



## Summary and recommendations

Expert Workshop on the Oldest-old.

### **Harnessing Academic and Social Organizations Knowledge to assess research needs for and contributions by persons 85+/90+**

The objectives of the workshop were

- To understand the growth of the 85+/90+ population across Europe and in Canada
- To discuss the implications of this growing population on services and supports, as well as on culture and social life
- To assess the gaps in research data and identify challenges and opportunities to address these gaps
- Using a partnership model of older persons' organizations and researchers, to develop areas where more research is needed to inform policy and practice.
- To identify potential activities for the JPI to strengthen the research in the area.

The workshop was organized jointly by the Scientific and the Societal Advisory Boards of the JPI-MYBL. The participants included senior research experts in the field and representatives of older person's organizations from Europe and Canada. Recognizing the expertise from both academic researchers and the experiences of older persons from their respective organizations, the workshop was structured to enable short talks on key issues from both perspectives on key issues in the field and followed by working group discussions to assess the implications of the findings for future research.

The main message was the limited research on the oldest-old mainly for two reasons (1) unprecedented growth in the cohort: Due to the rapid decline in old age mortality, the previously smaller numbers of those aged 85+ has significantly increased only for a few decades, but continues to growing very rapidly; and (2) due to frequent poor health, and also institutionalization, researchers face special methodological challenges accessing the 85+. More adequate data is needed to better understand the characteristics of this very heterogeneous age group, to develop adequate and sustainable services, to support intergenerational relations and for the society to take full advantage of the lengthening lives.

In addition, significant discussion centred on the importance of evaluation and implementation science in the research on the best ways to support the oldest old to continue to live and prosper in society. The role of family carers and the importance of an integrated model of care were also recommended to be central to filling the gaps of research on the oldest old. In addition, the definition of "what makes life worth living" was viewed as critical to filling research gaps in service delivery.

In an ideal world, the best way to proceed would be a multi-country comparative longitudinal study on health, quality of life and care on representative samples of the oldest-old. Understandably there are several major problems of feasibility, and not only in funding. Therefore, a more reasonable way to proceed would be data and information sharing, building expertise, for instance, in methodology, comparative evaluations of interventions with this 85+ population and potentially launching (a) more focused call(s).



The workshop emphasized the importance of methodology in survey studies on oldest-old. First, guidelines are needed to improve the participation and reliability of population studies. Second, validated instruments used in general surveys should be reviewed and develop a core set of instruments that are most useful and feasible in studies on health and quality of life among the oldest old, e.g. measures of health, physical and cognitive functioning, frailty. Where population-based register data is available, they should be used in parallel of population surveys.

Visibility of the oldest-old as a separate group should be strengthened, e.g. distinguishing the group 85+ from younger-old people in age-based statistics and research.

The oldest-old are the main population group in need for round-the-clock care, both formal long-term care and informal family care. Particularly on family caregiving the research data is scarce and inclusion of questions recognizing the role that they play is important.

The workshop also emphasized the importance of hearing the oldest-old's own voice on their quality of life, and on most important dimensions on health and preferences on care. Here, both qualitative and quantitative approaches could be used.

#### Recommendations

- Commission a paper on the methodology on survey/population research with the oldest-old (including the age categorization recommendations to official statistics...) . Write and publish the paper in an European research journal (and on the MYBL web page of course)
- Comparative study (through a workshop or Fast Track) on the importance of Advocacy and protection of agency among the oldest old.
- Through partnership with targeted governments/agencies/older person organizations, encourage discussion on best practices in health and social services of working with oldest old
- Launch a call, later, on the perspectives and views of the oldest-old themselves on their health, quality of life, possibilities of participation and preferences for care, not large population surveys but more contextual, perhaps qualitative research, with cross-country comparisons.
- Equity is a major issue also among the oldest-old, there are studies to tell that even in egalitarian countries both remaining life expectancy, health, functioning and care received varies between social classes. So either there should be a specific subproject on them as the paper now seems to propose or they should specifically be taken into account in appropriate subprojects now drafted.