,7	2,6	2,9	2,9	2,9
Spain <i>Mean</i>	17,4	17,0	17,2	15,4	14,2	14,8	13,6	12,2	12,7
<i>SD</i>	1,9	2,1	2,0	2,8	3,3	3,1	2,7	3,1	3,0
Israel <i>Mean</i>	16,8	16,0	16,3	15,2	14,9	15,0	13,4	11,8	12,5
<i>SD</i>	2,1	2,5	2,4	2,9	2,9	2,9	2,7	3,0	3,0

Subjective psychological health

Country	Age Group 25-49			Age Group 50-74			Age Group 75+		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Norway <i>Mean</i>	15,9	15,6	15,7	15,7	15,5	15,6	14,9	14,7	14,8
<i>SD</i>	1,9	2,1	2,0	2,0	2,0	2,0	2,4	2,5	2,5
England <i>Mean</i>	15,6	14,9	15,1	15,2	15,1	15,1	14,9	14,2	14,4
<i>SD</i>	2,4	2,7	2,6	2,9	2,7	2,7	2,7	2,9	2,8
Germany <i>Mean</i>	16,8	16,3	16,5	16,3	16,0	16,1	15,7	15,1	15,3
<i>SD</i>	2,2	2,6	2,4	2,6	2,5	2,5	2,3	2,5	2,5
Spain <i>Mean</i>	15,3	14,9	15,1	14,1	13,5	13,8	13,5	12,5	12,8
<i>SD</i>	2,3	2,4	2,4	2,2	2,2	2,2	2,1	2,4	2,4
Israel <i>Mean</i>	15,8	15,0	15,3	14,9	14,3	14,6	13,8	12,9	13,3
<i>SD</i>	2,2	2,3	2,3	2,2	2,6	2,4	2,5	2,6	2,6

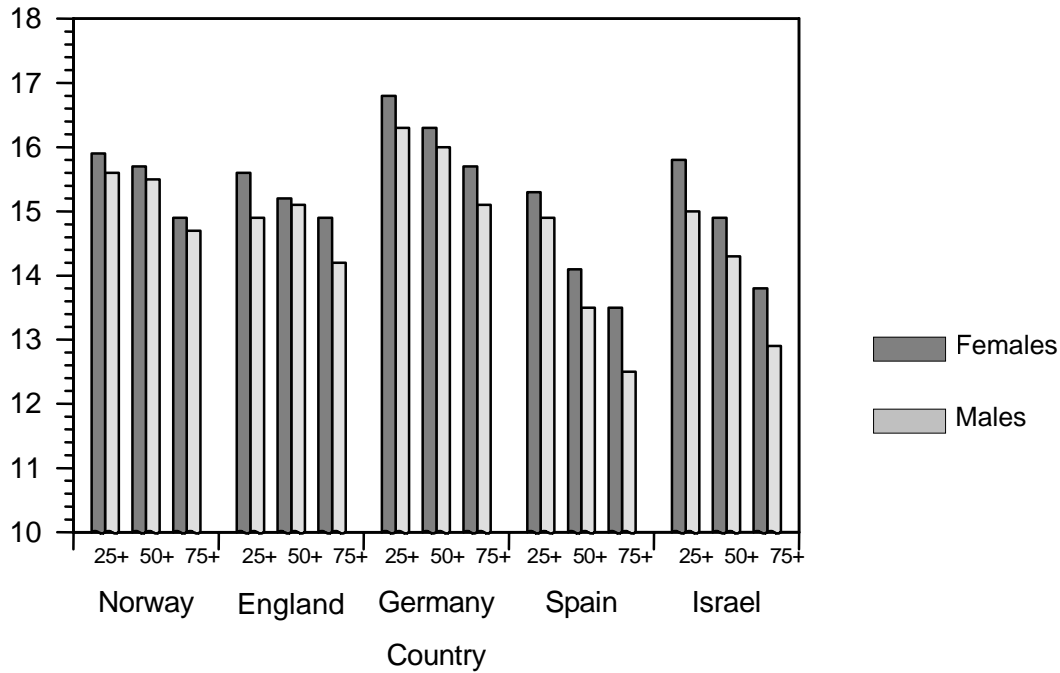
Satisfaction with social relations

Country	Age Group 25-49			Age Group 50-74			Age Group 75+		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Norway <i>Mean</i>	15,8	16,1	16,0	15,5	15,7	15,6	14,5	14,9	14,7
<i>SD</i>	2,3	2,0	2,2	2,3	2,2	2,2	2,2	2,3	2,3
England <i>Mean</i>	16,3	15,9	16,0	15,5	15,6	15,6	15,0	14,9	15,0
<i>SD</i>	2,7	3,0	2,9	2,5	2,4	2,5	2,3	2,3	2,3
Germany <i>Mean</i>	15,9	16,1	16,0	15,2	14,8	15,0	14,5	13,7	13,9
<i>SD</i>	2,4	2,6	2,5	2,5	2,7	2,6	2,2	2,2	2,2
Spain <i>Mean</i>	16,5	16,4	16,5	15,3	15,3	15,3	14,6	14,4	14,5
<i>SD</i>	2,2	2,6	2,4	2,2	2,3	2,3	2,3	2,2	2,2
Israel <i>Mean</i>	15,8	15,4	15,5	14,4	14,8	14,6	14,3	13,1	13,6
<i>SD</i>	2,8	3,2	3,0	3,0	3,0	3,0	3,0	3,4	3,3

Satisfaction with environment

Country	Age Group 25-49			Age Group 50-74			Age Group 75+		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Norway <i>Mean</i>	15,5	15,6	15,6	16,2	15,9	16,1	15,8	15,0	15,3
<i>SD</i>	2,0	2,0	2,0	1,9	2,0	2,0	2,0	2,2	2,2
England <i>Mean</i>	14,6	14,1	14,3	14,7	14,7	14,7	14,4	14,1	14,2
<i>SD</i>	2,4	2,6	2,5	2,5	2,5	2,5	2,2	2,5	2,5
Germany <i>Mean</i>	15,8	15,7	15,7	16,0	15,6	15,8	15,7	15,3	15,4
<i>SD</i>	2,0	2,3	2,1	1,9	2,2	2,1	1,9	2,1	2,0
Spain <i>Mean</i>	14,6	14,3	14,5	13,8	13,5	13,6	13,5	12,8	13,0
<i>SD</i>	2,1	2,1	2,1	2,0	2,0	2,0	1,9	2,0	2,0
Israel <i>Mean</i>	15,1	14,3	14,6	14,6	14,4	14,5	14,1	13,5	13,8
<i>SD</i>	1,9	2,2	2,1	2,0	2,2	2,1	2,3	2,4	2,3

Satisfaction with physical health in Norway, England, Germany, Spain and Israel by age and gender



Stepwise multiple regression coefficients of elders (75+) overall quality of life on demographics, functioning and intergenerational family solidarity+

	Norway	England	Germany	Spain	Israel
Gender	.101*	.080	-.024	-.049	-.035
Age	-.108*	.027	-.034	-.062	.070
Number of children	.073	-.020	.033	.011	-.009
Marital status	-.012	.027	-.074	-.010	.061
Financial	.158**	.166***	.270***	.216***	.212***
Education	.033	.042	.139**	.040	.063
Functioning	.588***	.628***	.441***	.360***	.494***
Solidarity S (proximity +association)+	.030	.038	.071	-.013	-.061
Solidarity S (affectual +consensus)+	.181***	.164***	.142*	.089	.101*
Help received	-.086	-.117*	.041	-.149*	-.041
Help provided	.096*	.039	.027	.051	.043
conflict	-.020	-.062	.088	-.030	-.017
Total N	N=311	N=307	N=328	N=315	N=291
Total R2	.512***	.534***	.401***	.320***	.456***
R2 change (solidarity dimensions)	.045***	.037**	.029*	.024	.016

* $P < .05$

** $p < .01$

*** $P < .001$

+The demographic variables were forced into the model, whereas solidarity dimensions were entered using stepwise regression

Standardised regression coefficients for overall quality of life, including demographics & countries (N=2,064)

	Model 1a	Model 2b	Model 3 c
Solidarity S (structure+ association)	.022	.003	.023
Solidarity A (affectual +consensus)	.146***	.065**	.097***
Help received	-.215	-.010	-.051*
Help provided	.154***	.054**	.053**
Conflict	-.010	-.010	-.032
Ambivalence	-.062	-.061*	-.087**
Gender		.046	.010
Age		.008	-.015
Marital status		.023	.003
No. of children		.031	.007
Education		.131***	.078**
Financial		.230***	.203***
Health score		.515	.496***
Norway			.152***
England			.171***
Germany			.241***
Spain			.034
Total R2	.090	.433	.472
R2 change		.343	.038

Reference category for country is Israel.

a Family relations; b Family relations, demographic and health; c Family relations, demographic and health and countries

<.05; **<.01; *<.001)*

DISCUSSION

The data indicate that of the family relations variables, when entered separately into the regression, the affective-cognitive factor and the reciprocal exchange of support (help received and provided) had the greatest predictive value.

This is congruent with other studies showing that affectual solidarity prolonged the lives of older parents who experienced personal loss (e.g., Silverstein & Bengtson, 1991). Similarly, comparative research in the US and India showed that emotional support contributed to well-being directly and indirectly (Venkatraman, 1995).

The structural-behavioral factor – Solidarity S - was not statistically related to Quality of Life which was somewhat surprising. Yet, the exchange of support, and especially reciprocal exchange, was found to contribute to elders' Quality of Life. As exchange of support entails contact, conceivably, the Solidarity S factor was confounded with these dimensions of instrumental exchange.

Even though family ties have generally been found to affect the well-being of the individual throughout the life course, some studies emphasize the importance of personal resources over family relations (*Fernandez-Ballesteros et al., 2001*).

Quality of Life in this study was associated with level of physical functioning and the personal resources of education and level of living. Apparently, personal resources that relate to basic needs are perceived as the first priority for the overall Quality of Life of people above the age of 75. These findings correspond to previous research showing that social integration, good health, and high SES are the central predictors of subjective Quality of Life (*Pinquart & Sorensen, 2000*).

Quality of Life Studies: Some Methodological and Cross-cultural Issues

Professor Rocio Fernández-Ballesteros
Autónoma University of Madrid, Spain

Quality of Life Studies 1995 2005:

Autónoma University of Madrid and Institute of Elders and Social Services IMSERSO

- Implicit theory of Quality of Life:
 - Quality of Life domain for the elderly
 - Internal structure
 - From exploratory to confirmatory analysis
- Quality of Life methodological issues:
 - Faking in Quality of Life questionnaires
 - Internal consistency in the Quality of Life domains
- Cross cultural comparisons:
 - Spain, Venezuela and Uruguay: main comparisons
 - CUBRECAVI as evaluation tools
- Some concluding remarks

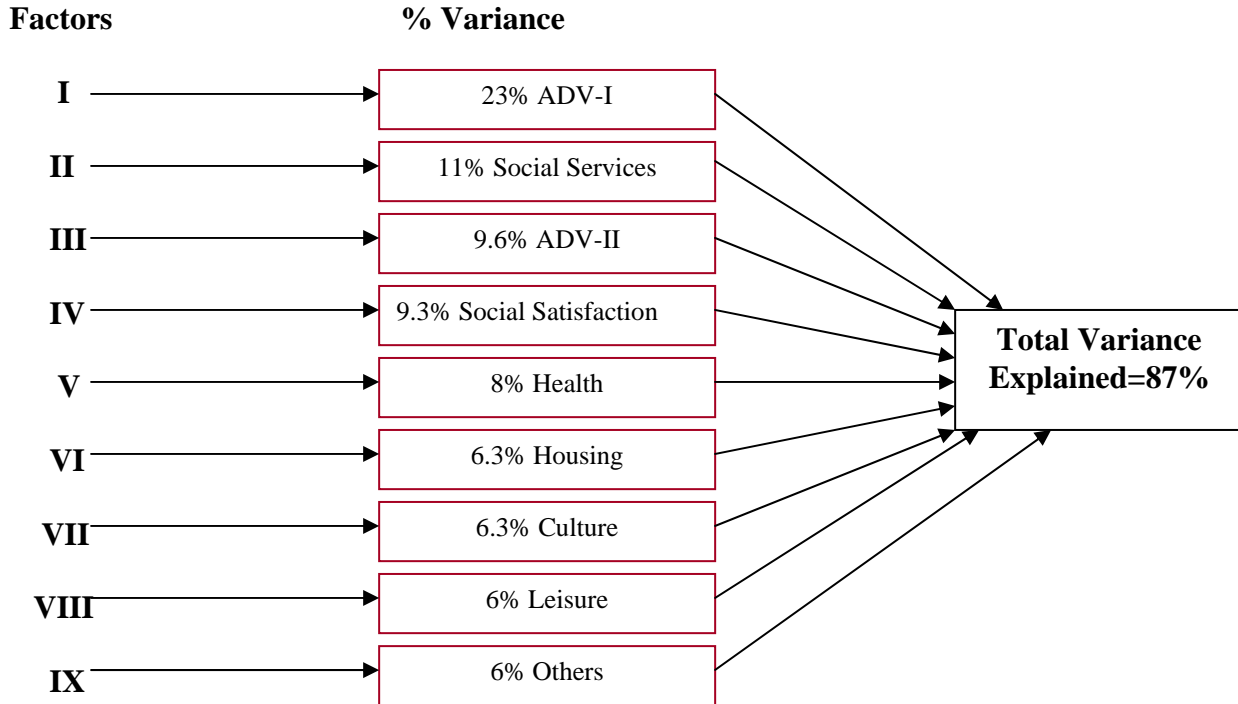
Implicit Theory of Quality of Life

Implicit Theory of Quality of Life (Representative sample older than 18 N=1205) (Fernández- Ballesteros & Maciá, 1996)	1st Option	1st,2nd,3rd Options
To have good health	70%	83%
To be independent	15%	66%
To have a good pension and/or income	2%	34%
To have good relationships with family members and friends	2%	31%
To be active	3%	26%
To have good social and health services	3%	24%
To have a good house or apartment	1%	17%
To feel satisfy with life	1%	11%
To have a good home or neighbourhood	-	3%
To have opportunities for learning	-	3%
Others/ None/ DK/NA	-	-

Other results

- No differences were found by:
 - Age,
 - Gender
 - SES
- Empirical construct validity through factorial analysis in two independent samples and with two methods (self-reports and relative reports)
- In summary: health, wealth and love (as in the song) are the three most important conditions of Quality of Life for Spaniards

Factorial Analysis
(Varimax Rotation)



Quality of Life of the Elderly in several contexts in Spain.

Subjects

- Subjects:
 - Representative sample (by age, gender, education) of older than 65 living in the community, N=507
 - Representative sample of older than 65 living in Residences (random selection) for healthy senior citizen N=507(public: N=256 and private:N=251)

Quality of Life of the Elderly in several contexts in Spain.

Methods

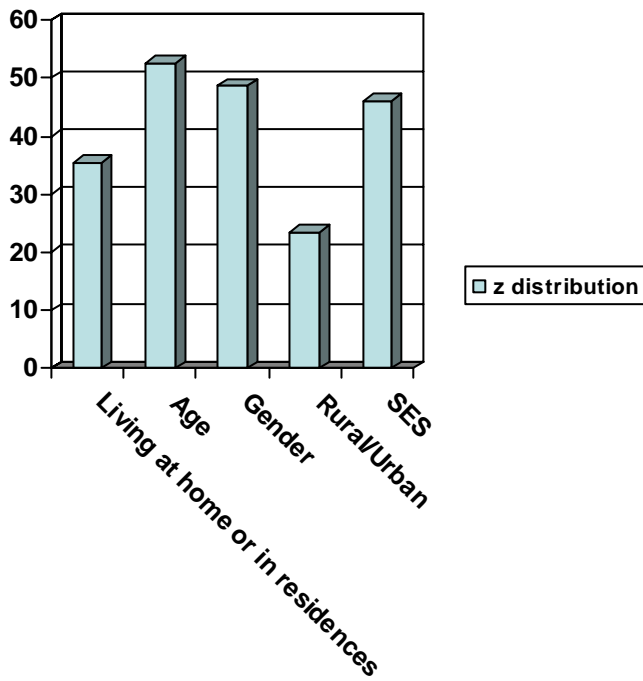
- In home interview through questionnaire (about 60 minutes)
- Questionnaire domains:
 - Health: Subjective health, Objective health (chronic problems, medicine intake, visit to the doctor, etc.), Mental health, Hearing and Vision, Life styles (smoking, drinking, diet, etc.)
 - Functional abilities (subjective appraisal, DLA-I and II)
 - Social Relationships: Frequency and satisfaction
 - Activity and leisure: Frequency and satisfaction
 - Environmental quality (in-home & neighborhood): Subjective (self-reported) and Objective (observed by the interviewer)
 - Life satisfaction: LSI and comparative appraisal
 - Social and Health services: Knowledge, Availability, Utilization, Satisfaction
 - Sociodemographics

Quality of Life of the Elderly in different context in Spain:

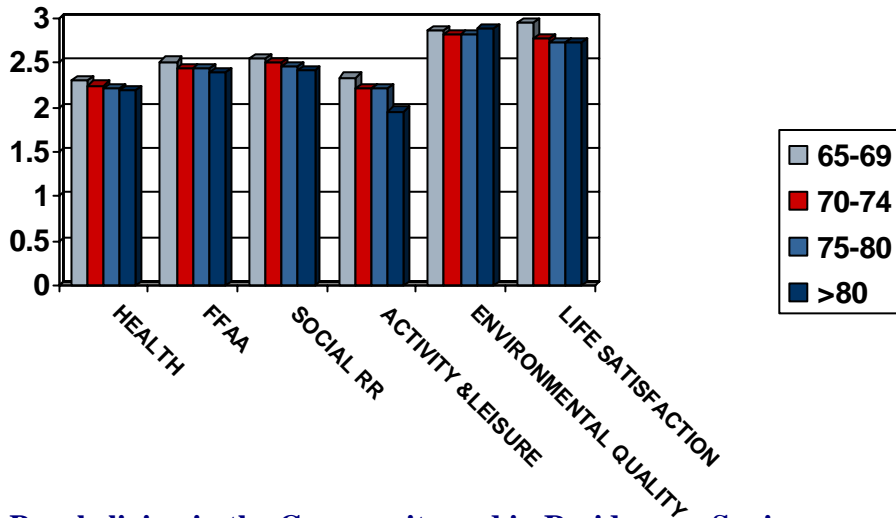
Other variables

- Classification variables:
 - Living conditions: Community/Residences (public/private)
 - Age (four groups)
 - Gender
 - Rural/Urban (three classes)
 - SES
- Intervening variables:
 - Eysenck Lie Questionnaire
 - Mental Status: SPMSQ

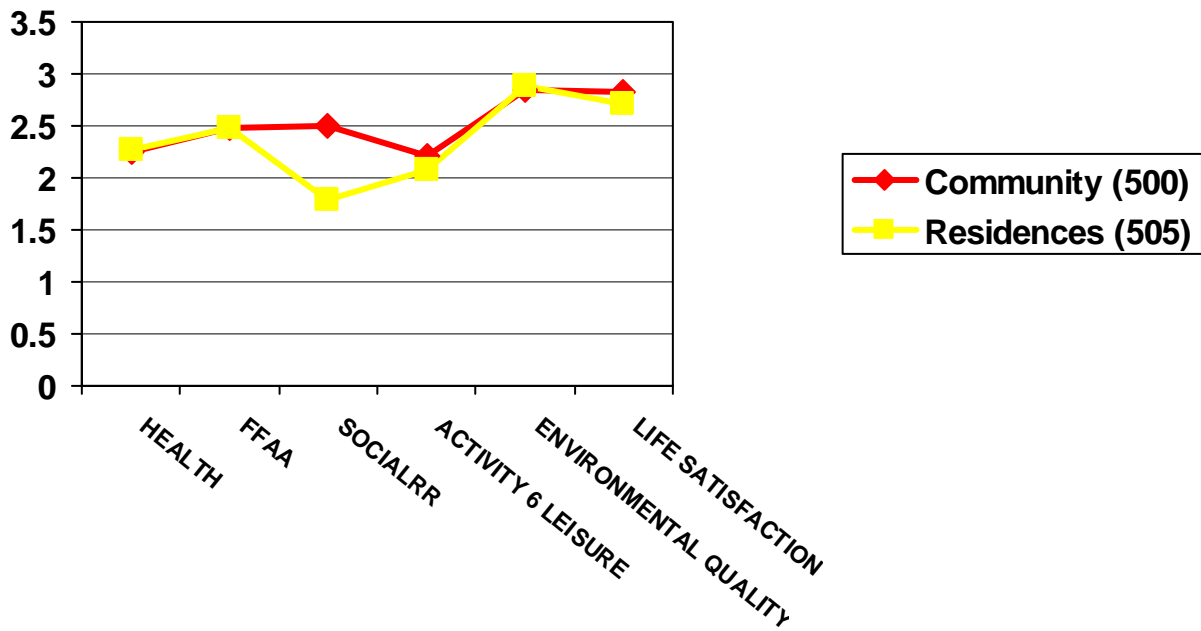
Discriminant power by contextual variables



Quality of Life Main Domains and age in Spain

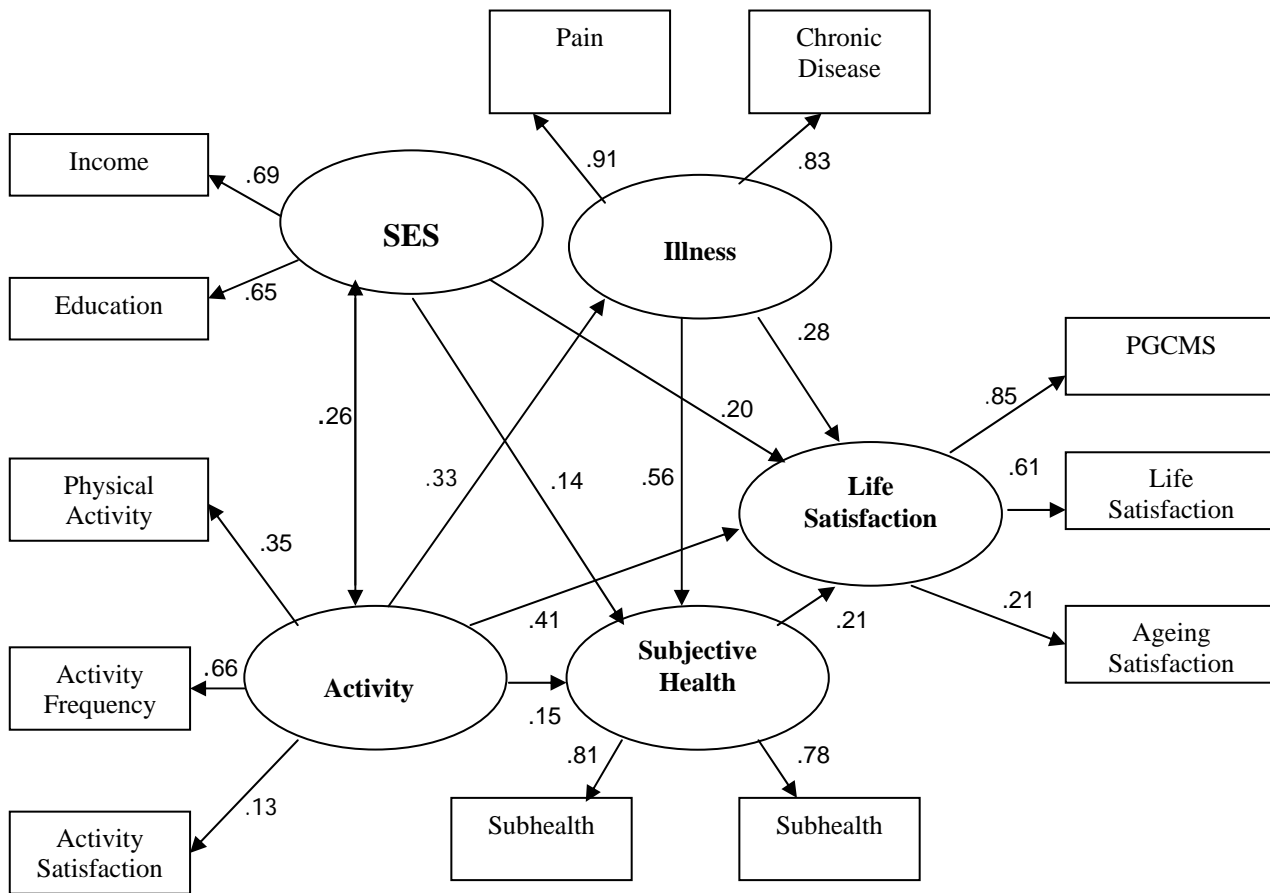


People living in the Community and in Residences: Spain



Community sample

$\chi^2 = 52,6; 46 \text{ gl}; p=.232$



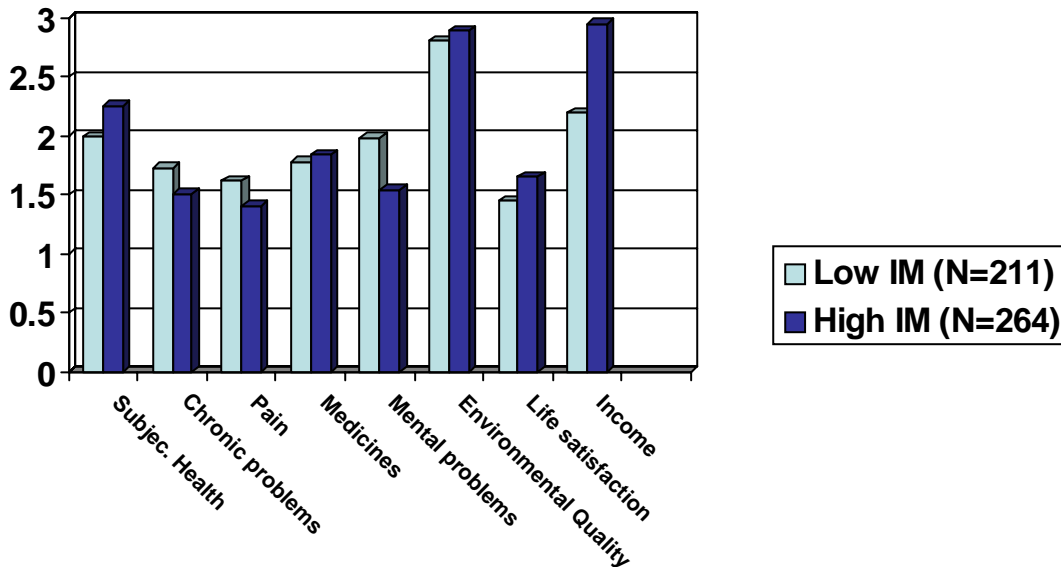
Developing an instrument for assessing Quality of Life: the CUBRECAVI

- Selecting 18 questions about the 9 Quality of Life Domains with high discriminated power
- Some methodological issues:
 - Internal consistency
 - “Faking” or “Impression Management”
 - Objective and Subjective “Environmental Quality”
 - Profile and Norms
 - Making cross-cultural comparison between Spain and Iberoamerican countries
 - Sensitivity of CUBRECAVI as a tool for evaluating Gerontological programmes

Internal Consistency in Quality of Life Domains

Domain	N	Alpha
Subjective health (5 items)	678	.73
Objective health (46 items)	864	.84
Mental health(12 items)	963	.86
Social Relationships (16 items)	114	.17
Functional abilities (17 items)	484	.66
Activity and Leisure (33 items)	92	.87
Life satisfaction (15 items)	881	.76
Environmental Quality(15-7 items)	1013	.77-.78

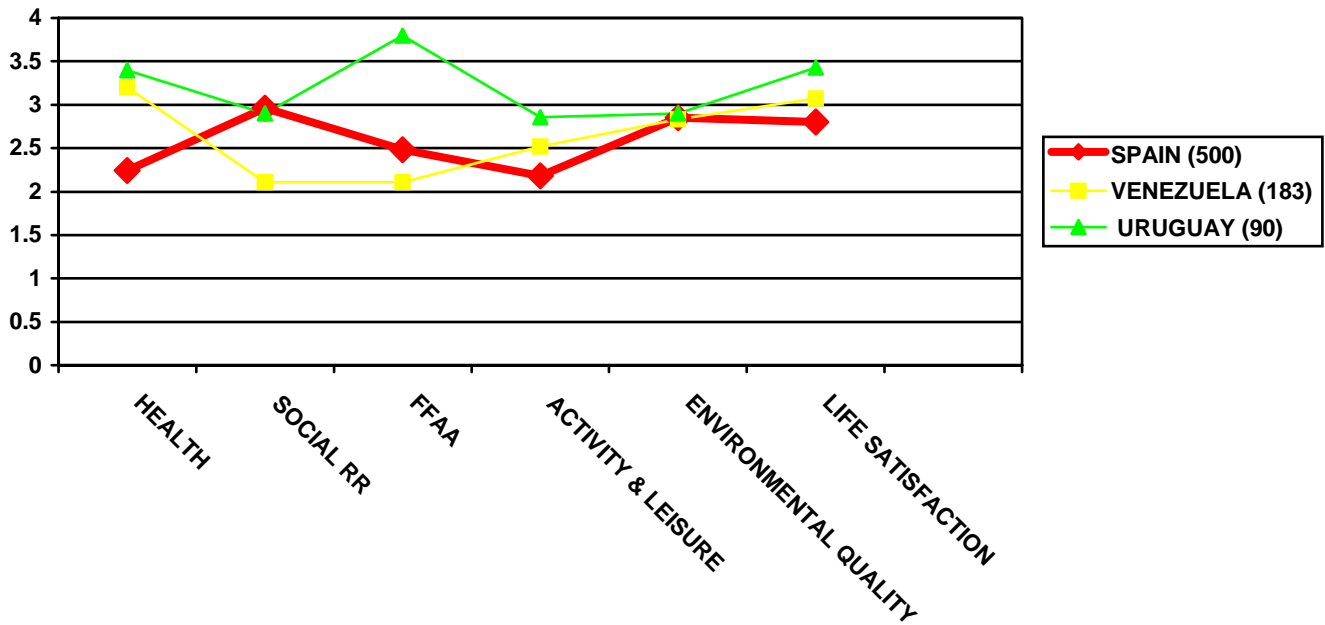
Impression Management (or faking): significant differences in Quality of Life domains



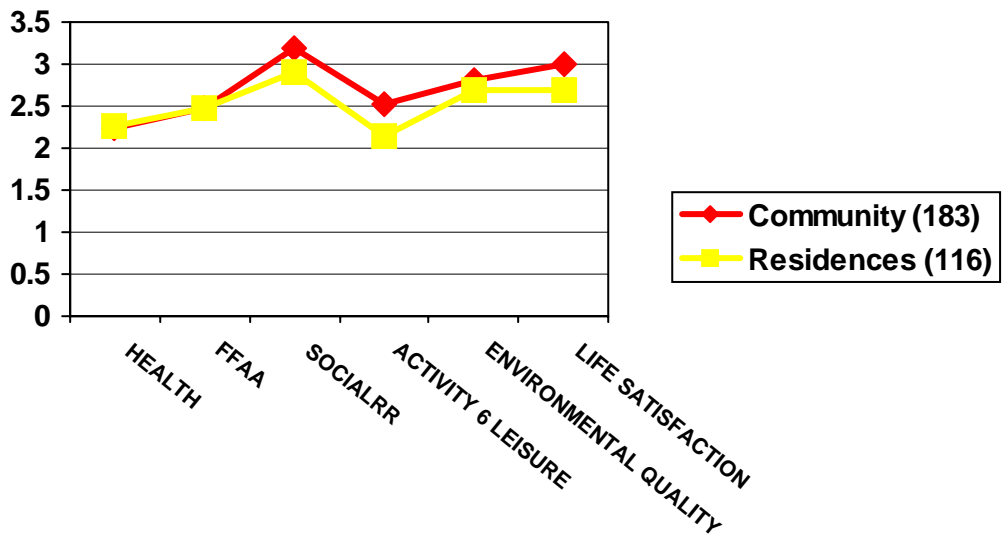
Problematic issues: Protocol (translation) adaptation

- Cross-cultural research: the myth of “back translation”.
- ITC: Guidelines for Test Adaptation (Hambleton, 1996)
- European Survey on Ageing Protocol (ESAP) EXCELSA-Pilot Adaptation procedures (Fernández-Ballesteros, Hambleton, der Vijver, 1999)
- Adapting in the same language:
 - Is the implicit theory in the target country similar to the domain country?
 - What about wording, idioms etc?
 - Scales used (level of education, income, services etc)?

Comparisons between countries with the same language:



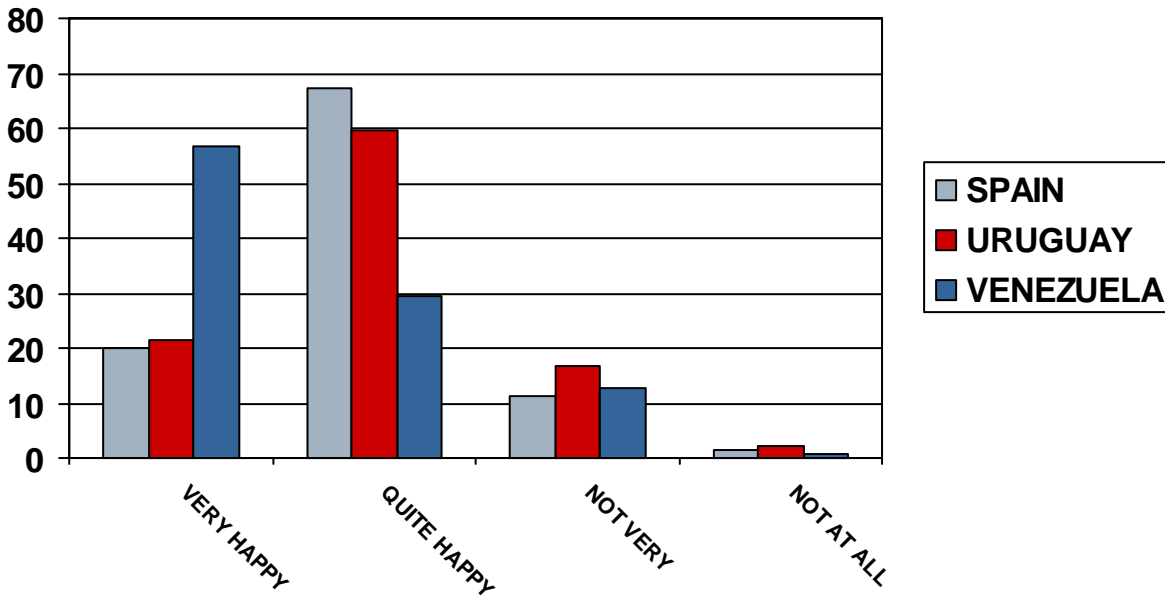
People living in the Community and in Residences for healthy elders in Venezuela (De Oliveira, Uribe y Peña, 2003)



Problematic issues in assessing a more specific and older concept such as happiness:

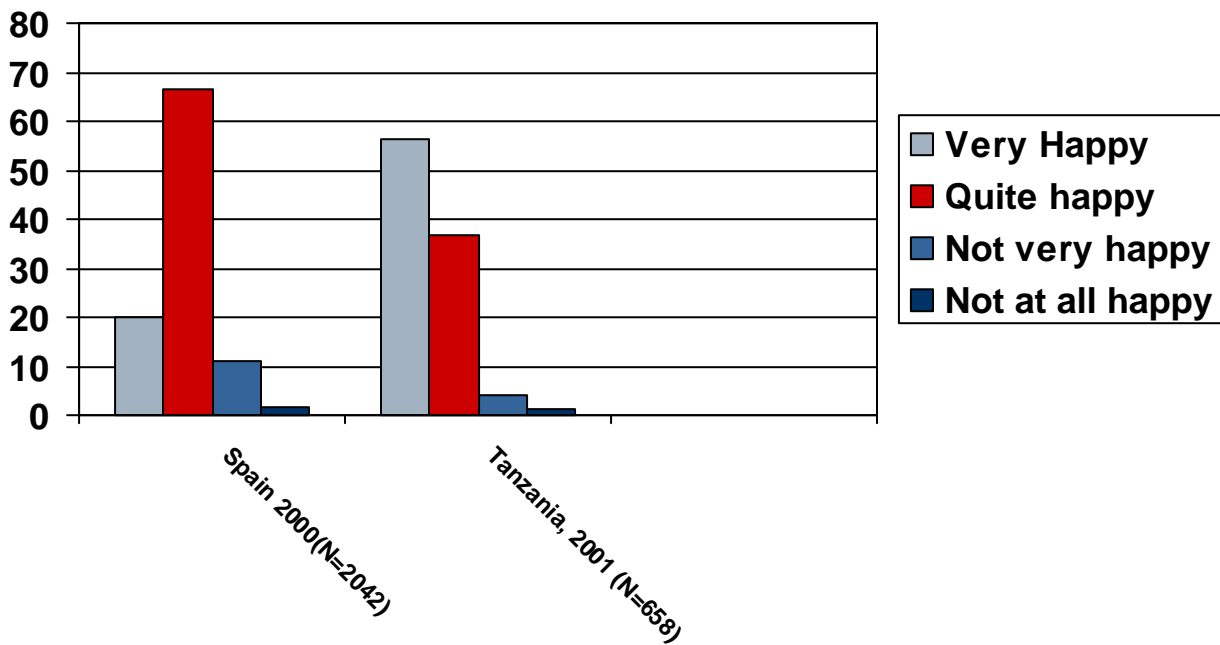
Feeling of happiness in countries with the same language: Spain, Venezuela & Uruguay (no age differences)

(N=3.409 per country; World Values Study, Inglehart, 1996/2000)



International comparisons: different languages/cultures

Spain and Tanzania (WVS: Inglehart, 2005)



Quality of Life as objective of Gerontological Programmes:

Examples of CUBRECAVI as an evaluation tools

- Colombia: Muñoz y Cabuya (2004), found significant differences in the expected direction in 7 CUBRECAVI domains (with exception to functional abilities) in two samples older than 60 (N=427 selected at random) assigned to two gerontological programmes.
- Venezuela: D'Alessandro y Peña (2004), found significant differences in 7 domains of CUBRECAVI in the expected direction in those people attending an active ageing program (N=300) than those in the control group (N=263).
- Uruguay: Koroky (2003) found differences in 5 CUBRECAVI domains in those people older than 70 working in voluntary work (N=100) than in the control group.

Some concluding remarks

- Implicit theories of Quality of Life
- Problematic issues in the use of self-reports as source of information
- Relationships between objective and subjective indicators
- Protocol adaptation in Cross-cultural studies in a Continent with more than 20 languages

**European Ageing Research on Environmental Resources and Quality of Life:
Needs and Avenues to Go**
Professor Hans-Werner Wahl
German Centre for Research on Ageing, the University of Heidelberg, Germany

Some observations

- The importance of the (physical) environment is taken for granted in much research in social and behavioural gerontology as well as geriatrics.
- ...but frequently not really spelled out in a balanced manner as compared to person characteristics and social environmental issues.
- ...or understood as an area to be met with one or two items (e.g., on residential satisfaction, some basic housing standards).
- Thesis: The (physical) environment is typically not taken serious in scholarly work in gerontology (though not ignored).

Outline

1. Basic definitional and conceptual issues
2. Importance of the environment for Quality of Life research with older people
3. Status Quo – Some glances (including own findings)
4. Possible (and needed) ways to go
5. Conclusions

Basic definitional and conceptual issues

Lawton (1991):

“Quality of life is the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current, and anticipated.” (p. 6).

Basic definitional and conceptual issues

Wahl & Lang, 2004, p. 3; Dannefer, 1992, p. 84:

The physical environment refers to the totality of the diverse range of phenomena, events, and forces that exist outside the ageing individual and is directly linked to the material and spatial sphere. The social environment refers to the totality of the diverse range of phenomena, events, and forces that exist outside the ageing individual and is directly linked to other persons.

Importance of the environment for Quality of Life research with older people

Time budget and action range argument

- Home environment as a major context of ageing, particularly for the very old.
- Berlin Ageing Study (M. Baltes et al., 1996): 85 + (urban population) about 80% of daytime in home.
- Neighbourhood and immediate environment as major out-of-home context.

Importance of the environment for Quality of Life research with older people

Scientific and real world implications (examples):

- Person-home transactions as a major target of research.
- Ongoing evolution of neighbourhood cultures directly related to older people's engagement.

Importance of the environment for Quality of Life research with older people

Longtime ageing at the same place argument

- In ENABLE-AGE (Germany, Hungary, Latvia, Sweden, UK) the mean of duration of residency of those aged 75 to 89 years was above 20 years in all countries involved (Oswald, Wahl, and Schilling, Nygren et al., submitted).
- Highly specific place attachments, meanings of home, highly personalised home environments.

Importance of the environment for Quality of Life research with older people

Scientific and real world implications (examples):

- Importance of the understanding of what long- time ageing at the same place means for ageing people.
- Continuity and striving towards attachment versus rapid change of environments (urbanization processes, globalisation).

Importance of the environment for Quality of Life research with older people

Competence argument

- Old age is – besides early childhood – a period in life, in which loss in competencies significantly enhances the “press” and the constraints of the physical environments.
- Of particular importance is that the fastest growing segment of the older population in many developed countries continues to be the 85+ group.

Importance of the environment for Quality of Life research with older people

Scientific and real world implications (examples):

- Importance of understanding frailty and functional dependence in a contextual view.
- “Environmental therapy” as a means of improvement, when personal resources are exhausted.

Importance of the environment for Quality of Life research with older people

Need argument

- Strong desire of old and very old people to “age in place“; consistent with societal and political priorities in most European countries.
- Desire may reflect an optimisation strategy critical to late life that affords continuance and control over important aspects of daily life (routines, self-care, self-defining activities).
- Home environment is rapidly evolving into the primary context in which medical, rehabilitative and palliative care is provided.

Importance of the environment for Quality of Life research with older people

Scientific and real world implications (examples):

- In-depth understanding of the “Fourth Age” in relation to supportive and constraining environments.
- Person-environment considerations as critical for the understanding of the potential and limits of private and professional caregiver arrangements.

Importance of the environment for Quality of Life research with older people

Cohort dynamics argument

- Ongoing changes in the person-physical environment system tell us much about changes in the culture of ageing.
- Development of new housing options such as assisted living facilities or multi-generational living arrangements can be regarded as a major reflection of new living styles of ageing.
- Out-of-home mobility has become as well a major indication of the “new ageing” and changing values toward maintaining efficacy and continuity in old age.

Importance of the environment for Quality of Life research with older people

Scientific and real world implications (examples):

- Understanding ongoing cohort dynamics in ageing can be furthered by person-environment research.
- Optimising environments for the full heterogeneity of ageing persons is among the most critical research as well as societal challenges in the future.

Status Quo – Some glances

- New substantial research on Quality of Life framed within a person-environment understanding of ageing has emerged on the European arena.
- Basic message supported by empirical research coming from environmental gerontology, social gerontology, urban sociology, occupational therapy research (and more): Consideration of the environment matters for the process and outcome of ageing in many respects, for example:

Status Quo – Some glances

- Home and out-of-home environments support (or limit) autonomy and well-being (e.g., ENABLE- AGE Project, Iwarsson, Oswald, Wahl et al.; Pathways Study, Krout et al.).
- Home and out-of-home environments add to the preservation of the ageing self and identity; “Spaces into Places” paradigm (Peace, Rowles, Sixsmith).
- Improving the home environment and out-of-home settings add to the improvement of autonomy and well-being (e.g., REACH, Gitlin et al.; Fixing to Stay Study, AARP).

Status Quo – Some glances

- Neighbourhood conditions are able to shape ageing and intergenerational interchange (e.g. deprived neighbourhood studies, Scharf et al.).
- Fine-tuned urban analyses reveal the diversity of ageing in place (ongoing comparative research on Paris, New York and Tokyo; Gusmano, Spira et al.) → public health links.

Status Quo – Some glances

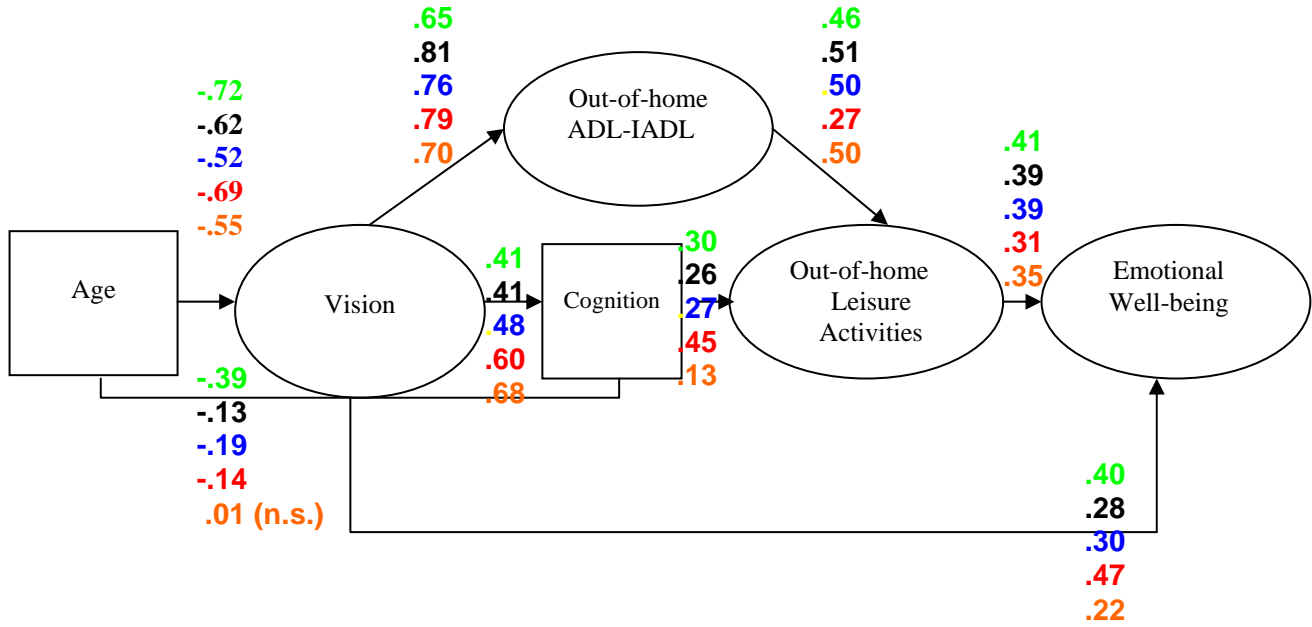
- Urban-rural differences still are a major driver of Quality of Life differences as people age (e.g., MOBILATE Project, Mollenkopf et al.).
- Institutional ageing also deserves a differentiated understanding of “ageing in place” (e.g., research by R. Kane on Quality of Life in institutional settings).

Own findings

- Personal resources and emotional well-being in different European countries and different regions (urban-rural) – (findings of the MOBILATE Project).
- Home environment, satisfaction with home and healthy ageing outcomes in different European countries (selected urban regions) – (findings of the ENABLE-AGE Project)

Emotional Well-being in Context-Different European Countries: Findings of the MOBILATE Study

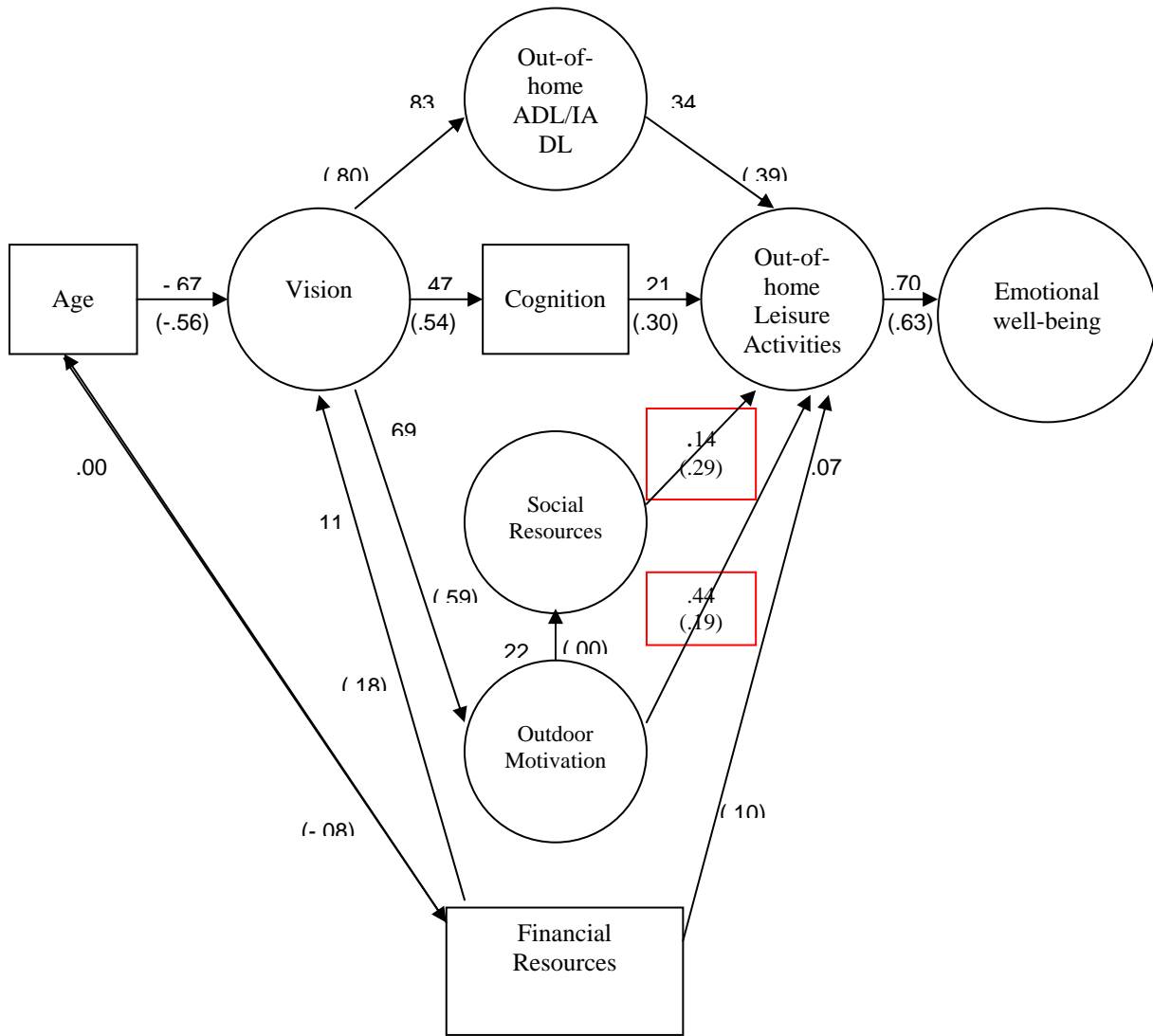
MOBILATE; N > 3,900, 55+



Finland Germany Hungary Italy The Netherlands

RMSEA = .024 CFI = .978 TLI = .959

Emotional Well-being in Context-Germany-urban-rural region: Findings of the MOBILATE Study (rural in parentheses)



Satisfaction with condition of home (urban region in Sweden, Germany and Latvia):

(Range from 1 “definitely not satisfied” to 5 “definitely satisfied”)

- Sweden (n = 397, 80-89): 4.8 (0.6).
- Germany (n = 450, 80-89): 4.6 (0.7)
- Latvia (n = 303, 75-89): 3.6 (1.3)

Source: Nygren, Oswald, Iwarsson, Fänge et al., submitted.

	Sweden		Germany		Latvia	
	T1	T2	T1	T2	T1	T2
Eigenvalues	0.79***	0.45***	0.75***	0.46***	1.2***	0.60***
Canonical correlations	.66 (86%)	.56 (56%)	.65 (93%)	.56 (78%)	.73 (83%)	.61 (70%)
<i>Housing set</i>						
Environmental barriers (total score)	-.01	-.12	-.01	-.04	.02	-.17
Housing accessibility (total score)	.55	.51	.47	.50	.54	.56
Usability in my home (physical env. aspects)	.38	.25	.35	.32	.31	.39
Usability in my home (activity aspects)	.53	.31	.56	.34	.62	.40
<i>"Healthy ageing" set</i>						
Independence in daily activities (ADL)	.58	.44	.58	.44	.67	.43
Perceived independence in daily activities	.58	.45	.54	.36	.62	.57
Psychological well-being (autonomy)	.03	.21	.10	.15	.15	.13
Life satisfaction	.20	.22	.24	.37	.13	.24
Depression (GDS)	-.31	-.35	-.29	-.42	-.38	-.31
Positive affect (PANAS)	.22	.23	.27	.24	.24	.17
Negative affect (PANAS)	-.09	-.24	-.14	-.20	-.12	-.05

Possible (and needed) ways to go

Research Strategies:

- Take the environment serious in empirical ageing research.
- Balanced person-environment assessment protocol needed for comparative European research.
- Qualitative protocol as an addition and complementary tool to a more quantitative approach (include ageing people’s voices on environmental issues).
- Link with IAG ‘s envisaged “World Ageing Survey“.
- Improve the data-base of comparative European research on person-environment issues as people age.
- Go for longer observation intervals.

- Make more systematic use out of available environmental data in existing data sets as a complementary strategy to new original research.
- Link European research with current key work in the U.S. on person environment research.

Possible / important research themes (examples):

- Analysis of existing / emerging housing options for the diversity of older people across Europe: Potential and cultural colours.
- Quality of Life of very old individuals in today's (and tomorrow's) urban settings: Constraints and resources.
- Potential of the home setting as a major arena for dealing with functional dependence, basic care needs and palliative care – specifics of different European countries.

Possible / important research themes (examples):

- Understanding the meaning of home and out-of-home experiences of older adults in different European cultures.
- Understanding home, out-of-home and technology interfaces across Europe.
- Understanding interlinkages between the physical and social environment in a diversity of cultural and political backgrounds (Wahl & Lang, 2004; in press).

Conclusions

- Not much what has been said is new.
- Consideration of environmental resources in a balanced manner is still a major challenge.
- Go for a more strategic approach → not to submit a study here and there, but instead...
- Priority of a large-scale (longitudinal) study involving a substantial number of European countries based on a balanced person and environment variable set.
- Link a set of more small-scale and detailed studies to the “reference study”.
- Extend existing studies / data sets in environmental terms in forthcoming data waves.
- Linkages with other Quality of Life themes addressed in the ERA-AGE initiative are substantial.

Care-related Quality of Life
Professor Marja Vaarama
STAKES, Finland

Quality of Life by frailty?

While many frail older people are dependent on long-term care

- Quality of Life research has given only limited attention to the relationship between care and well-being
- Quality of Life research in general has paid only little attention to Quality of Life by frailty

Care-related Quality of Life?

The multi-disciplinary CareKeys-project has:

- Developed a conceptual model of care-related Quality of life (crQuality of Life)
- Tested diverse Quality of Life measures for their fit with frail old people

Key questions

- Which factors constitute the Quality of Life by frail old people who are dependent on formal care?
- Are these different from the general models of Quality of Life by old age?
- Can care contribute to the Quality of Life of frail old people, and if yes, how should care be arranged to meet this goal?
- Are there differences between home care and institutional care? Gender etc. differences?

Theoretical Framework of Care Keys research

The five pillars:

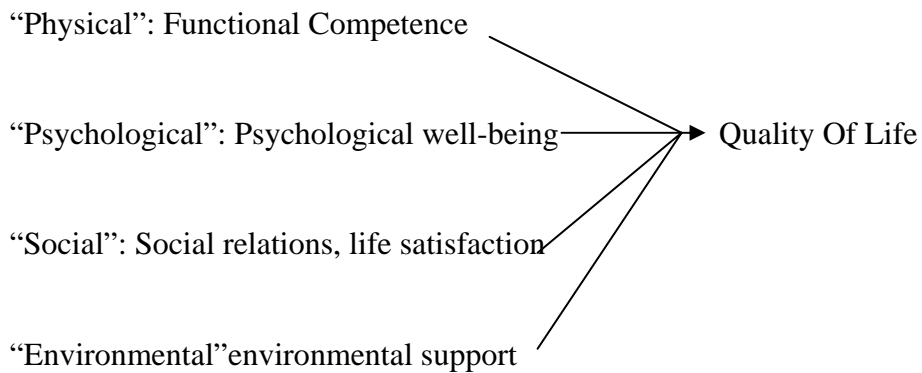
- “General” model of Quality of Life by Old Age (Lawton 1975, 1991, WHO Quality of Life Group 1998, Veenhoven 2000, Bowling et al 2002)
- POW – production of welfare approach (Davies & Knapp 1981, Knapp 1984; 1995, Vaarama 1995; 1999, Davies et al 2000)
- TEFF – concept of target efficiency Davies et al 1990, Kavanagh & Stewart 1995, Vaarama et al 1997)
- 3DQ – 3-dimensional quality of care (Övretveit 1998, Vaarama & Pieper 2005)
- crQuality of Life – care-related Quality of Life model (Vaarama 2002, Vaarama & al 2004)

General multi-dimensional Quality of Life model

Following Lawton`s 4-dimensional model:

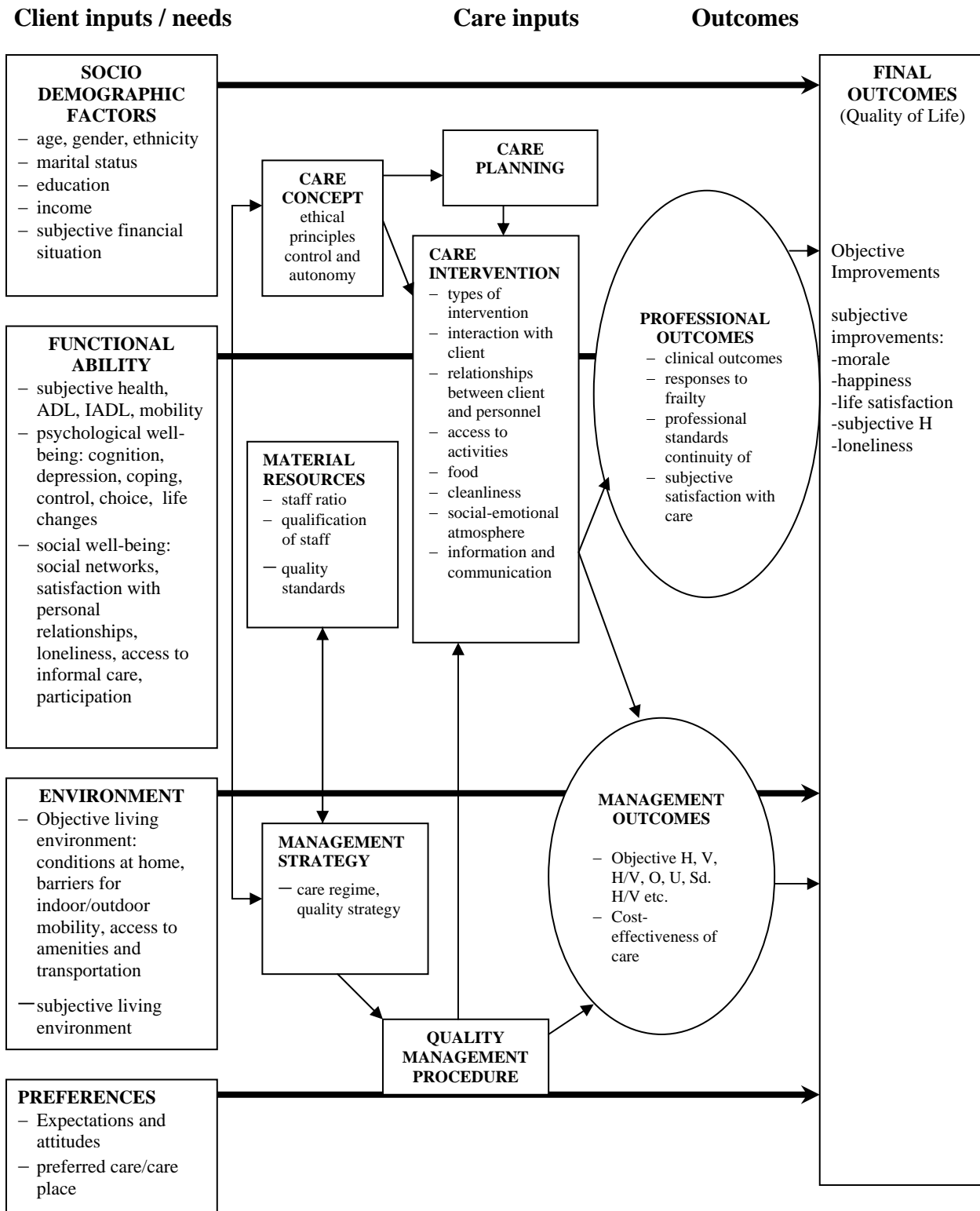
- Person-environment-fit
 - Competence in daily life activities
 - Environmental resources and support
- Psycho-social well-being
 - Social relations, life satisfaction
 - Psychological well-being

The four domains of Quality of Life

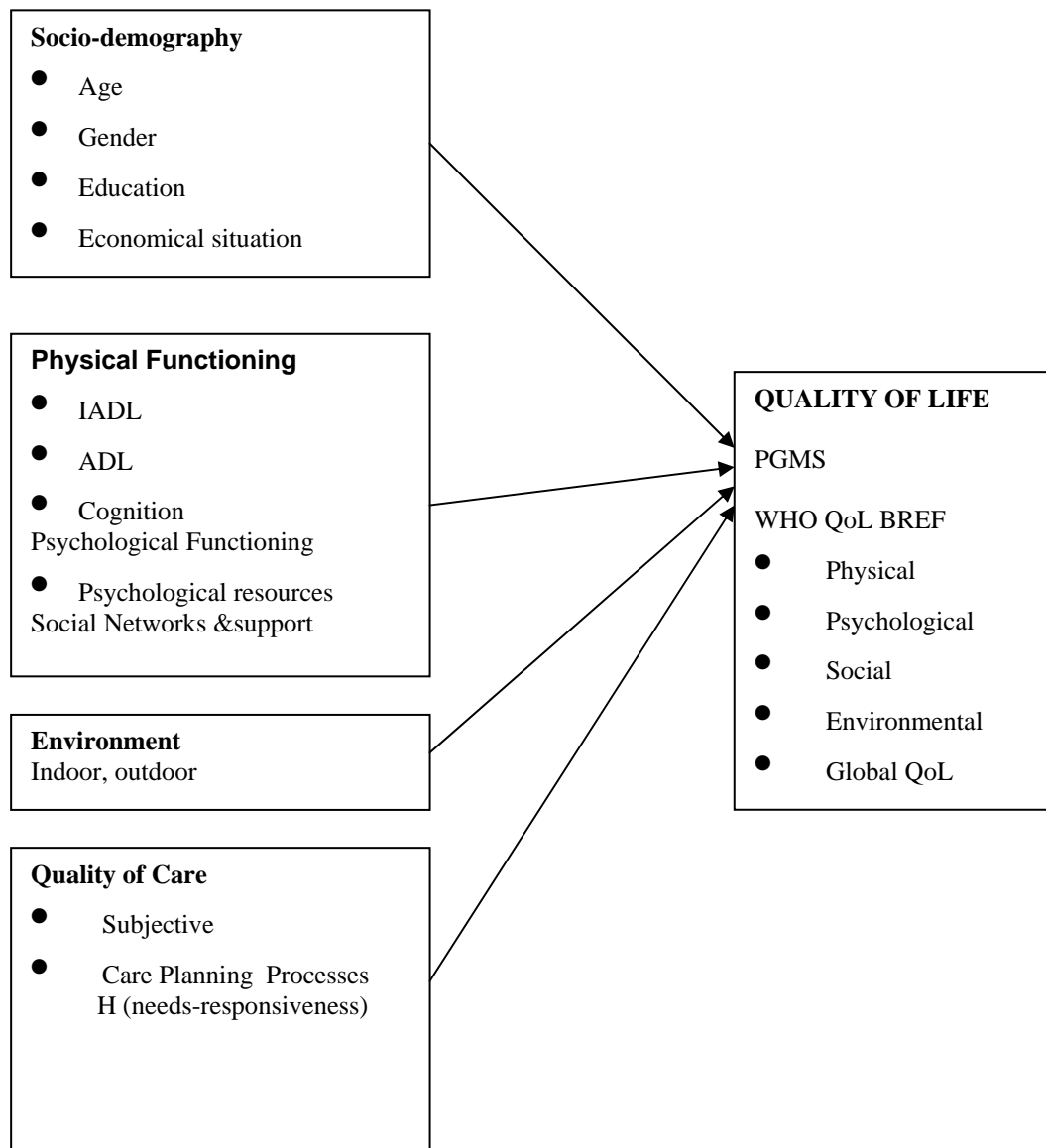


(modified from Lawton and WHO)

Production of QoL by formal care



Reduced Model for analyzing subjective crQuality of Life



Data and methods

- During 2002 - 2005, explorations on...
 - diverse Finnish (Stakes) survey datasets from the years 1998-2005, sample sizes vary from 75 - 3200 cases
 - Care Keys database of 5 European countries (n=1500)
- Randomly sampled, representative for both genders
- Using self-completed instruments and face-to-face interviews with people aged over 75 years living at home, in most mean age 81
- Using well-validated scales to measure living conditions and environment, subjective health and other person factors, morale (PGMS), happiness and life satisfaction, for subjective Quality of Life also WHO Quality of LifeBref included
- Statistical analyses, rotated factor analysis and logistic and linear regression analyses as main methods

Summary of Results-1

- All analyses support the multi-dimensionality of Quality of Life by frailty
- All analyses demonstrate a connection between the received care and subjective Quality of Life:
 - Subjective needs-responsiveness and subjective quality of care were connected with care satisfaction
 - Care satisfaction and subjective TEFF of care were in direct connection with subjective Quality of Life
 - TEFF was connected with care planning practices
 - TEFF impacts on Quality of Life considerably - well targeted care is effective!

Summary of Results-2

- All analyses emphasise the importance of indoor and outdoor living environment for Quality of Life by frail old people.
(=preventive potential)
- When differentiating between dependency, acute illnesses and traumatic life events, all have a role of their own for Quality of Life by frail old people (=risks & potential)

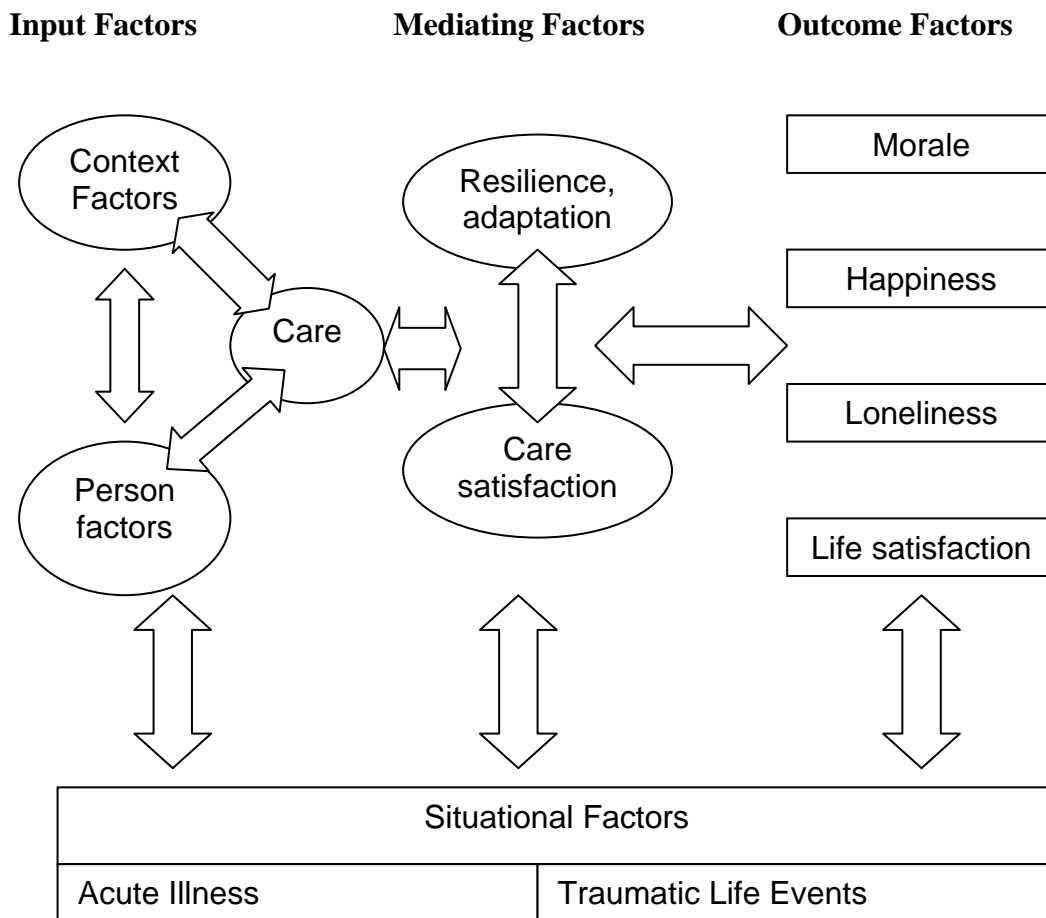
Summary of Results-3

- Some analyses demonstrate...
 - Care can impact Quality of Life positively only if objective living conditions meet some minimum standard
 - Poorest Quality of Life was found with poor living conditions, high dependency, and poor subjective TEFF (=impact of external care conditions)
- Some analyses suggest...
 - Quality of Life domains (WHO Quality of LifeBref) do not vary among age groups, but the importance of specific variables within domains varies and is different for ages 50-64, 65-79 and 80+

Summary of Results-4

- E.g. for 80+ Finns
 - Most important positive determinants of Quality of Life were: enjoying life, good subjective health, good access to leisure activities, satisfaction with self and support from friends. Anxiety and depressive and desperate feelings were greatest enemies of good life quality ($R^2 = .397$, $p = .000$)
 - Needs-responsive care and satisfaction with it increased the probability of good Quality of Life in all WHO Quality of LifeBref domains by 2 to 4 (OR=1.743 - 3.677)

Summary: “mediating model” of resilience and care satisfaction



Conclusions -1

- The domains and dimensions of Quality of Life by frail old people seem to be similar to general models of Quality of Life (e.g. Veenhoven 2000, WHO Quality of LifeBREF), but for frail old people, management of daily activities, access to care and environmental conditions seem to be more important than to old people in general (cf.Lawton)
- In addition to external (objective living conditions, living environment, amount and types of care) and internal (adaptation, resilience, care satisfaction) factors, *situational factors* or *risk-factors* (acute illness, traumatic life-events) play an important role for subjective well-being in old age.

Conclusions-2

- The results suggest that subjective well-being of an old person living at home with lowered functional abilities can be improved by appropriate care interventions and by improving their living environments
- The results confirm the value of the explored “mediating model” as a framework for crQuality of Life

Current research stage

- We are now further testing and developing models of:
 - Production of Quality of Life in Home Care
 - Production of Quality of Life in Institutional Care
 - A production function taking all three perspectives of quality simultaneously into the account (client, professionals, management)
- **The objective is:** A tool for care quality management designed to support the Quality of Life of frail older clients

Working Group Themes and Recommendations

The working groups were organised into the following key areas, each group had a chair and a rapporteur.

- **Group 1 - Health Resources** was chaired by Clemens Tesch-Roemer (German Centre of Gerontology, Germany) and the rapporteur was Lars Andersson (Stockholm Gerontology Research Centre, Sweden).
- **Group 2 - Personal Resources, Social Participation and Support Networks** was chaired by Svein Olav Daatland (NOVA – Norwegian Social Research, Norway) and the rapporteur was Sam Taylor (Sheffield Health and Social Research Consortium, UK).
- **Group 3 - Socio-Demographic and Economic Resources** was chaired by Heidrun Mollenkopf (Former German Centre for Research on Ageing at the University of Heidelberg, Germany) and the rapporteur was Maria Evandrou (University of Southampton, UK).
- **Group 4 - Environmental Resources** was chaired by Hans-Werner Wahl (DZFA, Germany) and the rapporteur was Peter Lansley (University of Reading, UK).

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

Working Group Questions:

- 1) What priorities should a research programme on ageing address in the field of quality of life?
 - a. What should be the main priority topics? Please list five topics maximum.
 - b. Are there any of these research topics that should be addressed by a single disciplinary perspective?
 - c. From a scientific perspective what are the key priorities in terms of research infrastructure and cooperation at European level?
- 2) Can you identify any examples of good practice in interdisciplinary and European collaboration that can be useful models to use and learn from?
- 3) What kind of support should a European programme provide to facilitate both interdisciplinary and European collaboration?
- 4) How can we address the fact that ageing has received such a low priority in Framework Programme 7?

The participants were provided with a background document that was designed to stimulate the group discussions. It consisted of two parts:

- 1) A summary of the recommendations that emerged from the two FORUM scientific workshops on Quality of Life for each research area and the policy recommendations.
- 2) Summaries of the research that the working group participants are currently undertaking in their own countries.

Prior to the workshop participants were asked to comment on the FORUM recommendations on European Research Priorities in the Field of Ageing and this was summarised into a document that was pre-circulated to the participants before the meeting.

The summary of the working group questions are organized as follows:

- Priorities for a research programme on quality of life.
- Key priorities in terms of research infrastructure and cooperation at the European level.
- Learning from good practices in interdisciplinary and European collaboration.
- A European programme as a facilitator for both interdisciplinary and European collaboration.
- Ageing research in the Framework Programme Seven.

1) Priorities for a research programme on quality of life

A disciplinary approach in ageing research

- All participants of the meetings rejected the single discipline approach in ageing research and strongly emphasised the need for creative interdisciplinary combinations in ageing research.

Priority topics for Health Resources

The participants felt that the concept of quality of life in relation to health is very important. The following research topics in the field of the health resources should be addressed by an ageing research programme:

- Health promotion and prevention.
- Mild cognitive impairment and dementia.
- Disability with respect to the question of morbidity compression versus expansion.
- Management of chronic diseases.
- Health and social care and its integration in the whole system.

- *Subjective aspects and user involvement.* The participants stressed the importance of subjective views on ageing and older people as well as the involvement of users of health and social care systems. They felt that the following issues should be addressed:
 - Societal importance of health in relation to the costs of medical and nursing care.
 - Attitudes towards the health system and policies in the society.
 - Psycho-social determinants of subjective perspectives need to be considered when addressing quality of life issues in research.
 - User groups should be involved to a greater extent in health and social care research at all stages.

- *A system approach is required.* Health in old age is affected by the specific attributes of each society and different systems that operate within the society, therefore a systems approach should be considered in ageing research. Within the system approach issues of availability of health care, acceptance and adequacy of services of health and social care as well as aspects of heterogeneity, diversity and inequality, including gender and class inequality should be addressed by an ageing research programme.

- *Methodological aspects of longitudinal studies.* The working group argued that longitudinal studies should be the method of choice in ageing research related to health. When carrying out longitudinal studies the cohorts should start at age of 40 + as these are the future cohorts of old and very old people and we should not restrict the samples only to the very old 75+. It was recommended to consider whether longitudinal studies should include the age groups starting at middle age 40+ or older age 75+. As to the design of these studies the group suggested using two measurement points during a seven-year period in the Seventh Framework Programme that could facilitate the success of an application. Longitudinal studies are costly for the European Commission to fund but by using two measurements points during a seven-year period might enable scientists to succeed in getting funding for this type of study under the Framework Programme Seven.

- *Comparative studies.* More research is needed on the quality of life of older people focusing on comparisons of different cultures and societies within the old Member States (EU 15) on one hand, and comparison studies on old and new Member States (EU 25), with the possibility of including also two candidate states. The studies should focus on evaluation of health policies and promote learning from each other that can be highly beneficial for everybody.

Priority topics for Personal Resources, Social Participation and Support Networks

The group prioritised the following research topics:

- There is a need for more *inter-generational research* where issues such as solidarity, sustainability and the welfare state should be examined and the following aspects explored.
 - Maintaining connections between generations specifically care and support provided by parents, children and grandparents.

- The relationship between traditional family and the interference by the state policies when a family becomes dysfunctional and breaks down.
- Working life in the new Member States, including implications of the labour market policies on older people, who should be considered as valuable resource for the society but at the same time they form a vulnerable group that will require health and social care.
- *Care systems, both formal and informal*, including the role of families, civil society and older people should be examined and the following issues require further studies:
 - The unknown facts about personal and societal resources, particularly the ones that examine different types of services, labour market policies and social care.
 - Issues of a sustainable and fair partnership in care between families, civil society, and the welfare state need to be explored.
 - More comparative studies between professional and non-professional sectors are needed.
 - The relations between care givers and care takers should be examined while carefully considering the lessons that can be learnt from existing research and addressing how we can take this further so the quality of life of older people can be improved.
 - The role of older people within a broader societal context like friends, neighbours, formal and informal social networks should be at centre of research.
 - There is very little known about the needs, the characteristics and the problems of quality of life of vulnerable groups such as ethnic minority, the very old, abuse of older people, people suffering from dementia and so on.
 - Healthy ageing and the role of older people in society require more research.
 - Family care and the labour market, especially differences between developed and developing central European economies and policies that have implications on pensions and retirement age.
- *Risks of social inclusion and exclusion*, including the role of families, civil society and older people need greater examination and to consider the following.
 - The risks of social exclusion which often result in isolation need to be studied in more detail, for example the effects of local, regional and national policies on exclusion and isolation; the relationship between older people and the information society; implications of social exclusion and inclusion on older people and society.
 - There are under-researched areas of factors such as bereavement, retirement, migration that often produce a shift from social inclusion to social exclusion.

- Differences between social policies and governmental policies at the regional, national and international level and their impact on social inclusion and exclusion, for example single mothers and parenting, migrants, long term unemployment need to be studied.
- Factors that result in vulnerability such as disability, income, living alone, especially older women need to be further researched.
- The importance of age-friendly and age-unfriendly attitudes towards older people in general and the social impact on older people should be examined.
- Heterogeneity of the European experience. There is a huge diversity among older people; in particular there are significant differences between Member States in formal and informal care systems. A European model that can be applied across countries is lacking, and therefore it is almost impossible to account for the differences between the formal and informal care systems across Europe.
- *Older people as resourceful agents.* Older people should be considered as valuable contributors to society rather than a burden.
 - The impact of labour market policies on older people need to be examined, specifically employment opportunities and the barriers to employment.
 - Older people's involvement in research should be considered as a valuable resource and be focused on their experiences.

Priority topics for Socio-Demographic and Economic Resources

- Research in this field needs to be more focused on *individual and societal changes in the second half of the life course*, both at the micro and macro level. These changes have consequences and impact on dependency, care issues, employment, economic and social resources, retirement, lifelong learning, and other important issues which need to be taken into consideration. Furthermore, these consequences have implications on inequalities and social exclusion in later life, and therefore there is an urgent need to integrate research with policy and interventions studies.
- Further research should be carried out on retirement issues, particularly on transition from work to retirement. In relation to these processes a number of issues need to be examined:
 - What are the knowledge gaps in this area?
 - What are the determinants of retirement?
 - What effects has retirement on quality of life and subjective well-being?
 - How does active ageing relate to the policies and politics of statutory retirement in Europe?
 - How do we define active ageing in different European countries? What are the differences across the European countries?

- What strategies and policies are needed to promote active ageing? For example, at the present in the UK a pertinent issue is concerned with pensions and a debate is taking place to explore incentives that can be used to encourage workers to remain economically active after the retirement.
- What is the meaning of active ageing beyond the working life?
- Of particular importance is a focus upon *economic and social resources* and the inter-relationship with experiences gained earlier in the life course and their relevance to policy.
- Special attention should be given to identify long-term effects of societal changes in the framework of global society and their impact on future cohorts of older people.
- *Technological changes* are very important in relation to the quality of life of older people, as technological advances have an immense impact upon different spheres of the everyday life of older people.
- The means to enable older people to cope with the changes in modern society and prevent them from social exclusion need to be identified.
- All ageing research topics need to have an interdisciplinary approach.

Priority topics for Environmental Resources

- There is a need for a better *understanding of living arrangements of older people* and the relationship between these and the community, neighbourhoods and care services. This is closely related to issues of personal mobility, accessibility, urban planning and transportation systems, as well as those of urban/community safety and security.
- *Intergenerational issues and the desire for social inclusion* have major implications for housing, urban design and transportation policy. The needs of older people are a major but not the sole consideration. Many of the issues faced by older people are faced by other social groups. Major societal problems are shared, for example poverty, unemployment, poor housing, ill health and so on.
- It may be valuable to study the *impact of exceptional situations* on older people. For example the impact of major crises related to environmental issues on older people should be examined. As a result of climate change there was a recent weather inclement (heat waves) and power supply shortages which had a significant impact on society, particularly on older people. The study of “emergency social relations” at times of crisis might be instructive.
- There are *fields of research such as dementia, stroke and other cognitive processes related diseases* that require particular attention. These topics are under-researched and under-represented yet. This is a great opportunity for involving a wide range of disciplines, among others biological disciplines in this field of research. It could also create new funding opportunities and stimulate interdisciplinary research in the ageing research field.

2) Key priorities in terms of research infrastructure and cooperation at the European level

- There is an urgent need to coordinate research activities in the ageing field at the European level. It is essential to develop a clearly defined strategy to promote ageing research activities in Europe.
- Strong infrastructures are needed to facilitate cross-national research, workshops, training and capacity building for future generations of researchers in the ageing field. This requires establishing scholarships and training schemes for PhD students and for and postdocs. It is essential to attract new talent to the field and develop strategies for their career development in order to retain this new talent. Further education of young scholars is needed to promote truly interdisciplinary research. Person-environment research has the potential to provide a particularly useful model for such interdisciplinary interchange on the young scholar level, for example involving young engineers, designers, architects, psychologists, sociologists, geographers, urban planners and encouraging them to work together.
- An institution is needed to coordinate the above tasks, it could be a European Institute on Ageing or other multi-task body, for example a virtual European centre or a data house on ageing and later life which could serve as a foundation of comparative research, including comparable data sets (databases), validated research methodologies (instrument bases) and updated conceptual reviews (theory banks). Part of the remit of such a European Institute would be to work towards an agreement between funding bodies across Europe and this will facilitate European research and collaboration.
- Developing a European omnibus survey on ageing and later life, undertaken on a regular basis, can be a tool for building cooperation in the ageing research field.
- Collaboration and partnerships among researchers, older people, practitioners, policy makers, NGO's should be established in order to develop effective research and support the translation of research results into policy and practice.

3) Learning from examples of good practice in interdisciplinary and European collaboration.

Participants of the meeting identified the following examples of good practice that should be considered as useful models to learn from.

European level

- European projects funded by the EC could be a valuable source of good practice in interdisciplinary and European collaboration, although this information is not easily accessible and disseminated through publications. The SHARE dataset, the European Social Survey, LIS panel data, SOCRATES programme are useful research resources that could be further extended and enriched. The European HIV prevention programme represents an example of good practice in the area of health.
- There are valuable sources of data available such as cross-sectional data that can be further extended and enriched with longitudinal data, biographical data and life course information.

This primary source could be used for development of the European Longitudinal Survey that the research community should aim for. Participants emphasized the importance of the longitudinal data for investigating the casual determinants of socio-economic experiences in later life.

National level

- Further examples of good practice could be sourced from the effective approaches at national levels across Europe. These examples need to be widely disseminated through publication and could be a valuable source to learn from.

Older people's involvement in research

- Models of involving older people in research need to be identified and the impact of older people's involvement in research should be examined. Older people should be involved in all stages of research commencing with planning and design of research, also involving them throughout the development of research, participation in advisory groups as well as in the final stages of research dissemination and implementation. It is essential that collaborative research involving users, researchers, NGO's, and policy makers is developed throughout the research process. Practice has proved that involving users as equal partners to researchers can be highly beneficial.

Research into policy and practice

- Research results need to be translated into policy and practice to guarantee the use of research. A mechanism and structures should be developed to ensure continuity of research that should build upon the existing research outcomes. Research results should inform new policies and serve as basis for further development of future research. It is common practice that the European funding ceases after a report submission. There should be funding available for a certain period of time after the study to ensure that the results have been implemented into practice. There is a need for coordination in this area at the European level to ensure that these outcomes of research are widely disseminated to the general public and policy makers as well as to the funders. The difference between dissemination and implementation should be more transparent and coordination is needed to facilitate the implementation of research results.
- A dialogue between researchers and policy makers should be stimulated, leading to the establishment of good working relationships between all stakeholders: researchers, older people and policy makers. There are some interesting examples to learn from, for example the UK 'OPPS' study, which is in a preparatory stage, in which older people's research carried out with university support underwrote the local government policy.

4) A European programme as a facilitator for both interdisciplinary and European collaboration

- The issue of establishing a European Institute on Ageing was discussed and groups concluded that the work on national agencies and institutes should be reviewed before taking further the establishment of such a pan- European institution. There is a need to create national centers and institutes that could be coordinated by a European virtual institute.

- Participants emphasized that more incentives for network building are needed. One of the possibilities might be a creation of a virtual ‘think tank’ that would address the issues of public importance, such as banking and ageing, pensions and insurance.
- A periodic audit of researchers’ community working on ageing related issues should be carried out. This would provide us with information on key issues, topics, datasets, relevance to policy issues and it would set up a taskforce in ageing which could interact with the ERA-AGE Steering Committee.
- New approaches to attract young and newly trained researchers to the field are urgently needed, for example a European Research Academy for PhD students and postdocs researchers could be established in the near future.
- National Forums of ageing research should be established across countries to improve collaboration.
- Cross-national studies such as the European Social Survey, supported by European funding mechanism, are of a significant importance and should be supported in the future. Cooperation needs to be strengthened between existing bodies such as Eurostart and the European Social Survey.

5) Ageing research in Framework Programme Seven

- A strategy on how to search for funding opportunities in the Framework Programme Seven should be developed. Participants addressed the fact that ageing research is not highly prioritised in the Seventh Framework Programme, therefore options on how to incorporate ageing research under Framework Programme Seven headings need to be examined more closely. One of the possibilities is to apply for funding under the technological, urban planning and environmental issues theme. Researchers should seek different disciplines to work with on ageing issues.
- It is indisputable that direct spending on ageing research is low in Europe compared to the USA, however, there are opportunities in other research fields such as health care and medical research where ageing research could look for funding opportunities. Funding niches should be sought and the definition of ageing should be stretched out to undertake ageing research under broader themes. However, finding the indirect ways of funding proves to be far more difficult.
- Ageing research needs to be lobbied for. An expert from the European Commission should be invited to the ERA-AGE scientific meetings. Also the European Parliament could be approached through involvement of NGO’s across Europe by writing a letter and highlighting the importance of ageing research for society and national governments.
- Ageing research groups should be approaching the EU with supportive evidence of research results demonstrating the importance of a continuity of ageing research.
- Researchers across Europe should be encouraged to develop a collaborative evidence base report to demonstrate the significance of ageing research.

- Presentations to national governments should be organised in European countries emphasising the social aspects of ageing rather than concentrating solely on biological ageing issues.
- A three pillar approach should be developed:
 - Strengthen the credibility of gerontology to national governments.
 - Integrate ageing research with policy research relevant to ageing.
 - Develop Interventions promoting quality of life in later life.

APPENDIX A

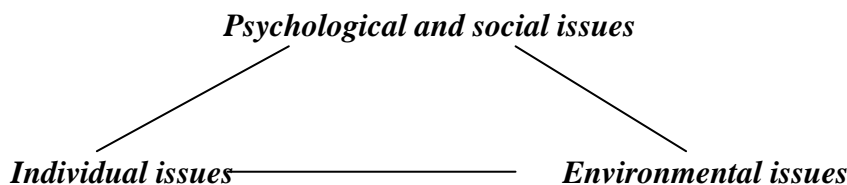
THE KEY RECOMMENDATIONS FROM THE SECOND QUALITY OF LIFE WORKSHOP ORGANISED UNDER THE FORUM PROJECT

Area Specific Research Priorities and Knowledge Gaps

Environmental Resources Working Group

The members of this working group supported the recommendations made at the first workshop in Heidelberg 2002, re-enforcing the point that 'environment' - from micro to macro - needs to be seen as an important component of quality of life: a dynamic rather than passive context bringing the space/place agenda into gerontology. A major reason to include person-environment transactions in any discussion on quality of life in old age is that there is a research gap in descriptive data concerning the everyday lives of older people and respective differences across European countries. This data forms a basis for ageing research in general as well being able to inform ageing policy on a very day-to-day level about the similarities and differences concerning ageing across Europe.

This working group began to develop a 3D framework for including environment within quality of life studies, bringing together the *individual issues* (from personal ability to life story); *psychological and social issues* (security, loneliness, autonomy, attachment, diversity - cohort, ethnicity, culture, gender, material resources) and *environmental issues* (migration, transportation, accommodation, nature). Participants felt that this complexity was important and they were not drawn to a common theoretical model.



This framework raised some important issues that need prioritising in research;

- The need to understand the experience of indoor and outdoor space in later life across Europe (rural/urban; developed/less developed).
- The recognition that we know far more about older people living in 'special' settings than those living in 'ordinary' settings.
- Very little research is carried out on the experience of older people with dementia living at home.
- How people with learning difficulties/mental handicaps are ageing in place, raises issues of involving older people with communication difficulties within research.
- The intergenerational issues of segregation/integration within public and private spaces/places. The spatiality of ageing - accessible/inaccessible environments for older people.

This group acknowledged that this type of quality of life model raises the need for developing different methodological issues incorporating the quantitative/qualitative spectrum; enabling the triangulation of material, and the collaboration of researchers with different expertise.

- In addition to the recommendations the group called for more evaluations of practical environmental measures being implemented in order to gain knowledge on how to improve the lives of older people.

Socio-Demographic and Economic Resources Working Group

The recommendations are as follows;

- Research on quality of life needs to further explore issues of diversity.
 - There is a need to understand the causal factors of inequalities between countries and social groups.
 - Including the extent to which issues are universal to all older people, how does the prioritising of factors shaping quality of life vary across different groups of older people.
 - This group also emphasised, in agreement with the environmental resources groups, that more comparative knowledge was needed on people living in residential setting verses people living in their own homes.
 - Traditional male and female life course trajectories are changing. It would be useful to look at the gendered changes in working life, experience of long-term employment, changes in pensions policy, transition into retirement, and the impact of these changes on quality of life.
- Of particular importance is a focus upon the economic position of future older people. However, in cross-national research, it is important to distinguish between issues that relate to the age of retirement and withdrawal from the labour market, and issues that relate to the age at which one first received pension income.
 - There is not enough known about how the income needs of older people change as they age, their perceptions of income and how these change over time.
 - Wealth and inheritance: it was proposed to further explore the economic power of older people, particularly the intergenerational transmission of wealth. What is the impact of inherited wealth? What is the impact on individuals, families, potential demand for long-term care services, and the impact on the financial markets?
 - A particular problem for this area of quality of life research is that little robust data exists that includes wealth and goods in kind. There is a need for research to gather data on the individual as a unit as well as household.
- Examining retirement and transitions in older age were also emphasised. The issue of how older people can be aided to adjust and prepare for retirement was raised. Expectations of retirement and retirement income vary markedly across different groups of older people. More research is needed on retirement and work life in general. For example,
 - what are the economic incentives for continuing to work in later life? What is the interaction between work, age of retirement/withdrawal, pensions and inheritance.
 - Do the classic inequalities remain or are there new inequalities? And not just between men and women but focussing on inequalities within older people.
 - Is the gap between the rich and poor older people widening? Is there polarisation or convergence?

Health Resources Working Group

The health resources group's discussion of research priorities is formulated into two levels of recommendations: 1) review based research priorities that prepare for European collaboration, 2) innovative, empirical research recommendations that are needed to close knowledge gaps in health resources and quality of life.

1) Review based priorities

- Reviews are needed of the existing conceptual and empirical work relating to the concept of quality of life for comparative and collaborative research (individual vs society, older people's perspectives and concepts, reviews, data base) not only subjective quality of life, but also for instance, levels of resources, competences, in short all aspects relevant for a person's agency (capability to act).
- Preparatory work for comparative research is needed which involves reviewing analyses of policy, health systems, societal structures and cultures.

2) Innovative, empirical research recommendations

- Examining aspects of prevention, rehabilitation and disease management in the health care system → effects on health behaviour and quality of life of older people (including household, state, intermediate organisation, market).
- More research is needed on the quality of life of older people with chronic disease (physical, mental).
- Inequality of health and quality of life (as related to material income, gender etc.) Is there an increase or decrease with age?
- Historic shifts, generational differences need to be given more focus in research. From an historical perspective, younger age groups ("youngest old") have become healthier over time; but in older age groups new forms of frailty have developed (e.g. high prevalence of very old people with dementia). The changing role of the health system also has to be analysed.
- Migration has effects on society and health care systems in different ways and these need to be researched more. (a) In most developed societies, there will be more migrants in the future. Health and social care systems have to take into account the multi-cultural background of users. (b) Migrants fulfil different tasks in health and social care systems (for instance, in Italy and Greece, migrants are living in the home, in the UK and Germany, migrants are working in nursing homes).

Personal Resources, Social Participation and Support Networks Working Group

This group made the following recommendations;

- More importance needs placing upon policy research and the role of the welfare state in shaping standard of living and quality of life in old age.
- Research should seek to include comparisons between rural and urban populations of older people.
- Housing and the impact of the person-environment relationship more generally for quality of life needs to be given a higher research priority.
- Issues of diversity, risk and marginality need greater examination, in particular research should focus more upon minority ethnic groups and older migrants within Europe.
- There is a lack of research on the interaction of the resources of older people and personal coping, and adaptation to risks and barriers related to ageing.

- Issues of empowerment and citizenship need to be examined more alongside the importance of advocacy and the continuance of ageist stereotypes.
- More research is also needed upon life course trajectories, family change and intergenerational relationships, including new family forms and the risks of social isolation and marginalisation.
- Mental (and physical) activity and social participation are under researched.
- Relationships between formal and informal care systems and the role of older people as caregivers needs further research.
- Implicit theory of quality of life requires further development.
- Need to focus on the quality of life of vulnerable groups like the frail and those suffering from demented, and to develop concepts and models that may help us study and monitor welfare among such groups.
- Quality of life studies need to focus on both objective living conditions, and how they are subjectively perceived and adapted to, and the extent to which it is possible to include both approaches in future studies.
- Comparative studies should be recommended as they help us avoid ethnocentric biases in the definitions and perceptions of what is a 'good life'.

Research Approaches and Methodological Issues

This section of recommendations begins by discussing interdisciplinary approaches and how to facilitate European collaboration, it then outlines research methodologies that require attention and finally discusses the issue of how to involve the users of research.

Interdisciplinary Approaches and European Collaboration

The first workshop on quality of life made good progress on identifying the barriers to interdisciplinary and European collaboration and a series of recommendations were developed that were reinforced and supported by participants at the second workshop. Participants were keen to stress the importance of working across the disciplines and national borders, and the specific benefits this could bring to research on the quality of life of older people. As with the other scientific workshops participants stressed the continued importance of disciplinary identities but they felt it was time to integrate this knowledge to produce broader analyses and models of quality of life.

The recommendations that emerged from the two workshops are;

- *Collaboration to examine the portability of models and approaches*
 - Increased interdisciplinary and European collaboration is necessary not just to enable us to share information on best practice but also for us to adopt a critical approach to the portability of different models of practice.
 - It is important to compare different conditions and their impact on quality of life in different countries but it is also relevant to examine these in their cultural context and with respect to the welfare system in that country.

- *Breaking down the barriers to interdisciplinary collaboration*
 - This working group also stressed the need for time to be provided for clarification of terminology, to enable understandings across the disciplines. This time must be budgeted in research funding as a precursor to interdisciplinary collaboration.
 - The environmental resources group felt that funding bodies need to understand the productivity of cross-national work. To show this they began to discuss how European research could centre on specific policy issues that were common to a number of countries. For example, intra-mural/extra-mural support for people, particularly those with dementia; intergenerational relations and city-life. The aim of such research would be to establish 'best' practice within specific cultural contexts.
 - The working groups stressed the contribution that cross national, interdisciplinary workshops can make to developing knowledge in this field. Participants stressed the need for more international interdisciplinary meetings and called for the European Forum project to work with them to develop ways of extending this collaboration.
 - In particular, there should be more funds for quality of life meetings and networking, particularly for brainstorming new research applications in response to research calls.
- *How might interdisciplinary collaboration be organised?*
 - The health resources group debated how interdisciplinary collaboration would work in an applied manner in their field of quality of life. It stressed that the kind of structure depended upon the research question being examined: the nature of the collaboration required could range from an integration of theoretical frameworks and approaches to produce a single study to individual contribution to an issue, which is then synthesised.
 - Democracy v dominance approaches. 'A caveat for the organisation of interdisciplinary teams is that one discipline should not dominate the others'. However, does "democracy" work? This makes it especially important to have strict decision making rules.
 - Interdisciplinary persons v disciplinary experts. It has been stated that a team of experts from various disciplines is not sufficient, but what one especially needs is interdisciplinary persons. This emphasizes the importance of educating such interdisciplinary persons. The problem is that the academic credit for such expertise is low, it is not recognised as "excellence". Until these barriers are removed this kind of interdisciplinary working is difficult.
 - Transplant methods. Should not only attempt to integrate theory and concepts from various disciplines, but also use methods that are current in one discipline to address research questions in another discipline. For example, sociological age-period-cohort analyses could be applied to epidemiological data.

- *Key gaps regarding resources and methods*

- Lack of capacity of young researchers across Europe. In particular, there is a shortage of young researchers in the field of ageing research and of those that exist there is too little support to develop capacity for comparative and interdisciplinary research.
- Training should be research based.
- There should be an infrastructure across Europe including dedicated journals and conferences and funding structures.
- A better balance should be achieved between geriatrics and gerontology.
- A web based database of European Research in this field is urgently needed.
- Establishing all these structures would enable a more inclusive understanding of quality of life to be developed, alongside a rich wealth of pooled data, competences, variation and diversity.

Recommendations on Research and Methodological Approaches

All of the breakout groups were keen to set out specific measures that should be supported by funding bodies. These were;

Methodological and research approach

- Research funding needs to target research that addresses issues of heterogeneity - no longer focusing on averages, but applying methods to show the heterogeneity.
- This should include the funding of research on specific subgroups of older people, including the combining of sources of information and gathering European-wide samples to increase sample size.
- Research needs to be targeted more towards persons aged 50 – 67 years, “tomorrow’s older people, – if quality of life research is to contribute to policies that meet the needs of this generation of older people. For example, research should start earlier in adulthood to develop more fine-grained age-specific research, so that transitions between age-groups can be studied.
- A necessary first step is to find out what work has already been done for other age groups, and/or what data are available on older persons that allow secondary data analysis.
- Harmonisation of values and concepts: if data are really to be compared across countries, they need to be harmonised. Post-harmonisation deals with existing data, and attempts to select the items closest in meaning, possibly based on reliability and validity analyses. Pre-harmonisation is aimed at designing comparable items/questions. Here, cultural values, ideas and contexts need to be considered so that the use of terms/questions makes sense and is meaningful when applied in practice. One of the working groups also argued that when designing comparable research questions ‘political correctness’ can render comparable questioning unfeasible. It gave the example of euthanasia. This group argued however, that when starting from a good scientific basis, political incorrectness can produce relevant questions.

- Research on the quality of life of older people is not only subject to knowledge gaps information gaps also cause problems. Access to research documents on approaches to and studies of quality of life in Europe must be improved. One way of tackling this information gap would be to set up a virtual quality of life documentation database library on the web. In addition better access needs to be created to international quality of life datasets.
- Training on how to develop and use datasets is also required, this links to the issue of planned action to invest in future generations of researchers in the field of ageing.
- Research on different levels requires combining more, for example, research on the life course should also take into account individuals and households, and this data should be inter-related with policy.
- The formulation of the research agendas should involve a partnership model in which all stakeholders contribute to its development.
- Theoretical development work needs to be prioritized alongside greater multidisciplinary collaboration. Currently the links between different factors shaping quality of life are underdeveloped. All the breakout groups emphasized the importance of integrating their aspect of quality of life with other strands of this research area.
- The need for theoretical work on indicators and scales, and longitudinal studies was also emphasised, including;
 - A basic definition of quality of life that captures standards and norms to which an individual compares their own circumstances.
 - Relevant dimensions of quality; these should reflect science, social policy and the views of older people. A model of quality of life should be developed that captures individual agency and well-being with other relevant factors as preconditions.
 - Building a theoretical model.
 - Incorporating different perspectives (e.g. individual, societal, and social policy).
 - These should be relevant to the development of assessment instruments and standards of intervention.
- The groups stressed the importance of developing innovative research methods that involve older people more in the research process and that focus on the perceptions and experiences of older people. (For example, issues such as the importance of family, pension systems, social security and mode of delivery).
- Research must focus upon examining the societal level as well as the individual level. Similarly research should include provision and providers as well as recipients.

Developing instruments and measures

We are still lacking many of the basic tools necessary for European collaboration, for example research funding needs to prioritise the development of,

- Ongoing cohort-sequential research;
For example the health resources group gave the example that most longitudinal studies now have one historic cohort in which ageing-related changes in quality of life are studied. However, each historic cohort is shaped by different experiences: generation effects. Also: societies change (period effects), so ongoing research is needed. To determine what changes are associated with ageing, what are based on generation differences and on period changes a cohort-sequential design is needed. Examples: Seattle Longitudinal Study, LASA - in this design, new cohorts are added at specific time intervals, which keeps the study viable.
- Comparative methodologies.
In addition to these recommendations, the participants at this workshop supported the recommendations on this theme made at the first workshop, which argued that the variations in available data and the need for comparable methods and measures posed significant barriers to advancement of knowledge on quality of life.
 - There is a need for consensus on how we define and measure quality of life. The optimal definition would be one that is comprehensive but parsimonious. Cross-cultural definitions need to be focused upon more if definitions and measures of quality of life are to be inclusive and comparable.
 - Cross-country studies should include both a standardised instrument plus additional culture-specific items. For example, there is a need to include the views and experiences of minority ethnic groups and little is known about quality of life in Eastern Europe. The fact that cultures are not static needs to be recognised in this research.
 - The possibilities offered by conceptualising quality of life in terms of the disparity between an individual's expectations and resources, i.e., as an "expectation gap" was suggested.
 - The personal resources, social participation and support networks group stressed the need for standard measures for situational comparisons of quality of life and the importance of process orientated perspectives to allow for comparisons to be made.
 - Little is currently known about how expectations and normative belief systems are set up, this is crucial because individuals use these as standards to formulate their quality of life judgements. Criteria relevant to the "youngest old" and the "oldest old" need to be developed, i.e., accommodating cohort and historical influences.
 - The need for predictors of active ageing, i.e., independence, was also suggested.

Involving Users

Breakout group discussions on user involvement reflected the desire to involve users in research and the contemporary dilemmas surrounding issues of who to involve, how and to what extent. All of the working groups discussed the problem of defining users, avoiding the tendency to lump all users together and having a clear strategy and purpose to their involvement.

Some of the working groups were concerned about some of the risks of adopting a catch-all approach to user involvement. For example the socio-demographic and economic resources group demonstrated some of the dilemmas of user involvement specific to their research field.

- They stressed that the process of involving users in the development of research may be more straightforward in some projects than others. Adopting a universal commitment to user involvement across all projects may pose difficulties in some cases: In particular in this field of economic resources there is a risk that private insurance firms may want to use pensions and long-term care research to cherry-pick potential clients for new long-term care insurance products. It may be useful to retain a certain degree of caution.

Concerns were also raised about the familiar problems of defining how to involve users and to what extent.

- The Environmental resources group stated that in considering the involvement of end-users in relation to research, discussion ranged from consultation to dissemination and the 'doing' of research where 'amateurs become professionals'. The latter has resource implications in terms of training, time and people that result in additional costs for research proposals.

A useful set of principles were developed at this workshop that should be taken into consideration when facilitating, planning and funding the involvement of users in research.

- No clear consensus exists amongst researchers on the involvement of users except that the approach should be defined by the nature of the research, the value and benefits of involving users and that user involvement should be guided by the views of users.
- While user involvement brings some important benefits to research it is also poses problems in terms of funding, logistics, time and process. If funders wish to encourage user involvement, particularly meaningful extensive involvement, then the additional funds and time must be made available.
- The involvement of users should follow some basic principles;
 - The aims and motivation for involving users need to be clear. i.e why involve users; for formulating of research projects, for advice and consultation, for disseminating knowledge, for carrying out research and so on.
 - Define who the users are; too often users are lumped together as one homogenous group. Research needs to identify which category of users it is seeking to involve; older people, patient groups, service providers and professionals, education in-service training, administrators, policy makers, media, representatives of older people ...
 - The diversity of older people should be at the forefront of user involvement; to ensure that involvement is inclusive of all groups of older people. For example, research needs to consider urban/rural differences, health status, ethnicity, nationality, gender and personal resources when seeking to involve users.
- A review of good practice and models of user involvement across Europe is urgently needed.

Policy Recommendations

This section summarises the key recommendations made by participants at this workshop and alongside the previous sections on research priorities, methodologies and approaches, and European integration, it provides an important starting point for developing successful and value added European collaboration in this field of ageing research.

General recommendations to all European and national funders and policy makers

- Support and encourage interdisciplinary research by giving credit and funding for each added discipline.
- Provide funds to enable groups to continue to collaborate as well as funds for new groups to establish themselves.
- Researchers in this field are ageing and there is a lack of new talent coming into ageing research-support structures need to be funded to attract new researchers. For example, visiting studentships, post-doctoral fellowships.

Recommendations for national funding bodies

National funding bodies must support the future of ageing research and in order to do so effectively, ageing research has to be seen as a priority for research funding across Europe. Largely the initial responsibility is with the nation state but the EU has an important facilitating, accompanying and coordinating role to play, for example, through networks and Framework funding. Specific recommendations for the national level were:

- Each national funding body should have a commitment to fund or co-fund a programme of research on ageing or at the very least a collection of coordinated projects. Otherwise the absence of this leads to exclusion from networks such as ERANET.
- National research funding should be designed to encourage action that aids both national and European funded ageing research. Investment in the networking infrastructure as well as specific pieces of research is needed.

European level recommendations

All participants agreed that the EU has a fundamental role to play in supporting, encouraging and if necessary obliging national governments to organise at least some form of ‘national agenda on ageing research’. Without such measures coordination of research on ageing will never reach the organised levels it receives in the US and this could limit our competitive advantage. However, participants expressed reservations about the extent to which the EC would be able to push for the strategic planning of national ageing research to enable real and productive European collaboration. These concerns were re-enforced by participant’s experiences that the EC had done little to enable the networking of ongoing framework projects.

Key barriers to European research and specific recommendations were identified:

- Current policy and research agendas do not encourage or enable research on ageing to develop in a planned way.
- There is too little funding available for European collaboration both in terms of networks and research projects.
- European researchers need to be encouraged and supported to bring together the different theoretical and contextual aspects of quality of life.
- The EU needs to fund more basic research, not just meetings/networks.
- Dissemination and knowledge sharing needs to be given targeted funding.
- Funding is urgently needed to enable European and interdisciplinary collaboration in the field of ageing and quality of life to continue and advance.
- Environmental variables, that is, physical-spatial as well as social environments, should become a prerequisite to any interdisciplinary study in the European context on quality of life.
- Funding for European wide NGOs is needed.
- The EU application forms should be more accessible, less bureaucratic and more user friendly.
- Currently research knowledge on quality of life is not sufficiently disseminated across Europe. Dissemination needs funding adequately in research bids and more effective methods of dissemination are needed.

Two central proposals emerged from this workshop:

- 1) The project should use its recommendations to argue for ageing research to be placed firmly on the agenda of the 7th Framework programme.
- 2) Key research and policy gains would be achieved by establishing a European Platform or Institute on Ageing. This should be funded and designed to address the follow aims:
 - to strengthen social and behavioural sciences
 - attract young researchers and provide training
 - share documents, knowledge, data sources, instruments, theories and methods
 - overcome disciplinary and national barriers
 - to create a new infrastructure:
 - creating a virtual centre
 - a list server
 - a membership directory
 - combining existing networks as well as identifying new members
 - evolve into a paying association

Basic steps in this direction were agreed upon;

- collect information about successful models
 - identify research funding

During its remaining life the FORUM project agreed to develop the following;

- 1) A virtual European centre on its website containing the major research centres on ageing in Europe.
- 2) Identify funding sources and put together an application for funding to extend the work of this group.
- 3) Form a working group to draft the application.

Working group members agreed at the workshop:

- Clemens Tesch-Romer (German Centre of Gerontology)
- Hans-Werner Wahl and Heidrun Mollenkopf (DZFA, Germany)
- Ariela Lowenstein (University of Haifa, Israel)
- Marja Vaarama (STAKES, Finland)
- Kees Knipscheer (Vrije University, The Netherlands)
- Rocio Fernande-Ballesteros (Autonoma University of Madrid, Spain)
- Lars Andersson (Stockholm Gerontology Research Centre, Sweden)
- Fiorella Marcellini and Giovanna Lamura (INCRA, Italy)
- Aurelia Curaj (Geron Foundation, Romania)
- Piotr Szukalski (University of Lodz, Poland)
- Alan Walker (University of Sheffield).

The overarching recommendation of this group was for the FORUM project to work with participants in identifying funding sources to enable these groups to continue to work together – to begin to put into practice the joint learning and research capacity building identified as priorities by this network of researchers.

A major priority of any future work together should be to develop a comprehensive European study on quality of life that includes all of the major aspects discussed in depth during the European Forum's meetings. This could become a major task of the network application now planned as one of the next major steps of the Forum.

Table 1

Quality of Life Research Priorities

	KEY RECOMMENDATIONS
<p><u>RESEARCH PRIORITIES</u></p>	<ul style="list-style-type: none"> ◆ <i>Structural Limitations</i> – 1) Urgently need comparable methods to be developed. 2) Research competency across Europe is extremely uneven due to differences levels of funding and support for ageing research. ◆ <i>Instruments and Measures</i> – 1) Ongoing cohort-sequential research. 2) Comparative methodologies. 3) Definitions and measures of QoL that are inclusive of cross-cultural differences – to account for variations across countries but also within borders amongst population groups. 4) Standard measures for situational comparisons of QoL and development of process orientated perspectives. 5) Examining expectations and normative belief systems, criteria for youngest and oldest old accommodating cohort and historical differences. 6) Predictors of active ageing.
<p><u>APPROACHES AND METHODOLOGICAL ISSUES AND INVOLVING USERS</u></p>	<ul style="list-style-type: none"> ◆ <i>Methodological and Research Approach</i> - 1) Research that addresses issues of heterogeneity and that examines specific sub-groups of older people. 2) Drawing upon the rich diversity of European populations to gather larger sample sizes of particular population groups. 3) Research on tomorrows’ older people – 50-67 years olds – to produce policy projections to meet the needs of this incoming generation of older people and examine the transitions between age groups. 4) Harmonisation of values and concepts. 5) Addressing information gaps, access to data across Europe. 6) Provide dataset training. 7) Combine research on life course with individual accounts, households and this data should be interrelated with policy. ◆ <i>Involving Users</i> – 1) No catch all approach – need to design method of involvement appropriate to the research area and project. 2) Research needs supporting to involve users, this requires providing funding for the time, complexity and resources needed to involve users in research. Indeed users group themselves need resorting for involvement in research. 3) Need to be clear about aims, motivation and benefits of involving users, which users target. 4) The diversity of older people should be at the forefront of all user involvement in research. 5) Need a review of good practice and effective models of user involvement.
<p><u>EUROPEAN AND INTERDISCIPLINARY COLLABORATION</u></p>	<ul style="list-style-type: none"> ◆ <i>Interdisciplinary Approaches</i> - 1) Breaking down the barriers to interdisciplinary collaboration, funders need to allocate time and resources for the development of approaches and research design etc. 2) Recommendations for organising interdisciplinary collaboration, methods need to fit with the issues under examination. ◆ <i>European Knowledge Gaps</i> – 1) Critically examining the portability of models and approaches. 2) Reviews are needed of existing conceptual and empirical research to prepare for comparative collaboration. 3) Data across Europe on QoL is insufficiently gathered together and difficult to access. ◆ <i>Systematic Approaches to and Support of European and Interdisciplinary Collaboration</i> - 1) Need to remove some of the difficulties caused by the variations in QoL data available in Europe. 2) Funding European interdisciplinary workshops to develop knowledge. 3) Address lack of young researchers in ageing field with interdisciplinary and comparative skills. 4) Provide training. 5) Developing a European infrastructure, dedicated journals, conferences and funding. 6) Balance between geriatrics and gerontology. 7) Web-based database of European research. 8) Set up a virtual QoL documentation database library to improve access and fill this information gap.
<p><u>POLICY RECOMMENDATIONS</u></p>	<ul style="list-style-type: none"> ◆ <i>Recommendations For All Funders</i> – 1) Support interdisciplinary research by giving credit for each added discipline. 2) Provide funds for groups to continue to collaborate as well as incentive funds for new groups to develop. 3) Provide incentives to bring new researchers into the field of ageing ◆ <i>National Funding Bodies</i> – 1) Ageing research must be a priority for national funding, either through programmes or targeted research project funding. 2) Encourage action that aids both national and European research such as investing in the networking infrastructure as well in specific pieces of research. ◆ <i>European Funders</i> – 1) Encourage national funders to establish and fund some form of ‘national agenda on ageing research’. 2) Need to develop a strategic approach to ageing research across Europe. Two key proposals for achieving this aim – a) Targeted funding for ageing research in the Seventh Framework Programme - both networks and research projects. b) Establishing a European Platform on Ageing to bring together and facilitate European and interdisciplinary collaboration in the field of QoL. 3) Targeted funding for dissemination and knowledge sharing. 4) Research to integrate different theoretical perspective on QoL are urgently needed. 6) Make EC applications procedures more user friendly.

Table 2

Specific Priorities for Quality of Life Research

QUALITY OF LIFE	RESEARCH PRIORITIES AND KNOWLEDGE GAPS	<u>AREA SPECIFIC RECOMMENDATIONS FOR EUROPEAN RESEARCH</u>
<u>HEALTH RESOURCES</u>	<p>1) Aspects of prevention, rehabilitation and disease management in health care systems and their effects on health behaviour and QoL. 2) QoL of older people with chronic disease. 3) Inequalities of health. 4) Historical shifts, generational differences and the changing role of the health care system. 5) Effects of migration health care systems ability to take into account the multi-cultural background of users.</p>	<p>1) Reviews are needed of existing conceptual and empirical research to prepare for comparative collaboration. 2) Preparation for comparative research is needed which involves reviewing policy, health systems, societal structures and cultures.</p>
<u>PERSONAL RESOURCES, SOCIAL PARTICIPATION AND SUPPORT NETWORKS</u>	<p>1) Research on policy and the role of the welfare state in shaping standard of living and quality of life. 2) Comparisons between rural and urban populations of older people. 3) Housing and the impact of the person-environment relationship more generally for quality of life. 4) Issues of diversity, risk and marginality – especially minority ethnic groups and older migrants within the Europe. 5) Interaction of the resources of older people and personal coping and adaptation to risks and barriers. 6) Issues of empowerment and citizenship alongside the importance of advocacy and the continuance of ageist stereotypes. 7) Life course trajectories, family change and intergenerational relationships, including new family forms and the risks of social isolation and marginalisation. 8) Mental (and physical) activity and social participation. 9) Relationships between formal and informal care systems and the role of older people as caregivers needs further research. 10) Developing the implicit theory of quality of life. 11) Quality of life of vulnerable groups like the frail, and the demented, and to develop concepts and models that may help us study and monitor welfare among such groups. 12) Objective living conditions, and how they are subjectively perceived and adapted to.</p>	<p>Same as adjacent and 1) Comparative studies should be recommended as they help us avoid ethnocentric biases in the definitions and perceptions of what a good life is.</p>
<u>SOCIO-DEMOGRAPHIC AND ECONOMIC RESOURCES</u>	<p>1) Diversity needs to be emphasised more including the causal factors of inequalities between countries and social groups and the extent to which these factors are universal. 2) Changing gendered life course trajectories. 3) More comparative knowledge on people in residential versus people living at home. 4) Need to focus more on the economic position of future older people – including how income needs, levels and perceptions change as people age, the impact of wealth and inheritance. 5) Retirement and transitions on older age, expectations of, support for, incentives to continue to work. 6) Do classic inequalities remain or new ones emerge and is the gap between rich and poor older people polarising or converging?</p>	<p>Same as adjacent box.</p>
<u>ENVIRONMENTAL RESOURCES</u>	<p>1) The environment from micro to macro needs to be analysed as an important component of QoL. 2) 3-D framework for including the environment in QoL – bringing together individual, psychological and social and environmental. 3) Understanding the importance of indoor and outdoor space. 4) More research on older people living in at home, and in particular people with dementia. 5) Older people with learning difficulties are aging in place. 6) Intergenerational issues of segregation/integration within public places and the spatiality of ageing. 7) More evaluations of practical environmental measures.</p>	<p>Same as adjacent box and 1) Research on environmental variables should be core to QoL.</p>

Appendix B

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Appendix C**STEERING COMMITTEE MEMBERS**

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