You can’t always get what you want
Can European care systems respond to the expectations and preferences of their citizens?

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

**Expected care arrangements**

- In my own home by a relative
- In my own home by a professional care service
- In my own home by a personal carer
- In my own home with mix of formal & informal care
- In the home of one of my close family members
- In a long-term care facility

**Preferred care arrangements**

- In my own home by a relative
- In my own home by a professional care service
- In my own home by a personal carer
- In my own home with mix of formal & informal care
- In the home of one of my close family members
- In a long-term care facility
Our results indicate an increasing mismatch between preferences and expectations.
THE GENDER GAP

Percentage point differences in expectation & preferences for care arrangements

More men than women

More women than men

- In a long-term care facility
- In the home of one of my close family members
- In my own home with mix of formal & informal care
- In my own home by a personal carer
- In my own home by a professional care service
- In my own home by a relative
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:
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THANK YOU FOR YOUR ATTENTION

“[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

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

“[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