1ER COLLOQUE INTERNATIONAL ADVANCE CARE PLANNING (ACP)

ACP dans le monde - ACP en France.
Du concept international à la mise en œuvre française

1ST INTERNATIONAL ADVANCE CARE PLANNING (ACP) SYMPOSIUM

ACP in the world - ACP in France.
From an international context to implementation in France

Mise en œuvre de la planification anticipée des soins, réussites et défis

Paris, vendredi 7 février 2025

Cristina Lasmarías
Infirmière. Responsable de la planification de la gériatrie et des soins palliatifs du ministère de la Santé de Catalogne
Vice-président de l'Association espagnole de ACP

Je déclare qu'il n'y a aucun conflit d'intérêt avec cette présentation.

Paris, 07 février 2025

Definition

Implementation meaning:

“The act of making something that has been officially **decided start to happen** or be used” (Oxford Dictionaries)

"The act of **putting a plan** or system into **operation**.“ (Cambridge Dictionary)

Is it possible to implement ACP?

The *success* of ACP depends on 8 steps

1. patients can articulate their values and goals and identify which treatments would align with those goals in hypothetical future scenarios
2. clinicians can elicit these values and preferences
3. preferences are documented
4. directives or surrogates are available to guide clinical decisions when patients' preferences have not changed and they lose enough decisional capacity for their ACP views to become operative
5. surrogates will invoke substituted judgment (make the decision the patient would make if they were able) and base their treatment decisions on the patient's prior stated preferences;
6. clinicians will read prior documents and integrate patient preferences into conversations with surrogates
7. previously expressed wishes will be honored;
8. health care systems will commit resources and care delivery to support goal-concordant care.

HHS Public Access
Author manuscript
JAMA. Author manuscript; available in PMC 2022 August 12.

Published in final edited form as:
JAMA. 2021 October 26; 326(16): 1575–1576. doi:10.1001/jama.2021.16430.

What's Wrong With Advance Care Planning?

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Diane E. Meier, MD,
Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York.

Robert M. Arnold, MD
Section of Palliative Care and Medical Ethics, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania.

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 wide-spread public initiatives promoting its use, physician reimbursement for ACP discussions, and use as a quality measure by the Centers for Medicare & Medicaid Services, commercial payers, and others. However, the scientific data do not support this assumption. ACP does not improve end-of-life care, nor does its documentation serve as a reliable and valid quality indicator of an end-of-life discussion.

Morrison RS, Meier DE, Arnold RM. What's Wrong With Advance Care Planning? *JAMA.* Published online October 08, 2021. doi:10.1001/jama.2021.16430

A PIECE OF MY MIND

Three Stories About the Value of Advance Care Planning

J. Randall Curtis, MD, MPH
Cambia Palliative Care Center of Excellence at UW Medicine, University of Washington, Seattle; and Division of Pulmonary, Critical Care, and Sleep Medicine, Department of Medicine, Harborview Medical Center, University of Washington, Seattle.

There is an ongoing debate among the palliative care community about the value of advance care planning and whether current evidence suggests that advance care planning is inherently ineffective. I'm not writing this essay to take a side in this debate—I believe both sides have merit. Rather, I write to tell 3 personal stories of the role advance care planning has played for my family and in my own life. My entire career has focused on developing and evaluating ways to improve communication with patients and families about serious illness care. These 3 stories are informed by that experience and yet are told not from the perspective of a physician and researcher, but from the perspective of a son-in-law, son, and patient.

The first story is about my mother-in-law. She was a vivacious and strong-willed woman who cared deeply for her family. When she was in her mid-70s, she underwent a multilevel lumbar fusion for insufferable pain and had a cardiac arrest on the operating table. Once it became clear that she was unlikely to ever regain consciousness, our family gathered with the medical team in the family conference room of the intensive care unit where she lay. As part of that meeting, we read aloud her handwritten living will, a letter to her family saying that she would never want to be kept alive on life support if she did not have the ability to interact with, and express love to, her family. This document did not

> I share these stories as examples of the diverse ways that advance care planning can support resilience, understanding, feelings of peace, and recovery from grief...

change the care she received at all because there was no doubt among any of us, even without that letter, that she did not want to be kept alive by life-support machines under these circumstances. In addition, despite our family's experiences of grief and sadness, I don't believe that any objective scale of symptoms of anxiety and depression experienced by our family would have been measurably altered by that letter. And yet, that letter was a profound source of comfort to my wife, my father-in-law, my brother-in-law, and me.

The second story is about my own mother. She was a remarkable woman who had polio as a teenager and lived her adult life in a wheelchair with one weak arm. Despite these physical limitations, she overcame adversity to marry her high school sweetheart, have 2 children, return to college after her kids were in school, and have a long career in academic administration. When she was in her late 70s, my extended family sat together to review The Conversation Project,[1] a guided conversation about our values and goals as they relate to end-of-life care. My mother's values represented what could be called a "values conflict." Her years living with disability made her fiercely independent, yet she was also an incredibly adaptable person who faced each new challenge with remarkable optimism. A couple of years after this conversation, she developed progressive postpolio syndrome and dementia, becoming unable to leave her bed, confused, and forgetful. The values elicited during the earlier exercise did not help our family decide whether her quality of life was one that she would find acceptable. We knew she wouldn't want to be hospitalized or have a feeding tube or be placed on a ventilator, but we struggled as a family to understand how to use her previously expressed values to guide decision-making about active feeding and oxygen therapy. Some of us put more weight on independence and others on adaptability. Even though this advance care planning didn't resolve differences in our opinions about the best care for my mother, knowing her values enabled us to understand and accept these divergent perspectives about what she would want and provides great comfort to me today about why we struggled with decisions for her end-of-life care. That initial discussion helped to prepare us as a family for having difficult discussions when they became necessary for medical decision-making. And yet, the value of this conversation would also not be captured by traditional outcome measures used to evaluate the benefits of advance care planning.

The third story is about me. In March 2021, I was diagnosed with bulbar-onset amyotrophic lateral sclerosis giving me a projected median survival of 2 to 4 years. My speech and swallow are deteriorating, and I am looking ahead to a future with decisions about a gastrostomy tube and tracheostomy. Discussing advance care planning with palliative care specialists—whether they are my friends or my own doctors and care team—helps me tremendously in coming to terms with my illness and making the most of the time I have left. These discussions help me focus more on joy and gratitude and a little less on grief and fear. Since I'm still in the midst of my terminal illness journey, the jury is out as to whether the value of these discussions can be measured with available outcome measures. I doubt it can.

I share these stories not as irrefutable evidence of the importance of advance care planning; they are only 3 anecdotes in a sea of anecdotes and rigorous research. Instead, I share these stories as examples of the diverse ways that advance care planning can support resilience, understanding, feelings of peace,

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Section Editor: Preeti Malani, MD, MSJ, Associate Editor.

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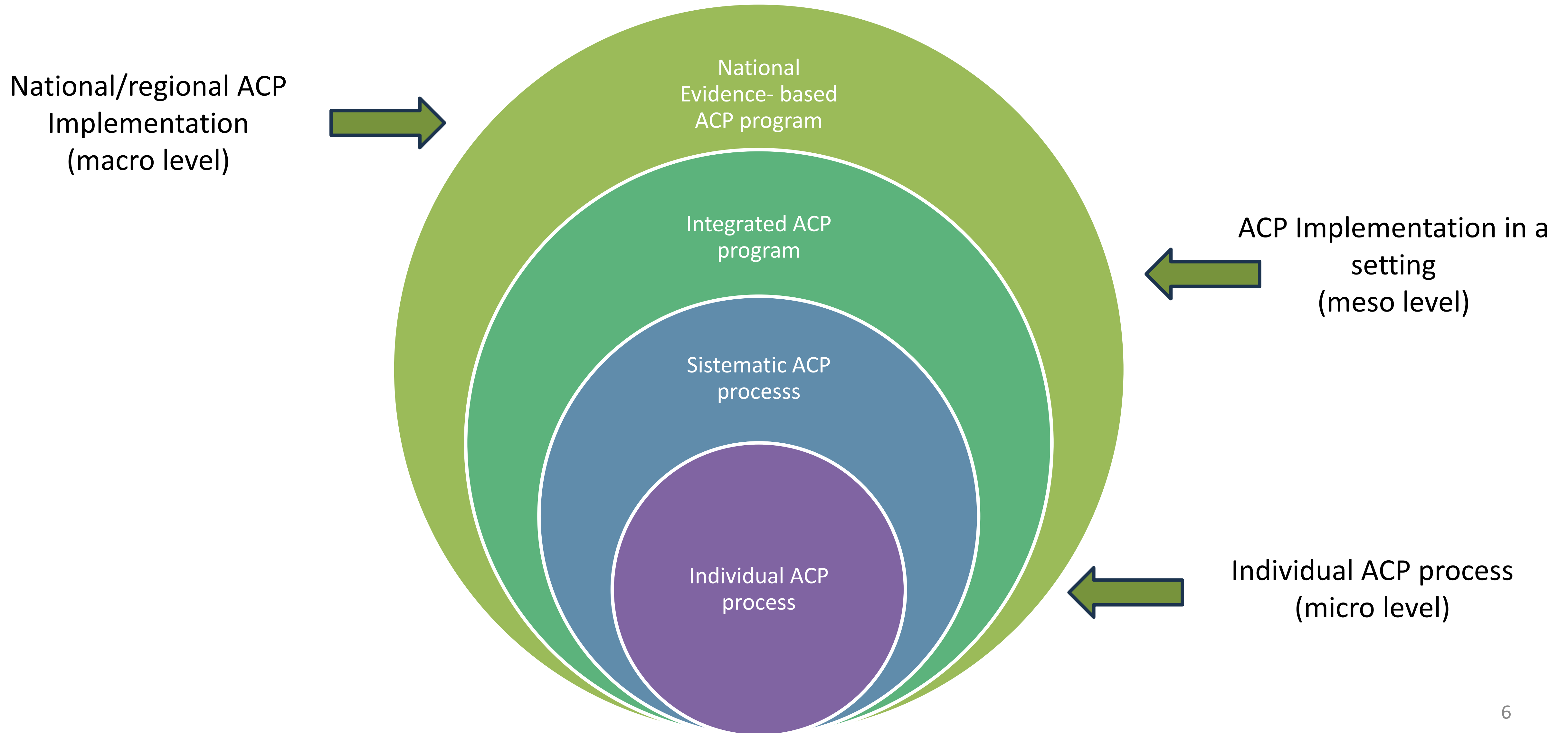
A personal experience

- His mother in law: writing living wills
- His mother: *The conversation project*
- Himself:

"Discussing advance care planning with palliative care specialists helps me tremendously in coming to terms with my illness and making the most of the time I have left.

These discussions help me focus more on joy and gratitude and a little less on grief and fear"

Implementing ACP: preliminary steps



Preliminary questions

- What do you want to do?
- Who will be involved?
- Who will be targeted?
- Where will be the intervention done?
- When ACP process will be conduct?

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1) Micro level context

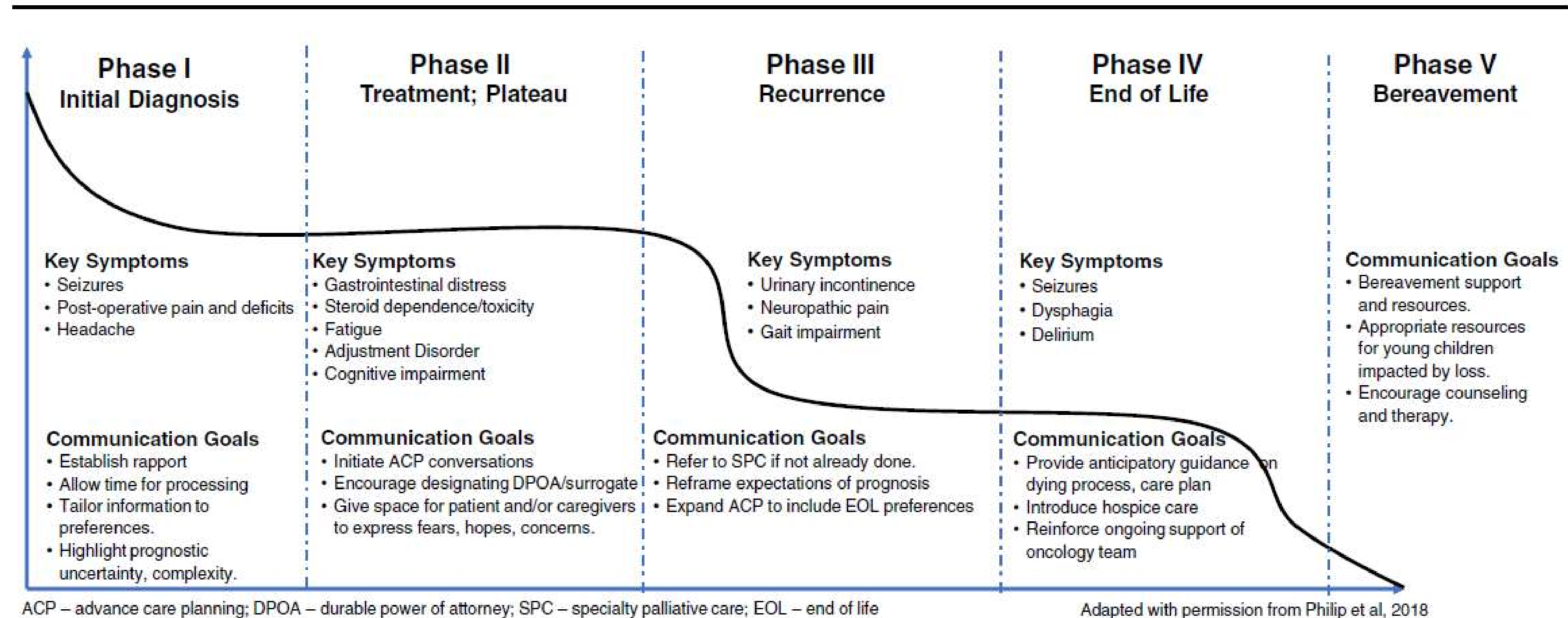
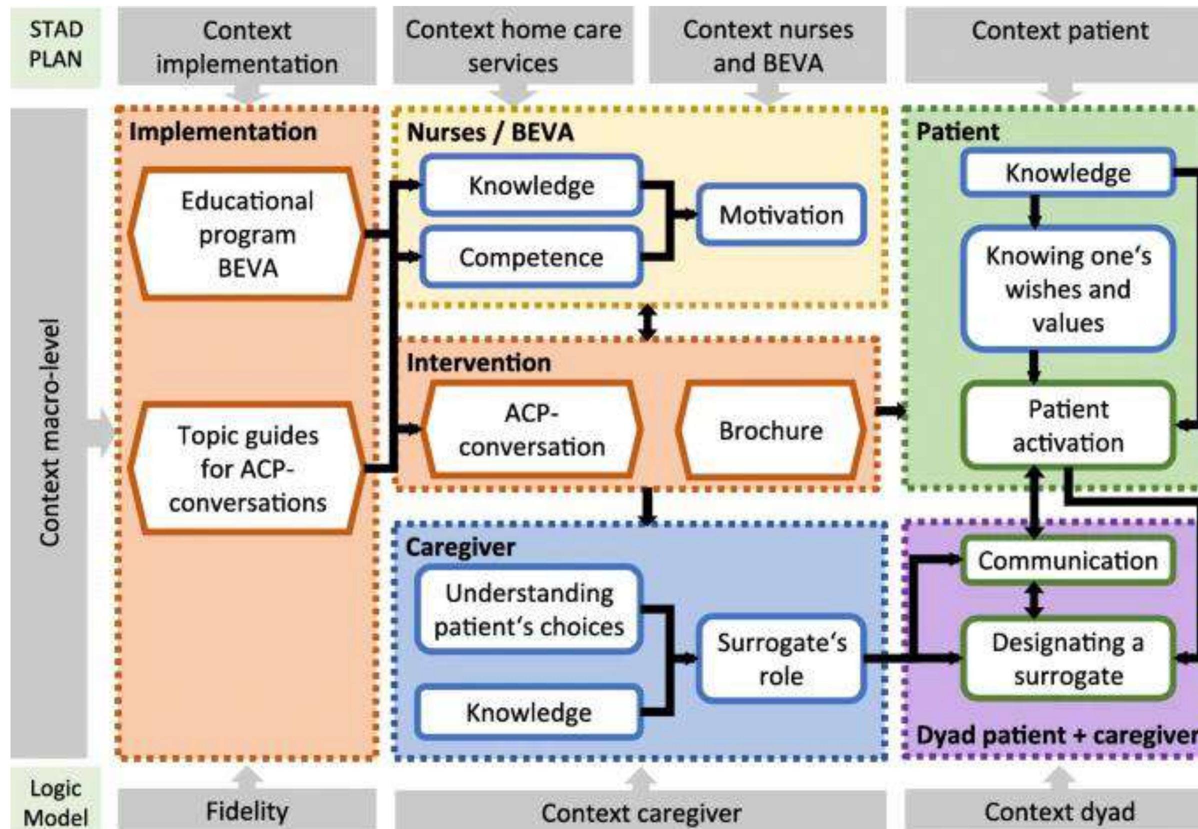


Fig. 1 Disease trajectory for the high grade glioma patient

Crooms, R.C., Johnson, M.O., Leeper, H. *et al.* Easing the Journey—an Updated Review of Palliative Care for the Patient with High-Grade Glioma. *Curr Oncol Rep* **24**, 501–515 (2022). https://doi.org/10.1007/s11912-022-01210-6

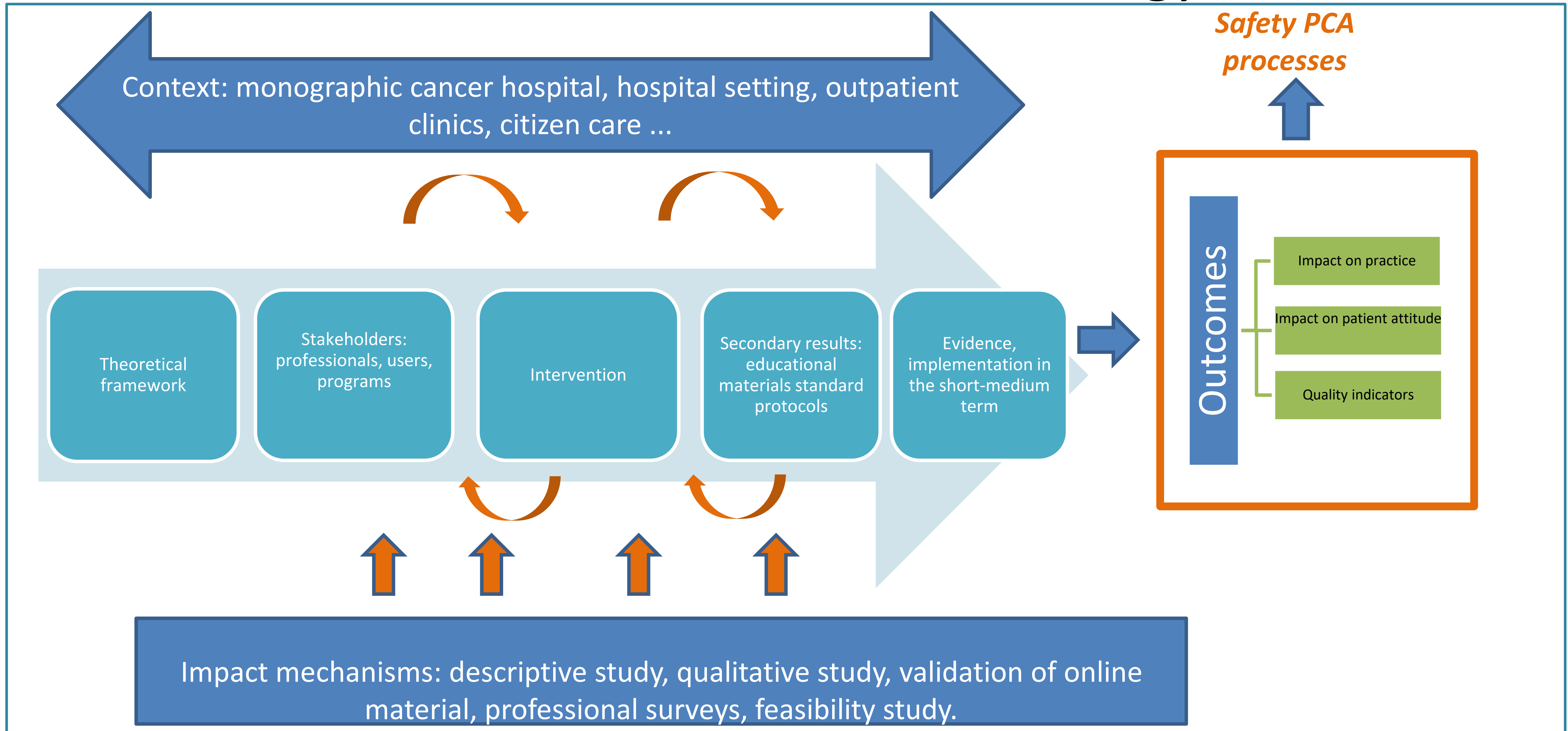
2) Meso level context



Components of the complex intervention—the STADPLAN logic model. BEVA, trained nurse facilitator; ACP, advance care planning; patient, participating client of the home care service; caregiver, family caregivers or surrogates of the participating patient

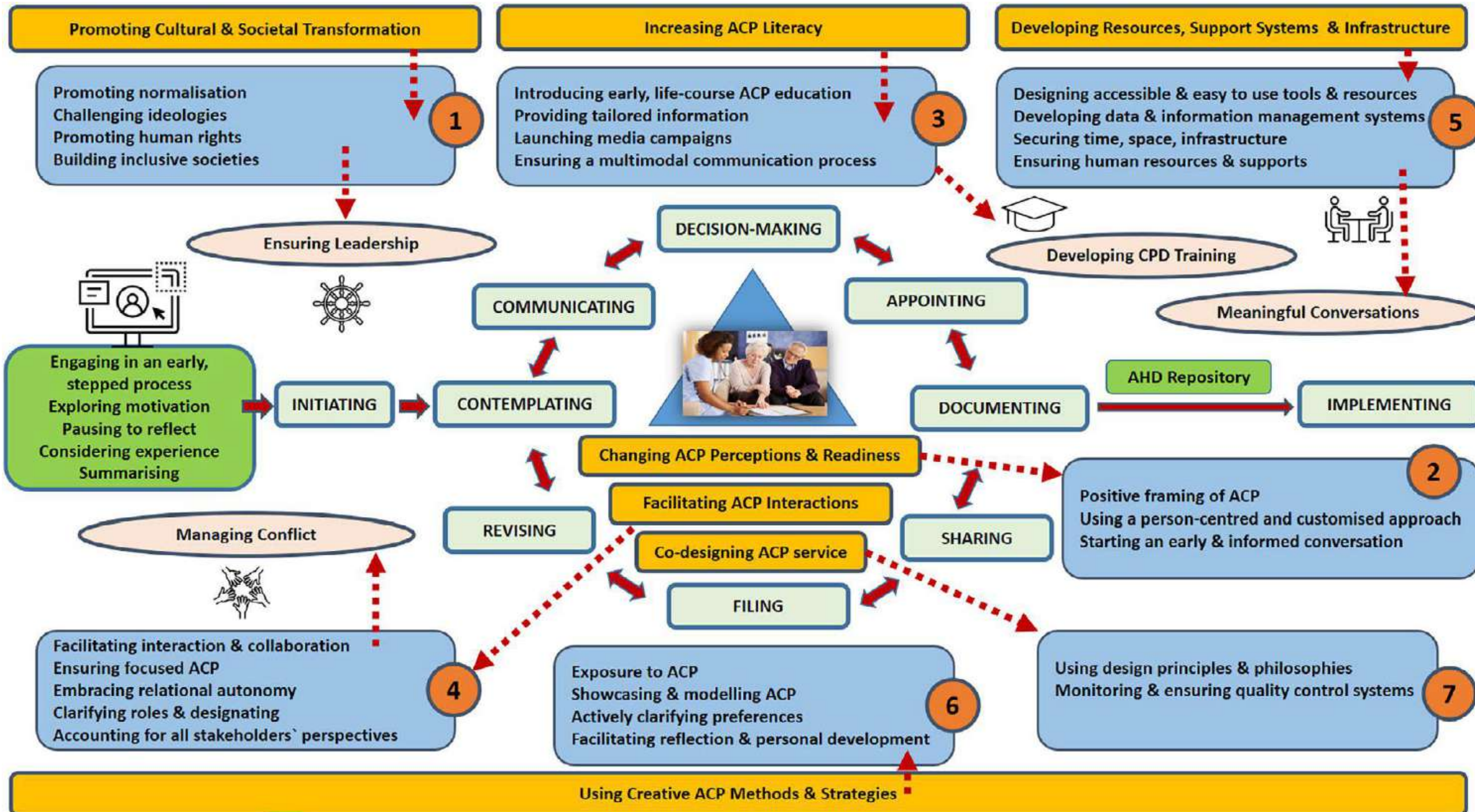
Silies, K., Schnakenberg, R., Berg, A. *et al.* Process evaluation of a complex intervention to promote advance care planning in community-dwelling older persons (the STADPLAN study)—study protocol. *Trials* **21**, 653 (2020). https://doi.org/10.1186/s13063-020-04529-2

The Catalan Institute of Oncology



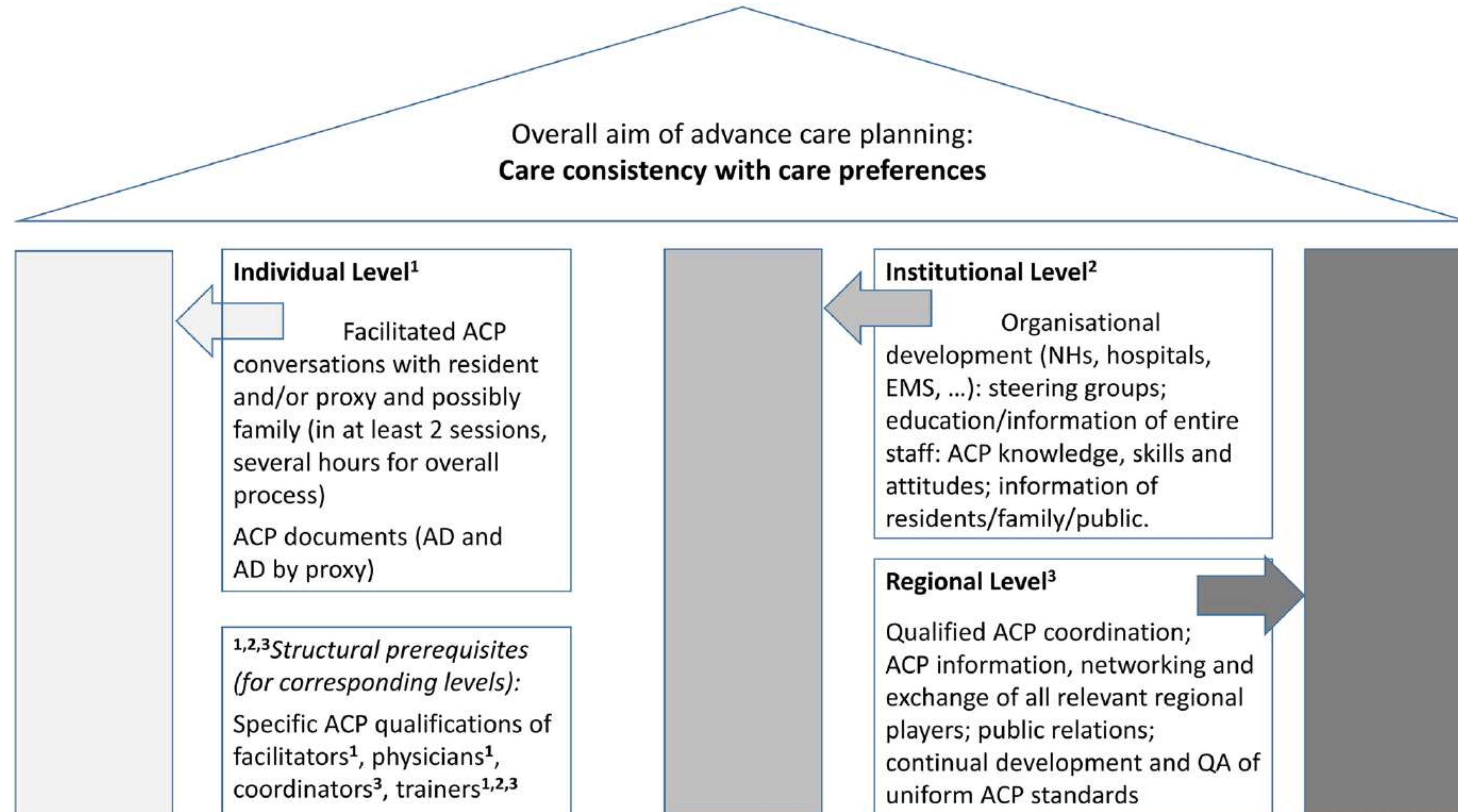
Lasmarías et al. *Perceptions and experiences of onco-haematology professionals in relation to advance care planning: a qualitative study*. Supportive Care in Cancer (2024) 32:180

3) Macro level context



Pilch M, Hayes CB, Harney O, Doyle F, Thomas S, Cooper Lunt V, Hogan M. Using Collective Intelligence to Develop Design Requirements for a Complex Intervention for Advance Care Planning in the Community. J Clin Nurs. 2025 Jan;34(1):230-246. doi: 10.1111/jocn.17549.

Overview of the elements of the regional ACP program



Götze K, et al.; BEVOR study group. Effectiveness of a complex regional advance care planning intervention to improve care consistency with care preferences: study protocol for a multi-center, cluster-randomized controlled trial focusing on nursing home residents (BEVOR trial). Trials. 2022 Sep 12;23(1):770. doi: 10.1186/s13063-022-06576-3.

The Spanish experience

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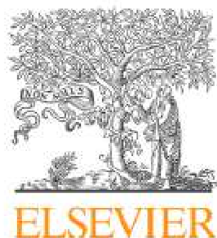
Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ) 180 (2023) 143–149



Contents lists available at ScienceDirect

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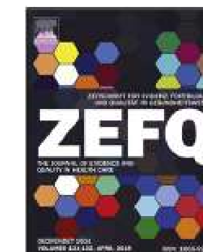
journal homepage: http://www.elsevier.com/locate/zefq



Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives“

Advance Care Planning in Spain

Advance Care Planning in Spanien

Cristina Lasmarías [a,*], Virginia Carrero [b], Júlia Fernández-Bueno [c], Helena García-Llana [d], Nani Granero-Moya [e], Javier Júdez [f], Núria Pérez de Lucas [g], Iñaki Saralegui [h], Tayra Velasco [i]

https://www.zefq-journal.com/issue/S1865-9217(23)X0006-3

In Spain...

Share Care Planning /Advance Directives Program 2015. Lead by The Basque Ministry of Health. I Saralegui

/Salut Generalitat de Catalunya

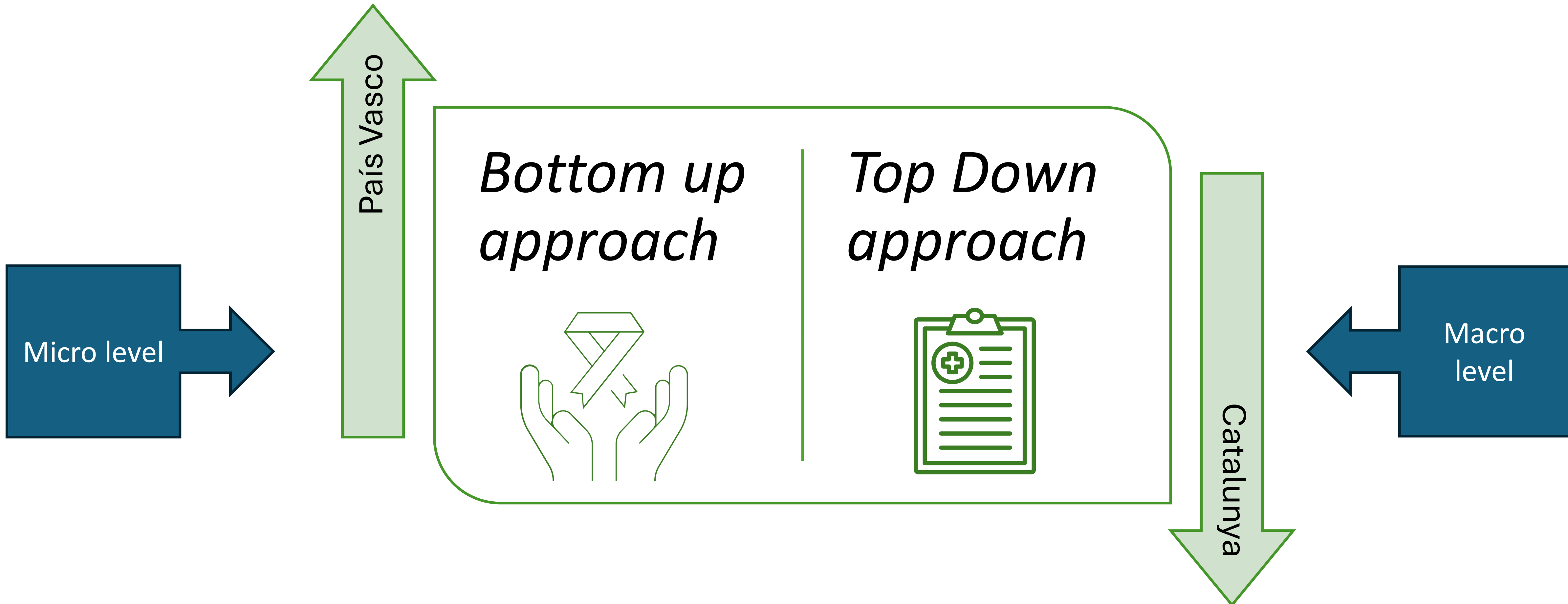
Less than 1 % people in Spain, has formalized an Advance Directive Document

The Catalan Model of Advance Care Planning. 2014. Ministry of Health and the Chair of Palliative Care

The ACP Spanish Association (2020)

/Salut Generalitat de Catalunya

Two models



The Catalan experience

/Salut Generalitat de Catalunya

ACP Catalan Project

- From 2011 to 2015 Chronic Care program was implemented
- ACP was included into the Model of Chronic care
- Over 11.000 professionals into the public health system

2014 Catalan ACP Project: Aim

To develop and implement the Catalan model of ***Advance Care Planning (ACP)*** for Chronic and Advanced Patients, in all settings, health and social services

Where will be the intervention done

Population targeted

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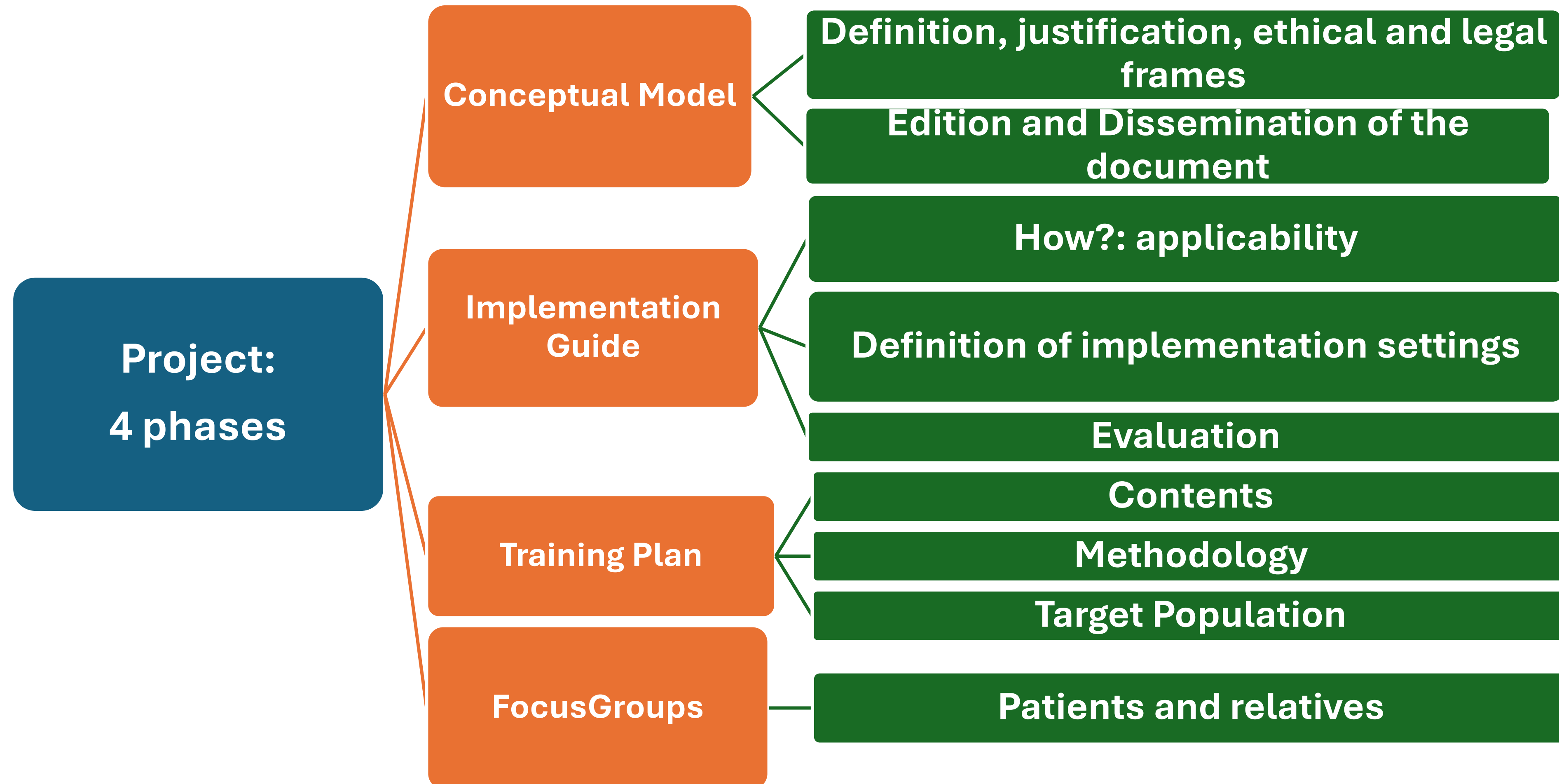
Methodoloy. Phases



Definition

PLANIFICACIÓ DE DECISIONS ANTICIPADES
(Advance Care Planning)

The plan to identify the patient's (and family, if convenient) values and preferences to foresee the care provision objectives and the resources needed to take care of him/her.

http://www.termcat.cat/docs/PDF/Cronicitat/Cronicitat.html

Products

/Salut Generalitat de Catalunya

✓Conceptual Model:

Open access

Model català de planificació de decisions anticipades

Document conceptual

Versió 7, de 9 de maig de 2015
Grup de treball del Model català de planificació de decisions anticipades

✓Implementation Guide:

Open access

Guia per a l'aplicació pràctica de la planificació de decisions anticipades

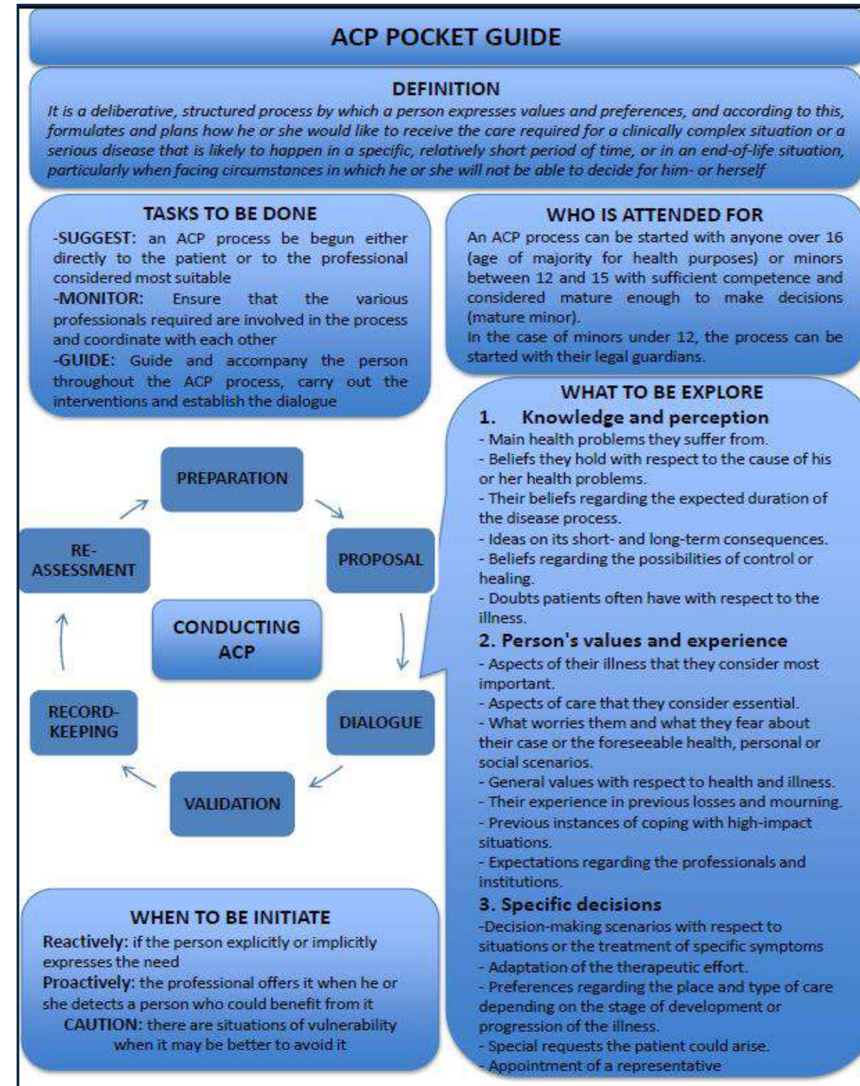
Document pendent de validació per CEC CESSC

GRUP DE TREBALL DEL MODEL CATALÀ DE PLANIFICACIÓ DE DECISIONS ANTICIPADES

Versió 11, de 4 de maig de 2015

ACP Pocket guide

- ✓ Useful
- ✓ Understandable
- ✓ Handy



ACP POCKET GUIDE

DEFINITION

It is a deliberative, structured process by which a person expresses values and preferences, and according to this, formulates and plans how he or she would like to receive the care required for a clinically complex situation or a serious disease that is likely to happen in a specific, relatively short period of time, or in an end-of-life situation, particularly when facing circumstances in which he or she will not be able to decide for him- or herself

TASKS TO BE DONE

-**SUGGEST:** an ACP process be begun either directly to the patient or to the professional considered most suitable
-**MONITOR:** Ensure that the various professionals required are involved in the process and coordinate with each other
-**GUIDE:** Guide and accompany the person throughout the ACP process, carry out the interventions and establish the dialogue

WHO IS ATTENDED FOR

An ACP process can be started with anyone over 16 (age of majority for health purposes) or minors between 12 and 15 with sufficient competence and considered mature enough to make decisions (mature minor).
In the case of minors under 12, the process can be started with their legal guardians.

WHAT TO BE EXPLORE

1. **Knowledge and perception**
- Main health problems they suffer from.
- Beliefs they hold with respect to the cause of his or her health problems.
- Their beliefs regarding the expected duration of the disease process.
- Ideas on its short- and long-term consequences.
- Beliefs regarding the possibilities of control or healing.
- Doubts patients often have with respect to the illness.

2. **Person's values and experience**
- Aspects of their illness that they consider most important.
- Aspects of care that they consider essential.
- What worries them and what they fear about their case or the foreseeable health, personal or social scenarios.
- General values with respect to health and illness.
- Their experience in previous losses and mourning.
- Previous instances of coping with high-impact situations.
- Expectations regarding the professionals and institutions.

3. **Specific decisions**
-Decision-making scenarios with respect to situations or the treatment of specific symptoms
- Adaptation of the therapeutic effort.
- Preferences regarding the place and type of care depending on the stage of development or progression of the illness.
- Special requests the patient could arise.
- Appointment of a representative

WHEN TO BE INITIATE

Reactively: if the person explicitly or implicitly expresses the need
Proactively: the professional offers it when he or she detects a person who could benefit from it
CAUTION: there are situations of vulnerability when it may be better to avoid it

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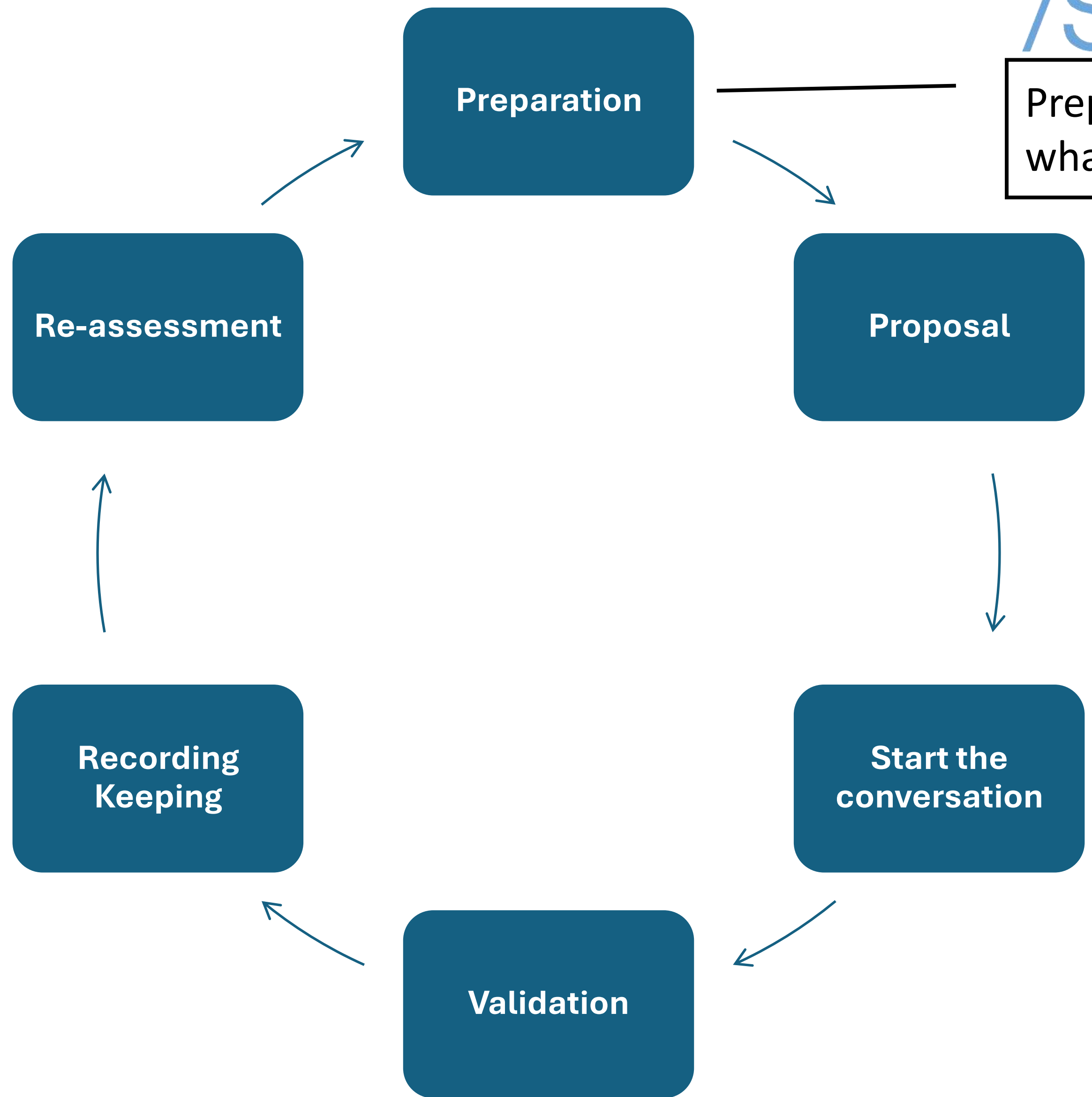
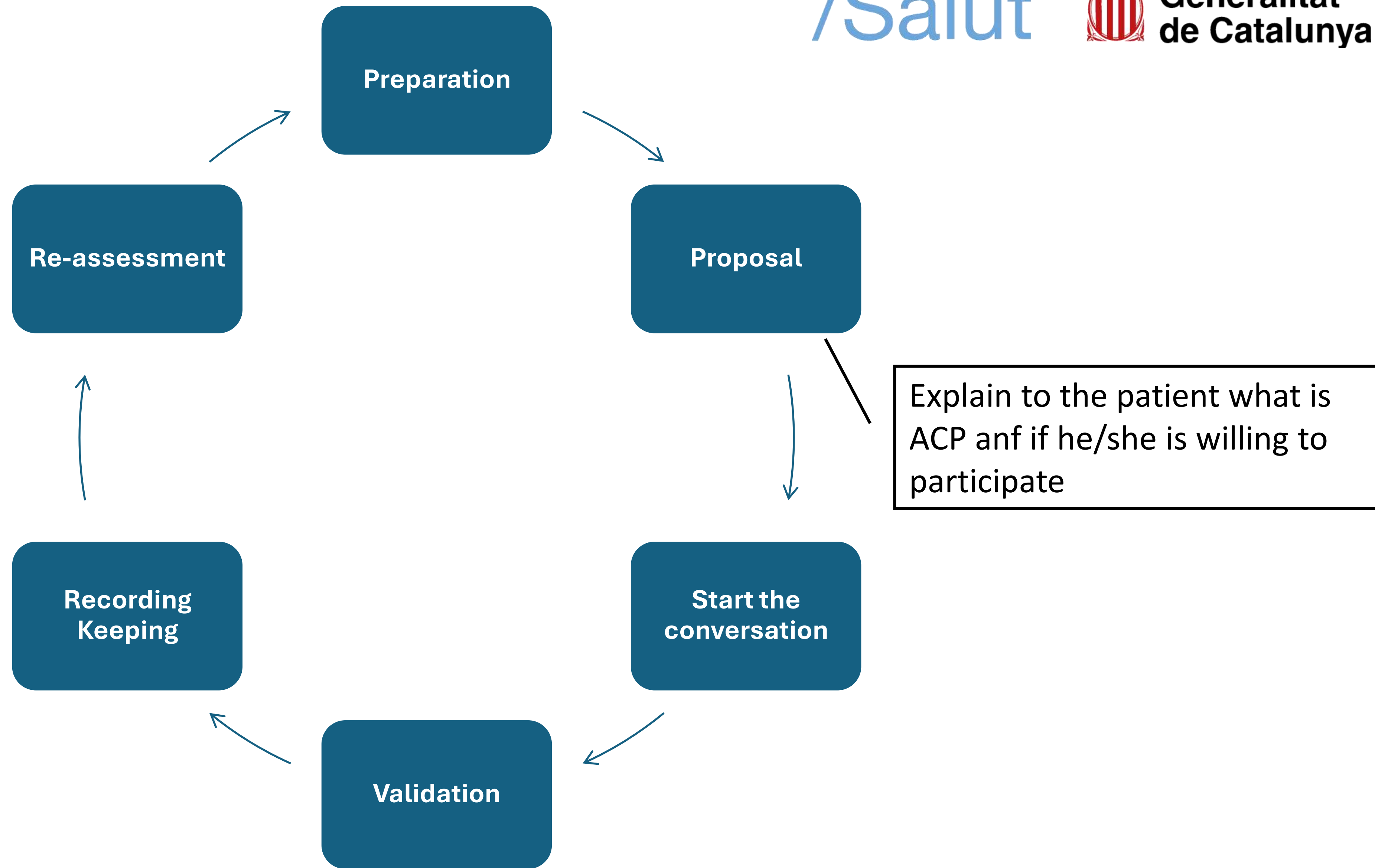
The ACP cicle



Prepare the conversation: what should be explored?

Practical Guide for the ACP in Catalonia. 2015

The ACP cicle



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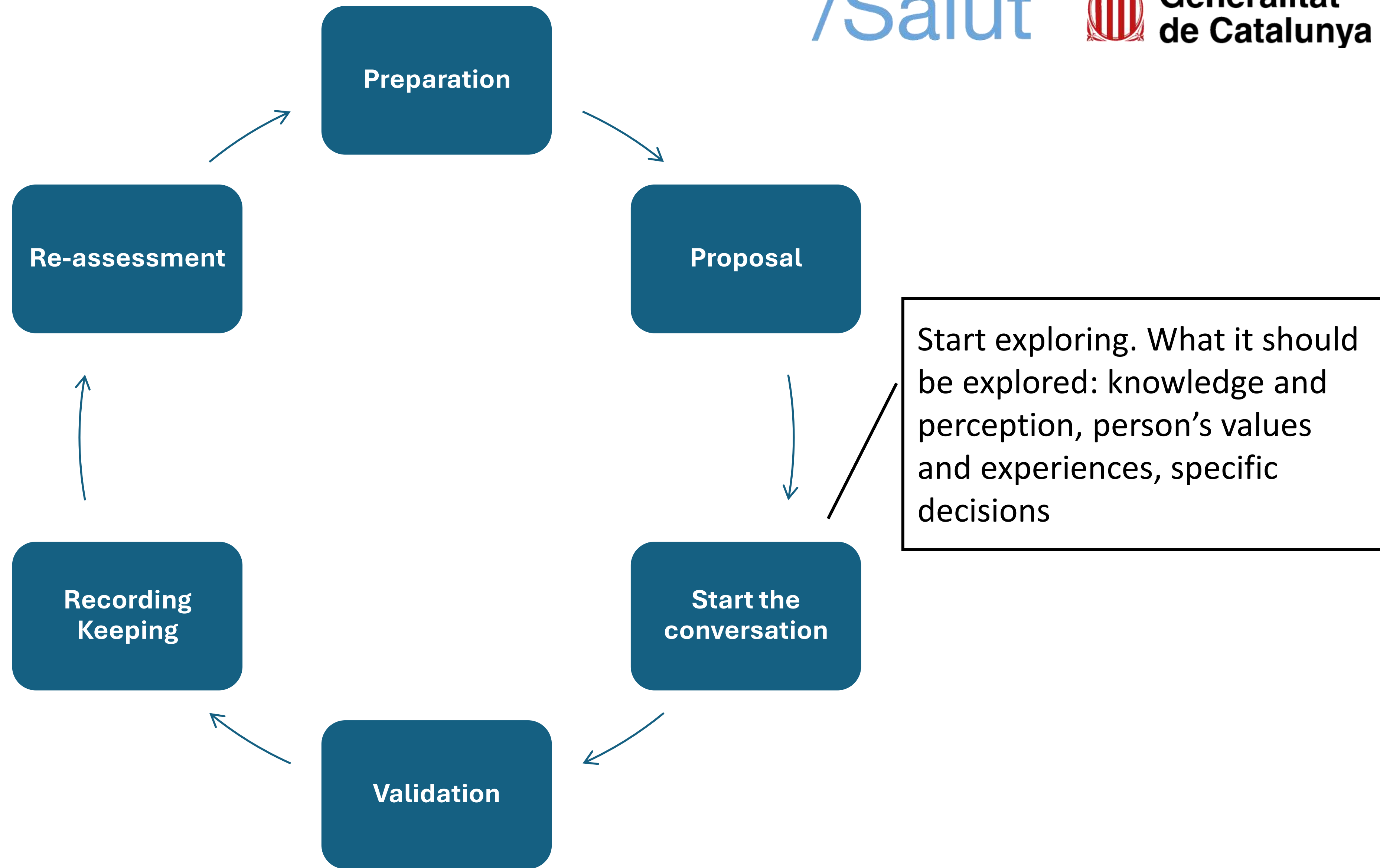
The ACP cicle



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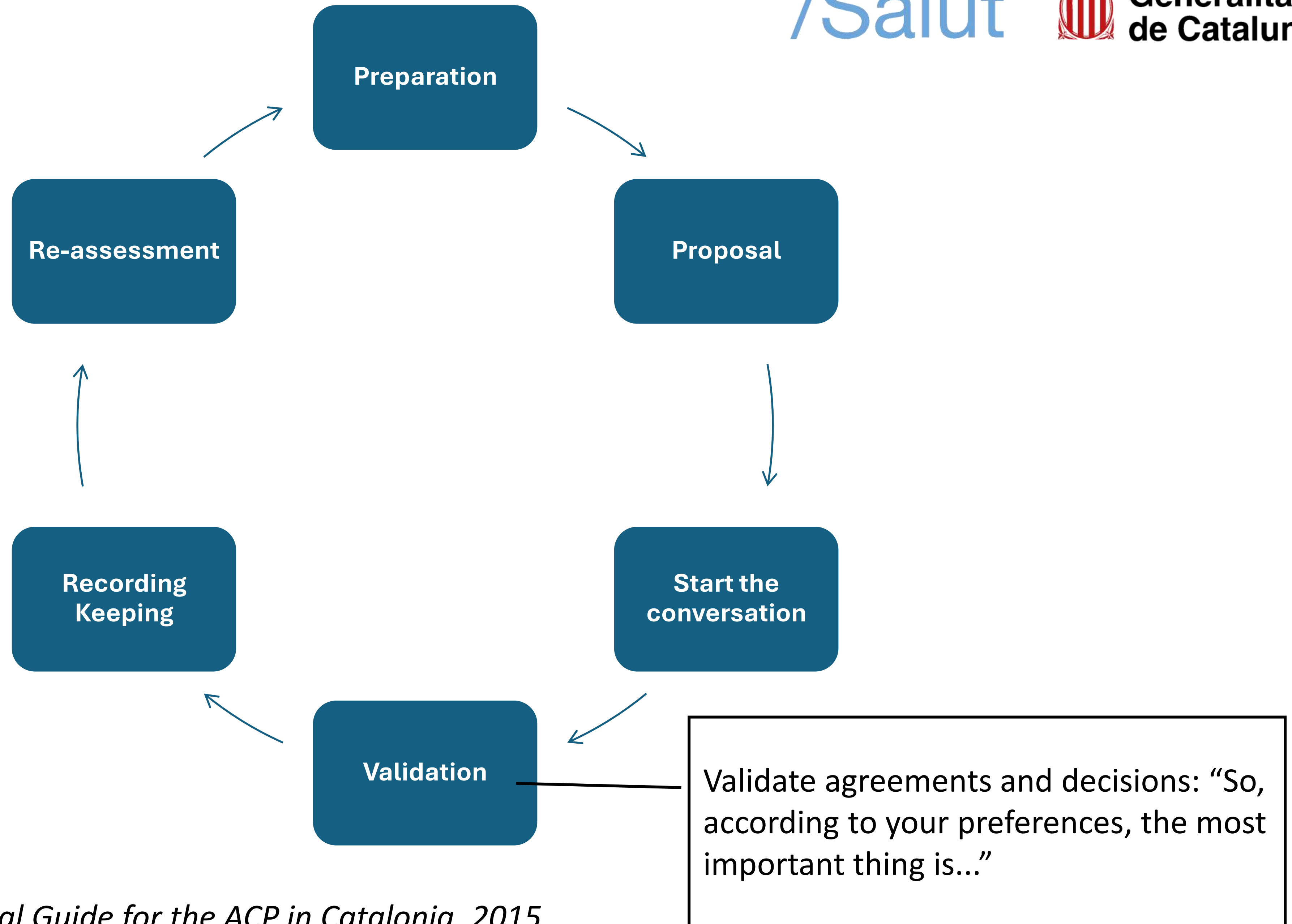

Practical Guide for the ACP in Catalonia. 2015

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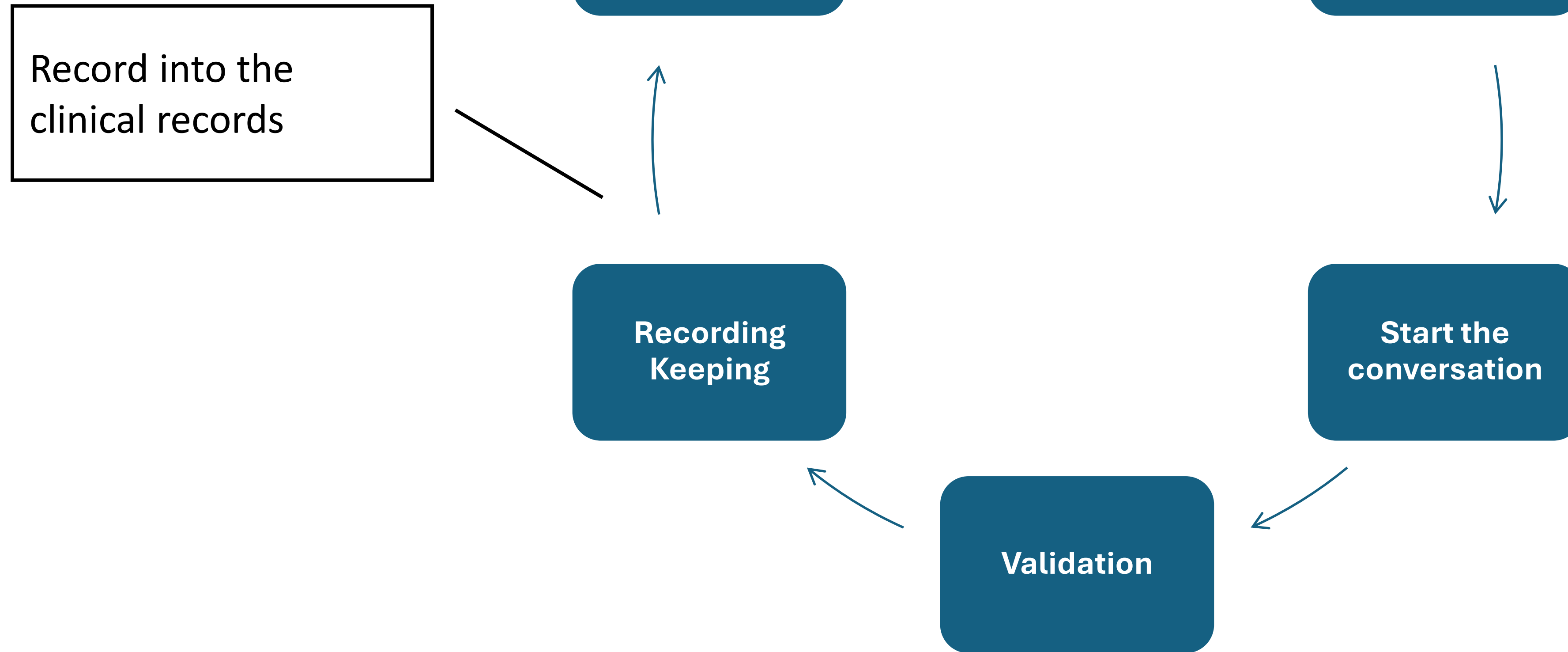
The ACP cicle

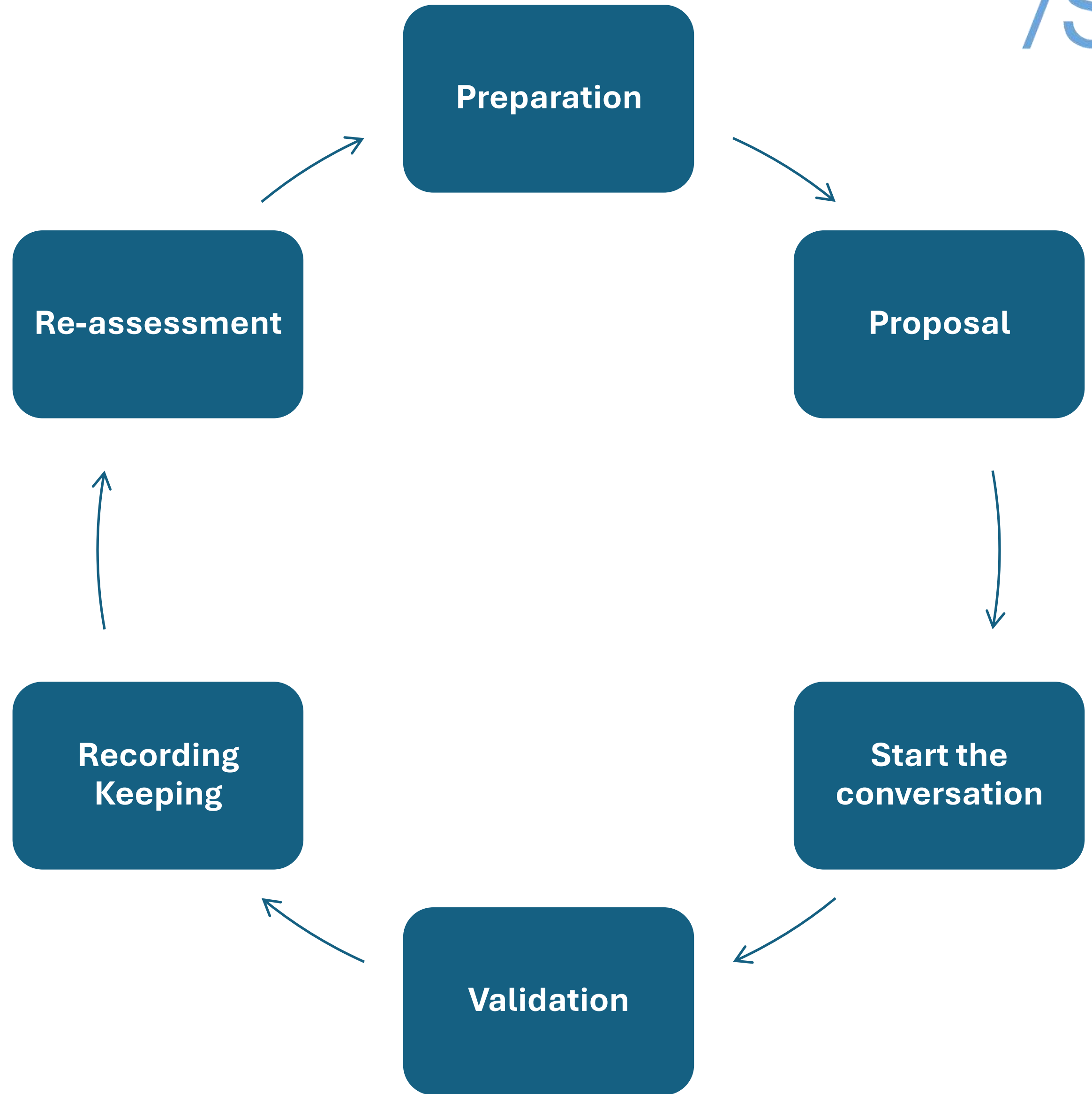


Practical Guide for the ACP in Catalonia. 2015

/Salut Generalitat de Catalunya

Re-assess as much as needed

The ACP cicle



Practical Guide for the ACP in Catalonia. 2015

Clinical records

1. The person is able to participate in an ACP process?
2. It has been explored to whom he/she would surrogate decisions in case he/she would not be able to express him/herself
3. The person has previously expressed any particular concern
4. What agreements have been made with the person regarding the therapeutic plan?

General aims in case of a crisis

Objectius generals:

Nivell assistencial proposat en cas de crisi

Has the patient expressed other values, preferences, desires or certain priorities? Does he/she have an advance directives?

Specific objectives

Training Plan

- **Contents**: communication skills; legal and ethical aspects; patient and family needs and shared decision-making
- **Products**:
  - ✓ 10 hours online course: over **1000** attendees in 2 years
  - ✓ 12 hours face-to-face course

Main conclusions

- **The Catalan Model of ACP** established the conceptual and pragmatic foundations of ACP and developed the training of the professionals who daily take care of such type of patients.
- **20.553 chronic advanced patients** were identified from 2014 to 2018.
- From those identified, **25% of ACP processes** were included into clinical records.
- Quality of the ACP process was not assessed
- **ACP is a challenge** for the model of chronic care towards advanced chronic patients.
- Professionals' **attitude** and **motivation**, **organizational improvements**, **institutional support** and **society involvement** are the key for the success of the ACP program

What did we learn?

Development and implementation of an advance care planning program in Catalonia, Spain

Cristina Lasmarías, B.A., R.N., M.SC.[1,2,3], Amor Aradilla-Herrero, R.N., PH.D.[4], Sebastià Santaeugènia, M.D., PH.D.[3,5], Carles Blay, M.D., PH.D.[3,6], Sara Delgado, M.D.[7], Sara Ela, B.A.[1,2], Núria Terribas, B.L.[8] and Xavier Gómez-Batiste, M.D., PH.D.[1,2,3]

[1]The Qualy Observatory-World Health Organization Collaborating Center for Public Health Palliative Care Programs (WHOCC-ICO), Catalan Institute of Oncology, L'Hospitalet de Llobregat, Barcelona, Spain; [2]Chair of Palliative Care, University of Vic-Central University of Catalonia, Vic, Barcelona, Spain; [3]Catalonia Chronic Care Research Group, University of Vic-Central University of Catalonia, Vic, Barcelona, Spain; [4]Escuela Universitaria de Enfermeria Gimbernat, Autonomous University of Barcelona, Sant Cugat del Vallès, Barcelona, Spain; [5]National Strategy of Integrated and Chronic Care, Ministry of Health, Government of Catalonia, Barcelona, Spain; [6]Medicine, University of Vic - Central University of Catalonia, Vic, Barcelona, Spain; [7]St Luke's Hospice, London, United Kingdom and [8]Chair of Bioethics, University of Vic-Central University of Catalonia, Fundació Grifols, Barcelona, Spain

Abstract

Objective. Implementation of an advance care planning (ACP) program for people with advanced chronic conditions is a complex process. The aims of this paper are to describe (1) the development of the ACP program in Catalonia, Spain, for patients with advanced chronic conditions and complex needs and (2) the preliminary results of the implementation of this program in health and social services.
Method. The ACP program was developed and implemented in a four-stage process as follows: (1) design and organization of the project; (2) selection of the professionals to carry out the project; (3) creation of four working groups to develop the conceptual model, guidelines, training program, and perform a qualitative evaluation; and (4) project implementation.
Result. The following deliverables were completed: (1) conceptual framework document; (2) practical guidelines for the application of the ACP; (3) online training course (3,763 healthcare professionals completed the online course, with an overall satisfaction rating of 8.4 on a 10-point scale); and (4) additional training activities (conferences, short courses, and seminars) in between 2015 and 2017.
Significance of results. This project was led by the Catalan Ministry of Health. The strengths of the project development include the contribution of a wide range of professionals from the entire region, approval by the Catalan Bioethics Committee and the Social Services Ethics Committee, and the ongoing validation by members of the community. A standardized online training course was offered to all primary care professionals and included as a quality indicator for continuing education for those professionals in the period 2016–2020. The main outcome of this project is the establishment of a pragmatic ACP throughout the region and training of the health and social care professionals involved in the care of advanced chronic patients.

Basis for an ACP program

Institutional Support	• Define implementation strategy and create the brand
Conceptual framework	• What we are talking about/ behavioural and social change
Training	• To whom, for whom and how
Patient and family engagement	• Educational programs by, for and with citizenship

Lasmarías C, Aradilla-Herrero A, Santaeugènia S, Blay C, Delgado S, Ela S, Terribas N, Gómez-Batiste X. Development and implementation of an advance care planning program in Catalonia, Spain. Palliat Support Care. 2019 Aug;17(4):415-424. doi: 10.1017/S1478951518000561.

Challenges in Implementation

- Cultural and communication barriers
- Lack of time and resources
- Legal and systemic barriers
- Resistance to change

Understanding the problem and building solutions

Pilch M, Hayes CB, Harney O, Doyle F, Thomas S, Cooper Lunt V, Hogan M. Using Collective Intelligence to Develop Design Requirements for a Complex Intervention for Advance Care Planning in the Community. J Clin Nurs. 2025 Jan;34(1):230-246. doi: 10.1111/jocn.17549.

Communication barriers

Figure. Illustrated Metaphor of Late vs Early Palliative Care. Source: Zimmerman C, Mathews J. Palliative care is the umbrella, not the rain. A Metaphor to Guide Conversations in Advanced Cancer. JAMA Oncology. 2022; 8 (5).

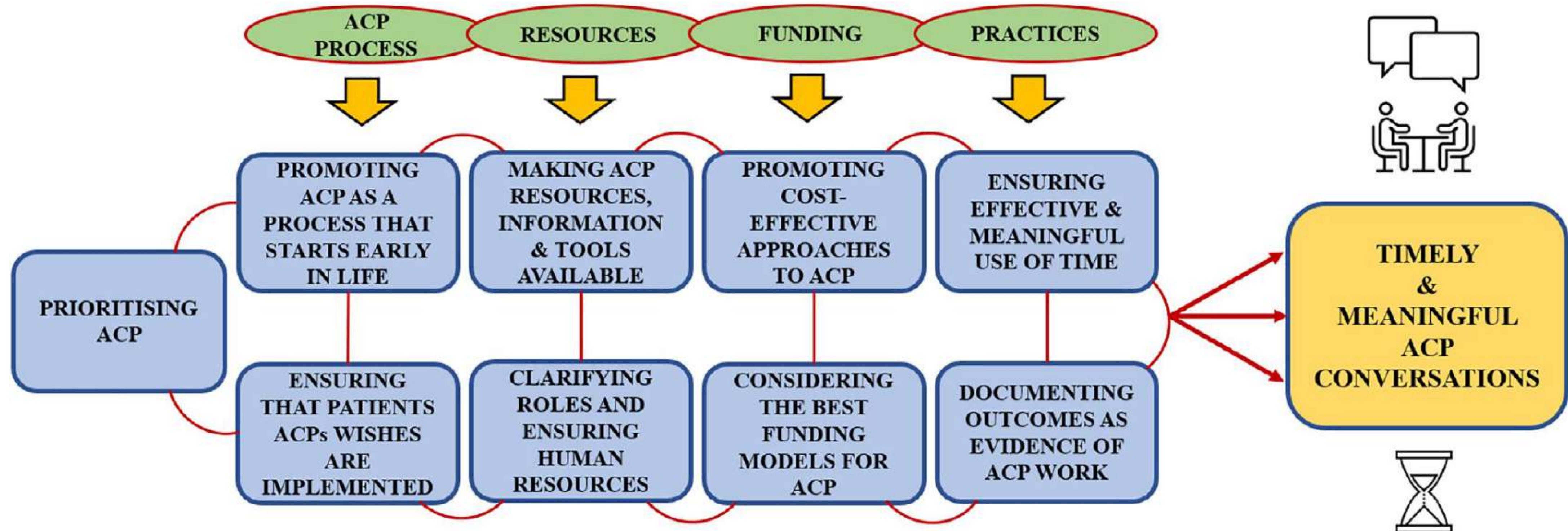
Cultural impact on ACP

- Cultural factors affecting ACP **acceptability** included **religiosity**, **trust** in the health care system, patient and clinician **comfort discussing** death, and **patient attitudes** regarding decision making.
- Informal, communication-focused approaches to ACP appear more cross-culturally acceptable than formal processes.

McDermott E, Selman LE. Cultural Factors Influencing Advance Care Planning in Progressive, Incurable Disease: A Systematic Review With Narrative Synthesis. J Pain Symptom Manage. 2018 Oct;56(4):613-636. doi: 10.1016/j.jpainsymman.2018.07.006. Epub 2018 Jul 17. PMID: 30025936.

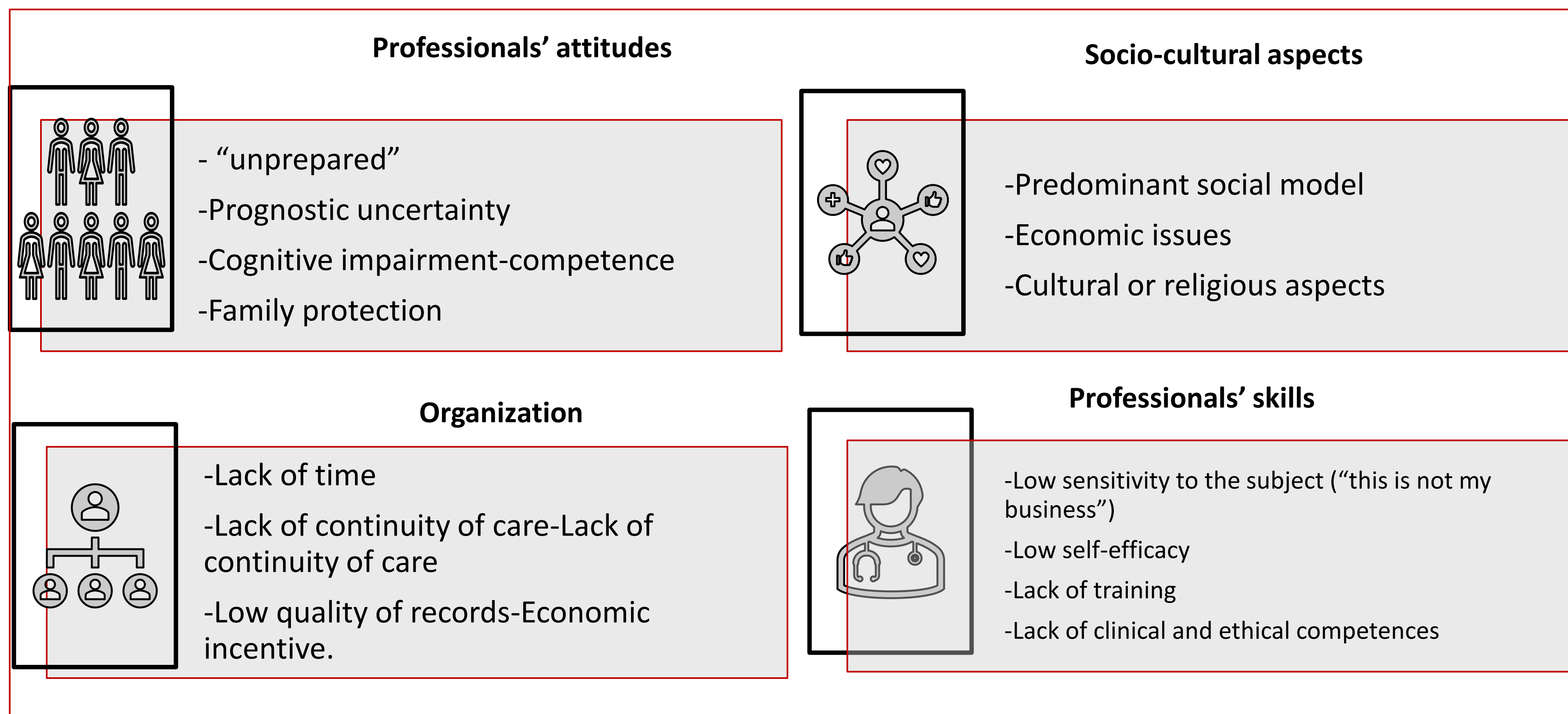
Family as a barrier to engage patients into ACP process?

Adressing Lack of time



Pilch M, Hayes CB, Harney O, Doyle F, Thomas S, Cooper Lunt V, Hogan M. Using Collective Intelligence to Develop Design Requirements for a Complex Intervention for Advance Care Planning in the Community. J Clin Nurs. 2025 Jan;34(1):230-246. doi: 10.1111/jocn.17549.

Resistance to change



- Risk J, Mohammadi L, Rhee J, Walters L, Ward PR. Barriers, enablers and initiatives for uptake of advance care planning in general practice: A systematic review and critical interpretive synthesis. BMJ Open. 2019;9(9):1-17.Street RL, Millay B. Analyzing Patient Participation in Medical Encounters. Health Commun. 2001;13(1):61-73..
- Lund S, Richardson A, May C. Barriers to advance care planning at the end of life: an explanatory systematic review of implementation studies. PLoS One. 2015;10(2):e0116629.
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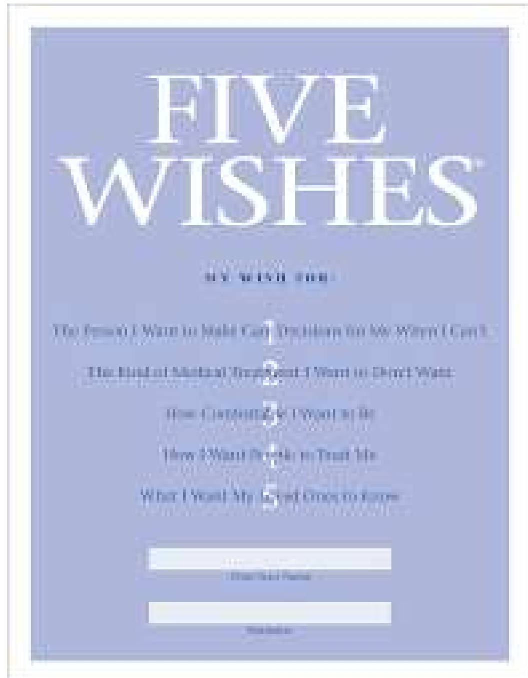
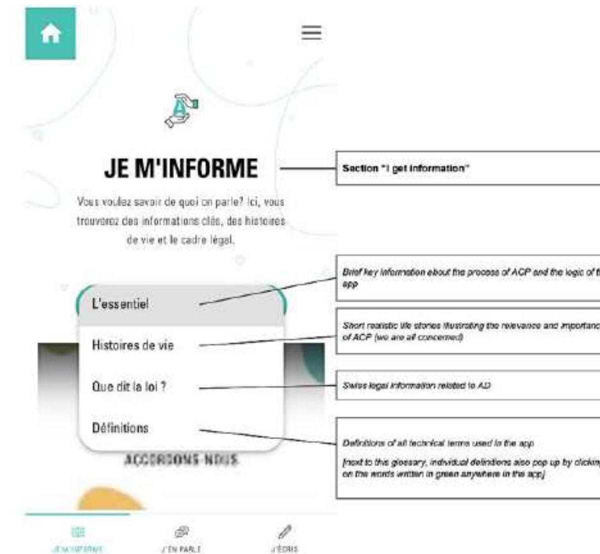
- Granero-Moya N, Frías-Osuna A, Barrio-Cantalejo IM, Ramos-Morcillo AJ. Dificultades de las enfermeras de atención primaria en los procesos de planificación anticipada de las decisiones: un estudio cualitativo. Aten primaria. 2016;48(10):649-56.

Involving citizens





Overview of Implementation challenges

- The most common combination of categories/subcategories used in defining ACP were: the purpose of ACP is to make decisions; patients should have conversations with family and healthcare providers; conversation should cover care options; and ACP should result in documentation (in the form of a legal document).
- A greater number of barriers for ACP were associated with the healthcare provider than the patient, or healthcare service. Enablers of ACP were greater for the patient than the healthcare provider or service.
- The majority of interventions to improve ACP target the patient rather than healthcare providers. Implied barriers that were targeted by ACP interventions and coded to Theoretical Domains Framework domains did not align with barriers identified in the included reviews as the most important in influencing ACP.

Guccione L, Fullerton S, Gough K, Hyatt A, Tew M, Aranda S and Francis J (2023) *Why is advance care planning underused in oncology settings? A systematic overview of reviews to identify the benefits, barriers, enablers, and interventions to improve uptake*. Front. Oncol. 13:1040589.

Final messages

ACP is not easy but…

"No culture of people has been naturally ready for ACP"

Bud Hammes, Singapore 2023

- **ACP is more about to be prepared than planning**
- An effective planning requires more than an outstanding planning conversation…a larger system is needed.
- To successfully implement advance care planning into clinical practice, a larger change is required in the social and medical culture.

Take Home messages

- Do nothing is not an option
- Do everything at the same time is not (the best) the option

Take Home messages

- Define the context (micro-meso-macro)
- Define what Theoretical/Conceptual Framework better suits
- Identify the target population
- Train healthcare professionals
- Develop and integrate documentation processes
- Engage patients and families

..........And Good luck!!!!

Merci beaucoup!

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