Erasmus MC
University Medical Center Rotterdam

# Definition and recommendations for optimal advance care planning: An international consensus

## *Supported by the European Association for Palliative Care*

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*"I'm right there in the room, and no one even acknowledges me."*


OBITUARIES
TWO YEARS YOUNGER THAN YOU
TWELVE YEARS OLDER THAN YOU
EXACTLY YOUR AGE
THREE YEARS YOUR JUNIOR
FIVE YEARS YOUR SENIOR
YOUR AGE ON THE DOT

# Invite the Elephant to the Table

- Empower the patient
- Empower the medical providers
- Normalize the discussion

**Lack of consensus regarding ACP**

**Worldwide considerable differences in:**

- Willingness and abilities to discuss disease progression and end of life care
- Integration of such discussions in health care and in the legal system

# EAPC Task Force on ACP

- **Aims:**

- To develop a definition of advance care planning;
- To develop recommendations of quality advance care planning;
- Supported by scientific evidence;
- Appropriate to a variety of cultural values

# Overview of process

- Round 1: core group
- Rounds 2-3: expert panel
- Round 4: core group
- Round 5: EAPC Board Members

- Manuscript under review

# Round 1

Task Force: 11 experts from 5 countries

Core domains:

definition, elements, roles and tasks, timing, policy, evaluation

Per core domain a working group, formulating recommendations

Basis: Literature search, meta review
Experts' knowledge

# Rounds 2 and 3: Delphi panel

Online survey

Set of 2 ACP definitions and 41 recommendations

7-point Likert scale

1=strongly agree

7=strongly disagree

Feedback in text boxes

# Rounds 2 and 3: Delphi panel

We invited 144 experts

124 agreed to participate (86%).

109 completed the questionnaire (response: 109/144=76%).

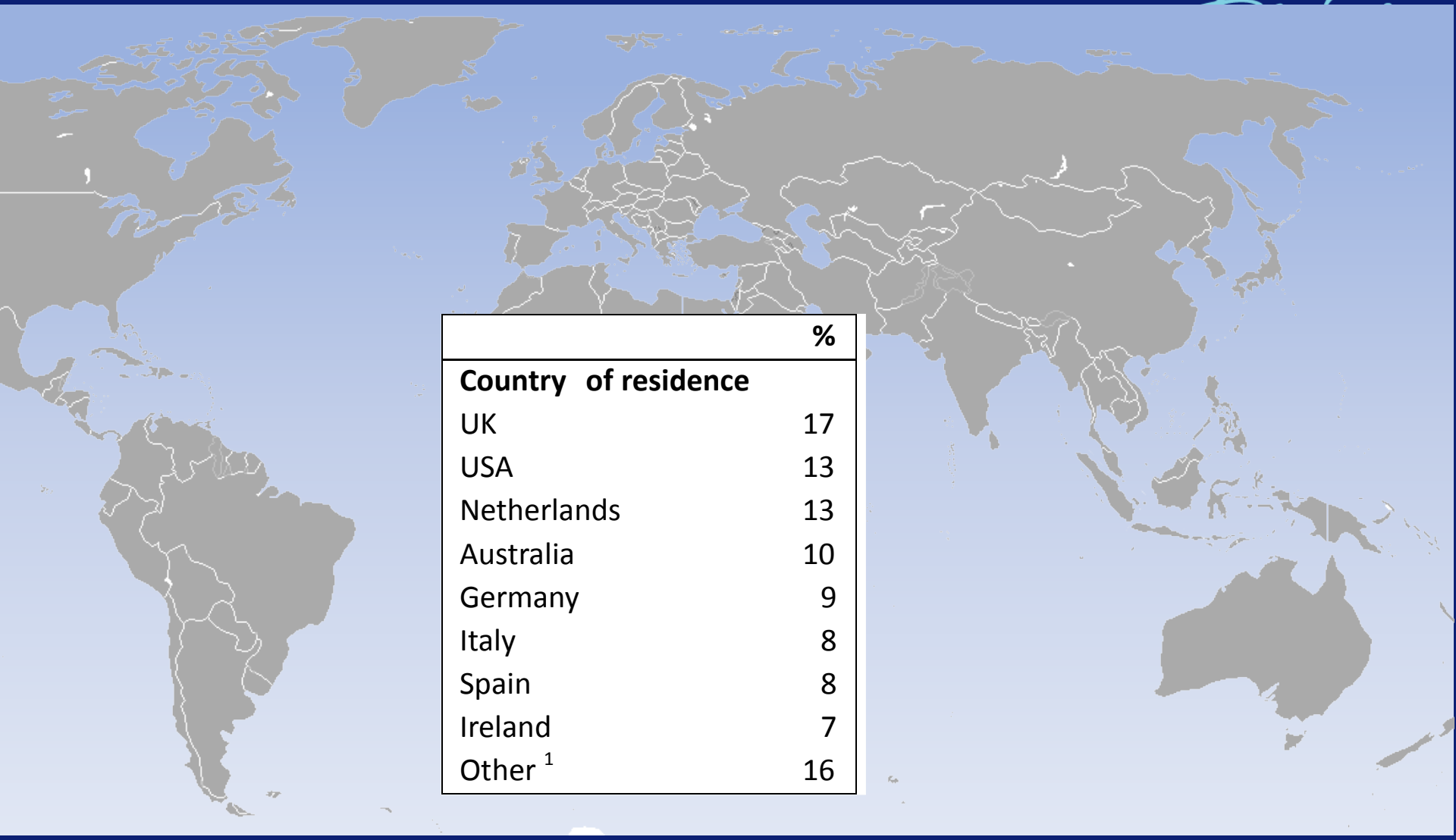
- 82 from Europe, 16 from North America, and 11 from Australia

# Panel

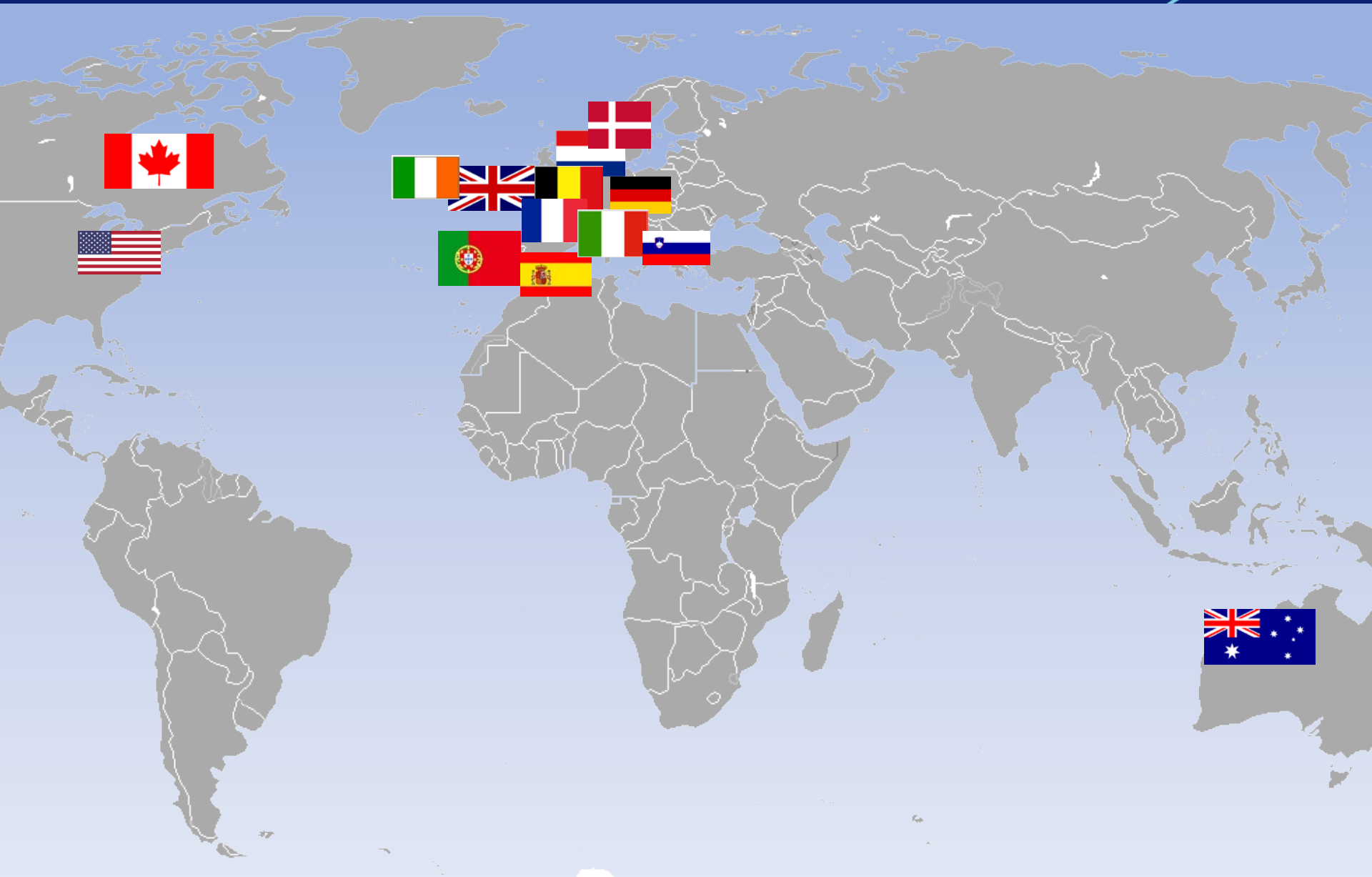
Female: 61%

Average age: 50 yrs
Range: 19-74 yrs

| | % |
|---|---|
| **Expertise** | |
| Medicine | 47 |
| Researcher | 47 |
| Ethics, Philosophy and Law | 24 |
| Nursing | 22 |
| Psychology | 11 |
| Patient representative | 7 |
| Policy | 7 |
| Social worker | 7 |
| Other | 5 |



| | % |
|---|---|
| **Country of residence** | |
| UK | 17 |
| USA | 13 |
| Netherlands | 13 |
| Australia | 10 |
| Germany | 9 |
| Italy | 8 |
| Spain | 8 |
| Ireland | 7 |
| Other [1] | 16 |



# Ratings of Delphi panel

Agreement:

with definitions and recommendations

with each other

In case of very strong agreement:

Definitions and recommendations accepted

Otherwise:

Adaptation of content, wording, and/or ordering, or elimination

# Definition of Advance Care Planning

# 25 definitions from the literature

## Definition – brief version

ACP enables individuals

- to define goals and preferences for future medical treatment and care,
- to discuss these goals and preferences with family and healthcare providers, and
- to record and review these preferences if appropriate.

# Definition – extended version

Advance care planning enables individuals who have decisional capacity:

- to identify their values,
- to reflect upon the meanings and consequences of serious illness scenarios,
- to define goals and preferences for future medical treatment and care, and
- to discuss these with family and healthcare providers.

ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains.

It encourages individuals

- to identify a personal representative and
- to record and regularly review any preferences,
- so that their preferences can be taken into account should they at some point be unable to make their own decisions.

# Central elements

- ACP is a process
- - identifying values and defining goals and preferences for future medical treatment and care
- - discussing these with family and healthcare providers

# Central elements

ACP may include

- - documentation of preferences
- - appointment of proxy decision maker

Preferences need regular review

# Central elements

Scope broader than physical domain

may encompass psychological, social, and spiritual domains

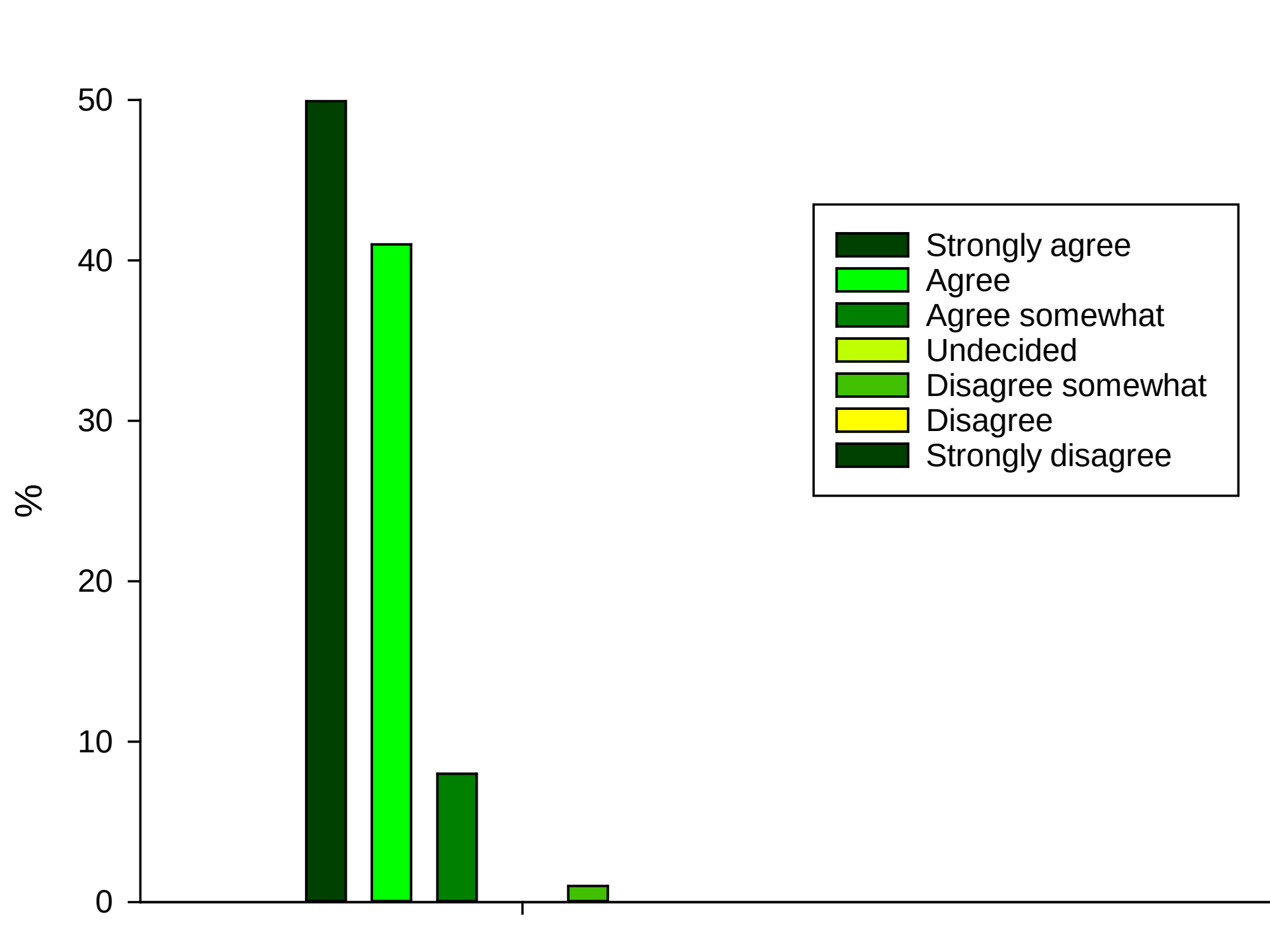
Not limited to specific patient groups

- yet should concern individuals with decisional capacity

# Delphi panel

- 88 open comments

- Adaptations:
- - decisional capacity
- - inclusion of social domain
- - importance of reviewing preferences.


50
40
30
20
10
0
%
Strongly agree
Agree
Agree somewhat
Undecided
Disagree somewhat
Disagree
Strongly disagree

# Recommendations for Advance Care Planning: Content, Roles, and Timing

# Key recommendations: elements

I. Exploration of understanding of ACP and individual's health-related experiences, concerns, personal values
II. Information about aim ACP; diagnosis, disease course, prognosis, (dis)advantages of possible treatment and care options (if appropriate)
III. Clarification of goals and preferences for future medical treatment and care
IV. Discussion and possible appointment of personal representative
V. Discussion and possible completion of advance care directive
VI. Encouraging the individual to provide family and healthcare professionals with a copy of the advance care directive

Overall agreement: 82-100%

# Key recommendations: elements

- ACP should be adapted to the individual's readiness to engage in the ACP process (99% agreement)
- ACP includes the exploration of the individual's health-related experiences, knowledge, concerns and personal values across the physical, psychological, social and spiritual domains (99%)
- ACP may include clarification of goals and preferences for future medical treatment and care. If appropriate, it includes exploration of the extent to which these goals and preferences are realistic (83%)
- ACP includes information about the option and role of an advance care directive as per local legal jurisdiction (95%)

# Example comments

*What does "realistic" mean?*

*A problem that arises every now and then in daily practice is: patient(s) or family (simply) WANT medical treatment 'what can be done needs to be ( must be)done'. In such situations verifying the extent to which such wishes are realistic can be troublesome*

*Addressing vulnerable topics is not always possible*

- “ACP may include clarification of goals and preferences for future medical treatment and care. If appropriate, it includes exploration of the extent to which these goals and preferences are realistic” (83%)

# Key recommendations: roles and tasks

- Healthcare professionals need to have the necessary skills and display an openness to talk about diagnosis, prognosis, death and dying with individuals and their family (99%)
- A trained non-physician facilitator can support an individual in the ACP process (91%)
- The initiation of ACP [..] can occur in healthcare settings or non-healthcare settings (98%)
- Appropriate healthcare providers are needed for clinical elements of ACP ( such as discussing diagnosis, prognosis, treatment and care options) (68%)

# Example comments

*This is less important in basic planning for healthy adults and essential for people with serious and end stage illness.*

*Recommend language inclusive of nurse practitioners, physician assistants for whom this is within scope of practice;*

- “Appropriate healthcare providers are needed for clinical elements of ACP, such as discussing diagnosis, prognosis, treatment and care options”. (68%)

# Key recommendations: timing

- Individuals can engage in ACP in any stage of their life, but its content can be more targeted as their health condition worsens or as they age (96%)

- As values and preferences may change over time, ACP conversations and documents should be updated regularly, e.g. as the individual's health condition worsens, their personal situation changes, or as they age (99%)

# Recommendations for Advance Care Planning: Policy and Evaluation

# Key recommendations: policy

- Governments, health insurers and healthcare organizations should secure appropriate funding and organizational support for ACP. (100% agreement)
- Healthcare organizations need to create reliable and secure systems to store advance directives so that they are easy to retrieve, transfer, and update (97%)
- Healthcare organizations should develop triggers for the initiation of ACP including but not limited to age, degree of illness, and transitions in care. (95%)
- Laws should recognize ACP documents (e.g. (proxy) advance directives) as legally binding guidance of medical decision making. (91%)
- Advance directives need both a structured format to enable easy identification of specific goals and preferences in emergency situations, and an open text format so individuals can describe their values, goals, and preferences (80%)

# Key recommendations: Evaluation

Depending on the aims of the project/study, the recommended outcome constructs are:

- Knowledge of ACP: 91%
- Readiness to engage in ACP: 92%
- Self-efficacy to engage in ACP (feeling to be prepared): 84%
- Identification of goals and preferences: 96%
- Identification of the personal representative (surrogate): 92%
- Communication about goals & preferences with family/health professional: 97%
- Quality of ACP conversations (rated by all involved): 90%
- Documentation of goals and preferences: 95%
- Revision of ACP discussions and documents over time: 96%
- Satisfaction with ACP process / helpfulness of ACP process: 95%
- Concordance of care received with goals & preferences: 92%
- Healthcare utilization (and associated costs): 83%

# Example comments

This is important but we should not forget that sometimes different populations and study goals may require adaptations or other tools.

ACP is fragile without a sound evidence base.

*→ Develop outcome measures that are methodologically sound (validated, reliable etc.) and practically applicable (brief).*

# General conclusion

Shift from

Elicitation of treatment preferences to be used when capacity is lost

→

Communication tool about goals and preferences for future medical care and treatment across the illness spectrum

Individualized approach, tailored to readiness, disease stage, local legal and cultural circumstances

# Discussion

## Strengths of the study

- Timely contribution to a currently dynamic field
- International, interdisciplinary expert study (in “Western” cultures) including patient representatives
- Rigorous methodology, large sample size, high response rate
- Overall very high degrees of consensus
- Recommendations  applicable to a variety of cultures, healthcare settings, populations

# Discussion

## Challenges

- Still general, may need to be specified for particular populations, contexts and other cultures
- ACP by proxy and pediatric ACP not considered → here we need specific research and best practice models
- White Paper is intended to be widely disseminated and recognized, may also be translated in other languages, adapted by national or regional policymakers, and valided in other cultural contexts
- Recommendations should foster joint reflection, colaboration and implementation of high-quality ACP programs

# Thank you!

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