

Exploratory Workshop Scheme

Standing Committee for Social Sciences (SCSS)

ESF Exploratory Workshop on

NEW HOUSING MODELS FOR PEOPLE WITH DEMENTIA TOWARDS THE END-OF-LIFE

Vienna (Austria), 1st -3rd December 2011

Convened by: Sabine Pleschberger & Elisabeth Reitinger

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SCIENTIFIC REPORT

1. Executive summary

The Workshop entitled *New Housing Models for people with Dementia towards the End-of Life* funded by the ESF "Exploratory Workshop Scheme" was held between December 1st and December 3rd, 2011. It took place at the University's campus in Vienna (IFF faculty) which offered suitable facilities to work and get together.

The workshop aimed at gaining an overview on an international level of the state of knowledge and practice in the area of end-of-life care for people with dementia living in new housing models. The expected outcome was to develop an interdisciplinary research agenda which should attempt to fill the gaps between new housing models for people with dementia and end-of life care. To sort out options for future collaborative research activities was a further interest of this workshop.

A total of 11 participants from six European countries attended the workshop, which was facilitated by the two convenors, to work on the subjects of interest. A range of academic as well as professional disciplines were represented including medicine, nursing, social work and social policy. This transdisciplinary character of the group was important to avoid "lifting off" but keep a focus on the challenges of care practice and the persons concerned. However, the group did not only represent different cultures based on different national backgrounds but also different scientific cultures regarding their main fields of interest. Naturally issues of death and dying affect people in a different manner than social policy might do. Hence the focus of the workshop was put on providing settings for exchange and reflection between the participants as a basis for developing perspectives for future research. Therefore, we deliberately abstained from including a series of presentations given by the participants in the workshop. Instead, we sticked to applying various interactive elements, like enhancing discussions in subgroups along predefined criteria (e.g. discipline, country, thematic areas).

Through this consistent interactive workshop format the following major thematic issues were processed:

- (1) Discussion of terms and definitions to better understand research and literature available with a specific focus on the countries involved. The aim was to find a set of convenient working definitions.
- (2) Mapping different types of housing models to understand the various developments and traditions in the different countries with reference to national frameworks and policies concerning dementia care, housing and EoIC.
- (3) Sharing knowledge of research available in the overlapping areas of end-of-life care and new housing models for people with dementia and identifying gaps and areas for future research.

The small size of the workshop and the interactive design we had chosen corresponded well and optimized opportunities for involvement of participants and collaborating with each other. A genuine interest in getting to know each other and learning from each other characterizes best the atmosphere of the workshop, which was invariably respectful and pleasant. The two conference dinners organized by the convenors supported the process of developing good working relationships. Feedback from the participants was positive without a dissenting voice with most of them stressing the innovative approach of stimulating

interdisciplinary exchange and discussion in the group without creating any hierarchy, neither by levels of academic or professional development nor by disciplines or countries.

Three fields of interest which were introduced by the convenors as a framework served as a basis for discussions and work on future research areas. However, all three of them referred to each other and implied the need for interdisciplinary and transdisciplinary research. As an outcome of the workshop the following areas were shaped as major streams of a research agenda:

- 1. Specific needs of people with dementia in end-of-life care
- 2. The challenges of providing good end-of-life care in new housing models
- 3. New housing initiatives and their role as change agents of welfare systems

Research questions and interests were sorted out along these main issues and an agreement on a common paper to raise awareness for this new emerging field of interdisciplinary research was reached within this workshop.

International comparison of the state of development in new housing models made it clear how big the differences between the six countries involved were and that discussions had to be strongly linked to the national frameworks. This emerged as a serious barrier for future international research in this field. Any research done at an international level will have to consider this carefully, which is why interdisciplinary and transdisciplinary accounts of research are of major importantance in this area.

The first day of the workshop was also attended by Professor Constantinos Phellas as a delegate of the ESF SCSS, who provided a useful introduction to the aims and interests as well as funding opportunities/strategies of the European Science Foundation. Furthermore, he encouraged the convenors as well as the group to go on with further work on the issue because of its relevance for future social and health policy in Europe.

2. Scientific content of the event

New housing models based on small units are supposed to offer high quality care for people with dementia, and a broad variety of different services has been developed all over Europe in the last years. However, end-of-life care in these settings still needs more attention, with implications of this challenge being elaborated on an interdisciplinary ground.

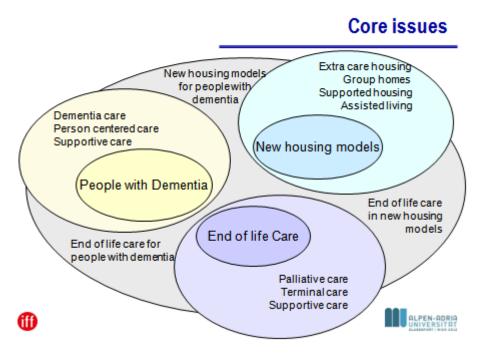
As stated above, we deliberately abstained from a series of presentations given by the participants, instead we sticked to various interactive elements throughout the whole workshop. Furthermore, delegates were invited, well in advance, to contribute with up to three relevant papers of their research group or country concerning issues of interest. A compendium of these articles was shared by all participants through an internet platform preliminarily and provided a first overview of the themes and topics involved. Forming different subgroups along predefined criteria (e.g. discipline, country, thematic areas) within the workshop, in connection with research-relevant questions, were a well-proven means to reach the goals.

The main aim of the *first day* was to create a good working atmosphere, to set the scene thematically and to get an overview of the state of development of new housing models for people with dementia in the different countries as well as terms and definitions involved.

After the *official introduction and presentation* of the European Science Foundation (ESF) by Constantinos Phellas the participants introduced themselves in interview-settings and everybody expressed his or her expectations regarding the workshop.

Following this the *convenors introduced the relevant topics and issues* in a power point presentation. In addition to the important fact that end-of-life care in small scale living models for people with dementia has been a neglected area we referred to commonalities between development and principles of palliative care and dementia care.

We identified a substantial body of research in the field of caring for people with dementia, in the wider area of palliative and end-of-life care as well as in the new housing models not only limited to people with dementia. However, research currently available covers mainly one of the fields or approaches two fields, while coverage of all three areas has not been reached yet. Graph 1 illustrates the thematic map as presented. It was mainly the overlaps that were considered to be most innovative and promising areas for future research. These overlaps were formed as (1) Development of new housing models for people with dementia, (2) End-of-life-care for people with dementia and (3) End-of-life care in new housing models. Beyond this we agreed that we should keep in mind the "blank spot" in the middle of these fields in the further course of the workshop.



Graph 1: Core issues concerning end-of-life care in new housing models for people with dementia

As a second step in the afternoon we started a *mapping exercise on terms and definitions* and state of development of new housing models for people with dementia across Europe. We formed small groups along the national backgrounds of the participants and asked them to prepare a short presentation of the status of development in their countries as well as relevant terms and definitions in the field of interest. The task was to present their countries with reference to the following criteria:

- Terms (national language/ common English expression)
- Period of founding initiatives
- Characteristics of type of initiative (Who is provider of care? Who is provider of facility? staffing, number of residents, concept of care, role and involvement of relatives, involvement of volunteers)
- Characteristics of initiatives regarding end-of-life care (Cooperation with specialized palliative care services, place of death, advance-care-planning, ethical issues and decision making, end-of-life policy)
- Framework of initiatives regarding community involvement, strategy of public policy and Health and social care regulations

Based on these items we gradually developed a table on a pinboard, with presentations of each country forming the lines. This process provided a good overview and learning opportunity for all participants. Moreover, it was a fruitful ground for discussion of the amazing differences which could be observed from country to country and at all levels. It was soon clear that national comparison would be difficult and afforded complex research designs. For example while in Germany initiatives have flourished in the last ten years, policy in Sweden has mostly withdrawn from investing in small housing initiatives and aimed at developing palliative care in care homes.

This overview set the scene for the broader thematic discussion on *the second day of the workshop* which focussed on further aspects of expertise relevant to the field as represented by the participants. The papers which had been were distributed in advance (see above) were used as a guide through the first part of day two. Each participant briefly commented on the papers s/he had submitted and thereby presented her/his specific expertise and potential for contributing to the field of interest. Each of the presentations was discussed thoroughly by the whole group. Finally we all had a good *overview of what has been reached already in research* in the various fields of interest involved. We are providing a short overview including references from up to two papers per person/country:

Silvia Kivi, an experienced nurse in group homes, and **Lennart Johannson** who is involved in the evaluation of National Guidelines in Dementia Care at the Swedish National Board of Health and Welfare, reported about the developments in Sweden based on a summary paper. New housing alternatives for people with dementia were developed in Sweden during the 1980s. A huge number of traditional wards in nursing homes had been converted to group homes then, mainly for economic reasons. Over the last years initiatives like the expansion of adult day care services as well as the introduction of dementia nurses have contributed to the improvement of care. However, until now there have been no special programmes, services or care facilities addressing the needs of people with dementia at the end of life.

Johannson L. (2011): Care of people with dementia and their families in Sweden. Unpublished paper prepared for the ESF Workshop on New Housing Models for People with Dementia towards the End-of Life, Vienna.

Erik van Rossum is a researcher at Maastricht University and a lecturer at the Zuyd University of Applied sciences in Heerlen. His working area is community and nursing home care and he has recently been involved in a study looking at effects of small-scale living facilities. In this study substantial differences between new housing models and nursing homes could not be identified. However, the latter had been developed in the last years along the experiences which had been made in the field of new housing models. There seem to be good conditions for people who live in new housing models for end-of-life care in the Netherlands.

Verbeek H., Zwakhalen S., van Rossum E., Ambergen R., Kempen G., Hamers J. (2010): Dementia Care redesigned: Effects of small-scale living facilities on residents, their family caregivers, and staff. Journal of the American Medical Directors Association

Verbeek H., van Rossum E., Zwakhalen S., Ambergen R., Kempen G., Hamers J. (2008): Small, homelike care environments for older people with dementia: a literature review. International Psychogeriatrics

Mirella Minkman and **Margje Mahler** are both researchers at the Centre of Expertise for Long-Term Care in Utrecht. They have been involved in programmes to improve dementia care in the community which achieved remarkable outcomes. It was evident that networks play a major role as well as case management in order to reach the provision of integrated care which is vital in the care for people with dementia.

Minkman M, Ligthart S., Huijsman R. (2009): Integrated dementia care in The Netherlands: a multiple case study of case management programmes. Health and Social Care in the Community 17(5), 485-494

Nies H., Meerveld J., Denis R.: Dementia Care: Linear Links and Networks. Commentary. Healthcare Papers Vol, 10(1)

Karen Croucher, who is a research fellow at the Centre for Housing Policy, has been working on various studies in the field of housing and care for later life, including residents' perspectives. Her latest project dealt with the evaluation of learning resources for end-of-life care in extra care settings. Results of the evaluation included the recommendation that basic skills in end-of-life care should be provided by care staff but specialist support should be available beyond that.

Jones A., Croucher K. and Rhodes D. (2011): Evaluation of Learning Resources for End of Life Care in Extra Care Settings. Report, Centre for Housing Policy, The University of York.

Birgit Schuhmacher, who is a research fellow at the University of Applied Sciences in Freiburg and has been active in the field of housing inititatives for people with dementia for some years, presented a German initiative called OASIS. An oasis is a specific ward within a nursing home to create the most suitable environment for people with end stage dementia. By proxy of Thomas Klie, who had to cancel his participation on short notice, Birgit additionally gave a short snap of the "Freiburger Modell" ("Shared responsibility in Living Groups for People with Dementia"). This is one of the most innovative models of community based small scale living for people with dementia. Group living in shared flats are representing user-driven services which are supported by professional care services and co-funded by care allowances.

Schuhmacher B., Klie T. (2011): Care oases as an alternative to single or double rooms for people with severe dementia. Unpublished working paper, Freiburg

Katherine Froggatt, Head of Division of Health Research and senior lecturer at the University of Lancaster, UK, presented her work on approaching dementia from a personcentered perspective and linking this to palliative care and nursing homes. She thought about the tensions between life-worlds and system-worlds and that there might be differences between small scale living environments and institutionalised long term care settings. Furthermore, she presented an explorative study on end-of-life care in the context of extra care housing in the UK.

Downs M., Small N. & Froggatt K (2006): Explanatory models and end of life care for people with dementia. International Journal of Palliative Nursing 12, 209–213

Crosbie B., Seymour J. & Froggatt K. (2008): Exploring End of Life Care: in the context of Extra Care Housing. Unpublished Report, The Sue Ryder Care Centre for End of Life Studies, University of Nottingham

Sarah Vallely is a business manager of Housing 21 which provides Extra Care Housing for people in need in the UK. These housing services are not focussed on the group of people with dementia, however, as most people live there for good, dementia as well as challenges in end-of-life care have become key issues in the last years. The provider's great efforts in this field are impressive. Apart from a literature review on "Extra care housing and people with dementia" Sarah presented various other projects in the field, e.g. "End of Life Care Larining Resource Pack", "Dementia Voice Nurse Service Pilot", ...

End of Life Care. Learning Resource Pack. National End of Life Care Programme and Housing 21.

Easterbrook L and Vallelly S.: "Is it that time already?" Extra Care Housing at the End of life: A policy-into-practice evaluation. Report. National End of Life Care Programme and Housing 21.

Marion Villez, who is active in the Alzheimer society in France and especially competent in the field of end-of-life care for people with dementia, presented a paper on "Supporting and Caring for People with Dementia throughout End of Life" and focussed on ethical issues as well as organisational aspects. Regaining identity in living with dementia is one of the most important care concepts and based on person-centered care. New housing models play a

minor role in the current debate on care for people with dementia, especially compared to other long term care facilities like nursing homes.

Martinez M.J. with Villez M. (2011): Regaining identity. New synergies for a different approach to Alzheimer's. Guidelines for professional practices. Fondation Mederic Alzheimer. Paris

Sabine Pleschberger and Elisabeth Reitinger, the convenors, presented their exploratory study on end-of-life care in shared flats for people with dementia. The results of the study show that shared flats for people with dementia are good places for death and dying. Close relationships, good communication with relatives and highly motivated staff are supporting factors. We identified clinical issues and coping with bereavement as main areas for improvement. Both are well covered by palliative care. Only few co-operations between hospice work, palliative care and the housing initiatives were found in Germany. We discovered a culture mainly inspired by social work in dementia care and housing initiatives on the one hand, and a more spiritually inspired approach in the field of hospice care, with substancial medical influence in the realm of palliative care. These cultural differences might pose some challenges in case of cooperation between both fields.

Reitinger E. & Pleschberger S. (2010): Living and dying in community based housing for people with dementia. An exploratory qualitative study. Zeitschrift für Gerontologie und Geriatrie 43(5), 285-290

Kai Leichsenring is part-time senior research fellow at the European Centre for Social Welfare Policy and Research working in the area of social and health care policies, in particular with respect to long-term care of older persons and quality management. He briefly reported on the Salmon Group Initiative, which developed small-scale living for people with dementia in six countries about 15 years ago. Furthermore, he referred to the Interlinks project. This project was funded by the 7th Framework Programme and aimed to construct and validate a general model to describe and analyse long-term care (LTC) systems for older people from a European perspective. An interactive website serves as a European resource including 13 country reports on the issue of long-term care.

Leichsenring K., Strümpel C. (1998): the use of small housing units for persons suffering from dementia. Final report of the Salmon Group. European Centre for Social Welfare Policy and Research.

http://interlinks.euro.centre.org/countries

In addition to these presentations short snaps were given to similar endeavours, namely the **ANCIEN initiative**, which provides country reports on long-term care as well as the **EAPC Network on Palliative care in long-term-care settings for older people**, which is coordinated by Katherine Froggatt and Elisabeth Reitinger. There was consensus in the group that all this work has to be used as a main reference and starting point to build on instead of duplicating research work.

http://www.ancien-longtermcare.eu/

http://www.eapcnet.eu/Themes/Organisation/Longtermcaresettings.aspx

In *part three of the workshop* we tried to draw *conclusions* from what we had learned and discussed so far (see below, 3). We identified *core themes of future research* in the field and worked out relevant research questions as well as ideas for future projects in more detail.

Specific needs of people with dementia in end-of-life care

- There is a lot of knowledge and expertise available on specific needs of people with dementia at different levels ranging from clinical issues (e.g. pain, nutrition, ...) to housing and service organization level. However, this knowledge is not accessible to all groups of interest in different countries. Therefore it is important to find out, how international exchange of this knowledge and expertise might be enhanced further and how research can contribute to this endeavour, e.g. by applying transdisciplinary approaches.
- Additionally, comparative research is necessary to find out more about the differences
 and specific needs of people with dementia at the end of life compared to other groups
 of elderly people, including their informal and professional carers.
- Ethical issues like decision-making, recognizing dying as well as attorneyship are of further interest for future research.

The challenges of providing good end-of-life care in new housing models

- In light of the different initiatives which have taken place in the field of new housing for people with dementia the need for comparative research is evident. One interest lies in comparing specific outcomes regarding end-of-life care between different housing models. Examples for such outcome factors might be place of death, satisfaction with care of family members as well as members of staff or economic outcome-indicators. However, the discussion about what are good outcomes and how to measure them is yet to be started.
- Another field of interest we discussed was the role of new care technologies and housing models, e.g.: How do they change care and living environments and their effect on end-of-life care?
- Differing cultures of care also have to be taken into consideration when doing research, with a cultural understanding linked to different nations on the one hand, and different organizational cultures on the other. Cultures can be linked to professional identities like neurology, dementia care and palliative care as well as to institutional contexts ranging from nursing homes to community care.
- Managing decision-making, e.g. regarding transitions into dying, is a further issue of interest for future research in this area.
- Finally, the question of how to raise the robustness of such housing initiatives in order
 to meet the needs of people with dementia at the end of life to avoid transition to
 hospitals or traditional nursing homes in the last phase of life seemed to be vital.

New Housing Initiatives and their role as change agents of welfare systems

- The part of new housing models for people with dementia in the development of a welfare mix has to be discussed more thoroughly in light of the differences in the countries involved. Most importantly the roles of state and market forces as well as the role of civil society apparent in the models need to be analysed. New housing initiatives, especially if they are user-driven, represent a new way of sharing responsibilities for care with regard to provision, payment and quality management.
- Thorough examination of programmes which promote new welfare mix models like the German "Dementia friendly communities" or "Dementia Action Alliances" in the UK is of additional interest.
- Raising public awareness of end-of-life-care issues with regard to people with dementia is an important step for further development. To do so research and policy from various fields have to collaborate.

In the *closing session of the workshop* we worked out common strategies and ideas for dissemination as well next steps (see below). An evaluation by collecting verbal feedback from all participants closed the workshop. Those attendants who stayed for a second night joined the convenors for a farewell dinner right after the official closing of the workshop.

3. Assessment of the results, contribution to the future direction of the field, outcome

Following the comments from the participants given in the final evaluation phase, the workshop provided the group with a lot of learning experiences. Looking elsewhere was considered a useful and inspiring exercise with a sobering effect, indeed: It became clear that research comparing different countries is enormously challenging in this field. We found only little commonalities between the initiatives of new housing models for people with dementia across Europe, while facing different frameworks of health and social care and different traditions and standards of delivering long-term care in the countries.

With no doubt new housing models for people with dementia have to meet the challenge of providing good end-of-life care in order to be a home for life. It became evident that most of them have not prepared for this task sufficiently. Instead, developments and programmes of implementing palliative care to nursing homes might put some pressure on the conception of new housing models while palliative care in the community has not been expanded sufficiently from cancer care to dementia care yet.

Improving end-of-life care for people with dementia within new housing models affords sufficient evidence about the specific challenges of end-of-life care for people with dementia in general. We have to check carefully what palliative care and other concepts can contribute to meeting these challenges. Moreover, it is important to develop this knowledge with regard to consideration of the organisational background where people with dementia are expected to live and die. For example, some issues like secludedness might be no problem because the small-scale environment works on a level of maximal inclusion and an open door is sufficient to be aware of a person's needs and condition. Similarly nutrition and feeding are embedded in a different culture and awareness in small-scale living environments with a substantial support from informal carers and family members.

International comparison of institutional backgrounds has to consider the national frameworks of health and social care (welfare system), policy and legal issues and therefore afford interdisciplinary research collaboration. Reasonable studies produced valuable background for international comparison and work, it is important that future studies should build on this (e.g. projects under the 7th Framework Programme like "Interlinks" or "ANCIEN").

Obviously community based small-scale housing models show innovative ideas how we can meet the societal challenge of people growing older and among them an increasing amount of people with dementia - as they promote a new welfare mix. To benefit from this at a European level specific research focussing on the following overlapping areas has to be pushed:

- Specific needs of people with dementia in end-of-life care and the role of the organizational context where this care is delivered
- The challenges of providing good end-of-life care in new housing models in light of different health and social care frameworks
- New housing initiatives and their role as change agents of welfare systems with end-oflife care for people with dementia as an example

We agreed on a number of **actions for dissemination** of the results which should further introduce the issues to the scientific communities of relevance, such as gerontology and geriatrics, palliative care as well as dementia care.

- An abstract has been submitted by the convenors and is accepted for poster presentation at the EAPC research congress in Trondheim (7-9th June 2012).
- A paper introducing the relevant issues and presenting the research topics will be written by the convenors and agreed on by all participants. This paper should be submitted to a scientific journal and used as a common basis for further activities.
- The participants had an interest in translating the paper into their national languages to further disseminate the issue by publication in relevant journals of national societies as well as via websites and platforms. It was agreed that either the final report of the workshop or the draft paper can be used for adaption by the participants.

As a follow up, some of the participants expressed interest in submitting a common research proposal under the EU-Framework Programme. We agreed on exploring the possibilities, depending on the exact nature of forthcoming calls for proposals as well as checking for colleagues who might be willing to take a lead for such an endeavour.

4. Final programme

Thursday, 1st December 2011

13.00-14.00 Registration and informal welcome (snacks provided)

14.00-14.15 Presentation of the European Science Foundation (ESF)

Constantinos PHELLAS (ESF Standing Committee for Social Sciences; SCSS)

14.15-15.30 Afternoon Session I: Getting in Touch

Introduction of People, Topics and Research

Sabine Pleschberger, Elisabeth Reitinger (convenors) & Involvement of all participants

15.30-16.00: Coffee / Tea Break

16.00-17.30 Afternoon Session II: Terms and Terminology

Terms and definitions related to housing models and end-of-life care, group work and plenary discussion based on mapping

exercise

Sabine Pleschberger, Elisabeth Reitinger (convenors) & Involvement of all participants

17.30-17.45: Break

17.45-18.30 Summary of the first day

19.00 Dinner at Restaurant Zoller 1070 Vienna

Friday, 2nd December 2011

09.00-12.30 Morning Session: State of Research & Practice

Presentation of participants' research & activities

All participants presented along their papers

10.30-11.00: Coffee / Tea Break

Presentation of European Research Projects in Areas of Relevance

by Kai Leichsenring, Katherine Froggat & Elisabeth Reitinger

Discussion of State of Knowledge

Facilitated by convenors

12.30-14.00 Lunch at Restaurant Schon Schön / Lindengasse 53, 1070 Vienna

14.00-17.30 Afternoon Session: Priorities and Interests

Work in 3 small groups to identify topics of further research

Presentation of results of subgroups by group members

Exchange of interests and collaboration

Facilitated by convenors

15.30-15.45: Coffee / Tea Break

17.30 - 18.00 Evaluation, Farewell & End of Workshop

19.00 Dinner at Restaurant Podium 1070 Vienna

5. Final list of participants

Karen Croucher, Centre for Housing Policy, University of York, Heslington, York, UK

Katherine Froggatt, School of Health and Medicine, Lancaster University, UK

Lenharth Johansson, Aging Research Center (ARC), Stockholm, Sweden

Silvia Kivi, Äldreomsorg, Ersta diakoni, Stockholm, Sweden

- **Kai Leichsenring,** European Centre for Social Welfare Policy and Research, Vienna, Austria
- Margje Mahler, Quality and innovation in Elderly Care, Vilans, Centre of Expertise for Longterm Care in The Netherlands, Utrecht, Netherlands
- **Mirella Minkman,** Vilans, Centre of Expertise for Long-term Care in The Netherlands, Utrecht, Netherlands
- **Birgit Schuhmacher,** Alter. Gesellschaft. Partizipation (AGP), Institut für angewandte Sozialforschung im Five e. V., Evangelische Hochschule Freiburg, Freiburg, Germany
- **Sara Vallely,** Business Development, Housing 21, Housing 21 Camden Office, Highgate Business Centre, London, United Kingdom
- **Erik van Rossum,** Kenniskring Autonomie en Participatie van chronisch zieken, Hogeschool Zuyd, Bijzonder lector Zorginnovaties voor kwetsbare ouderen, Heerlen, Netherlands
- Marion Villez, Pôle Initiatives Locales, Fondation Médéric Alzheimer, France

ESF Representative:

Constantinos PHELLAS, School of Humanities, Social Sciences and LawSocial Sciences, University of Nicosia, Nicosia, Cyprus

Convenors:

- Sabine PLESCHBERGER, Department of Palliative Care and Organisational Ethics, Interdisciplinary Faculty for Research and Education University of Klagenfurt, Vienna, Austria
- **Elisabeth REITINGER**, Department of Palliative Care and Organisational Ethics, Interdisciplinary Faculty for Research and Education University of Klagenfurt, Vienna, Austria

6. Statistical information on participants

Of those 16 participants who had confirmed their participation beforehand, a total of eleven colleagues managed to come and contribute to the workshop. The group of participants represented well the relevant research fields of interest and was sufficiently balanced with regard to national background and age. Detailed information is provided in the tables below, please note that while the representative from the ESF is excluded, the two convenors were included in the numbers below (total: 13 participants).

Age	Number of participants
21-30	1
31-40	2
41-50	8
51-60	2

Gender	Number of participants
Female	10
Male	3

Domain of research /interest	Number of participants
End-of-life Care	2
Care for Older People	8
Housing & Policy	3

Most of the participants had worked in interdisciplinary contexts and were experts in more than one of the relevant areas. Therefore we would like to present a broader picture of the sort of expertise which was covered by the interdisciplinary group.

Areas of expertise represented	Number of participants *
End-of-life Care	4
Care for Older People	9
Housing & Policy	5
Dementia	3
Long-term Care	5
Social Policy	3
Gerontology	3
Gender	1

^{*} multiple statements

The group of participants was not only interdisciplinary with regard to scientific disciplines but transdisciplinary because of its participants with a clinical background and professional background other than social research (solely), as listed below:

Professional background	Number of participants
Social scientist	5
Nursing	4
Medicine	1
Other	3