Rethinking Advance Care Planning: Challenges, Controversies, and Opportunities

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OVERVIEW

Rethinking ACP

What could ACP become if we designed for complexity rather than trying to remove it?

Q1 What if some of the **assumptions** we make about advance care planning are too simple?

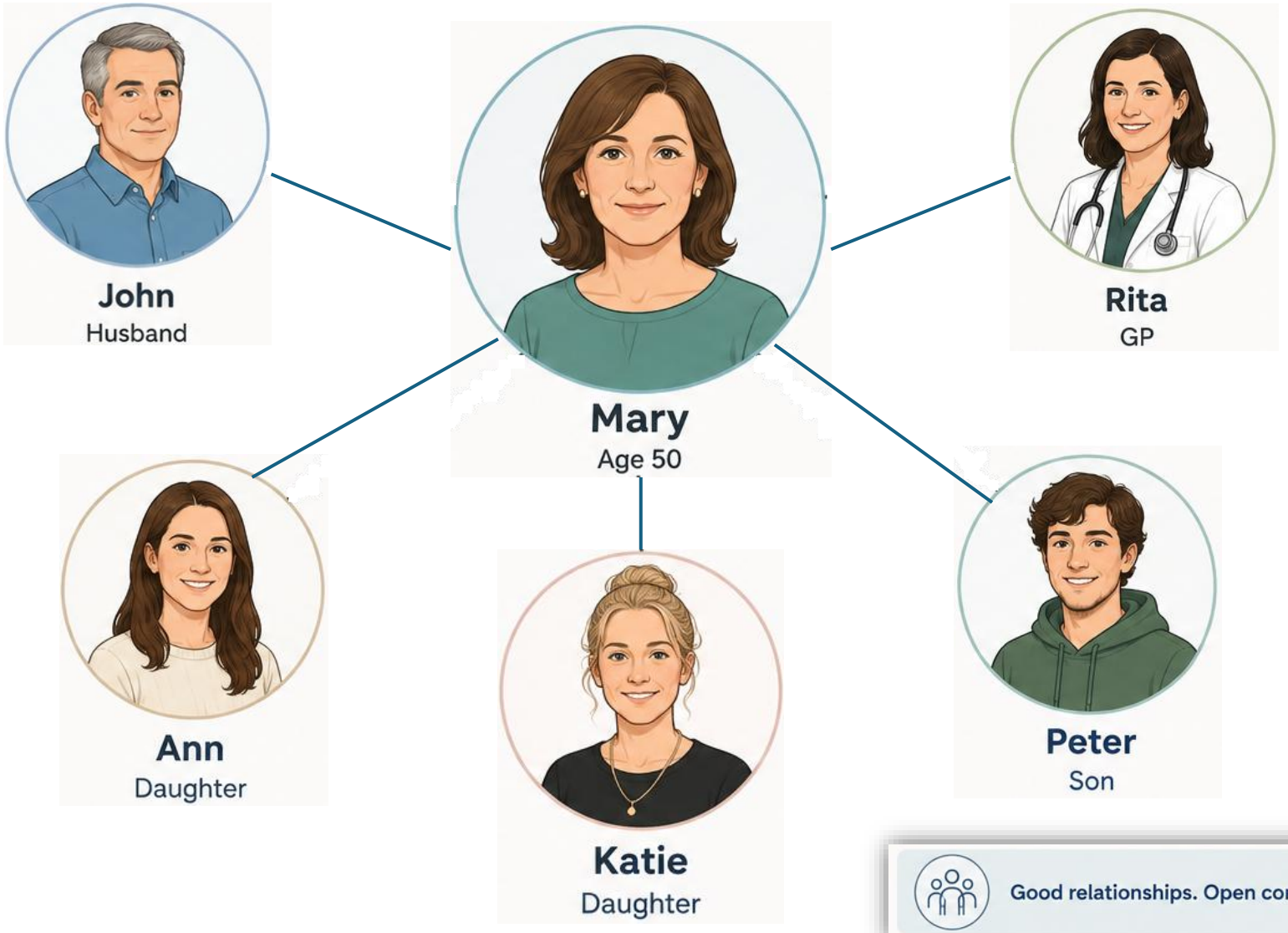
Q2 What if the **problem** isn't that we haven't yet persuaded enough people to engage in ACP?

Q3 What if part of the **problem** is how we conceptualise ACP in the first place?

THE PERSON

WHO ARE WE PLANNING FOR, AND WITH?

CHALLENGE 1
WHO IS THE “PERSON” IN PERSON-CENTRED ACP?



Good relationships. Open communication. Shared understanding.

MEET OTHERS

What matters to you?

Sinead

Sinead uses a wheelchair.

Carline

Carline does have a family, but she is not originally from Ireland and most of her meaningful social network lives abroad.

Paul & Mark

Paul and Mark are in a same-sex relationship.

Alex

Alex is transgender.

Mike

Mike has an intellectual disability.

Christi

Christi is neurodivergent.

Jamie

Jamie is a young person, still at school.

Aisha

Aisha is Muslim and her faith is an important part of her life.

Darren

Darren is a member of the Traveller community.

Olivia

Olivia is single and doesn't have family members whom she would naturally identify as decision-making partners.

PEOPLE ARE NOT CATEGORIES

People don't live their lives one variable at a time.

Kimberle Crenshaw
Intersectionality

Crenshaw (1989)

People occupy multiple, overlapping social positions and identities.

John
Husband

Mary
Age 50

Rita
GP

Ann
Daughter

Katie
Daughter

Peter
Son

Peter is more than one label.

- He could be gay.
- He could have a mental health condition.
- He could be living abroad.
- He could have very different beliefs about illness, autonomy or what constitutes a good death.

The neat distinction between "mainstream family" and "diverse cases" **collapses.**

Opportunity: Make diversity the staring condition and design for it.

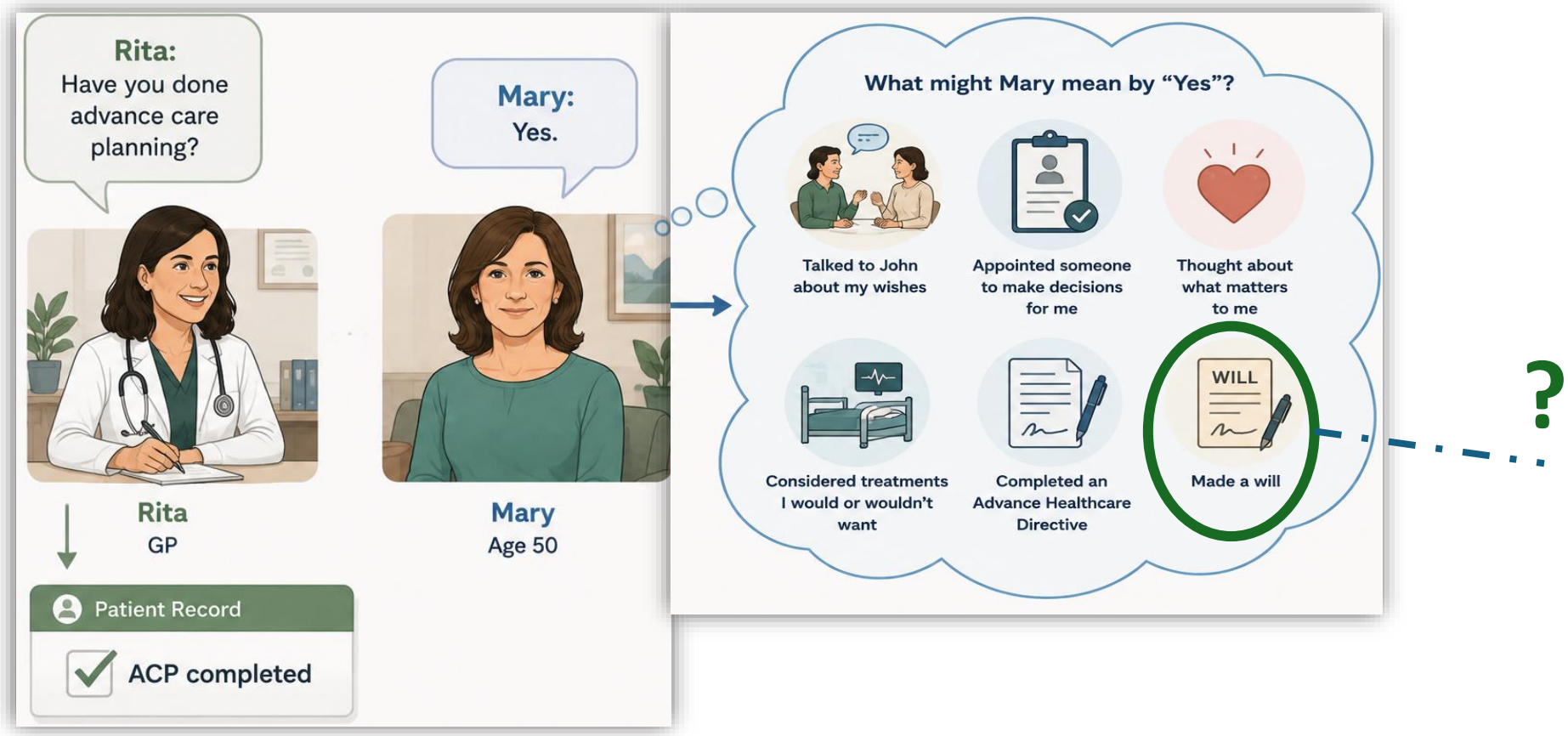
BEHAVIOUR

WHAT EXACTLY IS ACP?

CHALLENGE 2
HAVE WE AGREED WHAT WE'RE TALKKING ABOUT?

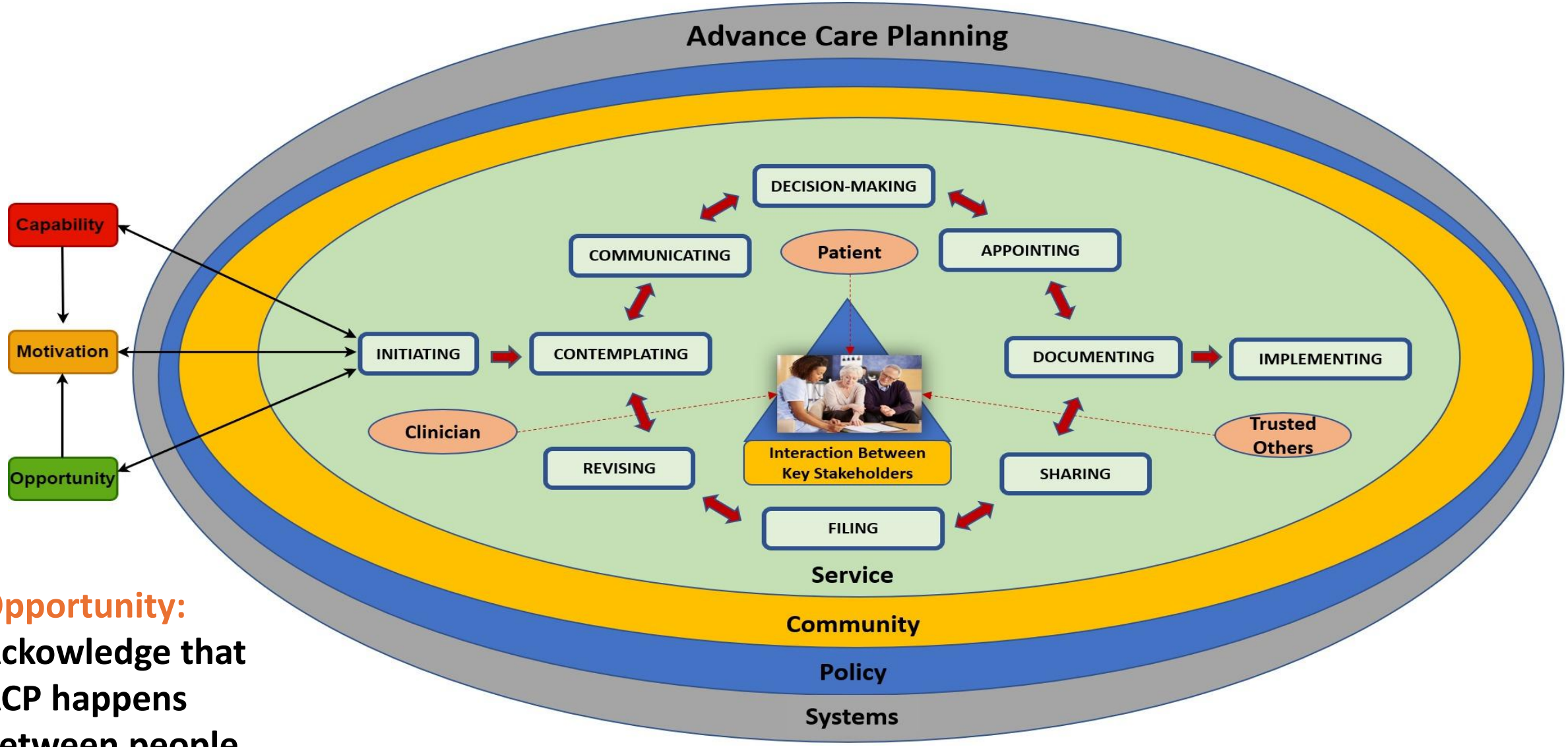
What exactly has Mary done?

Opportunity:
Clarify shared understanding and identify what exactly happened (or needs to happen).



(Lombard,2020; Pilch, 2023)

ACP IS NOT ONE BEHAVIOUR



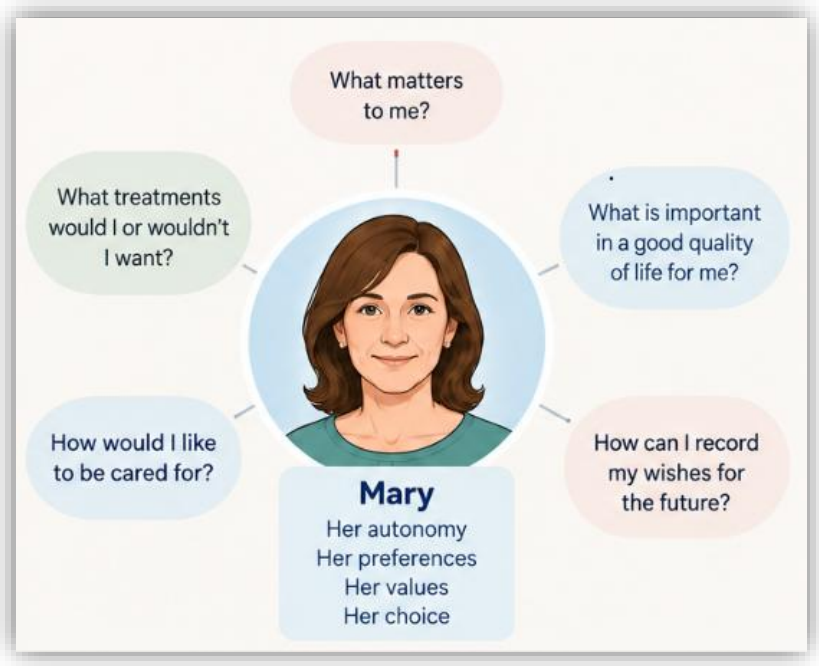
Opportunity:
Ackowledge that ACP happens between people, within a context.

More info in Pilch (2023), Pilch et al. (2025)

WHOSE AUTONOMY?

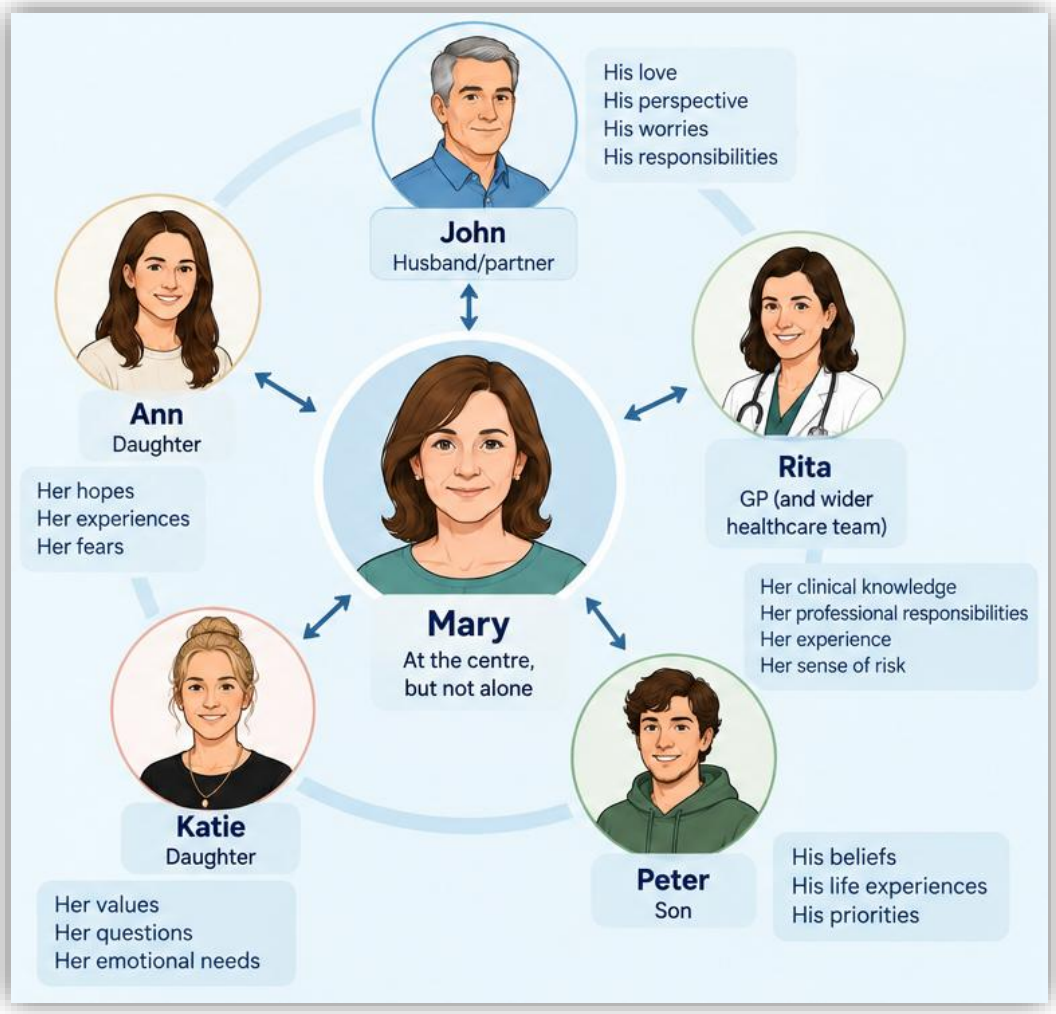
CHALLENGE 3
FROM INDIVIDUAL AUTONOMY TO RELATIONAL AUTONOMY?

Are different relationships and perspective aligned?



(Kutner, 1969)

Opportunity: **Build enough shared understanding for preferences to be meaningfully enacted.**



(Robinson, 2011; Killackey et al., 2020)

CHOICE IS MORE COMPLICATED THAN IT LOOKS

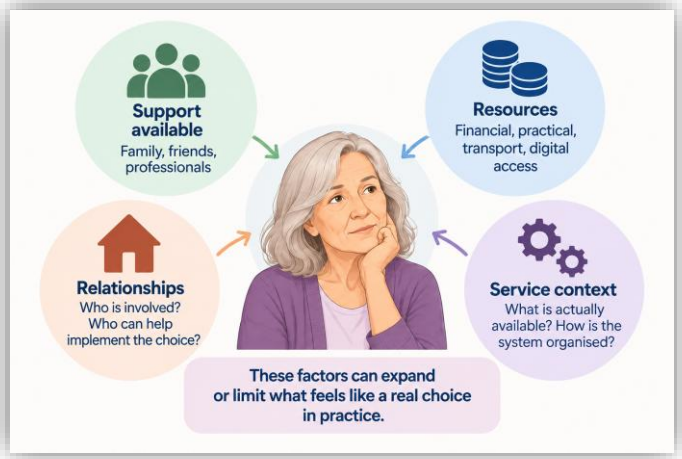
CHALLENGE 4
WHAT MAKES CHOICE MEANINGFUL?

Ogden et al. (2009)

Does Mary have options?

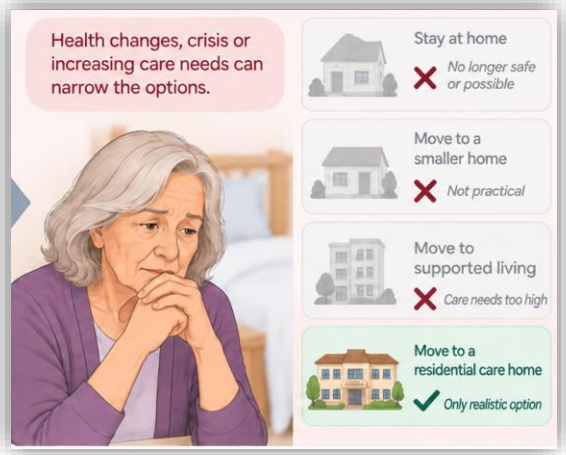
Does Mary want to make the decision?

Are those options genuinely possible for her?



Rabiee (2013)

Opportunity: Not only offer choice, support meaningful choice.

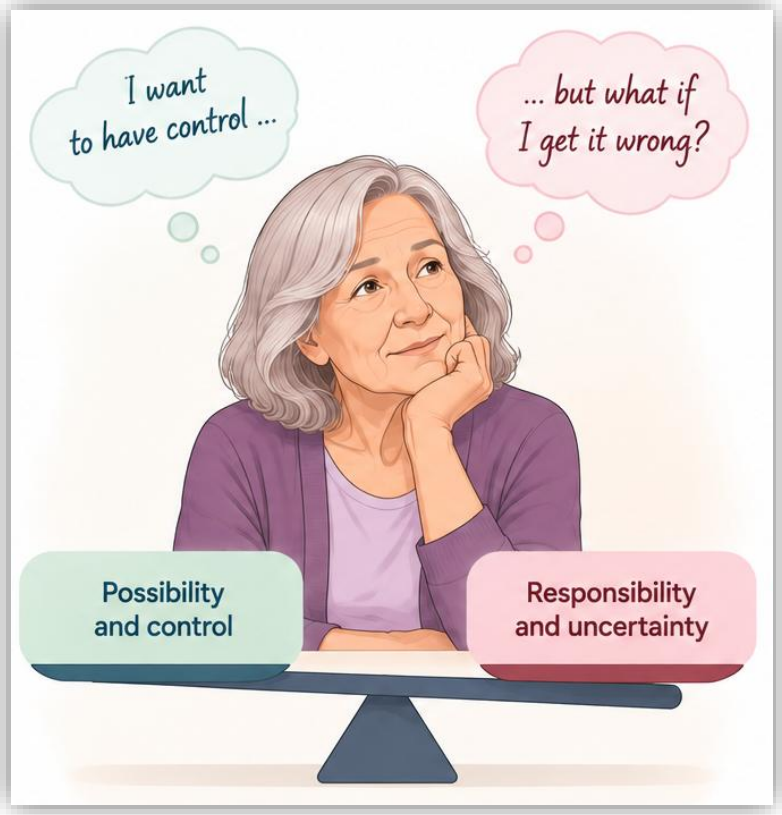


Nord (2016)

WHEN CHOICE BECOME A BURDEN?

How do we approach (read: avoid) sensitive topics?

Escaping from freedom



(Fromm, 1941)

Death anxiety

(Gao et al., 2025)

Opportunity: Rather than maximising choice, support people to exercise the amount and form of choice they want.

THE CONVERSATION WE SAY WE WANT

CHALLENGE 5
DOCUMENTATION OR CONVERSATION?

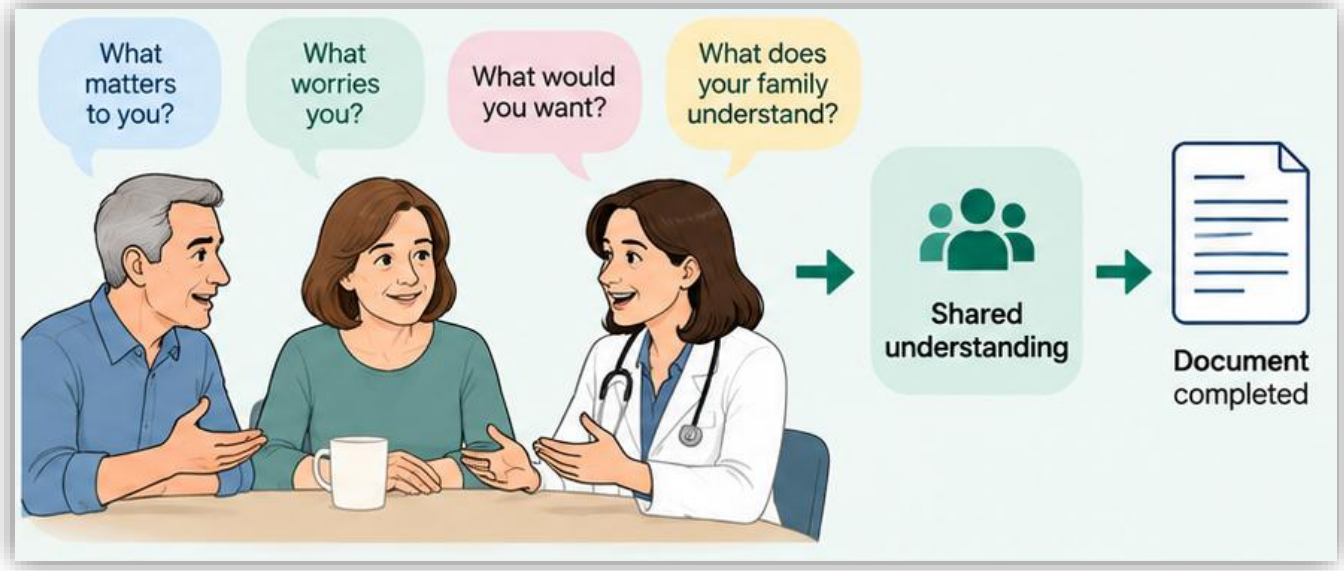
Do we have infrastructure for supporting high-quality conversations that produce high-quality documents?

Number 64 of 2015

Assisted Decision-Making (Capacity) Act 2015

seirbhís tacaíochta cinnteoireachta
decision support service

Irish Hospice Foundation
To die and grieve well wherever the place



Opportunity: Understand the conversational processes that produce shared understanding, not simply better documentation.

A document is an output. Shared understanding is the process.

Sudore & Fried (2010); Sudore et al. (2017); Rietjens et al. (2017)

TRUST: NECESSARY, BUT NOT SIMPLE

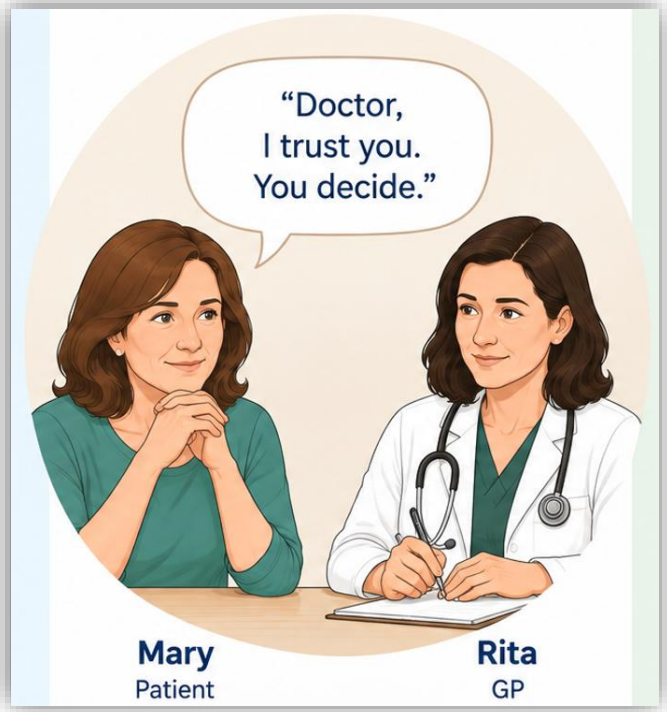
CHALLENGE 6
TRUST YOUR HEALTHCARE PROFESSIONAL

Foundational

For patients

Trust enables...

- Vulnerability
- Disclosure
- Engagement



For healthcare professionals

Trust is valued...
but it has limits.

- Valued
- Has limits
- Carries responsibility

Opportunity: **Consider what do people mean when they say: 'I trust you'. What builds trust? What damages it? Do not assume we understand.**

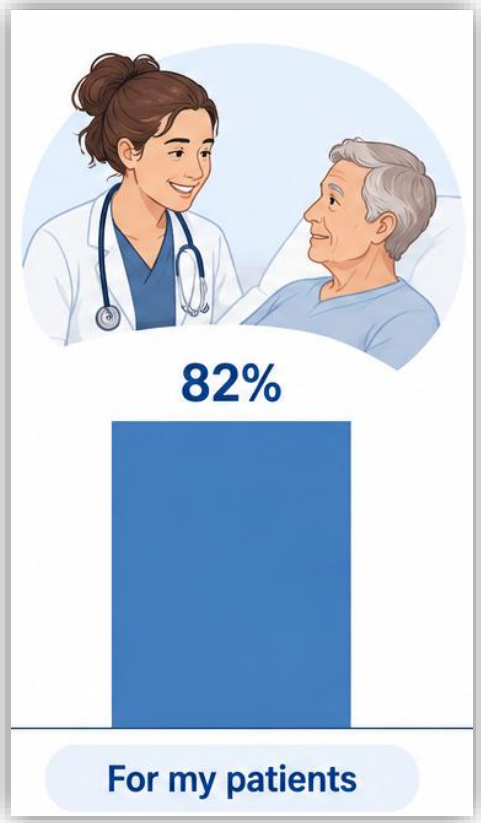
(Acerbi, Gleeson, McQuillan, Pilch, *in preparation*)

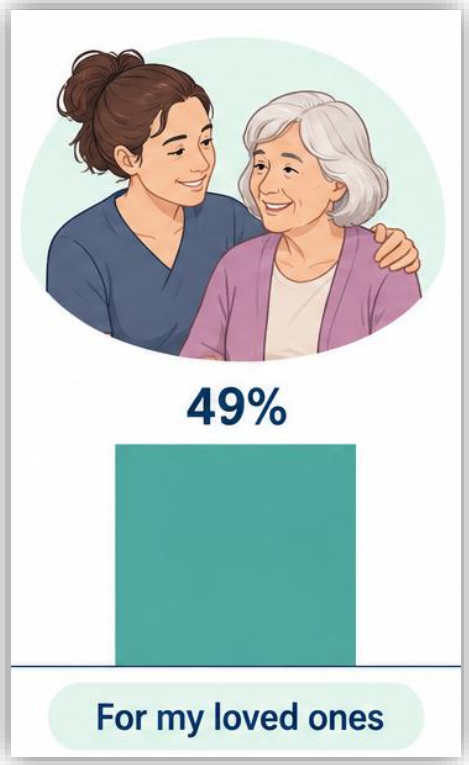
THE PROFESSIONAL IS ALSO A PERSON

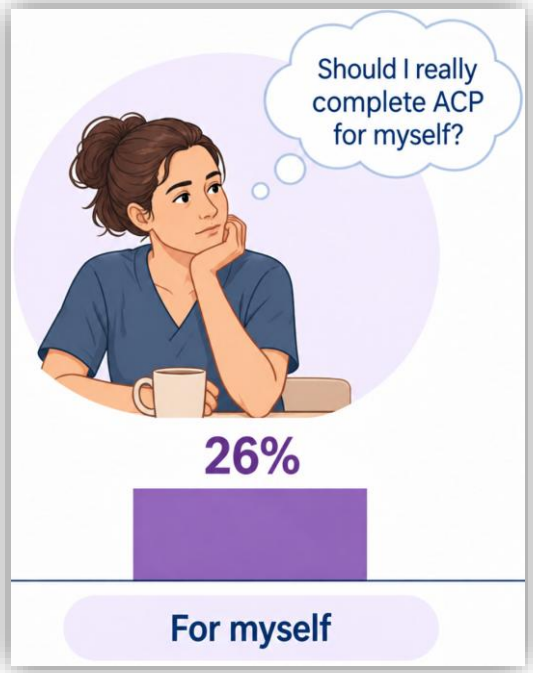
CHALLENGE 7:
WE PRETEND THE CLINICIAN ENTERS ACP AS A NEUTRAL ACTOR

(Pilch, 2023)

ACP IS FOR MY PATIENTS, NOT FOR ME...







Journal of Health Psychology
1–16

DOI: 10.1177/13591053261477733
journals.sagepub.com/home/hpq
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Personal and professional perspectives on advance care planning among palliative care staff: An observational study

Tadhg Gleeson[1], Regina McQuillan[2,3] and Monika Pilch[1]

Opportunity: Understanding self and having the lived experience of ACP processes may help us understand and support others.

(Gleeson, McQuillan, Pilch, 2026)

If you knew you had 100 days left to live, what would you do with this time?
What would really matter to you?

If you became terminally ill, would you aim to extend your life at all cost?

… even if it came at the expense of quality of life and time spent with your loved ones?

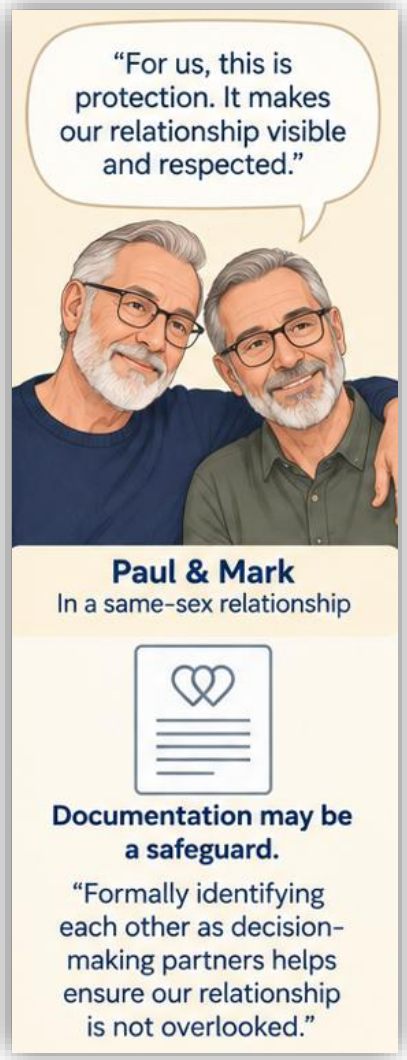
If you become sick and lost capacity to communicate and decide for yourself right now,

would your loved ones know what kind of care you would like to receive?

Have you had these conversations with your loved ones?

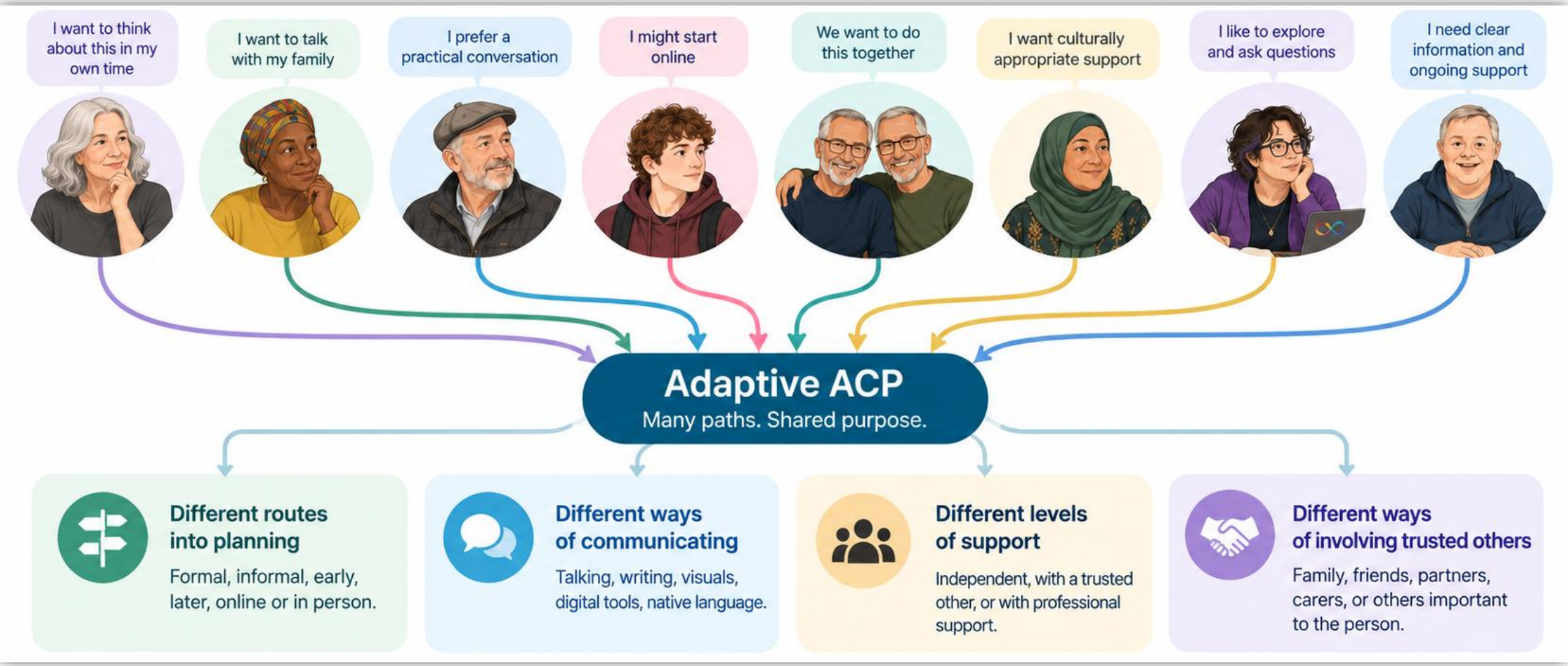
DESIGNING ACP INTERVENTION FOR WHOM?

CHALLENGE 8
THE UNIVERSAL INTERVENTION THAT ISN'T UNIVERSALLY EXPERIENCED



Whitehead (1991); Braveman & Gruskin (2003); Braveman (2006)

EQUALITY IS NOT SAMENESS



(Kacar et al., under review; Pilch, 2023; Thomachan, McQuillan, Pilch, *in preparation;* Goldsmith, McQuillan, Cooper Lunt, Pilch, in preparation)

DOES ACP ACTUALLY WORK?

CHALLENGE 9
THE EVIDENCE PROBLEM

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Notes from the Editor

Advance Directives/Care Planning: Clear, Simple, and Wrong

R. Sean Morrison, MD, Senior Associate Editor

JOURNAL OF PALL
Volume 24, Number
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Weaver et al's Response to Morrison: Advance Directives/Care Planning: Clear, Simple, and Wrong (DOI: 10.1089/jpm.2020.0272)

Meaghann S. Weaver, MD, MPH, FAAP,[1] Lori Wiener, PhD,[2] Shana Jacobs, MD,[3] Cynthia J. Bell, PhD, RN,[4] Vanessa Madrigal, MD,[5] Kim Mooney-Doyle, PhD, RN, CPNP-AC,[6] and Maureen E. Lyon, PhD, ABPP[7]

VIEWPOINT

What's Wrong With Advance Care Planning?

R. Sean Morrison, MD
Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York; and James J. Peters VA Medical Center, Bronx, New York.

Advance care planning (ACP) has emerged during the last 30 years as a potential response to the problem of low-value end-of-life care. The assumption that ACP will result in goal-concordant end-of-life care led to widespread public initiatives promoting its use, physician re-

goal-concordant care or patient quality of life. Additionally, these reviews found no association of ACP with subsequent health care use, including emergency department visits, hospitalizations, and critical care. Subsequently, 5 large multisite randomized clinical trials that

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Senior Associate Editor's Response to Readers' Comments to Morrison: Advance Directives/Care Planning: Clear, Simple, and Wrong (DOI: 10.1089/jpm.2020.0272)

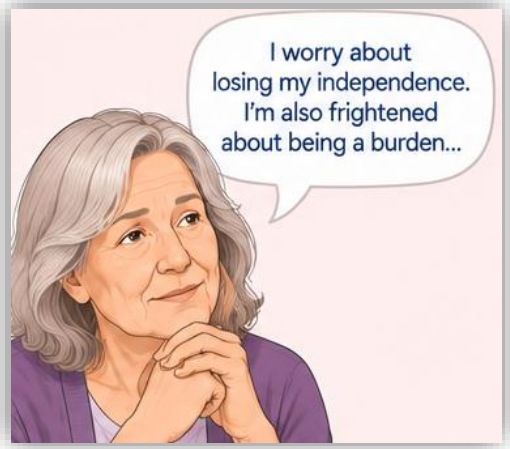
R. Sean Morrison, MD

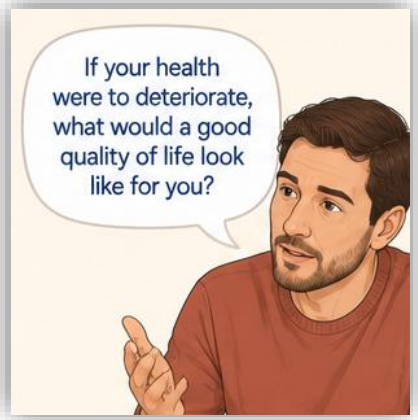
Controversies About Advance Care Planning

To the Editor We have grave concerns about the advance care planning (ACP) evidence review and policy implications presented in the recent Viewpoint,[1] which concluded that ACP is not essential because it does not support goal-concordant end-of-life (EOL) care. First, the authors misrepresented the

Morrison (2020); Weaver et al. (2021); Morrison et al. (2021); Rigby et al. (2022)

PERHAPS WE MEASURE THE WRONG THING?





Mary feels heard.

"I feel relieved. It's a weight off my mind."

John feels more prepared.

"I feel I understand better, and I'm more confident about what to do."

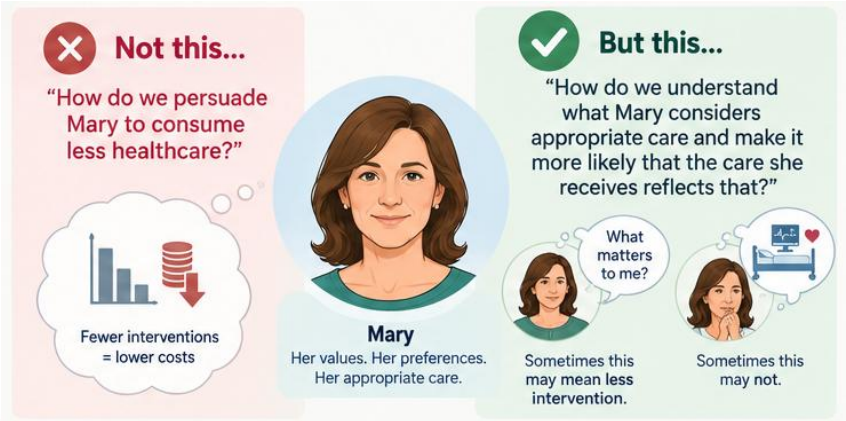
The family understands one another better.

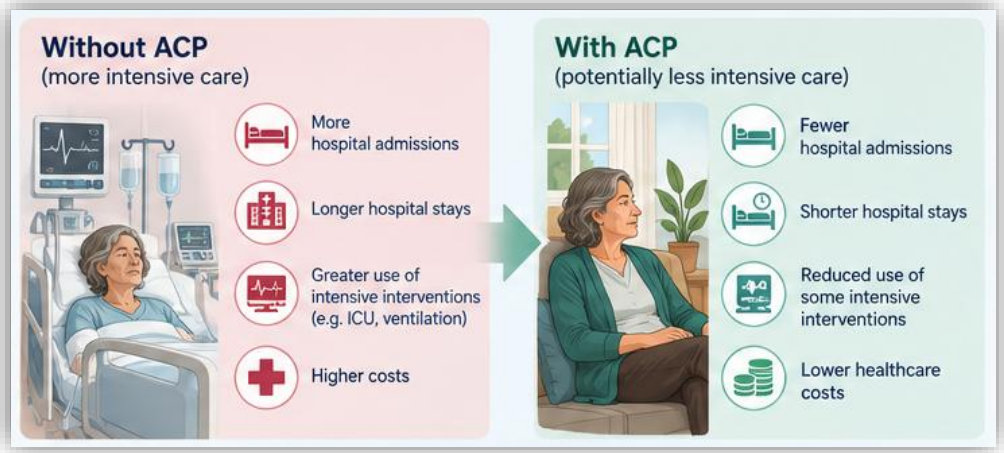
"We feel closer, and we can support each other."

Opportunity: ACP can improve communication, clarification, preparation, and reduced uncertainty.

SAVING COSTS

CHALLENGE 10
WHAT IS ACP TRYING TO SAVE?





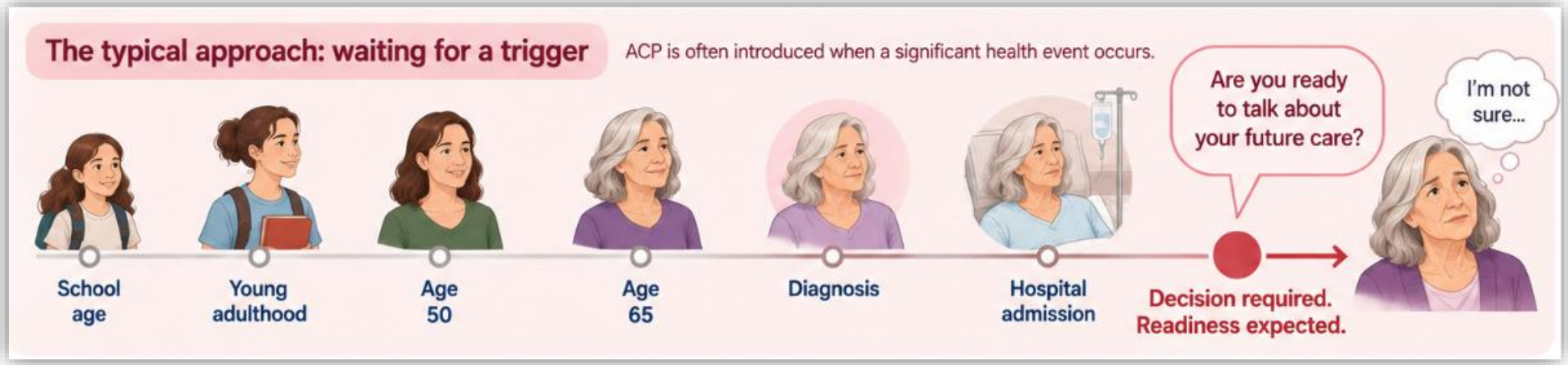
Khandelwal et al. (2015), Klingler et al. (2016), Malhotra et al. (2022)

Wendler & Rid (2011)

Opportunity: Consider:
Cost to whom? Cost of what?

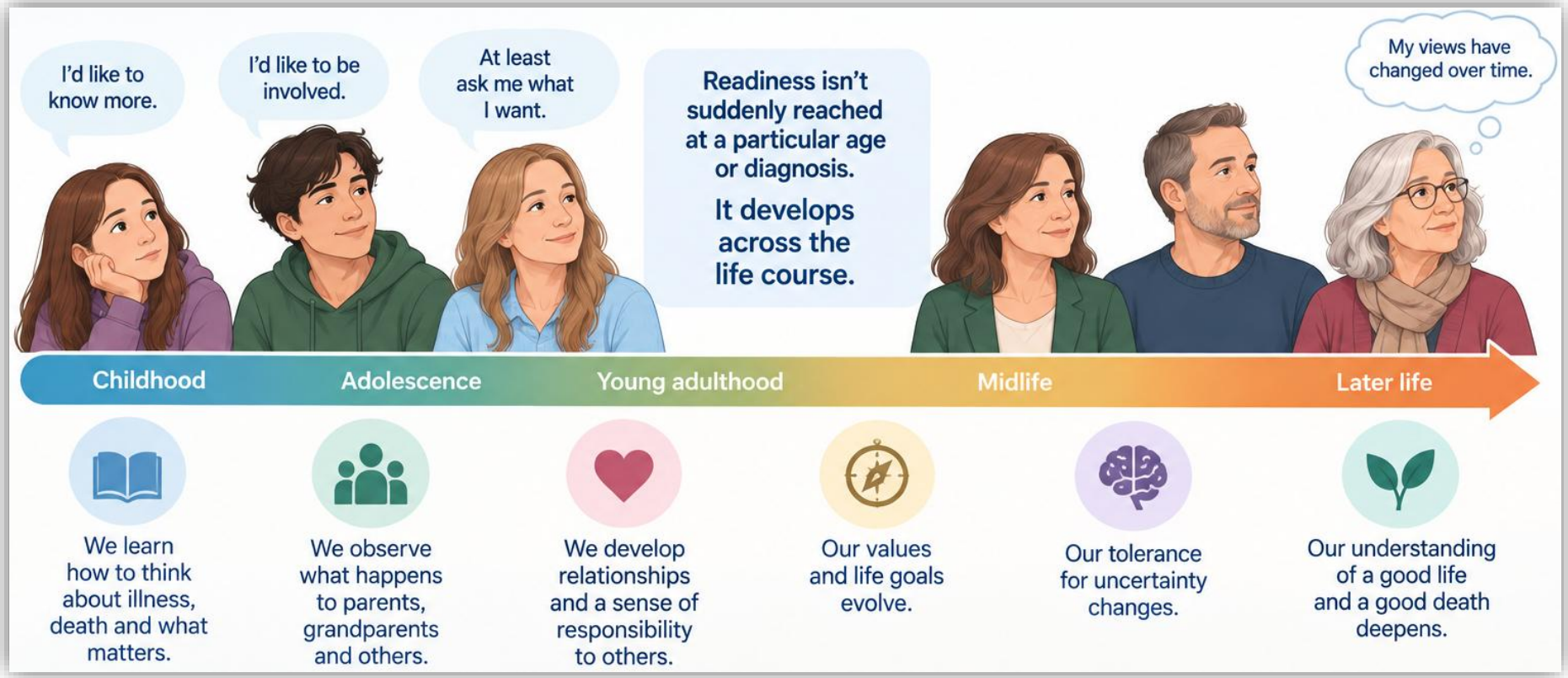
WHEN SHOULD ALL OF THIS HAPPEN?

CHALLENGE 11
WHEN ARE WE“READY” OR HOW DO WE BECOME READY



(Pilch, 2023, 2025)

READINESS, NOT A DEADLINE



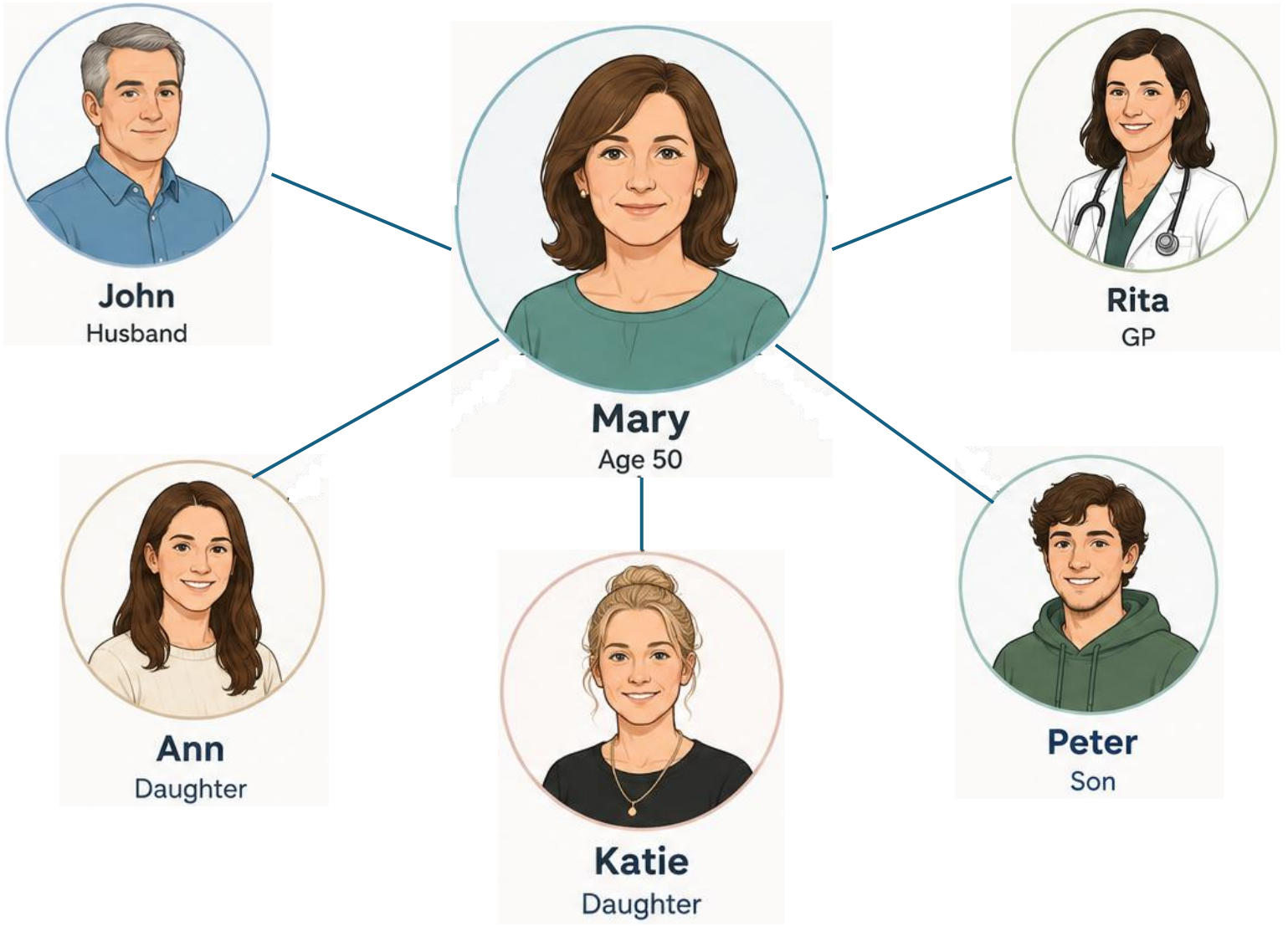
Don't exclude by age.
Younger people may want information, involvement, or at least to be asked.

Ask, don't assume.
Preferences for involvement vary and can change over time.

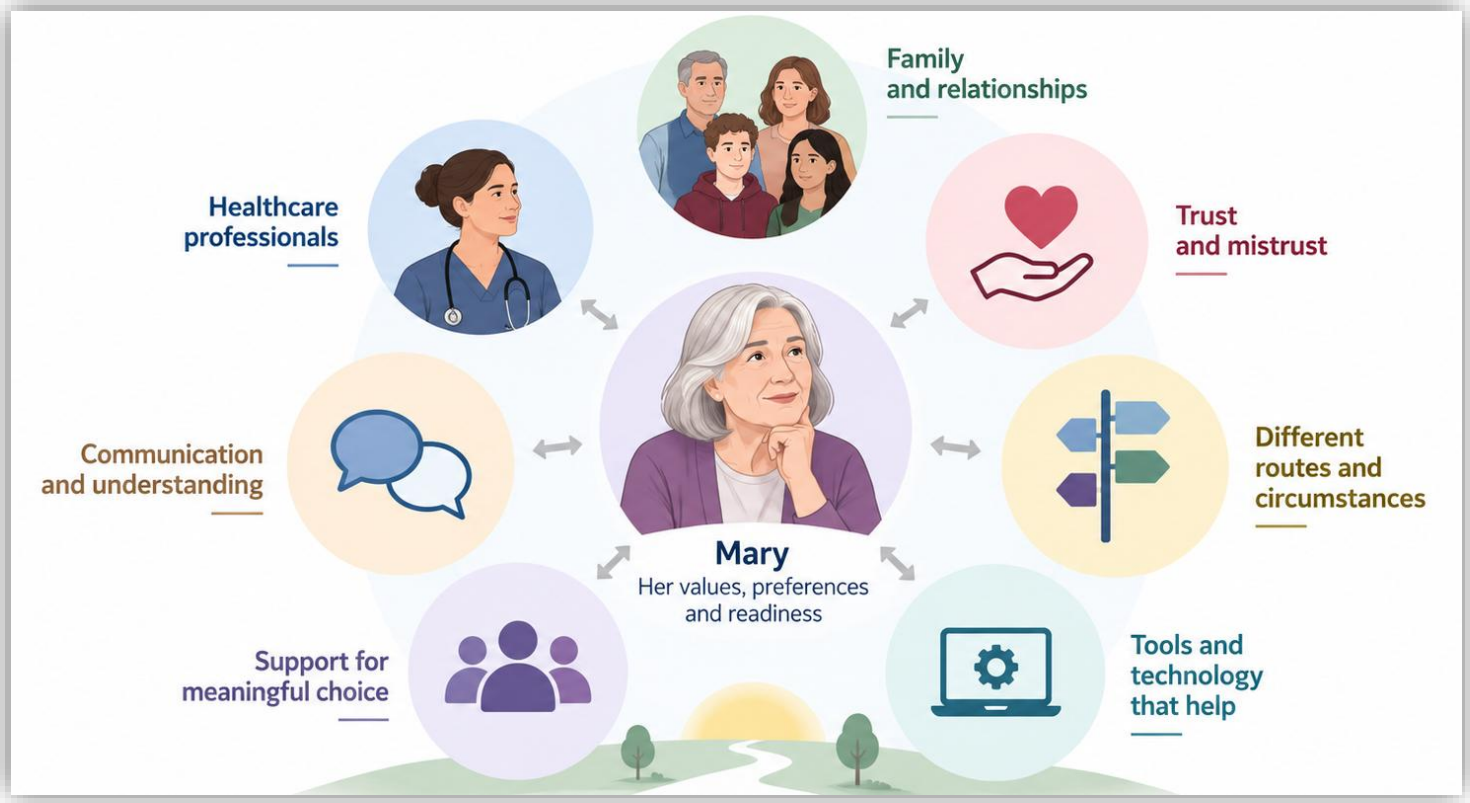
Support readiness across the life course.
Conversations, experiences and reflection help build the capability for future decisions.

(Pilch, 2023; Kacar et al., *under review;* Hamed Aly et al. *in preparation*)

BACK TO MARY


John
Husband
Mary
Age 50
Rita
GP
Ann
Daughter
Katie
Daughter
Peter
Son

THE OPPORTUNITY
FROM ACP AS A TASK TO ACP AS A DYNAMIC RELATIONAL SYSTEM EMBEDDED IN BROADER SYSTEMS



St. Francis Hospice Dublin

Beaumont Hospital
Ospidéal Beaumont

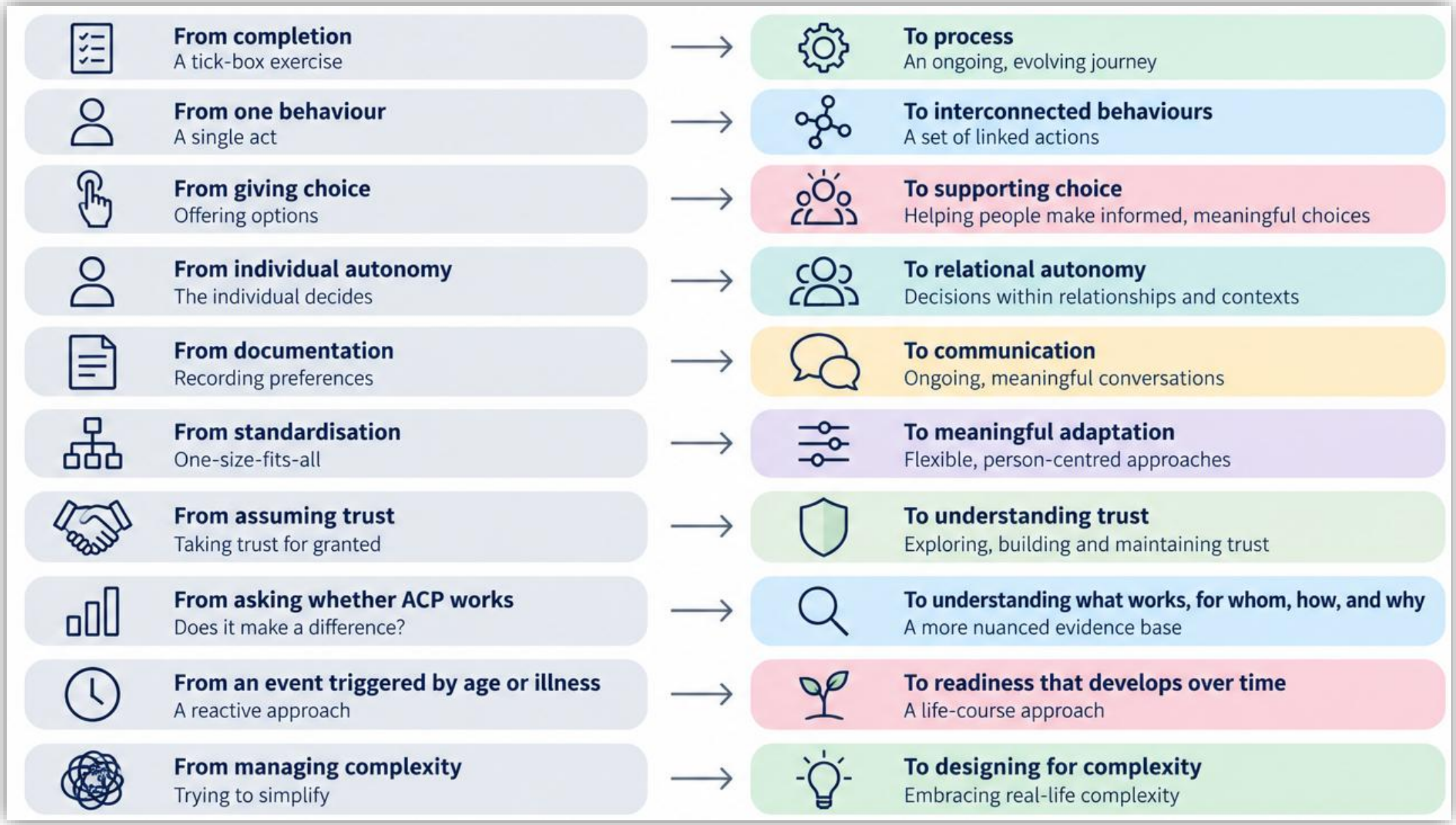
ARC HUB for ICT

Enterprise Ireland

Taighde Éireann Research Ireland

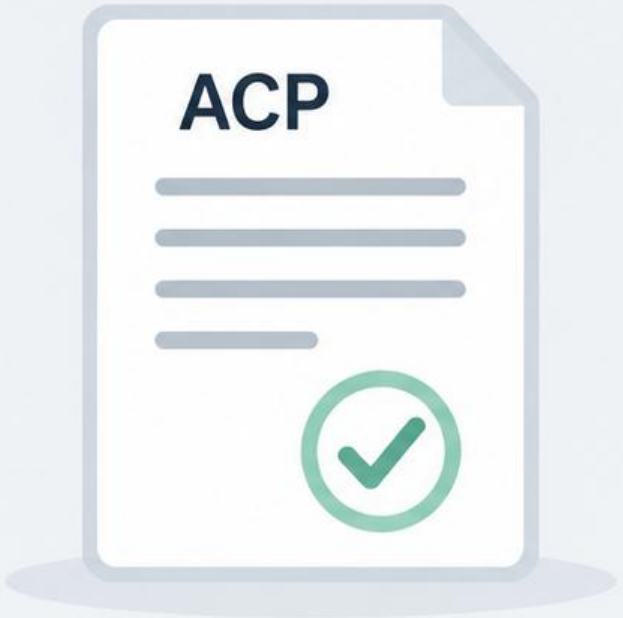
UCD DUBLIN NovaUCD

RETHINKING ACP



Not the goal:

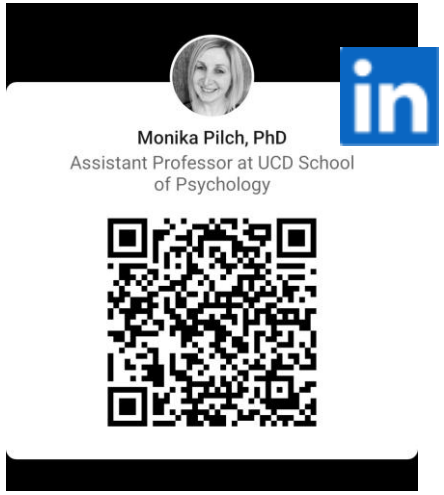
A completed ACP.



The goal is:

A person whose future care can still reflect who they are, even when they can no longer tell us.

Thank you



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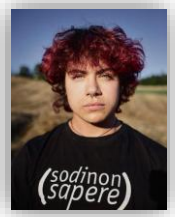

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DRAGONFLY LAB

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Dragonfly Lab logo: Marco Acerbi, 2026

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