



You can't always get what you want

Can European care systems respond to the expectations and preferences of their citizens?

Stefania Ilinca, Cassandra Simmons, Max Salcher, Adelina Comas & the InCARE team



# THE INCARE SURVEY ON ATTITUDES, EXPERIENCES AND EXPECTATIONS ON LONG-TERM CARE

- Launched at the end of September 2021 will run until January 2022
- Several topics addressed in the survey: informal care, experiences with formal care, financing of care, expectations for the future, gender roles and preferences for care
- Many questions drawn from Eurobarometer 67.3 (2007)
- Nearly 3000 responses so far from over 30 countries but clustered around the InCARE project countries (Spain, Austria, North Macedonia)

## THE INCARE CONSORTIUM & COLLABORATORS



Federal Ministry Republic of Austria Social Affairs, Health, Care and Consumer Protection

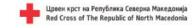


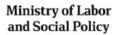


















#### **Collaborators**

HelpAge International - Moldova

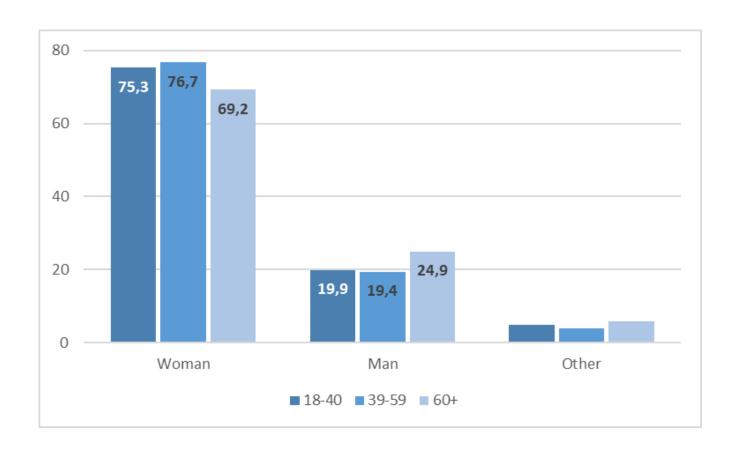
Gender Alliance for Development Centre (GADC) - Albania

Social Services Unit, Centre for Social Work of Pristina - Kosovo

Department of Psychology, Spiru Haret University - Romania

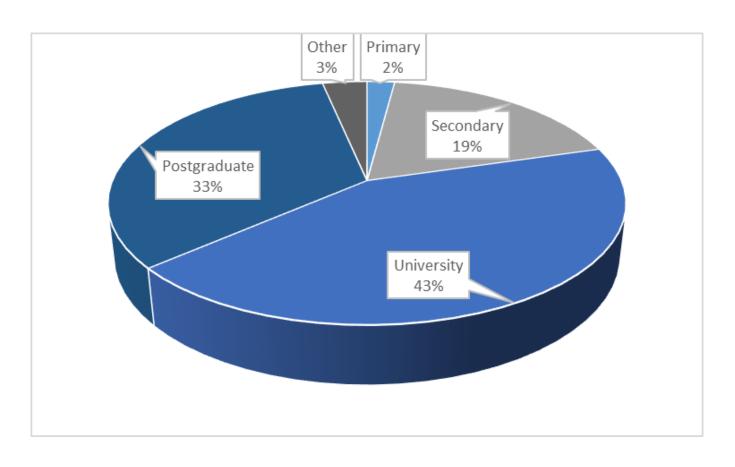
Department of Public Health at Babes-Bolyai University - Romania

# **OUR SAMPLE - GENDER & AGE**



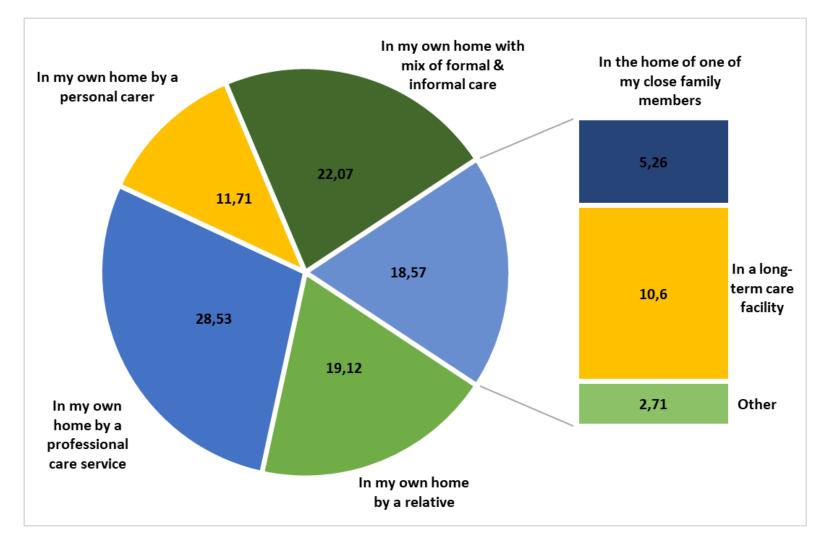
- Gender unbalanced many more female respondents, than male respondents
- Over-representation of older age groups with respect to their population share (particularly for men)

# **OUR SAMPLE - EDUCATION**



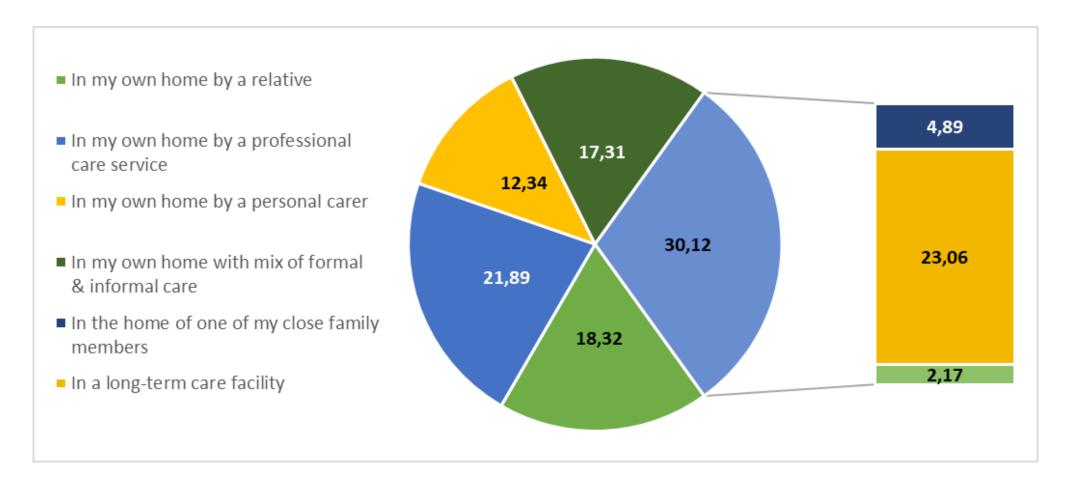
- Under-representation of primary and secondary educated groups
- Large majority of respondents (76%) obtained university diploma or higher

# PREFERRED CARE ARRANGEMENTS



Overwhelming preference for care in one's own home (over 80%)

## **EXPECTED CARE ARRANGEMENTS**

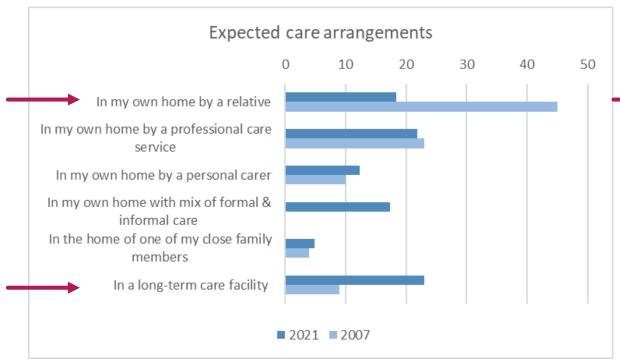


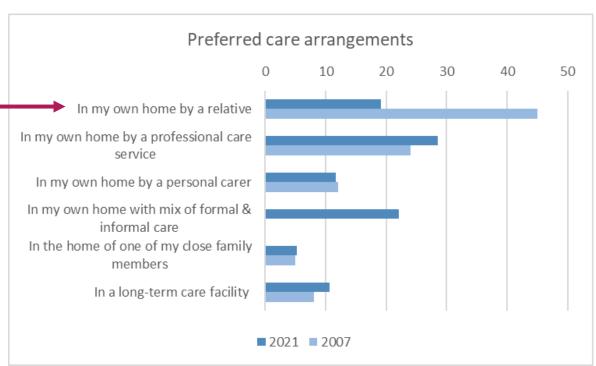
Almost 1 in 4 respondents expect to be cared for in a care facility

#### MISMATCH BETWEEN PREFERENCES AND EXPECTATIONS

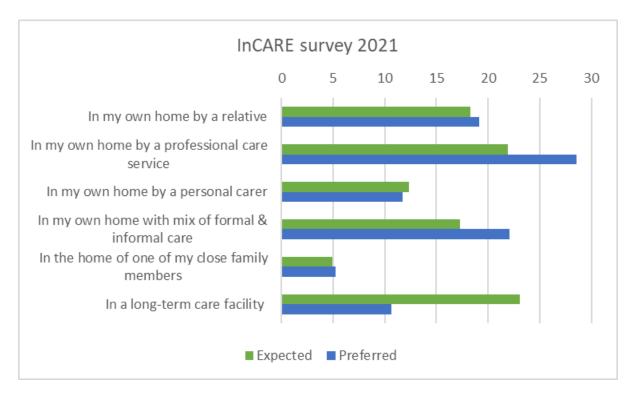
- For 80% of our respondents, the type of care they expect they will receive does
   NOT match the type of care they would prefer to receive
- 20 % of respondents expect they will be cared for in a residential facility, but only
   10% would prefer it
- More respondents would prefer to receive professional care in their homes (either alone or in combination with informal care), than expect to receive it

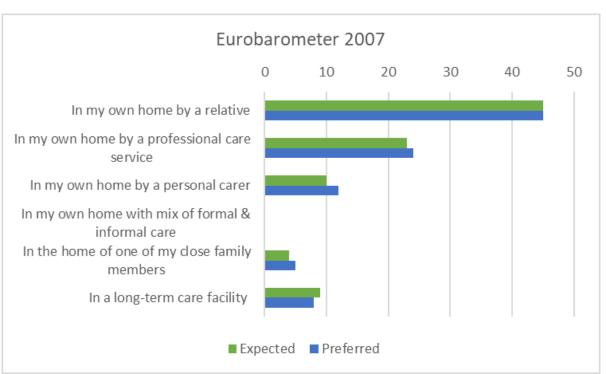
# WHAT HAS CHANGED IN THE LAST 15 YEARS?





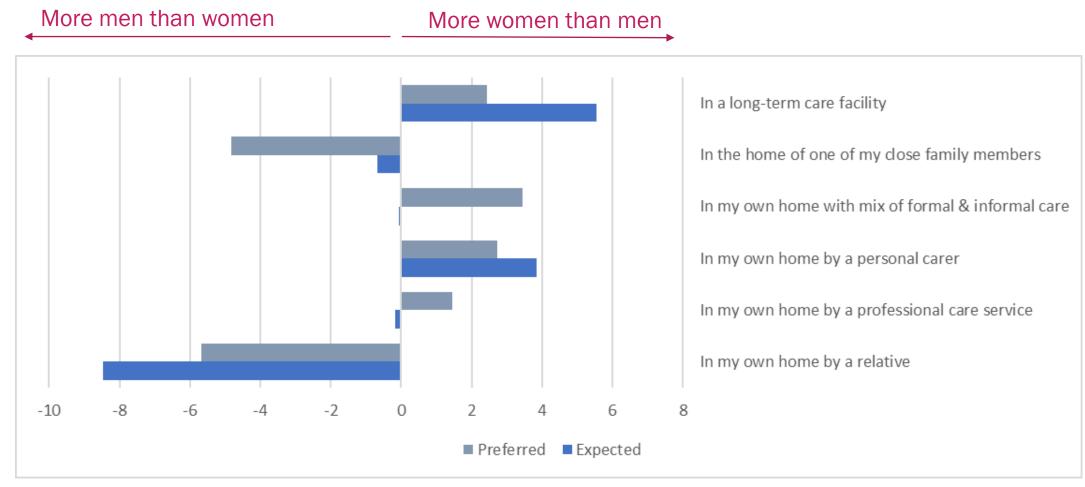
# WHAT (ELSE) HAS CHANGED IN THE LAST 15 YEARS?





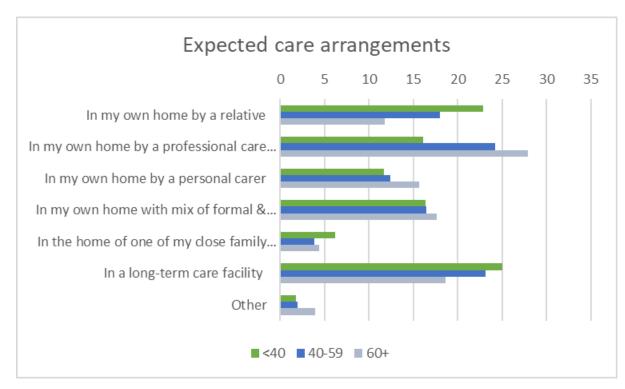
Our results indicate an increasing mismatch between preferences and expectations

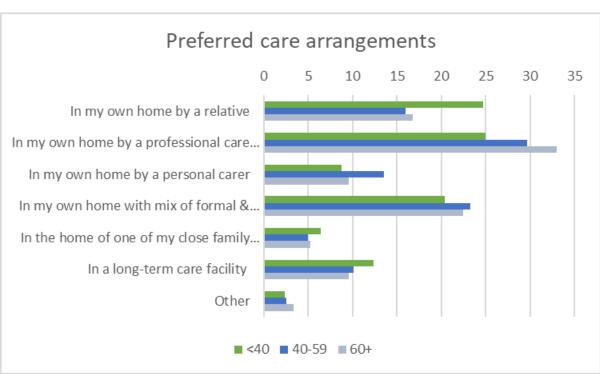
## THE GENDER GAP



Percentage point differences in expectation & preferences for care arrangements

## THE GENERATIONAL GAP





Younger groups express stronger preferences and expectations for informal care arrangements

#### **MAIN TAKE-AWAYS**

- Very strong preference for remaining in one's own home in case of care needs
- Strong indication that European citizens neither expect nor do they prefer to rely on families and informal support ALONE should they need care
- Gender gap in both preferences and expectations men prefer and expect informal support, whereas women both prefer and expect formal care
- The mismatch between expectations and preference is indicative of a lack of trust that individuals can choose the type of care they receive, should they need it
- Pronounced increase in the mismatch between expectations and preferences highlights need to bring user voices closer to the decision-making processes

# PLEASE HELP US SPREAD THE WORD! AND CONSIDER JOINING OUR COLLABORATORS NETWORK

- Data collection will run until January 2022
- The data will be made available for research and non-profit purposes
- Collaborators can access data before the end of the embargo period
- Do not hesitate to write for more details:

ilinca@euro.centre.org simmons@euro.centre.org



#### THANK YOU FOR YOUR ATTENTION

"You've made me think ... I will need to figure out a plan for the future". - Woman, 58, Romania

"[translated] I was my husband's caregiver for 7 years. He passed away from a rare and orphaned neurodegenerative disease (PSP). When the diagnosis was announced, we felt abandoned. Our last and most terrible test was to have his advance directives respected. I had to fight again and again to have his wishes respected. So abandoned from beginning to end!"

- Woman, 62, France

"I have Parkinson's Disease and I dread what the future holds for me physically and mentally"

– Woman, 75, Ireland

"[translated] The way we care for people in need will show what kind of society we live in, We build our present but also our future." - Woman, 38