Catalan model of care for people with frailty, complex chronic (CCP) and advanced chronic (ACP) conditions



ppac | pdss | deap

Chronicity Prevention and Care Programme (PPAC)

Intermediate care Programme (PDSS)
Strategic Direction of Primary Care (DEAP)

Catalan model of care for people with frailty, complex chronic (CCP) and advanced chronic (ACP) conditions

Barcelona, 2021



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Jordi Amblàs Novellas

Graphic design

Víctor Oliva

Editing

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- Santaeugènia, Sebastià. Chronicity Prevention and Care Programme (PPAC). Health and Social Master Plan (PDSS). Ministry of Health of the Government of Catalonia.
- Ruiz, Rafael. Strategic Direction of Primary and Community Care (DEAPiC). Ministry of Health of the Government of Catalonia.

Coordination and editing

• Amblàs, Jordi. PPAC. PDSS. Ministry of Health of the Government of Catalonia.

Authors (in alphabetical order)

- Amblàs, Jordi. Geriatrician. PPAC. PDSS. Ministry of Health of the Government of Catalonia.
- Amil, Paloma. Primary care nurse. PPAC. Ministry of Health of the Government of Catalonia.
- Bocanegra, Ignasi. Secretary of the PPAC and the PDSS.
- Bullich, Íngrid. Nurse specialised in geriatrics. PDSS. Ministry of Health of the Government of Catalonia.
- Contel, Joan Carles. Primary care nurse. PPAC. Ministry of Health of the Government of Catalonia.
- Gil, Esther. Primary care nurse. PPAC. Ministry of Health of the Government of Catalonia.
- Giráldez, Gemma. Secretary of the PPAC and the PDSS.
- González, Assumpció. Primary care nurse. PPAC. Ministry of Health of the Government of Catalonia.
- Melendo, Eva Maria. Nurse specialised in geriatrics. PDSS. Ministry of Health of the Government of Catalonia.
- Mir, Victòria. Social health worker. PPAC. PDSS. Ministry of Health of the Government of Catalonia.
- Ruiz, Rafael. Physician specialised in Family and Community Medicine. DEAPiC. Ministry of Health of the Government of Catalonia.
- Santaeugènia, Sebastià. Internist. PPAC. PDSS. Ministry of Health of the Government of Catalonia.

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Executive summary

What does this model seek to promote?

This model seeks to promote a **more individualised model of care**, which should focus on results that are important to people. This model should serve as both a **lever of change** towards a more humanised system and the **common theme of care**—especially for people with frailty, complex chronic conditions and/or advanced chronic disease

It aims to facilitate the work and **leadership of professionals**, as the **guarantors of this model of care** and the people in charge of personalising treatment.

From an inclusive vision, it seeks to promote **collaborative practices** in all areas, at **all care levels**, from a perspective of vertical and horizontal integration.

Why is it important?

Because based on a pragmatic model, it provides **specific responses** to the challenges of chronicity, complexity and end of life.

These responses are formulated from a **threefold view**: **people**—who are at the core of the model of care, **professionals and teams**—as the guarantors of good practices and quality healthcare, and the **population perspective**—as an essential element needed for planning, to guarantee equity and quality care, as well as to monitor the results.

How is it implemented?

By providing the what's (**person-centred care model**) based on evidence with a pragmatic vocation and consensus with professionals and organisations, whom it seeks to equip with a tangible **story**, a **shared vision** and specific **tools**.

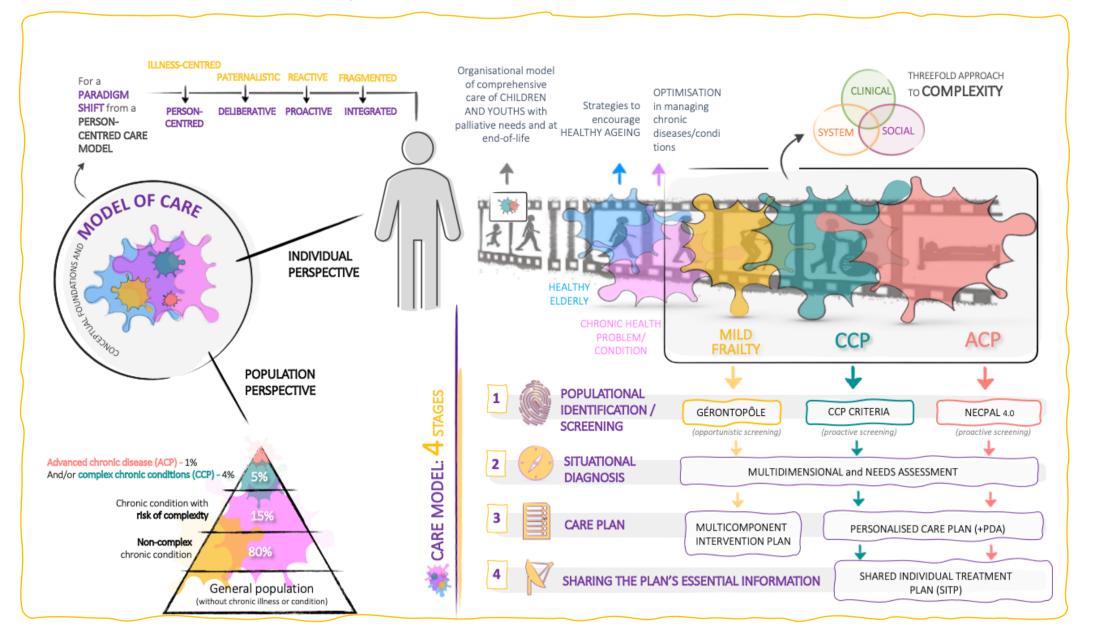
By promoting the how's (deliberately **territorial proposals)**, adapted to the features and needs of each territory, fostering local leadership.

What is the expected impact?

An **improvement in the results** of care from a fourfold perspective:¹

- The health and wellbeing of people receiving care.
- The experience of care received by people and the families and/or caregiver.
- The experience of care provided by the professionals.
- The appropriateness of the service utilization and efficiency.

Visual summary



1. Introduction

1.1 Justification

We are faced with the epidemiological outbreak of a group of **older people**, many in good health, others with **chronic health problems and** multimorbidity,^{2–4} some of whom—including younger people and children—have complex care needs and palliative needs.⁵ In the forthcoming years, this will become one of the most important **challenges** facing healthcare systems^{6,7} both for **organisations and policies**—which will have to deal with the complexity stemming from the heterogeneity of this population and the difficulty of meeting their needs and the costs of care that can stem therefrom—and for **professionals**, who will have to excel in addressing the needs of these people, meet the need for personalised care and take charge of the complexity stemming from the difficulty of taking decisions about them and with them.

One of the **barriers** that has to be overcome to offer outstanding care for these people is the stereotyped perceptions often held about the older people and/or people with chronic health problems, which can lead to discrimination and inequity. Today, this discrimination on the basis of age and health condition may be even more widespread than discrimination based on factors like sexism and racism. 9,10

Within the framework of the **2020 European health policy**, in 2012 **guidelines** were approved with the goal of 'supporting the actions of the Government and society to improve the health and wellbeing of people, to lower healthcare inequalities, to reinforce public health and to ensure that healthcare systems are person-focused, equitable, sustainable and high quality'. These guidelines steer healthcare systems on how to deal with the main challenges related to chronic illnesses: the investment in health from a broad perspective—which includes the entire lifespan, citizen empowerment, the creation of environments that foster health and resilient communities, the prioritisation of public health and **person-centred care**.

In parallel, the **World Health Organisation** (WHO) recently published its *Global Strategy and Action Plan on Ageing and Health*, ¹² which particularly emphasises the need to promote the healthy ageing of the population, as well as the need to adapt healthcare systems to the characteristics of the older people and/or people with chronic health problems. In this sense, the WHO has designed a

Global Strategy on Integrated People-centred Health Services 2016-2026,¹³ whose key elements are promoting people, avoiding the fragmentation of services and encouraging collaboration among providers. Therefore, in the first place, people and communities—not illnesses— should be at the core of the healthcare system, they should be empowered to take charge of their own health (instead of being the passive recipients of services); and the provision of services should take a perspective centred on poeple, families and communities, which are considered the participants and beneficiaries. This requires people to have the education and support they need to take decisions and participate in their own care. In the second place, a change in the model of healthcare organisation is needed, to redesign it to shift from an illness-centred model to a model centred on the needs and health outcomes which matter to people. In the third place, we must guarantee that people receive a continuum of services that promote health, prevent illnesses and provide diagnostics, treatment, illness management, rehabilitation and palliative care services at different levels of care within the healthcare system and according to their needs throughout their lifetime.

There is broad consensus on the fact that **comprehensive**, **integrated and person-centred care** is the best approach in this context.^{14,15} The current evidence confirms that integrated care contributes to improving access to services, lowers unnecessary emergency admissions and readmissions, improves compliance with treatments, ^{16–18} boosts the satisfaction of the persons receiving care, increases literacy and self-care, improves the job satisfaction of the professionals and improves healthcare outcomes. ^{19,20} There is also increasing evidence of the efficacy of integrated healthcare services, especially when managing people with chronic health problems. ^{21,22}

1.2 Underpinnings and objectives of the model

Through the past decade, there has been an increasing interest in adapting services to people's needs and fostering their engagement and participation in caring for their wellbeing and health. This has prompted a shift in the orientation of the model of care and has made people the crux of the healthcare system, thus promoting respect for their dignity and autonomy as fundamental ethical cornerstones.

People's empowerment and personalised care models are two examples based on this strategic proposal in which the goal is to make person-centred care tangible in accordance with the three pillars sustaining it: scientific evidence, the person's needs and individual priorities.

Care of the older people and people with chronic health problems requires a **broad**

approach that ranges from healthy ageing to preventing disability and optimising the way chronic pathologies and situations of complexity are addressed, and to people facing their end of life and palliative needs. The identification of each of these stages is justified by the proven benefits of care based on **specific care models** adapted to the features and needs of **each stage**.

1.2.1 Person-centred care as the common theme of the model

In 2008, the **WHO** defined people-centred health care as 'the care that is achieved when the person is made the axis around which the other dimensions interact, related to: treatment based on scientific evidence and organisation of the service, the equipment, interdisciplinary and the environment'.

Even though there is no universal agreed-upon meaning of person-centred care, one of the most frequently referenced ones in the documents drafted by the **National Voices** coalition is: 'I can plan my care with people who are working to understand me and my caregiver(s), giving me control and providing me with the services to achieve the goals that are important to me'.²³

Currently—and 30 years after the Ottawa Charter for Health Promotion—in accordance with the Shanghai Declaration on promoting health, the following are identified as three basic pillars: good governance, healthy cities and knowledge of health. In this vein, the paradigm shift towards a person-centred model of care can help improve the quality of care and outcomes, lower the healthcare burden and make more efficient use of health and social services. For this reason, laws and documents of the health policies on wellbeing are increasingly seeking to distance themselves from the paternalistic model and encourage citizen voices.

Finally, the framework of integrated, person-centred health services was presented in April 2016, at the 69th World Health Assembly of the WHO. It contains **five strategies** with the consequent interventions for the development of more integrated and person-centred healthcare systems.²⁴

Catalonia is currently working towards a consensus on an **evaluative framework** that could guide the different organisations and professionals in implementing a person-centred model of care based on the eight principles of the Picker Institute²⁵ (Figure 1).

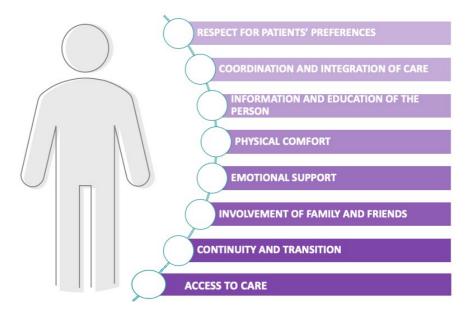


Figure 1. The eight principles of person-centred care from the Picker Institute.

Source: Authors.

1.2.2 Person-centred care as the lever to change the system

The **person-centred care (PCC)** model should be the engine to shift a 'classic' healthcare system—as we have known it in recent years—to a healthcare system adapted to the needs of the older people and/or people with chronic health problems (Table 1):

From a system... To a system...

Disease-centred and stereotyped.

Historically, the centre of gravity of medical knowledge have been conditions and their management.

For instance, even today the hospital organisation is based on pathologies or by systems. The progresive increase in the number of people with multimorbidity (multiple health chronic problems) is this oranisational system, which is becoming less oriented towards people's real needs.

Person-centred and individualised,

with the possibility of comprehensive, personalised care, which identifies the characteristic features of each individual and respects his or her values and preferences. All people, especially the older people or those in situation of complexity, should have right to receive care based on scientific evidence, individualised – based on their needs –, and personalised, based on their own preferences.

Paternalistic

It has often been assumed that professionals were the only ones with knowledge of—and therefore the guarantors of—people's health and the ones in charge of taking decisions, in which patients were given information geared at what the professional thought was best for that person. In this sense, the possibility of creating spaces of debate that allow other ways of addressing the issue have not always been valued (for example, until recently there was no possibility of getting a second opinion).

Deliberative,

where the person is guaranteed to be given accessible, understandable information. This should be the necessary point of departure for a shared decision-making process that should combine the professionals' expertise (in the situational diagnosis, prognostication, treatment options, etc.) with that of the people (in their experience of the disease, attitude towards risk, goals, values and preferences).

Reactive

Healthcare systems have often been more focused on responding to acute imbalances or problems than on proactiveness (health promotion measures or preventative measures), either in relation to illnesses or for any other chronic health problems (disability, frailty, etc.).

Proactive and with the capacity to respond,

where, despite the presence of illnesses and/or chronic health problems (often advanced), the care seeks to be more preventative and anticipatory. This approach should include both measures aimed at slowing the progression of the illness and avoiding imbalances or addressing the consequences, and addressing the resulting care needs early on and planning or taking decisions in advance.

Fragmented

Until just a few years ago, the different actors and areas in the system were characterised by having different goals and little interaction. This has led to a distancing or tensions which have negatively affected the care of people, either in relation to health outcomes, process (poor transitions, increase in hospital admissions, etc.) or a poor care experience by the persons receiving care.

Integrated,

where there is true alignment of the goals among the different care areas with the goal of guaranteeing true personcentred care by the healthcare system. Integrated care is one of the key elements in caring for people with complex and advanced chronic conditions (CCP and ACP). Some key elements are consensual health targets and shared care plans, meticulous transitions of care, collaborative work among the healthcare and social areas, and mutual knowledge transfers, overcoming the fragmentation of care in different areas to instead promote co-responsibility in the care and results for the population.

Table 1. Paradigm shift in the care of chronicity and the older people.

Source: Authors.

1.3 What is the target population of this model?

Even though anyone could benefit from a person-centred care model, the personalisation of the treatments is **especially necessary** in people who mostly require a comprehensive, integrated approach, primarily **people with chronic health problems**—especially when this chronicity is complex and/or advanced—and the **older people**—especially when there is a situation of frailty (Figure 2).

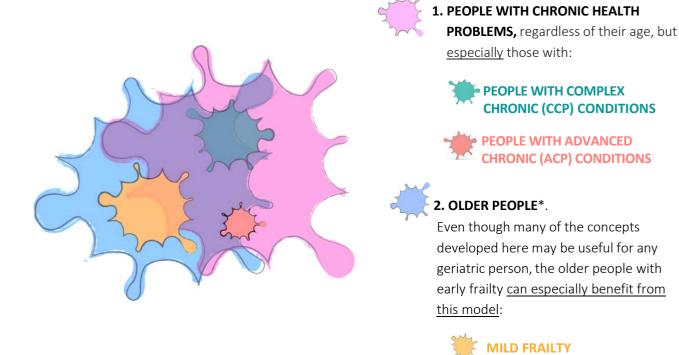


Figure 2. Target population of this document.

Source: Authors.

* TERMCAT defines the *older people* as 'people who are in a period of life in which they have ceased their professional activities or people over the age of 65'.²⁶

1.4 What guarantees does this model advocate?

The goal of this document is to help take a step forward in the model of care for these people, where professionals and organisations have to serve as the guarantors of providing authentically person-centred care.

1.4.1 For people

The frail older people and people with complex and/or advanced chronic conditions must be guaranteed a **person-centred** model of care in accordance with the aforementioned dimensions outlined by the Picker Institute²⁵—contained

in the integrated social and health model of care of Catalonia—²⁷ as well as in the *Charter of Rights and Duties of Citizens in Relation to Health and Healthcare*.²⁸ Briefly we can summarise this as:

- The right for the person's values and preferences, beliefs and priorities to be respected.
- The right to **information**, **empowerment** and **participation** of **people**, families, the caregiving environment and communities—meant as providing the opportunities, capacities and resources that people need to take effective decisions on their own health. This means:
 - That people may participate in decision-making by means of a shared decision-making process, as a key element in person-centred care.
 - The inclusion of the family and/or caregiving environment that the patient wants, as key elements in the support network.
- The right to receive care from a **comprehensive model of care with a multidimensional vision** that includes:

A proactive identification system of people who may benefit from a specific model of care that is visible for all the agents participating in the care process.

A multidimensional assessment with a holistic view of all of people's dimensions and needs.

A personalised care plan which is comprehensive, interprofessional, unique and agreed upon with the person and/or the caregiving families and/or environment. This plan should include elements related to the person's wellbeing, psychological-emotional support and the specific care proposals to be delivered.

The sharing of essential information in the comprehensive care plan and ensuring accessibility to it by both the people and all the professionals caring for them.

Receiving a consensual or shared response—from both a health and social vantage point—in line with their needs.

• The right to receive **coordinated and/or integrated care,** care that is continuous and coherent with the care plan in transitions with (such as, from youth to adulthood) and between health areas (such as between the hospital and the community).

1.4.2 For professionals and organisations

PROFESSIONALS

In order for professionals to be able to act as the guarantors of the personcentred model of care, they should:

- Have the **tools** and **resources** needed.
- Participate actively in clinical leadership and the co-design of projects associated with strategic planning, as well as in their subsequent implementation and monitoring.
- Have access to the **training** they need to provide the best possible response to these people in a standardised way throughout all the territories of Catalonia and all the healthcare services.
- Have the spaces, time and resources to be able to **participate in the improvement and innovation process** in caring for these people.

ORGANISATIONS

This model seeks:

- To provide organisations with a specific **conceptual framework** that enables them to focus their care services on the older people and/or people with chronic health problems and high needs from a person-centred perspective.
- To promote **best practices initiatives** (right care), collaborative practices and integrated care of the older people and/or people with chronic health problems based on the best evidence available.

2. The epidemiological context and the twofold (individual and population) perspective

2.1 Epidemiological context

The ageing of the population and epidemiological, demographic and transitions of care are the point of departure of a rapidly changing reality which has led us to an unprecedented paradigm shift.

2.1.1 Demographic ageing and transitions

Over the past few decades, the sum of different epidemiological, demographic and care transitions has conditioned an **ageing** of the population—meant as the increase in the proportion of people older than 65 over the total population—which, along with the phenomenon of migration, is the most important social and sociological fact in the early 21st century.²⁹ Demographic ageing is a globe-spanning phenomenon. According to figures from the WHO:¹²

- Between 2015 and 2050, the percentage of inhabitants of the planet over the age of 60 will almost double, from 12% to 22%.
- In 2020, the number of people aged 60 or over will exceed the number of children under the age of 5.
- In 2050, 80% of the older people will live in countries with low income and means.
- The population ageing pattern is much quicker than in the past.
- All countries are dealing with major challenges to guarantee that their healthcare and social systems are prepared to deal with this demographic

shift.

The concept of *epidemiological transition*³⁰ refers to the shift from a preponderance of infectious illnesses as the cause of death to the predominance of degenerative, cardiovascular and oncological illnesses, and it is the outcome of the shift in mortality associated with these illnesses, attained by the advances in medicine and improvements in social conditions. This broader vision leads to the concept of the *transition of care*, ³¹ in reference to a much broader set of factors conditioning health: social, economic, technological and political, as well as environmental and job-related. The sum of these two transitions has led to the *demographic transition:* ³² a rupture in the continuity of population movements, where at a given point in time, it shifts from high to low mortality and birth rates—a phenomenon which in Catalonia and Spain is now quite advanced, with total population growth next to zero. ³³



In Catalonia, the population has aged considerably over recent decades:³⁴ not only is the percentage of people over the age of 65 rising but so is the ageing index—the number of people over the age of 65 compared to the number of people under the age of 15. The population statistics from IDESCAT³⁵ show that the percentage of people over the age of 65 increased 23% from 1991 to 2011, and that the ageing index rose from 85 to 108. In 2020, the percentage of people over the age of 65 in the population of Catalonia as a whole rose to 18.94%, and the rate of very old people—over the age of 85—was 17.1%.

But that's not all: all projections suggest that this ageing will be increasingly notable³⁴ (Figure 3):

- The population over the age of 65 will almost double—from 1.3 million to 2.45 million people.
- The number of people over the age of 80 will double—from 0.41 million in 2013 to 0.94 million in 2051.
- The number of centenarians will go from 1,700 people in 2013 to 21,600 people in 2051.
- The life expectancy at birth will rise 5 years between now and 2050, to 85.33 years for men and 90.21 years for women.
- In this regard, the life expectancy at age 65 will rise almost four years: for men, it will go from 18.7 years in 2012 to 22.6 years in 2050; for women, from 22.7 years to 26.5 years, respectively.

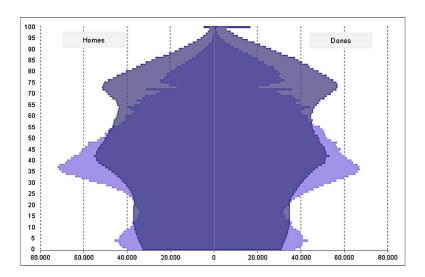


Figure 3. Evolutionary and dynamic projection of the population pyramid for Catalonia in the period 2015-2050.

Source: IDESCAT. Note: the light colour represents 2015 and the dark colour represents 2050.

2.1.2 Epidemiology of chronicity

Aware of this ageing of the population and the fact that morbidity will focus on around advanced ages, we realise that there is an increasing number of people around us who are suffering from a chronic health problem:

• A higher prevalence of chronic health problems: according to figures from the Catalonia Health Survey (*Enquesta de Salut de Catalunya*, ESCA),³⁶ 34.3% of the general population has a chronic or long-term illness or health problem. This percentage is higher in women for all age groups (except under the age of 15), among people from more disadvantaged social classes and in people with only primary school or no education, and it is closely linked to age—it goes from 12.3% of the population age 0 to 14 to 69.7% of the population over the age of 75. According to the 2006 National Health Survey of Spain and the 2009 European Health Survey, in Spain, people between 65 and 74 have an average of 2.8 problems or chronic illnesses, and this rises to 3.23 among people over the age of 75.^{37,38} These figures are coherent with those published internationally, which also report that the number of comorbidities increases with age and is higher among people over the age of 65.³⁹



In **Catalonia**, around 2,579,000 people suffer from one or more chronic disorders, especially illnesses of the musculoskeletal system, the circulatory system and mental health problems. This rate rises with age and is also higher among women. The percentage of people with some chronic illness by age bracket is as follows (Table 2):

AGE GROUP			
AGE GROUP	Men	Women	Total
0-14	12.8	11.7	12.3
15-33	20.3	20.8	20.4
45-64	43.5	50	46.8
65-74	59.5	69.2	65.7
75 and older	67.5	71.1	69.7
TOTAL	31.7	36.8	34.3

Table 2. Prevalence in the Catalonia population of some chronic illness by age brackets and sex.

Source: ESCA 2015.

- **Higher prevalence of disability.** The prevalence of disability increases as age increases. On the other hand, the overall prevalence of disability in the population is steadily decreasing (around 15.7% of the population age 15 and older: 13.6% in males and 17.7% in females).
- Mortality and chronic illnesses. A WHO report from 2005 stated that 60% of deaths in the world were the consequence of chronic illnesses. ⁴⁰ Heart disease, cancer, respiratory diseases and diabetes are the leading causes of death in the world and are responsible for 63% of all deaths. ⁴¹



In **Catalonia**, in the period 2010-2014, the standardised mortality by age dropped 8.5%. The main causes of death are:

- **In men:** lung cancer, coronary heart disease and respiratory illnesses.
- In women: dementia, cerebrovascular disease and heart disease.
- **Higher use of resources**. The impact of these chronic health problems goes beyond the direct effects on the person: it is estimated that more than 50% of the resources in the healthcare system are allocated to treating illnesses or their associated imbalances. ^{42–49} This proportion could increase to almost two-thirds of spending if we bear in mind the use of both healthcare and social services ⁴⁹—in a 2007 study in the United States, expenditure on caring for patients with chronic illnesses accounted for 78% of healthcare costs. ⁴⁷

People with chronic illnesses and health problems generate 80% of visits to doctor's offices in primary care and 60% of hospital admissions—which are also longer—and they also visit emergency units and outpatient hospitals more.^{37,50,51}

• Impact on health policies and systems. This scenario has had a substantial impact on current and future policies in both healthcare and social services and is a source of considerable concern, ⁵² especially in a context in which healthcare systems and organisations have historically been geared towards caring for and solving acute health problems in younger people. ⁵³ Given this reality, people with multiple chronic health problems and limitations on their activities of daily living have more difficulty accessing and moving through healthcare services, given that the healthcare model is not designed with their needs in mind ⁵⁴ and they thus suffer from the consequences of healthcare systems not adapted to them. ⁵⁵

2.2 From the individual to the population perspective

In caring for the older people and/or people with chronic health problems, **two necessarily complementary visions** are often related to each other, even though they are the two sides of the same coin: the healthcare system vision, in which care is synonymous with resource management and healthcare planning, and the professional vision, which is closely associated with caring for people's multidimensional needs. The key to success lies in harmonising the model of care with both the population perspective (organisational models) and the person-centred model (individualised multidimensional assessment and comprehensive personalised care plan):

2.2.1 Individual perspective

To adapt care to the needs of the older people and/or people with chronic health problems, it is essential to make a 'precision' or individualised approach, that is, one in line with the person's specific or unique characteristics.

This **personalisation of care** is crucial for these people, whose characteristics often extend beyond care approaches based on protocols and clinical practice guides. This requires:

- 1) The **identification** of this situation, bearing in mind of mild frailty, complex chronic (CCP) or advanced chronic (ACP) conditions.
- 2) A **situational diagnosis**, which requires a multidimensional assessment and needs assessment.
- 3) An individualised **care plan**, within the context of a decision-making process shared between professionals and people, setting health targets⁵⁶ at the right therapeutic intensity⁵⁷ and ensuring the proportionality of the actions in accordance with the person's clinical situation and desires.⁵⁸

4) **Sharing** information among all professionals and the different organisations and areas of care that participate in caring for each person, *especially in situations where there are complex and/or palliative care needs*.

Conceptually, we can distinguish different times in a person's lifespan which should be borne in mind, as shown schematically in the figure below (Figure 4):

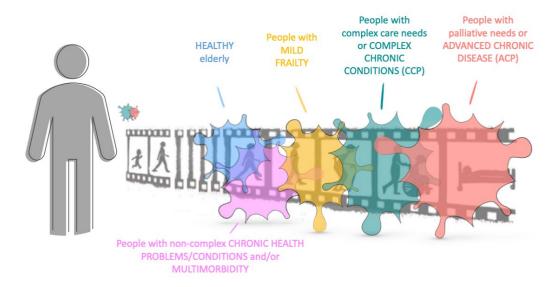


Figure 4. Simplified visual/conceptual representation of the life stages of the older people and people with chronic health problems. It should be borne in mind that not all people follow each of these stages chronologically or sequentially.

Source: Authors.



There are two situations that are also the motive for special care that can benefit from this model: **end-of-life care and paediatric complexity**, as well as **other non-age-related situations of complexity** (such as: situation of complex mental health).

2.2.2 Population perspective

In recent years, the healthcare systems in developed countries have had to retool their strategies to match the increasingly large numbers of people at risk of disability, chronic illness, complex care needs and/or palliative needs.²

Despite the obvious overlaps, we can identify population subgroups with chronic health problems with specific features (Figure 5):

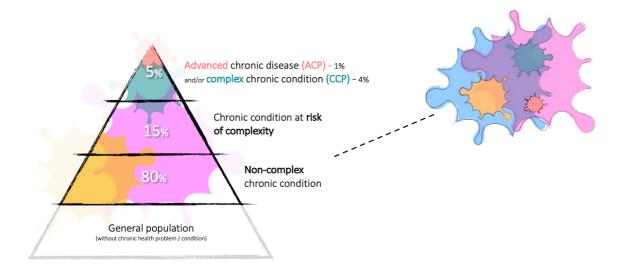


Figure 5. Adaptation of the Kaiser pyramid; representation of the population distribution (%) in relation to their degree of risk of complexity, in relation to people with illnesses and/or chronic health problems.

Source: Authors.

Indeed, from a global/population point of view, and with the goal of providing specific care given the reality and needs of each group according to their features, most countries around us have developed screening and stratification systems for people with frailty, complex care needs and/or palliative needs, 59-62 either through predictive systems—which have shown relative reliability when used in isolation 63—or based on professionals' clinical knowledge, or with a combination of both. 64

This stratification allows different groups of people with different levels of complexity to be distinguished with the goal of addressing them in a different, specific way. In this sense, the Kaiser Permanente proposal⁶⁵ (Figure 5) stands out, a pyramidal model where four population segments can be distinguished, each of which should be addressed differently:

- At the base of the pyramid are people who need prevention and health promotion strategies targeted at a healthy population to be implemented.
- 80% of people with **chronic health problems** are capable of caring for their illness themselves, within the context of a good strategy to **encourage self-management**.
- Another group, **almost 15%**, require **disease management models**, which imply interactions between providers from different areas of care: clinical pathways, longitudinal clinical trajectories.

• Finally, **5%** of the population is in a situation or has a profile of complex chronic conditions (4%) and/or advanced chronic disease. This population benefits from proactive **case management** strategies and **integrated care approach**.

3. Methodology used to develop this model

The contents in this document were constructed and developed based on the experience gained previously, evidence in the literature and the opinions of professionals and beneficiaries. Nonetheless, it **only aims to be a point of departure in the co-design of a strategic plan that deliberately is and should be shared with all parties**. Therefore, we must continue working together to agreed upon the strategic lines, the objectives and the specific actions that should comprise the future strategic proposal.

3.1 Experience gained in previous periods

This model is intensely informed by knowledge, the work undertaken and the lessons of the Intermediate care Programme (PDSS), which has more than 30 years of experience; the Chronicity Prevention and Care Programme (PPAC), created as part of the 2011-2015 Health Plan; and the National Primary Care and Community Health Strategy (ENAPISC), created in 2017 within the framework of the Strategic Direction of Primary Care. The utterly enriching experience of these proposals (see Table 3) has been essential in tackling the current unified proposal.

PLAN	Documents
PDSS	 Health and Social Master Plan. Strategies 2017-2019 Adaptation of the social-health network to care for chronicity Portfolio of health and social care services Proposals for the health and social outpatient hospital Foundations for the development of the organisational model of integral care for the adult population with palliative needs and at end of life Foundations for the development of the organisational model of integral care for the child and youth population with palliative needs and at end of life Specific resources for palliative care. DirCat-CP2019

PLAN	Documents
PPAC	 Foundations for a Catalan care model for peoople with complex needs The prevention and care of chronicity programme of Catalonia Results of the evaluation of the prevention and care of chronicity programme Milestones 2015-2018
ENAPISC	 ENAPISC conceptual document Care process of care for chronicity and complexity in the primary care network

Table 3. Summary PDSS, PPAC and ENAPISC documents (Catalan version).

On the other hand, the last two **health plans** (2011-2015 and 2016-2020) have become essential catalysts in improving the care of people with chronic health problems in Catalonia; they have fostered the alignment of the departmental and interdepartmental plans, programmes and strategies. Just as the model described in this document is informed by these two plans, it also aims to lay the groundwork for the care for the older people and people with chronic health problems in the upcoming plan (2021-2025).

3.2 Participation of people

Given the evidence of the benefits of people's participation in the design of health policies—spearheaded by the experience of the English coalition National Voices^{66,67}—and continuing the line started by the Ministry of Health of the Government of Catalonia to promote people's participation in healthcare policies, the professionals who have designed this document have felt the need to **incorporate people's perspective**, both those who are healthy and those who have chronic health problems, to check the most important points. As Angela Coulter says, 'the best way to know what concerns people is by asking them their opinion'.⁶⁸

With the premise of developing a document from a person-centred perspective in conjunction with the Health Plan and the Secretariat of Healthcare and Participation, **discussion groups** were held to learn about people's vision of care of chronicity. Based on a qualitative methodology involving assessment and collecting data through conversation and interaction among the participants, this has allowed us to learn about their experiences, opinions and values.

The discussion groups were designed bearing two features in mind:

• Homogeneity, grouping people according to a common denominator (in this case, the relationship with chronic disease for people affected by it, or caregivers or healthy people).

• Heterogeneity, ensuring that each group has people of differing ages and sexes who have been cared for at different levels within the healthcare system, from different geographic regions and with diverse socioeconomic statuses.

The results of these discussion groups can be seen in the document 'People's Vision of Care for the older people and Chronicity: Qualitative Study to Construct a New Model of Care'. They were crucial in incorporating new perspectives and reinforcing aspects that users of the healthcare system value.

For the projects and actions stemming from this strategic proposal, people must continue to be incorporated as true **cocreators** of the future projects, as a key element in building a shared narrative in future projects.

3.3 Participation of professionals and organisations

Obviously, given that **professionals** are the ones who are the most familiar with the healthcare and territorial reality, this document is also largely informed by their multiple contributions, proposals and assessments, which were obtained using different methodologies.

For example, in the **reformulation of the construct and the story** about people with complex care needs and palliative needs (**CCP and ACP**), particularly valuable was the *qualitative assessment of the process of identifying and caring for patients with complex needs and advanced disease in primary care*, created through discussion groups with different professional and care profiles (healthcare professionals, clinical and professional leaders from fields related to chronicity, case managers, professionals from specific functional units, managerial teams).

On the other hand, particularly inspiring and crucially important was the **consensus work** done when developing the document *Caregiving Process of Caring for Chronicity and Complexity in the Primary Care Network*. When drafting this document, which was promoted by ENAPISC, around 30 professionals from primary care participated, as well as professionals from other areas within the healthcare system—especially from geriatrics and palliative care. Its content was ultimately validated in a participative process with more than 500 professionals.

The incorporation of **frailty** as a useful concept in the healthcare practice of caring for the older people and/or with chronic health problems also started with a collaborative and consensual process. This process was carried out using the meta-forum methodology among multiple professionals from different areas, scientific societies and institutional representatives. Section 4.2 of this document provides a summary of the consensus on the conceptualisation of frailty; however, a complete document will be published in the near future.

With the goal of incorporating professionals' expertise in the co-design of both the **model of care** and the **tools** that may be helpful in implementing it, different participative processes were organised—once again, from an interdisciplinary, interinstitutional and interterritorial perspective. Some examples of this work are the consensus of a rapid geriatric/multidimensional evaluation system and the Catalan case conference model for taking shared decisions.

Finally, based on the **recent WHO report** on the health system of Catalonia, *Thirty-year Retrospective of Catalan Health Planning*, ⁶⁹ we compiled the recommendations on fostering value-based and person-centred practices, citizen participation in the co-design of the strategies, professionals' leadership, a systemic and integrative view and the need for evaluation and innovation.

4. Background

The planning of care for the older people and/or people with chronic health problems requires first that the professionals and organisations share the same **vision** and **story**. In this sense, we must stress the need for **conceptual consensus** which enables all the actors who participate in caring for these people to share the same view. In this section, therefore, we briefly review the concepts of *multimorbidity*, *frailty*, *complexity* and *end of life* with a pragmatic purpose. For each of them, we provide the following sections:



Conceptualisation, where the key elements for each area of knowledge are reviewed



Tools that are useful in implementing the model.



Recommendations based on the available evidence in each area of knowledge.

Secondly, it is essential to agree upon a **single, shared model of care** with the goal of guaranteeing that regardless of the place where the person is cared for, the person-centred approach is preserved—which includes their values and preferences, as well as their needs. This requires shared knowledge and common tools, as well as a framework of collaborative practices among organisations, teams and professionals.

4.1 Multimorbidity as a heterogeneous, prevalent reality



Healthcare systems are geared to providing reactive responses from a perspective focused on providing single responses to single illnesses. This reality is becoming obsolete given the increasingly frequent epidemiological reality of people who live with two or more chronic health problems; that is, people with **multimorbidity**—meant as 'any combination of one chronic disease with at least one other (acute or chronic) diseases or a biopsychosocial factor (associated or not) or a risk factor'.⁷¹

From this perspective, any biopsychosocial determinant, any risk factor, the social network, the burden caused by conditions, the use of healthcare resources, the concurrent presence (or not) of social issues and the person's

coping strategies can act as modifiers of the effects of multimorbidity and thus lead to more disability or frailty and lower quality of life. There is a close relationship between frailty and multimorbidity: more frail individuals have multimorbidity, although not all people with multimorbidity are frail.⁷² (Figure 6)

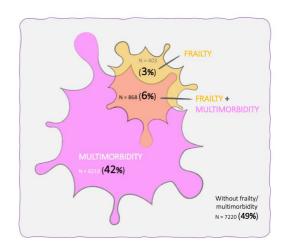


Figure 6: Intersection between frailty and multimorbidity (data combined from 9 studies of people who live in the community; n = 14704).

Source: Authors, based on Vetrano et al.72

People with multimorbidity are involved in more than half of hospital admissions and 75% of pharmaceutical prescriptions. However, this is still an incipient reality: recent studies show that the number of people with multimorbidity is sure to rise. The figure of people with four or more chronic health problems will double by 2035—and two-thirds of these people will have mental health problems (cognitive degeneration, dementia and/or depression).⁷³



In Catalonia, it is possible to monitor the degree of multimorbidity of the population by means of modules to track quality indicators (abbreviated MSIQ). Among a great deal of information available, adjusted morbidity groups (abbreviated AMG), are particularly useful, which provide three types of information (Figure 7):

- They allow the population to be **classified** into unique morbidity groups (healthy, pregnancy and birth, acute disease, chronic disease in 1, 2-3, or 4 systems, or people with active neoplasia), which are also divided into 5 degrees of severity.
- They allow the population to be stratified, assigning a single value to each individual's complexity. This value reflects the care needs that people may have based on their health problems.
- Finally, they allow you to identify the people who suffer from certain major health problems (such as type-II diabetes, neoplasia, high blood pressure, arthritis or depression), which helps track people with more complex care needs.

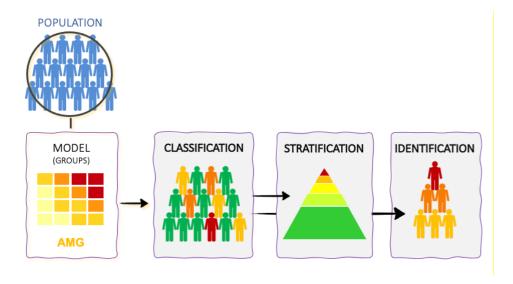


Figure 7: Utilities of the AMG.

Source: Emili Vela

Even though identifying a person necessarily requires professionals' validation/evaluation, information systems can be extremely helpful as a support tool in this process. In this sense, some **2-stage screening** scenarios (proposal of identification by information systems and subsequent validation by professionals) may be useful.



The **guide to multimorbidity** of the National Institute for Health and Care Excellence of the United Kingdom (**NICE**) emphasises the following phases:⁷⁴

- Identifying people in a situation of multimorbidity.
- Assessing their frailty.
- Developing an individual care plan according to the person's values, preferences and goals.
- Reviewing drug prescriptions and adherence with them.
- Promoting the coordination of care among services for these people.
- From an **individual perspective**, the concept of frailty (identification, evaluation and how to address it) can become a tangible, useful way to respond to people with multimorbidity in professionals' clinical practice.⁷⁵
- From a **population perspective**, it is essential to better understand the epidemiology of multimorbidity, as well as to continue making progress in segmenting the population according to their care needs with the goal of developing treatments to prevent it, lower its burden and align the healthcare service more closely with the patients' needs. ⁷⁶ In this sense, the use of health and social databases to examine the distribution of multimorbidity in relation to age and socioeconomic deprivation and the relationship between the comorbidity of physical and psychological disorders is a vitally important element in the strategic planning on how to deal with this challenge. ⁷⁷

4.2 Frailty as a cross-cutting concept in assessing the older people and/or people with chronic health problems



Frailty is a **multidimensional entity** which is defined as a state of 'vulnerability' to stress factors. It is conditioned by a limitation of the compensatory mechanisms, which places the individual at a high risk of poor health outcomes such as disability, institutionalisation, hospitalisation, long-term hospital stays, readmissions, falls, adverse results from specific treatments (such as chemotherapy or surgery) and especially an increase in mortality. Frailty can also be considered a **chronic health problem**, as it can be improved but not cured; it is progressive, even though there may be episodic crises; it negatively impacts the patient's experience; and it conditions costs both individually and for organisations.

Even though there is some consensus that the **population prevalence** of frailty in people aged over 65 years is close to 10%, there is no consensus on the data on the frailty prevalence rates in the population as a whole, most likely because of differences in the conceptualisation and measurement of frailty.^{78–81}

4.2.1 Utility of the concept of frailty in healthcare practice

Even though there is a broad consensus among experts on the **need to assess a person's frailty**, there is still some controversy over how to actually address it given the breadth of the concept.^{82–85} Thus, frailty can be approached as a dichotomous reality (*'Is the person frail or not?'*, Figure 8a), or as a continuum (*'How frail is the person?'*) (Figure 8b).

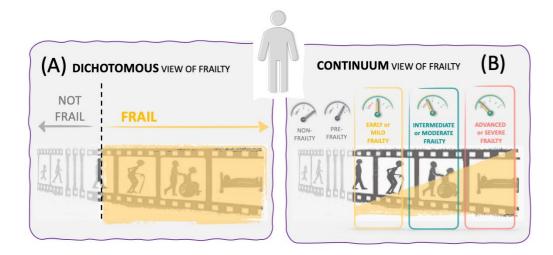


Figure 8. Frailty spectrum: (A) Dichotomous/syndromic vision, (B) Continuum. Source: Authors.

Therefore, it is plausible to think that depending on the objectives of assessment frailty, different tools are needed because not all tools are useful in all situations:

A. Screening people at risk of developing a disability

Frailty—especially when it's in an **early phase**—is potentially reversible. Therefore, it makes sense to identify people with pre-frailty or early frailty at risk of developing a disability who may potentially benefit from **preventive actions** (Figure 9). In this sense, there is a host of evidence (some from here)^{86,87} on the benefits of treatment programmes—especially when done from a comprehensive approach with multicomponent treatment.⁸⁸

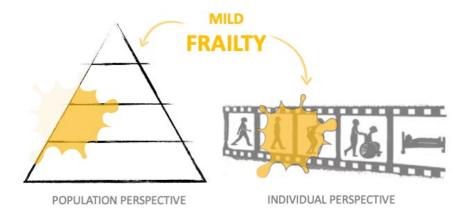


Figure 9. Population-based area of interest in screening people with mild frailty. Source: Authors.

For this reason, currently **a proposal to prevent disability and promote personal autonomy** is being developed in Catalonia jointly between the Ministry of Health and the Ministry of Social Rights, which also corresponds with one of the lines in the Integrated Social and Health Care Plan (PAISS). This project, which has thus far been launched in five pilot territories and should gradually be implemented throughout Catalonia in the forthcoming years, is also framed within the *European APTITUDE project*.



This approach, based on the classic syndromic approach to frailty developed by Fried,⁸⁹ requires populational screening tools (usually dichotomous) which enable these people to be identified early. Some useful tools towards this goal are: functional tests (such as the *Timed Up and Go*, the *walking speed* test and the measure known as the *Short Physical Performance Battery* [SPPB]), the *FRAIL* scale or the frailty screening tool from Gérontopôle or the *Gérontopôle Frailty Screening Tool (GFST)* (Table 4).90-95

People aged 65 and older , autonomous (AVD ≥ 5/6 or Barthel ≥ 90), without any			
	Yes	No	Don't know
Does the patient live alone ?			
Has the patient involuntarily lost weight in the past 3months?			
Has the patient felt more tired in the past 3 months?			
Has the patient had more mobility difficulties in the past 3 months?			
Does the patient complain about memory problems ?			
Does the person walk slowly (more than 4 seconds to go 4 metres)?			
If the answer to one or more of these questions is YES: Do you believe the patient is frail? YES \square NO \square			

Table 4: Gérontopôle Frailty Screening Tool.

Source: Adapted from http://frailty.net/frailty-toolkit/diagnostic-tools/looking-for-frailty-in-community-dwe-lling-older-persons-the-gerontopole-frailty-screening-tool-gfst-2/

Finally, in recent years populational screening proposals for frailty have been made thorough the use of the data stored in **information systems**, where the electronic de frailty index (**eFI**) is the test with the most evidence.⁹⁶

Work is underway in Catalonia to develop an adaptation of the eFI (eFragicap).



Most programmes caring for **people with early frailty and preventing disability** and the **risk of falls** recommend incorporating the following aspects:82,91,173-177

- Screening (proactive or opportunistic) these people.
- A multidimensional assessment of the person.
- An individualised care plan or multicomponent treatment which bears the following factors in mind:
 - Treatment of health problems and geriatric syndromes and a review of medication.
 - Physical exercise. In this sense, the programme with the most published evidence that is endorsed by the WHO is *Vivifrail*. 102
 - Nutritional management. The Consensus document on a community approach to malnutrition related to chronic disease in people with clinical complexity contains some of the keys.
 - Social relationship and participation.
- Evaluation of the results and setting improvement plans.

B. Evaluation of frailty degree

If the goal is to evaluate a person's frailty degree and/ or a situational diagnosis, a multidimensional approach is needed that evaluates both the person's degree of frailty and their evolution over time. In other words, if we usually have a full 'health reserve' when we are born, as diseases and chronic conditions accumulate, this 'reserve' is emptied and we become increasingly vulnerable. Therefore, the degree of frailty provides an approach to a person's 'biological age', which is not always equivalent to their 'chronological age' (age in years), given that not everyone accumulates the same problems at the same speed (Figure 10).

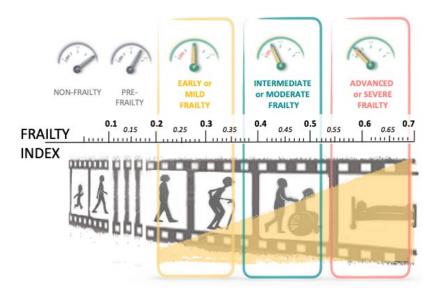


Figure 10. Degree of frailty, frailty index and situational diagnosis. Source: Authors.



In clinical practice, the standard of reference when dealing with complex patients and patients with frailty is the **comprehensive geriatric assessment** (CGA),¹⁰³ although both *clinical frailty scales* and frailty indexes (Figure 10) can be useful when measuring people's degree of reserves.

In Catalonia, a frailty index has been developed based on the CGA (Índex Fràgil-VIG), 104,105 which has proven to be a tool that is simple (in terms of content) and quick (in administration time), with a good capacity to discriminate (in relation to the different degrees of frailty) and a good predictive capacity (with a high correlation with mortality).

These **two approaches to the concept of** *frailty* are not only not incompatible, they are actually completely complementary. For example, in healthcare practice, a sequential proposal could be considered in the use of frailty: 1) populational screening of people with frailty, and 2) multidimensional assessment to assess the degree of frailty (Figure 11):

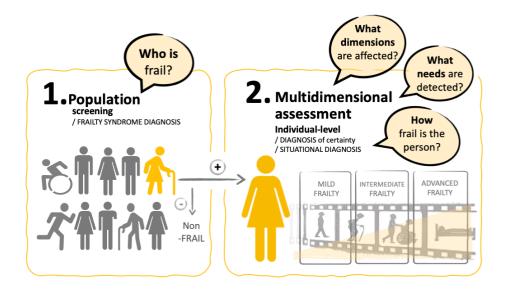


Figure 11. Example of the usefulness of the concept of *frailty* in healthcare practice.

Source: Authors.

4.2.2 Frailty as a dynamic reality

The condition of frailty is far from being a static phenomenon: throughout their lifetimes, people make **multiple transitions** between non-frailty and frailty, as well as between different stages of frailty (Figure 12).

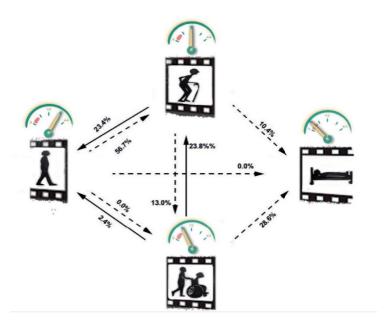


Figure 12. Transitions between different degrees of frailty in a cohort of frail people tracked over the course of a year.

Adapted from Marchiori GF et~al. ¹⁰⁶ It shows the percentages of people who have gone from one degree of frailty to another throughout the tracking period

This is particularly important, as it fully justifies healthcare treatments aimed at reversing the situation of frailty or at least at slowing down the 'frailty' process.

4.2.3 Frailty, functional capacity and intrinsic capacity

WHO's 2015 global report on ageing¹² mentioned above suggests the need to promote healthy ageing for the population by encouraging, developing and maintaining functional capacity as the key factor in facilitating people's wellbeing.

That document defines *functional capacity* as the health-related attributes that allow a person to be and do what is important to them. Functional capacity consists in the person's intrinsic capacity, the characteristics of the environment that affect this capacity and the interactions between the person and these characteristics. *Intrinsic capacity* is defined as the combination of all the physical and mental capacities that an individual can attain (Figure 13).

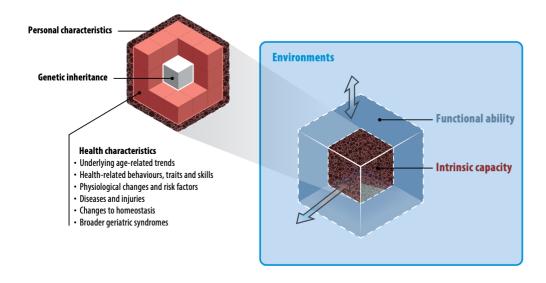


Figure 13. Diagram of the concepts of functional capacity and intrinsic capacity. Source: OMS.¹²

For example, we could say that a person with a hearing loss has lower intrinsic auditory capacities; this also conditions their functional capacities, as it limits the person when they interact with their environment. The use of a hearing aid does not change their intrinsic capacity but it does improve their functional capacity to interact with their environment.

In practice, *intrinsic capacity* can be defined as 'the flip side of the coin' of frailty (Figure 14): while *frailty* represents the cumulative deficits, *intrinsic capacity* represents a person's 'degree of reserves'. When discussing *intrinsic capacity*, WHO is trying to place a greater stress on the concept of preserving capacities than on the losses or deficits acquired.¹⁰⁷



Figure 14. Complementary visions of the concepts of *frailty* and *intrinsic* capacity.

Source: Authors.

4.2.4 Conceptual relationship between frailty and complexity

Even though concepts like frailty, multimorbidity, complexity, CCP and ACP are often intertwined and a part of the daily reality of professionals in Catalonia, they are not either synonymous or mutually exclusive.

Thus, **from the person-centred approach**, bearing in mind their vulnerability, the continuum ranges from a robust person to a person with advanced frailty. From a **systemic approach**, the continuum runs from the state of a healthy person to their possible identification as ACP, with all the stages of chronicity with their different levels of complexity in between, and bearing in mind that the situation of complexity tends to be related to difficulties of the person, their environment or the system in managing the response to people's needs (Figure 15).¹⁰⁸

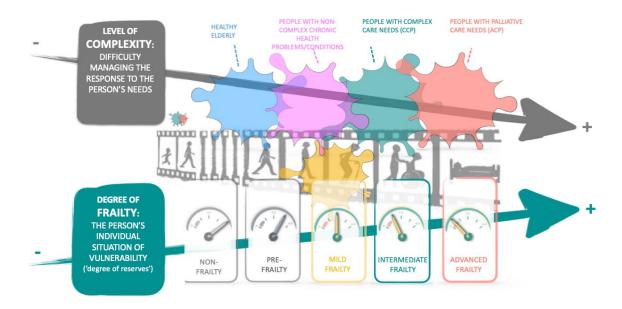


Figure 15. Continuum of frailty and complexity.

Adapted from Limón E, et al. 108



- There is a consensus on the opportunities provided by viewing frailty as the core factor in clinical practice, research and healthcare planning in the care of the older people.^{85,109,110}
- Therefore, frailty is often advocated as a transversal concept that must be taken into account in any plan, programme or treatment targeted at the older people, which range from preventing disability to people with complex care needs and palliative needs.^{97,111,112}

4.3 People with complex chronic (CCP) conditions



Complexity in health is as difficult to address as it is to delimit, and it is conditioned by multiple layers or dimensions that reflect different circumstances, such as the characteristics of their multimorbidity, clinical uncertainty or difficulty taking decisions. On the other hand, other non-health-related issues arise which are directly related to the person and their environment (social conditions, community network, dependency, etc.). This enables us to distinguish **three dimensions of complexity** (Figure 16): clinical complexity, contextual complexity and complexity of the health and care system itself.



Figure 16. Dimensions of complexity in healthcare.

Adapted from Kuipers et al. 113

Clinical complexity



This refers to the interaction among a host of factors related to the illness, such as: the diagnosis, the severity of the problem, the presence of symptoms that are difficult to control, multimorbidity and the degree of disability that could arise from it.^{114,115} For healthcare professionals, these factors tend to condition clinical complexity in relation to two closely related circumstances:⁵⁸ the difficulty of a precise diagnosis and the difficulty taking decisions.

Contextual complexity (social, psychosocial and familiar)



This refers to the social needs and psychosocial condition caused by the illness, which can aggravate or hinder the management of health complexity, as well as the social functionality (or dysfunctionality) of risk to deal with the health needs with/in the same social support network due to the impact of social and psychosocial risk factors in one or more of the following areas:

- Area of organisation of care
- Area of the family unit and/or caregiving environment
- Area of family cohesion and affective climate
- Area of the structural, safety, comfort and privacy conditions
- Area of the relational network
- Area of the environment (community and access to home)

Complexity

related to the healthcare & social systems



Paradoxically, and given the multiple possible responses to the challenge of complexity, ^{116–118} the system itself can end up becoming a source of complexity which cannot necessarily be solved with more services. ¹¹⁹ In fact, more services and professionals can often end up generating complexity by creating multiple pathways, which can be more confusing and lead to uncoordinated responses, duplications and gaps in the continuum of care. ¹¹³ This complexity cannot be addressed using standard models and requires creative solutions, flexibility, versatility, the capacity for innovation and a common foundation of shared knowledge. ¹²⁰ Based on this multidimensional reality of complexity, it is clear that the response to these people's care needs requires this three-fold approach, with coherence, and to a greater or lesser extent.

Therefore, we see that complexity is not only a reality that is limited to and inherent in the individual but that it is also a conjunctural and to some extent perceptive phenomenon: something that is 'experienced as complex', because of both person's difficulty—or that of their environment—managing their own needs and the difficulties guaranteeing a response by professionals and healthcare system.¹²¹

According to the consensus of experts contained in **TERMCAT** (the terminology centre of the Catalan language),¹²² the **concept of** *complexity* means a situation which reflects the difficulty of managing the care of a person and the need to apply specific individual plans for them because of the presence of concurrence of illnesses, the way they use the services or their environment. The presence of complex care needs are the common thread in this group of people—which are estimated to account for approximately 4% of the population—for whom we proposed using the identifier **CCP** (Figure 17).

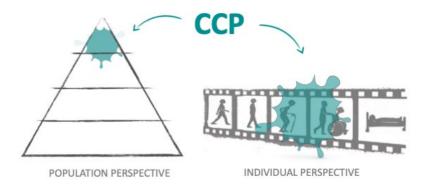


Figure 17. CCP: population perspective and individual perspective. Source: Authors.

4.3.1 Criteria for identifying CCP



There is no specific instrument to populationally screen patients with chronic complex (CCP) conditions. Identifying them is based on the **presence of criteria**—based on the consensus of experts and the results of earlier epidemiological studies²⁷—in any of the three dimensions of complexity, which are summarised in Table 5.

Problems related to the person's clinical situation

- Multimorbidity. Single severe or progressive chronic pathology.
 Rare illnesses.
- Dynamic evolution.
- Appearance of geriatric syndromes with criteria of severity/progression (polypharmacy, cognitive impairment, frailty...).
- High user of services or consumption of resources. High likelihood of suffering from imbalances.
- Classification within the 5% highest risk group according to the adjusted morbidity groups (AMG).

Social/ contextual criteria	Social situation of risk or dysfunction which requires care according to their needs in one or more of the following areas: Organisation of care. Family unit and/or caregiving environment. Family cohesion and affective climate. Structural conditions, safety, comfort or privacy. Relational network and environment.
Related to professionals and the healthcare system	 Benefit of multidisciplinary management. Need for access to different devices. Uncertainty in decisions and management doubts. among different professionals or teams in their clinical Benefit of integrated care strategies.

Table 5. Criteria for identifying CCP, grouped by domains of complexity. Source: Authors.

There are **no unequivocal guidelines** on how many or what criteria or combination thereof should be met to be considered a CCP. Enough criteria should be met for the referring professional to believe that the case management is particularly difficult and therefore to clinically validate and identify, in accordance with the person, that they are a CCP. A person that meets none of these criteria is unlikely to present complex care needs.

4.3.2 Stratification of complexity based on information systems

Epidemiological studies have enabled us to calculate that approximately 3-5% of the population is in a situation of complexity. In this sense, particularly important is the contribution made by **stratification models** based on **groupers of morbidity**, which enable sub-populations with a high interest in terms of high mortality, hospitalisation, frequency of primary care utilization and drug consumption to be identified. Thus, they are people who have high care needs and high costs, which is why they are called *High Needs High Cost*.

It is clear that the isolated use of stratification has limitations because of the large number of variables—some of which are not currently available in the information systems (such as many social variables)—which are related to a situation of complexity. Nonetheless, it may be useful for professionals given its reliability in terms of the dimension of clinical complexity. 123

For example, there is a high **correlation between high risk AMG and the identification of CCP**: almost two-thirds of people identified as CCP are in the AMG group with the highest risk (Figure 18).

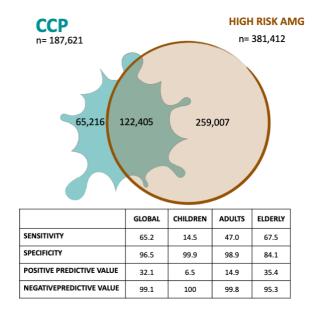


Figure 18. Relationship between the population in a situation of complexity and the AMG population at high risk.

Source: CatSalut.



Any specific care proposals for people with complexity will need this **threefold view of complexity** (clinical, social and systemic), as well as the need to individualise the approach to care.

The **model of care** for these people must necessarily include **four key elements** to guarantee quality care.^{113,123,124} (see section 5 of this document): proactive identification or screening, situational diagnosis or multidimensional assessment, development of an individualised care plan and sharing this information with the teams that care for these people.

One of the key factors in this populational group is nutrition. Some of the keys to this factor can be found in the *Consensus document on a community approach* to malnutrition related to chronic conditions in people with clinical complexity.

4.4 People with advanced chronic (ACP) conditions



The **end-of-life process**, meant as the last phase in the life cycle, which can range from a few days to many months or even a year, is also conditioned by multiple variables, is strictly individual and has a paradigm of complexity as described above. In these people, complexity is also determined by personal factors (given the coexistence of multiple chronic health problems, and health needs and the dynamic behaviour of these needs), contextual factors (the emotional impact of the entire crisis, family and social support) and care factors (in terms of the organisation and use of resources such as the existence of psychological or other kinds of care).

Approximately three-fourths of the population will die because of one or several advanced and progressive chronic illnesses after a developmental period with frequent crises, a high need of care and frequent clinical and ethical decisions, as well as a high frequency of health and social services. This close relationship between end of life and illness led these people—which are estimated to account for 1% of the population—to be called ACP (MACA is the Catalan abbreviation for advanced chronic disease) (Figure 19).

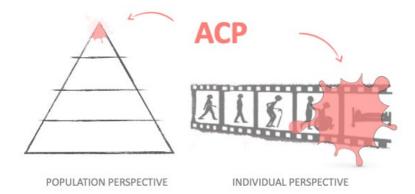


Figure 19. ACP: population perspective and individual perspective. Source: Authors.

People with advanced chronic disease share the presence—to differing degrees—of palliative needs, as well as a limited life prognosis and/or a situation of nearing end of life, meaning the last phase in the life cycle, which can range from a few days to many months or several years.

4.4.1 Foundations of palliative care in the 21st century

Care for people with advanced chronic health problems is experiencing a **paradigm shift**^{133,134} from an approach essentially focused on people with cancer in their last weeks or days of life with a dichotomous vision (curative vs palliative treatment) to the early identification of people with palliative needs with a gradual, synchronous approach for any chronic advanced illness or health problem. The key elements in this paradigm shift are summarised in Table 6.¹³⁴

Shift from	То
Terminal disease	Advanced and progressive chronic conditions
Prognosis of weeks or months	Early identification (based on palliative care needs)
Cancer	All chronic progressive conditions
Progressive course	Progressive course with frequent crises, needs and demands
Dichotomy curative—palliative	Synchronic, shared, combined care
Prognosis as criteria for intervention of specialist services	Complexity as criteria

Shift from	То
Rigid one-directional intervention	Flexible, shared intervention
Passive role of people	Advance care planning
Specialise palliative care services	Palliative care in all areas of the health and social system
Fragmented care	Integrated care

Table 6. Conceptual transitions in palliative care in the twenty-first century. Adapted from Gómez-Batiste *et al.*¹³⁴

4.4.2 Early identification of the end-of-life

One of the key elements in this paradigm shift lies in **early identification** of people with palliative needs, which has been proven to have multiple benefits: it allows patients' preferences and values to be known, so the objectives fit them better and early decision planning is easier. ¹³⁵ It also improves quality of life and control of the symptoms, lowers anxiety, allows them to receive less aggressive care and can even boost the person's survival. ^{136–138}

On the other hand, this early identification of people with palliative needs (regardless of their illnesses or underlying chronic health problems) has opened up the range of characteristics of the people who can benefit from this approach. With the goal of facilitating a progressive instead of dichotomous approach to end-of-life care adjusted to the dynamic needs of each patient, **two** end-of-life **transitions** have been identified¹³³ (Figure 20):

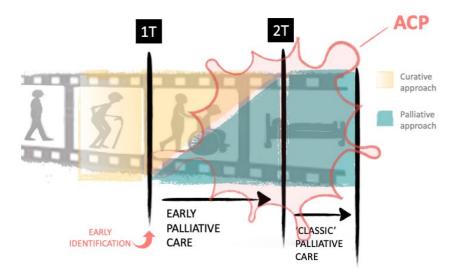


Figure 20. Two end-of-life transitions (1T and 2T) and progressive model of care according to needs.

Source: Authors.

- The **first transition (1T)** answers the question 'might this person die in the upcoming months or years?' and starts as soon as a situation of advanced illness has been diagnosed, often a few months or years before their death. This identification should be made proactively, early and universally by means of specific instruments designed for populational screening with the goal of answering the following questions: Is this truly an irreversible situation? Is the treatment of their underlying pathologies optimised? Is the support environment sufficient? Can they begin to benefit from a palliative approach?
- A **second transition (2T)** answers the question 'is this person ill enough to perhaps die in the next few days or weeks?', and it therefore corresponds to the last few days or weeks of the person's life, that is to their being '**terminal**'. It is important for professionals to be alert to the possibility that a patient may have entered this second transition, as it is a turning point in which the decision must be made to prioritise the strictly palliative approach.

The **early identification** of these people is the essential point of departure for a progressive approach, ^{133,139,140} in which palliative care is offered as needs arise, either related to the illnesses, to the individual characteristics of each person or to the family or caregiving environment.



Given the vast trove of evidence on the benefits of this approach, ^{136,137,140} some countries have developed specific strategies and different **instruments** to assist in this early identification, such as the *Prognostic Indicator Guidance* (PIG) of the Gold Standards Framework (GSF) programme in England, ¹⁴¹ Supportive & Palliative Care Indicators Tool (SPICT) in Scotland ¹⁴² and RADboud Indicators for PAlliative Care Needs (RADPAC) in Holland. ¹⁴³

In Catalonia, for the early identification or screening of people with palliative needs and advanced chronic disease (ACP), the *NECPAL CCOMS-ICO® instrument* is used. 134,144,145 This instrument is based on a negative response ('it would not surprise me') to the **surprise question** 'Would you be surprised if this person died over the course of the upcoming year?', **associated with** detecting **criteria** related to palliative needs, functional and/or nutritional loss, multimorbidity, use of resources and/or criteria on the severity and progression of advanced illnesses (Figure 21 shows version 4.0 of the NECPAL CCOMS-ICO® instrument).

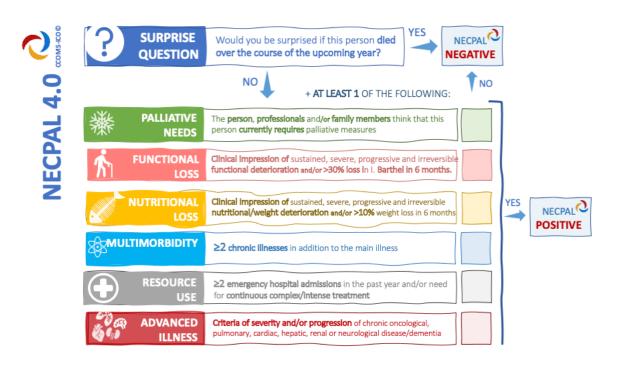


Figure 21. Version 4.0 of the instrument NECPAL.

Source: UVic-UCC Chair of Palliative Care, ==

Version 4.0 of the NECPAL enables us to distinguish between different degrees of advanced chronic disease and palliative needs via the cumulative number of criteria. Based on the very concept of the accumulation of deficits on frailty indexes, there is a direct, proportional relationship between the number of positive criteria and the person's mortality prognosis. Thus, for example,

a person with a positive NECPAL test with only 1-2 criteria is likely to be in the first transition to end of life, while a person with 5-6 criteria is probably in the second transition or is terminal. Obviously, this should be corroborated by conducting an in-depth multidimensional assessment.

The epidemiological studies on **prevalence** conducted here⁵ show that between **1% and 1.5%** of the population of Catalonia may have palliative needs and a limited life prognosis. Of this percentage, almost 90% are living in the community (about 20% in residences). Most of these people have dementia and advanced frailty (55%), followed by organ illnesses (32%) and cancer (13%).

However, end-of-life situations are not alien to hospitals: up to 70% of people in health and social care centres may be in an end-of-life situation, compared to 37% of people admitted into acute care in hospitals.

4.4.3 Complexity and end of life

The process towards end of life is conditioned by multiple variables and is strictly individual,⁵⁸ and not everyone reaches end of life in the same circumstances, nor by the same circumstances, nor with the same needs, nor with the same complexity of care from professionals.^{113,146} Even though not everyone who reaches end of life presents the associated complexity, advanced chronicity and complexity often go hand in hand.



In this sense, the **complexity hexagon** (HexCom®2018) has been developed in Catalonia, which is a tool that facilitates the implementation of the model of care—interdisciplinary and comprehensive, focused on the person and their family and/or caregiving environment—for the home care of people in situations of advanced illness and/or end of life. This tool has been validated at different healthcare levels, ¹⁴⁹ and it is comprised of three different instruments: an extensive one (Hex-Com-Clin®2018) geared at clinical application; a brief one (HexCom-Red®2018) designed to **facilitate management/referrals among healthcare levels according to the level of complexity**—which will be adopted in Catalonia with this same goal—and a quick detection/referral one (HexCom-Det®2018).

4.4.4 Palliative paediatric care

According to the **WHO**, palliative care for children consists in total active care of the body, mind and spirit of the child, and in providing support for the family. It begins when the illness is diagnosed and continues regardless of whether or not the child receives treatment for it.

The Association for Children's Palliative Care of the United Kingdom (ACT) defines palliative care for children and youths with health problems that limit or threaten their life or who are at risk of death as an active, total approach geared

at caring for the child from the time they are diagnosed or the health problem is recognised through the rest of their life and in their death. It encompasses physical, emotions, social and spiritual elements and approaches to improve the child or youth's quality of life and the family's support. It includes management of anxiety-causing symptoms and the provision of brief respites and care during dying and the grieving process (Figure 22).

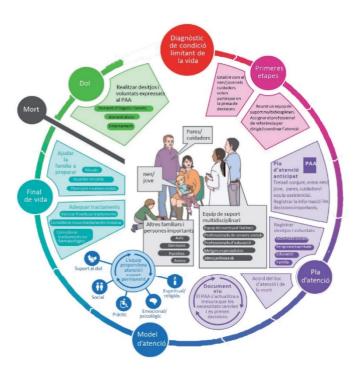


Figure 22. End-of-life care for children and youths.

Source: End of life care for infants, children and young people with life limiting conditions: Summary of NICE guidance, BMJ 2016; 355, doi.org/10.1136/bmj.i6385.



Bearing in mind the document Foundations for developing an organisational model of comprehensive care of children and youths with palliative needs and in end-of-life situations which the Ministry of Health published in 2018, in Catalonia, the document Organisational model of comprehensive care for children and youth with palliative needs and at end of life, which will be published soon, specifies the organisation of care for children and youths with complex palliative needs and in end-of-life situations.

Working as a network according to the degree of complexity of each case contributes to the goal of the efficiency and sustainability of the public healthcare system, to improving rationalisation and to appropriately using resources. It should also facilitate an improvement in knowledge transfer and innovation.



The successful proposals for individuals with palliative needs and advanced chronic disease share the following aspects: 122,194-196

- Early identification of people with palliative needs. This early identification has multiple benefits: it allows us to know the preferences and values of the patients, it better defines the goals and it facilitates the process of planning decisions in advance (PDA).¹³⁵ It also improves quality of life and control of symptoms, lowers anxiety, allows patients to receive less aggressive care and lowers the healthcare costs and can even improve survival.^{136,137,13}
- It goes beyond the diseases and/or chronic health problems that condition the palliative needs.
- It is based on a community approach to these patients, with the intervention of specialised teams according to the complexity of needs.
- It guarantees the **accessibility** to the reference professionals.
- Advanced planning, shared and decision-making focused on the results that matter to the person.
- It takes place in an integrated healthcare context, with collaboration among the primary care and specialised professionals, from social work (including the third sector) and healthcare with an interdisciplinary mission.
- **Support** for the caregiving families and/or milieu.
- The model of care for these people should necessarily also include four key elements to guarantee quality care,113,123,124 (see section 5 of this same document): proactive identification or screening, situational diagnosis or multidimensional assessment, development of an individualised care plan and sharing this information with the teams that care for these people.

5. Model of care

Even though all older people and/or people with chronic health problems benefit from an individualised, person-centred approach to care, this document seeks to particularly stress **three specific situations** which benefit from this model of care: people with **mild frailty and risk of disability**, people with complex care needs or **complex chronic (CCP) conditions** and people with palliative needs or **advanced chronic (ACP) conditions** (Figure 23), given their specific characteristics:

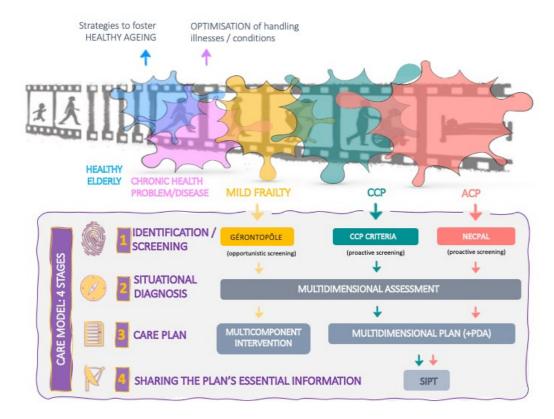


Figure 23. Summary of the specific proposals for people with mild frailty, CCP ACP for each stage in the model of care.

Source: Authors.

All of these people, and especially CCP or ACP, share the need for an eminently person-centred approach which transcends the strictly protocol-based approach (Figure 24).

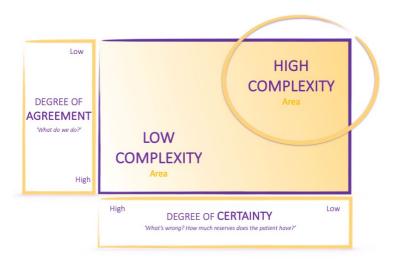


Figure 24. Management of uncertainty and complexity. Adapted from Amblàs *et al.*¹⁵⁴

The measure of clinical complexity is conditioned by the degree of evidence of 'What is wrong with the person?' and the degree of agreement on how to proceed given this situation and decision-making ('What do we do?'):

For example, for a young person with acute myocardial infarction (A), the diagnosis tends to be simple and the action protocol is clear; even though it could potentially be a very dangerous situation, it is not a situation of high complexity in terms of decision-making, and it is easy to outline an action proposal: in this area, guides to clinical practice and clinical pathways are the framework of action that facilitate good practice. However, in the case of a person with clinical complexity (B), given the multiple chronic health problems and the tendency to show imbalances in multiple systems in an intercurrent process, often with imprecise clinical symptoms—such as functional deterioration or repeated falls— the diagnostic uncertainty tends to be high. In these situations, decision-making also tends to generate uncertainty, as it is difficult to follow a protocol. This group of people benefit from a strictly personalised proposal or model of care that is adaptable to their situation and needs.

Therefore, these people need a 'bespoke suit' adapted to their characteristics, that is, a specific **model of care** which consists in four **steps** (Figure 25):



Figure 25. Model of care that facilitates person-centred care. Source: Authors.



STEP 1 Identification/populational screening



Even though the majority of the older people or people with chronic conditions and health problems require some degree of personalisation of their treatments, from the populational perspective it is essential to **focus** primarily on people who—due to their characteristics and circumstances—can **most benefit from this individualised model of care**.

For both people with mild frailty and those CCP or ACP, specific population screening strategies of people with specific needs are proposed:



People with **mild frailty** or risk of disability

As part of the project to prevent disability and promote personal autonomy of the PAISS—which is currently only being implemented in five pilot territories—the proposal is to use the *Gérontopôle Frailty Screening Tool (GFST)* for the **opportunistic screening** of people with early frailty or risk of disability.⁹⁵

Once the person has been identified, they must be **registered in the electronic health record** as a 'person with early frailty' with the code **R54.**



People with complex chronic (CCP) conditions

The identification is based on the **presence of criteria** (see section 4.3.1 of this document) and is done via proactive **screening**.

Once identified, **the person should be registered** as a **CCP** in the information systems.



People with advanced chronic (ACP) conditions

We recommend using the **NECPAL instrument** for the early identification of or **proactive screening** of ACP and palliative care needs. 135-138,153

Once identified, **they should be registered** as such in the information systems. Identification as a person with ACP is equivalent to the international coding of palliative care (**V66.7** in the ICD-9-MC, **Z51.5** in the ICD-10-MC or **A99.01** in the CIAP-2), as explained in the document *Standardisation of the codes of advanced chronic conditions (ACP) and palliative care (V66.7 ICD-9/z51.5 ICD-10)*.



- Despite the fact that the current evidence does not recommend doing universal, proactive screening of people with early frailty, there is a consensus on the benefits of opportunistic screening of the older people (with some associated characteristics) who could potentially benefit from actions to prevent disability.^{81,155-157}
- The proactive identification of people with complex care needs is essential as a point of departure in individualising the care plan. 158–160
- The early, proactive identification of people with palliative needs has proven to have multiple benefits, as mentioned above in section 4.4.2. 135-138



STEP 2Situational diagnosis

Despite the fact that identifying someone as a person with early frailty, a CCP or an ACP already implies a certain previous multidimensional approach, situational diagnosis requires a more in-depth multidimensional needs assessment.



The concept of *situational diagnosis*⁵⁸ refers to the outcome of the **multidimensional needs assessment process** which enables professionals to determine the **degree of reserves** or frailty of the patient (*How vulnerable are they? At what point in their life trajectory are they?*) (Figure 27), as well as the **deficits or dimensions** affected and the **needs** which must be met.

In this diagnostic process, it is important to bear in mind both the situation at the time (the 'snapshot' of the situation, the degree of severity) and its dynamic evolution (the 'film' or criteria of progression) (Figure 25):

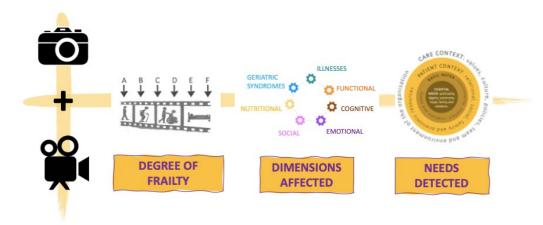


Figure 26. Key elements in the situational diagnosis. Source: Authors.

5.2.1 Multidimensional assessment

The situational diagnosis of a person with early frailty, CCP or ACP necessarily requires a broad vision that bears in mind the different dimensions or health problems: clinical, functional, emotional, cognitive, social, etc. This is a complex undertaking that requires time. It should not just be an accumulated string of scales but the compilation of substantial information that enables a situational diagnosis to be made.¹⁰⁸



Given the need to systematise this evaluation, there are essentially two approaches which need more or less time and expertise, and which can be complementary: **comprehensive geriatric assessment and quick multidimensional/geriatric assessment systems**.

Comprehensive geriatric assessment

Comprehensive geriatric assessment (CGA) is **the standard of reference** in the multidimensional assessment of people with a geriatric profile, ¹⁰³ in the area of primary care as well. ¹⁶¹ CGA is defined as a diagnosis approach and multidisciplinary process that identifies the medical, psychological and functional conditions of an older people and/or frail person with the goal of designing and developing a care plan to maximise their overall health within the context of ageing. For this reason, different areas of health have to be assessed, including their clinical problems, their functional state (basic and instrumental activities), their mental state (cognitive and emotional) and their social milieu.

Even though CGA should not be viewed as merely the administration of a series of **scales**, to get an overall picture of the person, it is essential to **assess each of the dimensions** (Table 7):

DIMENSION		PROPOSED ASSESSMENT INSTRUMENT
FUNCTIONAL	Instrumental activities of daily life (IADL)	Lawton and Brody Scale
	Basic activities of daily life (BADL)	Barthel Index (BI)
MENTAL	Cognitive	Pfeiffer's Mini-Mental State Examination (MMSE) Test Mini-COG
	Emotional	Yesavage geriatric depression scale

SOCIAL	Social risk	Gijón Scale
	Social complexity	Self-Sufficiency Matrix
	Perceived social support	Oslo 3 Scale
	Caregiver overload	Zarit Test
NUTRITIONAL		Mini-Nutritional Assessment (MNA)
GERIATRIC SYNDROMES AND SYMPTOMS	Delirium	Confusional Assessment Method (CAM)
	Pressure ulcers	Braden Scale Norton Scale
	Dysphagia	Volume-viscosity test
	Falls/gait	Tinetti Scale
	Symptoms	Edmonton Symptom Assessment System (ESAS)
QUALITY OF LIFE		Euroqol 5D

Table 7. Examples of scales to assess the different dimensions.

Source: Authors.

Even though CGA is the standard of reference, it also has **some limitations** to promoting its widespread use among professionals in healthcare and social systems:¹⁷

- It requires expert knowledge.
- An in-depth CGA requires a lot of time: close to 1 hour or more.
- This assessment process is conducted by the entire interdisciplinary team.
- It is more 'qualitative' in nature, which often limits interprofessional communication in a healthcare context familiar with using scores and algorithms.

Quick multidimensional assessment systems

For these reasons, the recent literature is suggesting that rapid multidimensional geriatric assessment tools be developed. These allow for a broad multidimensional approach, although the depth of each of the dimensions is limited, in a limited time period (approximately 10 minutes), and they are usually administered by a single professional from any field within the healthcare system. Different tools of this kind have proliferated in recent years, such as the Saint Louis University Rapid Geriatric Assessment (RGA), the abbreviated Comprehensive Geriatric Assessment (aCGA), the 10-min

Targeted Geriatric Assessment,¹⁶⁴ the Resident Assessment Instrument-Minimum Data Set (RAI-MDS)¹⁶⁵ and the G8 (Geriatric 8) Health status screening tool.¹⁶⁶

In Catalonia there are examples as well, such as the *Índex fràgil-VIG*, ¹⁰⁴, ¹⁰⁵ a frailty index designed specifically to facilitate a quick, quantified geriatric assessment, and the emergency assessment ^{3D/3D+}. Finally, spearheaded by the PPAC and the PDSS and endorsed by the PAISS, the **consensus** on a rapid multidimensional assessment/geriatric tool (**VIG-express**) has been promoted as a shared, universal system of initial multidimensional assessment to be made available to all professionals in the healthcare and social system of Catalonia. This tool is currently in the validation stage.

Therefore, one of the essential objectives of situational diagnosis—regardless of whether a more qualitative approach (such as a VIG) or a more quantitative approach (such as a frailty index) is used—it to determine the **degree of frailty** of the person (Figure 27).

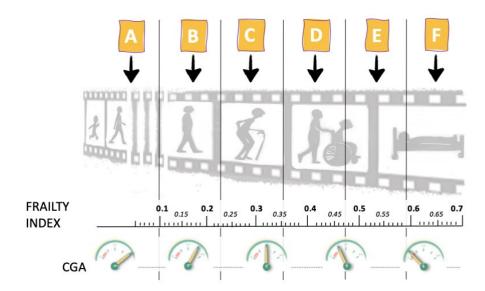


Figure 27. Situational diagnosis and degree of reserves of the person: *How vulnerable are they? At what point are they in their life course?* A? B? C? D? E? F?

Source: Authors.

5.2.2 Identification of needs

Care of **people's health needs** should be the core objective of the care response of healthcare professionals, teams, organisations and systems. Especially in the situations with the most complexity, people require comprehensive, integrated responses that are appropriate for the different times in their life course. These needs should not only encompass those stemming from the illness but also the person's capacity to care for themselves and manage their life in their closest social environment. The range of needs that should be taken into account is broad

and ranges from the most basic to the most complex. 167

This identification of needs is part of the situational diagnosis process and is a fundamental objective in the care for these people. In this sense, it is essential to determine the problems that present the most complexity, their causes, the factors that contribute to their appearance and the person's capacities and resources to find solutions, and then bear this in mind when developing the therapeutic plan.

There are different models for assessing needs; the best known in nursing field are Virginia Henderson's 14 basic needs, 168 which stresses the importance of people's independence, particularly in their decision-making processes; Marjory Gordon's 11 functional health patterns, 169 which assess the functionality and dysfunctionality of each of them; and Maslow's pyramid of needs, ¹⁷⁰ which is a fivelevel pyramid in which the higher needs depend on the lower ones.



Especially designed for people with advanced chronic disease, the essential needs model of the Catalan Institute of Oncology was developed in Catalonia (Figure 28).¹⁷¹

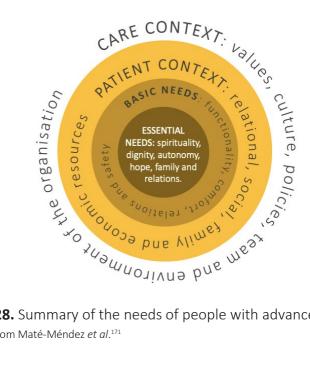


Figure 28. Summary of the needs of people with advanced illnesses. Adapted from Maté-Méndez et al. 171

Essential needs are those that are inherent and specific to the human condition and intrinsic to the person, and they are particularly important in situations of vulnerability and/or advanced disease. 172-175 Here we shall briefly define them:

- Spirituality: This is the private, individual experience of the person. It includes transcendence, the meaning of life, beliefs, values, practices, forgiveness and pending affairs.
- **Dignity**: This refers to the respect and acknowledgement that a person deserves for their value, social history and life history.
- **Autonomy**: This refers to freely participating in decision-making, wishes and

focal points of their attention from both the physical and spiritual standpoints.

- **Hope**: This includes adjusted, realistic, flexibility and reasonable expectations.
- Affection / family and personal relations: This includes the emotional support, love and assistance provided by the people near the patient.



- A comprehensive or holistic assessment of the person should be made bearing in mind their care, personal, basic and essential needs,¹⁷¹ as well as a care plan that incorporates them.¹⁷⁶
- Beyond the needs detection model used, this assessment should include the person, the people around them and the healthcare context.¹⁷⁷
- In this sense, health and social care should focus on caring for the needs detected, and the preferences, whishes and values of the people receiving care, more than solely on their illness.¹⁷⁸





Once the situational diagnosis has been made, the **care plan** has to be developed. This plan should define the therapeutic plan* for each of the health problems, along with the proposed care for the needs detected.

*The **therapeutic plan** is the set of recommended resources (pharmacological, technical, action guidelines) that the healthcare professionals propose in a gradual, planned fashion with the goal of maintaining, improving, controlling and achieving the maximum potential health for the individual or collective benefit of the people they care for and in accordance with these people.

This care plan should be based on the **situational diagnosis** done previously, and on the exploration of the person's **values and les preferences** with the goal of (Figure 29):

Agreeing on the **health targets** of the proposed treatment, which should be focused on the results that are important for the person, which in turn should be agreed upon with the person and proportional to their situation.

Identifying the **dimensions** in which action is needed, as well as the **needs**

that must be met—which are quite often associated with the deficits detected during the multidimensional assessment.

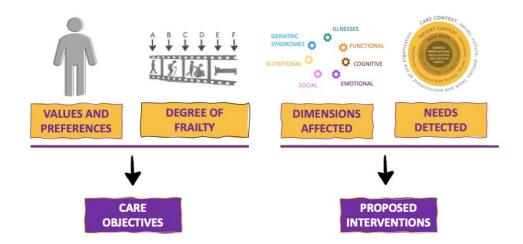


Figure 29. Health targets and proposed treatment as key elements in developing a person-centred care plan.

Source: Authors.

5.3.1 Health targets

General objectives and specific objectives

Even though the objectives of the care plan can be multiple, dynamic and nuanced, from a pragmatic perspective, it is useful to group the **general objectives** into three main categories (Figure 30):

- Improving survival: Do strategies to increase the survival time make sense?
- Improving or maintaining the functionality or stability: Do strategies geared at stabilising or maintaining the current situation make sense? Is there room for functional improvement?
- Improving wellbeing and quality of life: Does an approach focused on improving the person's quality of life make sense from both the physical and the emotional or spiritual standpoint? And does it in more advanced situations, which are primarily focused on controlling symptoms and essential needs?

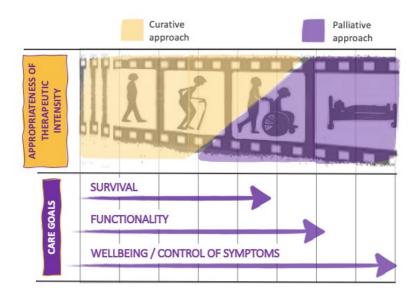


Figure 30: Conceptual proposal of health targets and appropriateness of the therapeutic intensity according to the person's situational diagnosis.

Source: Authors.

Having established the general objectives by consensus, next we must specific its **implications in specific situations** that may arise in the evolutionary context which would be considered 'good practices' in each case. For example, what to do with regard to the following aspects should be specified:

- Use of preventive medication.
- Management of infections and use of antibiotics.
- Nutrition, if ingestion problems arise.
- Levels of care action (home, intermediate, acute).
- Additional tests.
- Indication of appropriateness of the therapeutic intensity and level of healthcare.
- Support for basic and instrumental activities in case of the momentary/permanent loss of autonomy.
- Replacement of the main caregiver if they give up or are temporarily incapacitated.
- **...**

Situational diagnosis and appropriateness of the therapeutic intensity

The previous situational diagnosis, as well as the consensus on the health targets, are fundamental in the **appropriateness of the therapeutic intensity** (Figure 26). For example, when faced with a person with advanced frailty and/or who has been identified as ACP, the risk/benefit of aggressive interventions, which could be disproportionate or overly aggressive, must be weighed. In contrast, for the older people with a good degree of reserves, the situational

diagnosis helps avoid the age criterion from being used to deprive them of an additional diagnostic effort or a specific therapeutic test that could potentially be beneficial.

Several factors which can help this reflection are:

- Evolutionary prospects to date: Consider the person's evolution in recent months from a multidimensional perspective (stability, decline, improvement), the severity and progression of the problems, their identification as a CCP or ACP, the likely evolution and the final resolution of care for their needs to date.
- Reversibility or irreversibility of the problems detected.
- Cost-benefit of the treatments.
- Prospects of future evolution when planning possible evolutionary scenarios and the corresponding implications in their care, and anticipation of future needs, considering any imbalances or crises which may arise, their characteristics and how they will be managed.
- The capacity of the people and their milieus to deal with new needs, care and problems.
- The person's values and preferences.
- Discrepancy analysis: contradictions among the different professional assessments and/or between the person's objectives/preferences and the actions proposed by the team.



In Catalonia, there are different specific experiences designed to make it easier to **register** the agreed upon level of therapeutic intensity in both hospitals⁵⁷ and from a territorial perspective.¹⁷⁹ Sharing the Shared personalized care plan (SPCP) also aims to facilitate sharing indications on the appropriateness of the therapeutic intensity.

Values and preferences, autonomy and empowerment of the person

Even though the health targets and the therapeutic intensity should be geared to the person's situational diagnosis, it is essential for them to be aligned with **the person's values and preferences**.

A person's **autonomy** is defined as the 'capacity to control, cope with and take on their own initiative personal decisions on how they should live according to their own norms and preferences, as well as how to carry out the basic activities of daily life.' Autonomy is essential in managing a health process, given that it helps improve information, training and awareness of one's illness and evolution.¹⁸⁰

Empowerment is defined as the process whereby people gain more control over the decisions and actions that affect their health, while **self-care** refers to a set of actions based on empowerment that the person does for their wellbeing and

Shared decision-making

The best way to guarantee autonomy, empowerment and the alignment with the person's values and preferences is for this process to be undertaken in a joint fashion. Shared decision-making is considered the **key element of person-centred care** and has been identified as one of the levers of change in improving the quality and safety of healthcare. Shared decision-making should be viewed as a meeting of expert minds: on the one hand the healthcare professional, an expert in handling clinical situations, and on the other, the patient, an expert in 'themselves', their values, wishes and what 'really matters' to them.

This shared process requires people and professionals to be informed, motivated and committed, and capacitated. This capacitation is related to the level of demands of the decisions to be taken: a decision on what drug to choose to treat hypertension is not the same as a decision to perform a screening for oncological pathology or a process of planning decisions in advance (PDA). Table 8 provides some specific **recommendations** related to this capacitation.¹⁸³

Recommendations for healthcare professionals	Recommendations for people	
1) Encourage the complicity and engagement of the person.	1) Choose a team that you trust and define the type of relationship you want to have with them.	
2) Write down their preferences and values.	2) Let them know what is really important to you (feelings, values, beliefs and expectations).	
3) Assess the person's attitude to the risks (degree of risk they can accept).	3) Share it transparently and calmly with the team. Find the right time to do it.	
4) Identify the different options and their effectiveness.	4) Access the relevant information on your health problems.	
5) Help the person to reflect on these options.	5) Evaluate the information. Reflect on the different options along with your team.	
6) Develop a care plan together, and validate it together. If needed, agree upon a 'plan B'.		

Table 8. Recommendations for healthcare professionals and patients on decision-making.

Font: Modified from Angela Towle $et\ al.$ 183

There are many benefits of going through this process together. 184-187

- It improves the relationship between patients and professionals, which also helps facilitate implementation of the model of care.
- It fosters the individuals' engagement in their own health, with beneficial results in terms of therapeutic compliance (more compliance).
- It boosts the person's empowerment, their involvement in self-care, their satisfaction with their care and improved communication with the teams.
- It exerts a corrective effect on overdiagnosis and overtreatment, helps to optimise resources and lowers the variability of clinical practice and equity.
- It seems to improve health outcomes and the pattern of resource use, although more studies are needed to confirm this. Some studies find that shared decision-making can lower the pressure on the healthcare and social system, especially in contexts of integrated care.

Finally, there are different **tools** which can help in this shared decision-making process in daily practice, which range from passive proposals (like essential information for people) to more active proposals (which facilitate consensus on objectives and developing objectives and action plans). Ideally, both approaches should be combined.¹⁸⁸



In Catalonia, different proposals of this sort have been developed which can be seen on the webpage 'shared decisions'.

Planning decisions in advance

One paradigmatic example of the shared decisions methodology is planning decisions in advance (PDA). PDA is the process that identifies a the values and preferences of a person, their family or their caregiving environment, if applicable, to **plan in advance the care objectives and resources** needed to care for them. ¹²² This is the dialectic and conceptual core of the process to encourage the patient to co-lead, in accordance with their values, wishes and preferences, the determinants in the course of their health problems at any time, especially when they occur in situations with a limited life prognosis. This requires **6 steps** (Figure 31):



Figure 31: The 6 steps of PDA.

Source: Authors.



There is a *Catalan PDA model*, which is an innovative proposal that addresses the ideas, practices and implementation strategy in a field in which the advanced chronic disease strategy converges with personcentred care initiatives.¹⁸⁹

5.3.2 Proposed treatment

Defining the care plan means that based on the list of problems and needs of **every dimension or area** assessed (clinical, functional, emotional, cognitive, social, etc.), and on the situational diagnosis and the person's values and preferences, **specific actions** are established to meet them. For example, for a person with early frailty, the care plan should probably be geared more towards preventive measures (for example, with a predominance of physical exercise programmes and nutritional improvement), while for a person with an ACP profile, aspects more geared towards psychosocial and support for caregivers become more important (Figure 32).

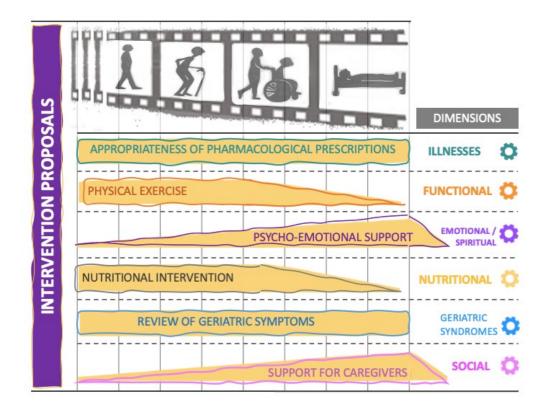


Figure 32: Conceptual representation of some of the interventions from a multidimensional perspective and their intensity according to the situational diagnosis.

Source: Authors.

Generically, the overall actions or those related to one of the different dimensions can be grouped into four areas:

- Interventions involving literacy, empowerment, self-care and support.
- Interventions involving **relations and communication** (with the person and the caregiving environment).
- Changes in **pharmacological prescriptions**.
- Changes in **services** (health, social and community).

Health literacy and support

Health literacy is related to people's knowledge, motivation and competences to access information on health and to understand, evaluate and apply it in order to have a fact-based personal opinion and thus be able to make judgements and decisions on health and everyday life problems related to it, health promotion and disease prevention to maintain and promote lifelong quality of life.¹⁹⁰

A person with a health problem needs continuous **support** beyond their healthcare professionals. Their closest caregiver plays a key role within the process.



Currently in Catalonia, community peer learning interventions are gaining ground, such as the *Expert Patient Programme Catalonia®* and the *Expert Caregiver Programme Catalonia®* targeted at people with chronic conditions and informal caregivers, which foster self-care, self-responsibility and empowerment, and try to improve health literacy and facilitate shared decision-making. These programmes, which already have a long tradition, have been organised around the training and support needs identified by both the target audience and the health professionals who participate in them.

Interventions involving relations and communication

Proactive **communication** between the healthcare professionals and the population is essential for person-centred care. Through communication and direct interaction, people are encouraged to gain knowledge that helps them take shared decisions on their health, where the individual plays a core role. It is worth highlighting the key **role** played by **healthcare professionals** within this area of action. The relationship between these professionals and the people receiving care requires a series of key elements within the process. They include active listening, personalisation of the relationship, a joint perspective with the person and their family or caregiving environment and the communication and interaction skills they must have. All of this is part of a set of requirements to achieve people's engagement, motivation, capacitation and coping with their illness.

Changes to prescriptions

Approximately 30% of people aged 65 or over take five or more drugs, a trend that has risen steadily in recent years, ¹⁹¹ and they are concentrated in specific areas—in the case of geriatric residences, this figure is over 90%. Quite frequently there is more harm than benefits from polypharmacy, in which the side effects of the drugs and problems involving compliance with treatment are the two main associated problems. ¹⁹²⁻¹⁹⁴

In the process of developing an individualised care plan, the **revision or adaptation of the pharmaceutical prescriptions**, as well as **adherence with treatment**, are some of the specific actions to be taken with the most irrefutable evidence.²⁰⁰⁻²⁰⁶



There are many initiatives aimed at dealing with this prime health problem (Beers criteria, STOPP-START criteria, MAI criteria, STOPP-Frail criteria, etc.).

In Catalonia, specific consensuses have been reached on how to encourage the appropriate use of prescriptions, most notably the document *Rational use of drugs. Basic handling of medication in chronic patients: reconciliation, review, de-prescription and compliance.* Likewise, the **person-centred prescription methodology**^{200,201} was also developed from a pragmatic, person-centred perspective, with a specific proposal on reviewing medication in three steps (Figure 33):

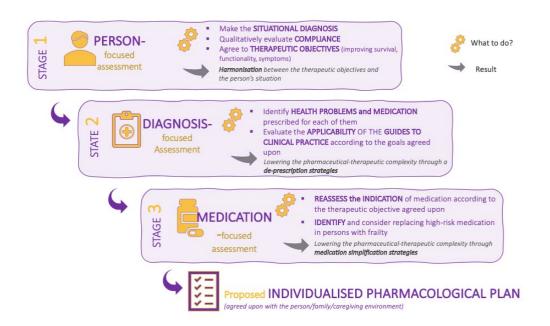


Figure 33: Conceptual diagram of the stages in the person-centred prescription model.

Source: Authors.

5.3.3 Specificities for people with mild frailty, CCP and ACP



People with early frailty or risk of disability

Once the diagnostic process is completed, information on the diagnosis of frailty must be provided to the person and, if applicable, to their family or caregiving environment, in an understandable way. Communication of the diagnosis should be accompanied by a discussion of the **treatment plan** or with the person and their family or caregiving environment, if applicable. The care plan for people with frailty is aimed at preventing or delaying the appearance and evolution of frailty and disability and their associated dependence, in which a **multidimensional and multicomponent approach** to the

interventions planned is needed (physical exercise, nutritional treatment, treatment and management of health problems and geriatric syndromes, etc.).



People with chronic complex (CCP) and advanced chronic (ACP) conditions

People identified as CCP or ACP have to agreed on their care plan with their professionals—the SPCP (stage 4) has an abbreviated or 'distilled' version designed to be shared—which should be reviewed periodically (8-12 weeks after making it and at least once a year) and reconciled in every transition of care. On the request of the reference professionals in the primary care team (PCT) and the individuals, the adaptation of the therapeutic plan may be recommended, especially in transitions, prioritised people and new cases identified as CCP/ACP.



- Encouraging their autonomy, empowerment and self-care should be a priority strategy when caring for the older people and people with chronic health problems.^{122,180,181}
- The evidence on the incorporation of PROM and PREM has demonstrate that it improves the relationship between professionals and patients in shared decision-making and the efficiency of work.^{68,202-204}
- Shared decision-making has been proven to be essential in guaranteeing that people do not receive more treatment than they want or less treatment than they need.²⁰⁵ PDA is the most paradigmatic example of this.²⁰⁶
- Any individualised care plan should also include a review of the pharmaceutical prescriptions, which should be coherent with the agreed upon objectives 200-206
- The care plan should constantly be evaluated or reconsidered, according to the evolution of the needs of the person, their family or their caregiving environment. 176



STEP 4

Sharing the "Shared personalized care plan (SPCP)" and **Coordination**



All the strategies targeted at people with complex care needs and palliative needs consider **sharing the information among the professionals** caring for them a **crucial factor** in generating healthcare responses that are optimal quality and effective in that they meet the needs and preferences of the person and their family environment, if applicable.

Within this context, creating and publishing the Shared Clinical Record of Catalonia (SCRC) of the **Shared personalized care plan (SPCP)** can be an instrument that fosters better care of people with clinical complexity.

The proposal is to share the most important information in the care plan of CCP and ACP:



People with **complex chronic (CCP)** and **advanced chronic (ACP)** conditions

Once the care plan is made, the professionals should develop a SPCP, which is a 'distilled' plan with the most important information. The SPCP is a dynamic document which is based on the Shared Clinical Record of Catalonia (HC3), it contains the most important health and social information on the person identified as CCP or ACP and it is deposited in a shared information environment (HC3).

It is primarily a **communication tool among professionals**, in which the people who know the patient the best summarise and provide the most important information on the case. In this way, when the person is cared for by professionals other than their referents, they can use the SPCP to have the essential information on the case, which encourages them to take better decisions that are more congruent with the person's needs, values, whishes and preferences.

Thus, the SPCP aims to guarantee **continuity in the care provided** in contexts 24 hours a day, 7 days a week during transitions of care (hospital, and health and social admissions). The SPCP is a virtual extension, in time and space, of the therapeutic agreement and best practices criteria, which have been agreed upon jointly with the reference caregiving team and the people identified as CCP or as a person with ACP from a comprehensive perspective, as well as with their family or caregiving environment.



In Catalonia there is a *document on recommendations* and a proposal of good practices when drafting an SPCP.²⁰⁷ Currently, a qualitative audit of SPCPs is underway as the point of departure for developing a new SPCP model (3.0) which will be agreed upon with the professionals.

6. Factors facilitating the model of care

The healthcare responses geared at the model of care described require both the **involvement of professionals**—as the main asset of the system—and the **commitment of institutions and organisations**—as the guarantors of quality and equity.

In this sense, **six elements** have been identified—beyond financing, hiring and procurements systems and governance—which are essential in order to implement this model of care, as briefly described below:

- 6.1 Teamwork and collaborative practices
- 6.2 Clinical pathways and transitions of care
- 6.3 Integration of care
- 6.4 Information systems and shared clinical record
- 6.5 Assessment of results and redirecting
- 6.6 Training, research and innovation

6.1 Teamwork and collaborative practices



Care of the older people and people with chronic health problems—especially people with complex chronic (CCP) or advanced chronic (ACP) conditions—requires interdisciplinary and team work, as well as the promotion of **collaborative practices** among different professionals and teams.

6.1.1 Teamwork and interdisciplinarity

Complexity in managing a CCP or ACP—in terms of the diversity and interaction of different clinical, physical, functional, psychological and social aspects—requires a series of knowledge, skills and aptitudes that a single professional seldom has.

The participation of **different professionals**—from both healthcare and social work—in addressing the different aspects of the care of this type of person requires the gradual development of the teamwork methodology. This way of

working makes overall care possible aimed at offering comprehensive care, where all the professionals work to achieve a shared objective for the patient.

6.1.2 Collaborative practices and networking

Networking is based on **joint work among different professionals and teams to achieve a common objective**, which in this case is to provide a joint response to all the needs of the person and their environment. Therefore, not only do the person's referent and continuing professionals play a key role, but according to the intensity of the treatment, networking is also needed among the professionals from the hospital, health and social care centres and units and the alternatives to conventional hospitalisation offered by these centres (at-home hospitalisation, outpatient hospitals, children and adolescent care teams, multidisciplinary functional units, etc.) and from the social services and third sector in the territory, with whom the necessary information must be shared to ensure proper comprehensive care.

This objective requires collaborative practices among professionals and teams. One paradigmatic example of collaborative practices is the case conference.



The **case conference** methodology helps to collaboratively develop the care plan or SPCP with all the professionals participating significantly in the care of the person. Given the evidence and positive experience here, we suggest establishing territorial dynamics of case conferences for situations with greater complexity with the goal of sharing information and reaching agreements with the person or their family and caregiving environment, which are essential to developing the person's therapeutic plan and SPCP.

Over recent months, work has been done in Catalonia with professionals from different territories with experience in the case conference dynamic to agree upon a *Catalan Case Conference Model*.



- The interdisciplinary approach can improve both the results of care processes and the experience of care of the person and the professionals.²¹ It can also shorten hospital stays and avoid duplicating evaluations, which leads to more comprehensive holistic records.²¹¹
- There is extensive evidence on the **need to reach consensuses on collaborative practices** among the teams involved in caring for people, especially when they have complex care needs.²²⁷⁻²³⁰

6.2 Clinical pathways and transitions of care



The term *transition of care* (TC) refers to the agreement between professionals and organisations from different healthcare areas operating in the same territory and caring for the same population affected by a specific chronic health problem to apply best practices criteria, optimise the healthcare circuits and plan responses to foreseeable scenarios.¹²²

One key element in clinical pathways is guaranteeing seamless transitions *transition of care* meaning the process by which a patient is moved between locations, services, levels of care or different healthcare areas.²¹⁶

Therefore, the **objective of the TC** is to improve the healthcare continuum, as well as to improve the quality of care, optimise resources, promote people's safety and satisfaction, and improve health outcomes while lowering the variability in care and the fragmentation of the system by encouraging integrated care. In this sense, HRs are useful for monitoring healthcare processes and maintaining or improving the quality within the concept of person-centred care.

Ideally, any TC should:217

- Contain an explicit statement of the objectives and key elements of the care based on evidence, best practices and the expectations of the patients and their families.
- Facilitate communication among the team members and the patients and their families.
- Coordinate the care process, establish the functions and sequencing of the activities of the interdisciplinary team, patients and their families.
- Contain the documentation, monitoring and evaluation of the health variability and results.
- Identify the resources needed.



In Catalonia, and within the context of the previous Health Plan, the PPAC developed the *generic framework for designing TCs* with the goal of improving the care of people with certain health problems by means of cooperation among professionals, coordination among providers, the establishment and optimisation of pathways and the promotion of best practices, to provide the most appropriate resource given the developmental situation of each person.

Since then, HRs have been developed for some of the most prevalent processes

or those with the most impact on the healthcare system. HRs focused on specific illnesses (heart failure, chronic obstructive pulmonary disease, diabetes mellitus, dementia and depression) were initially developed, and later HRs focused on conditions and situations (complexity) were added.

Currently, work is underway to redesign/update some of these pathways.



■ There is evidence of the **efficiency** of developing and implementing HRs in the process of caring for people with chronic health problems.²¹⁸

6.3 Integration of care



Care of people with chronic health problems, especially CCP and ACP, requires care environments which often surpass the capacities and scope of the individual professional or organisation.

Even though the person may have a referent professional or team, the evolution of the process itself often implies the intervention of a broad, variable range of professionals and devices that can act in a fragmented way and cause harm and damage in the healthcare process itself. This is why a **territorial vision** is essential with prior coordinated work by the management and clinical leaders of the territory, who plan a set of expected responses for different situations and an effective relational scenario so that a person-centred model of care can be implemented with the participation of the professionals involved in the care process.

By *integrated care* we mean care that unifies planning, clinical management and the provision of social and health services and that guarantees quality as a model of collaborative practice with the goal of obtaining good health outcomes, using services appropriately, improving quality of life and satisfying users.¹²² Integrated care is one of the key elements in caring CCP and ACP.

We can distinguish between vertical, horizontal and triple integration (Figure 34).²¹⁹

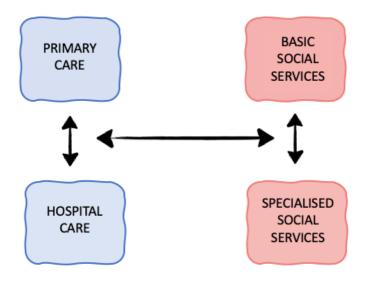


Figure 34: Vertical, horizontal and triple integration.

Source: Authors



Vertical integration means the joint work and/or coordination of services among professionals and/or organisations that offer care at different intensity levels according to the severity and complexity of needs. Its main benefit is ensuring that the services are provided at the right time in the right place, as close as possible to patients' homes. The challenge lies in ensuring that patients with multiple conditions receive appropriate referrals and management.

This vertical integration can occur in two areas:

- Between primary care and hospital care, the purpose of this document on strategic bases.
- Between basic and specialised social services.

Horizontal or transversal integration refers to the joint work and/or coordination of care in all the services the person receives, both health and social. The most important benefit of horizontal integration is its ability to address the person as a whole. This is the context of the Integrated Social and Health Care Plan (PAISS)*.



* The objective of the PAISS is to promote personal autonomy and facilitate these person's remaining in their usual setting and their social inclusion, so it is essential to reinforce the value of comprehensive and integrated care of people and the value of efficiency and the quality of the provision model while promoting the alignment between health and social services. The development of integrated care models in the different networks and devices should facilitate shared knowledge and the optimal use of the capacities, resources and data in such a way that they eventually create an interrelated, integrated network of services for users, notwithstanding the competences of each department inherent to their field: health or social.



By *triple integration* we mean when both the horizontal and vertical perspectives are integrated into the model of care. The more severe and multifactorial the situation of complexity is—especially for people with concurrent social and health complexity—the more essential this triple approach becomes.

However, it is important to emphasise that **horizontal integration cannot be considered** a **replacement for vertical integration**. What is more, they are two complementary and interdependent approaches which must move forward synchronously in order to gear the systems to the needs of the older people and/or people with chronic health problems.



The evidence confirms that integrated care has a positive impact on the satisfaction, accessibility and people's perceived results, in which the results are still heterogeneous in relation to the use of services and costs. The variability among the different integration models is a hindrance to evaluating them globally.²²⁰

The **key elements** in the development of integrated care proposals require a minimum set of critical elements, all of them interacting synergistically, with a multi-level effect which facilitates the effective implementation of a personcentred model of care with a capacity for response and proactiveness in the care process. Most notably, the following are needed:²²¹

■ Territorial governance that encompasses all the authorities with competences in the care process.

- A 'local micro-system of care' in the region, with a community base and local agreements contained in TRs and well developed services within the community.
- Each person should have a unique care plan shared with all the agents that might potentially participate; the principle of 'one person, one plan' should be adopted.
- Case management model for people with complex care needs.
- Facilitating elements must be implemented: shared information systems, shared evaluative frameworks, a financing model that provides incentives for artificial intelligence (AI) and that overcomes the current barriers in payment systems by lines.

6.4 Information systems and shared clinical record



The **information and communication technologies** (ICT) are the entire set of instruments used to process, transmit, store, disseminate, share and generate knowledge and services in digital format.¹²² ICT are a key element in implementing integrated care processes which guarantee:

- First, that all the professionals involved in the care process have the minimum relevant shared knowledge of the care process.
- Secondly, that all the professionals involved can have a technological environment that enables them to work collaboratively when conducting the comprehensive joint evaluation, the comprehensive care plan, the periodic follow up and reassessment and introducing more advanced support functionalities in the process of caring for people.



Catalonia currently has a *shared clinical record (SCRC)* which contains data, information and clinical assessments of the situation and evolution of the person throughout their care process, and which follows a decentralised care model that allows healthcare professionals to access all the updated, relevant information on people, regardless of their field of care or geographic location.

The SCRC allows for the **traceability** of people as they go through the healthcare system, enables services related to proactive care required by some patients to be incorporated (alerts, notifications, communication among fields of care, organisations and professionals) and promotes continuity in healthcare.

Given this scenario, it is essential to **develop functionalities** that provide support in the care process of the older people and people in complexity. Currently, all the ICT developments underway imply collaborative actions among functionalities:

■ Intensive use of Personal Health Folder"called "La Meva Salut" in Catalonia

by the target populations of the care model, as well as the caregivers of people with complexity or in home care (dementia, etc.).

- Development of ICT solutions that allow a single care plan to be created for people who require collaborative practice in an integrated care model from both the social and health standpoint.
- Incorporation of solutions from the *iS3* project in terms of safe messaging in collaborative practice environments: safe and proactive transitions, communicating alert situations between areas of care (post-care report in intensive care units or the Medical Emergency System, etc.), interconsultations in safe environments between primary and specialised care.

In Catalonia, one of the most frequently used functionalities is generating and sharing the identification of a situation of complexity and SPCP.



There is a great deal of evidence tht care models of people with chronic health problems, complex chronic conditions or advanced chronic disease benefit from the **development and incorporation of ICT**. Some paradigmatic examples are in Kaiser Permanente and the Veterans Health Administration.²²²

6.5 Assessment of results and redirecting



In modelling processes of integrated care, **population-based evaluation frameworks** are needed that are **common and transversal** for all the organisations and professionals working in different fields of care. This evaluation of results requires the joint effort of all the parties with the goal of having a **single dashboard**. The **choice of indicators** should be based on the principles of objectivity, validity, sensitivity, specificity and consensus.

Through either reports or a common, congruent package of indicators, the information obtained should make it possible to **monitor** the model of care, **report** the results transparently, contribute to identifying margins of **improving** care and suggesting new initiatives for the procurement and provision of services to healthcare policymakers, managers and planners, **redirecting** the approach of the healthcare systems, if needed.

Thus, the **objective of the evaluation** of results is to track the established healthcare policies from a comprehensive perspective related to fulfilment of the objectives and agreements established with the ultimate goal of working towards improving the quality of care provided to people with chronic illnesses

or complex and palliative needs.

This evaluation should necessarily be shared among the different actors with a **quadruple AIM** approach:¹

- To improve the health and wellbeing results of the population. This includes indicators on the impact of multimorbidity, the control of certain chronic illnesses and the expected results of good care and improvements in quality of life at different points in the course of the people receiving care.
- To improve efficiency and guarantee the sustainability of the healthcare system by adapting the cost of care and the use of services—especially emergency admissions which could be avoided —of the patient population.
- To improve the care experience of the patients and their families.
- To improve the experience of the professionals when providing care.

Therefore, beyond the classic results on process or structure, the tendency as a healthcare system should be to focus on people's individual objectives (or 'results that matter to people'), either in relation to their **health outcomes** (PROM indicators or patient-reported outcome measures) or **the results of the experience of care** (PREM indicators or patient-reported experience measures).

68 (Table 6). To be useful, these measures must:

- Be meaningful for patients, their caregiving environment and professionals.
- Not be difficult to obtain or entail duplications.
- Be easily interpretable and contextualisable.
- Help support collaborative work.

These are measures that go beyond the concept of *satisfaction* and become a key factor in evaluating whether the care received has truly been 'personcentred'. Generally speaking—and more specifically in people with chronic health problems—people tend to prioritise keeping their independence, their social role, a lower treatment burden and control over their life (Table 9).⁶⁸

	PROM	PREM
What do they evaluate?	They capture people's perception of their health.	They capture people's experience of care in relation to the healthcare system and the treatments received.
Examples	 Symptoms Unmet needs Quality of life Functional independence Self-perception of health status 	 Wait times Accessibility Participation in decision-making Awareness of the treatment plan and pathways Quality of communication Support in managing chronic health problems

Table 9. Evaluation and examples of PROM and PREM.

Source: Authors.



In Catalonia, **several initiatives to evaluate** the policies geared at improving the care of the older people and people with chronic health problems have been undertaken. Even though these initiatives show that there is still a long road ahead, the most important ones are:

- The *Results Clearinghouse* of the comprehensive public healthcare system in Catalonia has the mission of measuring, evaluating and disseminating the results attained in both healthcare and by the different centres (hospitals, primary care teams, health and social care centres, mental health and addiction centres, research centres and health research institutes) in the public healthcare system.²²³
- The evaluation of programmes on chronic conditions poses the challenge of identifying those that show the best results attained bearing mind the perspective of professionals, patients and caregivers. As part of the 2011- 2015 Health Plan for Catalonia, AQuAS developed an evaluation of the most coordinated and integrated organisational models or experiences of caring for chronic conditions in Catalonia by developing indicators and implementing them to evaluate these models.²²⁴
- In this sense, the **PPAC** conducted a series of studies to share the results of the programme:
 - Qualitative evaluation of the process of identifying and caring for patients with complex needs and advanced illness in primary care.²²⁵
 - Results of the evaluation of the Chronicity Prevention and Care Programme.²²⁶
 - Milestones 2011-2014 of the Chronicity Prevention and Care Programme for Catalonia.²²⁷



■ There is plenty of evidence of the need for **evaluative frameworks with a comprehensive and integrated vision**; prominent in this sense are the *Triple Aim* and *NHS Outcome Frameworks* models from the English healthcare model^{228,229} and the indicators of integrated American organisations known as *accountable care organizations* (ACO). ^{124,230}

6.6 Training, research and innovation

6.6.1 Training and knowledge transfer



Training is essential in dealing with health problems related to ageing and chronicity with the **maximum professional competence**. Despite the sound training of the professionals of Catalonia in caring for these people, continuous training is an essential tool the quest for outstanding care.

This training should emphasise the following **specificities**:

- Interdisciplinary approach, promoting joint training actions among different healthcare professionals.
- Pragmatic, competence-based approach: that is, training strongly geared towards providing professionals with useful tools for their day-to-day care practice, with specific conceptual frameworks focused on boosting the professionals' competences.
- Multidimensional vision of care for people which goes beyond the disease-centred approach.
- Integrative mission, with a special emphasis on the elements of interaction among the different healthcare fields and levels.
- Reflexive approach, where analyses of specific situations lead to a constructive debate among professionals.
- Breadth and depth, with the ability to adapt the contents to the levels of breadth in the dissemination of knowledge and depth in the knowledge that the training targets of each training action require (Figure 35):

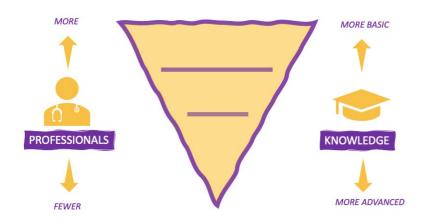


Figure 35. Conceptual summary of the training actions.

Source: Authors.



In Catalonia there is a longstanding **tradition of training in chronic conditions**, promoted by different actors (both public and private) targeted at both citizens and professionals in all healthcare fields and disciplines. This training includes everything from literacy and empowerment programmes for citizens to higher or university education and specialised training in massive open online courses (MOOC).

6.6.2 Research and innovation



Research and **innovation**, and their integration into healthcare practice, encourage higher quality healthcare services and a broader and quicker implementation of the scientific advances in preventing, diagnosing and treating chronic health problems, as well as more ethical and efficient treatments for people.

Catalonia has an extensive **tradition of research and innovation** on ageing and chronicity, both in caregiving and more academic environments (universities, research institutes, research groups, etc.), as well as in official institutions and agencies (AQuAS, Directorate-General for Health Research and Innovation, etc.).

Research and innovation must be promoted in all areas related to the older people and chronicity: healthy ageing, prevention of disability, care for people with chronic health problems, complexity and end of life. This includes everything from qualitative research focused on the values, preferences and needs of patients and their caregivers to descriptive ecological/epidemiological studies, treatment studies and innovation on care models—using the quadruple aim approach, caregiving devices and integrated care.

We advocate **incorporating people** into the co-design of research and innovation projects with the goal of reorienting research towards the areas that can have the most interest for and impact on society. We should also emphasise the **specific importance of the role of women** in caring for chronicity, as people who both require the right treatment and often take on the role of caregiver.

Finally, responding to the model of care proposed in this document requires environments with **organisational innovation**, with the combination of a minimum set of critical actions generating an impact in different dimensions of population health, the appropriateness of the services and a good experience of care in the caregiving environment. Therefore, a methodology of innovation

must be fostered, and a community of good practices should be created to facilitate and magnify this shared organisational learning with the goal of facilitating or accelerating the scalability of the care projects and models.

7. Next steps

Catalonia is choosing to become a benchmark country of good practices in the comprehensive and integrated care of people with frailty, complex chronic conditions and advanced chronic disease. To achieve this, we have a mature **society**, extraordinarily competent and committed **professionals** and now, too, a solid, pragmatic **model of care** with support **tools**. However, the effective implementation of this model requires specific objectives and actions.

In this sense, and from the perspective of the **horizontal integration** of care, work is beginning to develop 9 strategic lines within the framework of the PAISS, which are already providing explicit responses to the care challenges in this group. Likewise, over the forthcoming months the strategic planning must be furthered from a perspective of **vertical integration** (Figure 36).

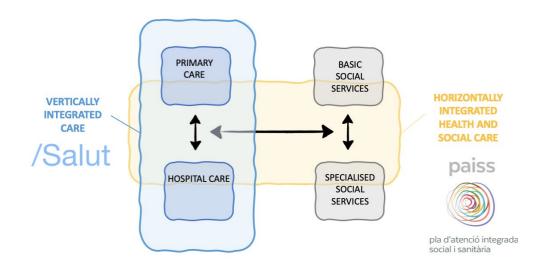


Figure 36. Integrated care strategies in Catalonia.

Finally, the first goal of this document outlining the conceptional foundations and model of care is to help generate a shared view, story and tools among both professionals and organisations. However, we must continue to work to ensure that this inspiring dynamic ends up working as a true **lever of change** towards an authentically person-centred system.

8. Appendix: Implications of the model in the context of the COVID-19 pandemic

Characteristics of people affected by COVID-19

The current pandemic caused by the coronavirus SARS-CoV-2 (which causes COVID-19) has **particularly affected older people and those with complex chronic conditions and advanced chronic disease and** (Figure 40). While the majority of people with COVID-19 develop a mild illness without complications, the early figures report that approximately 14% of all people develop a serious illness which requires hospitalisation, and 5% require admission into an intensive care unit²³¹ (Figure 37).

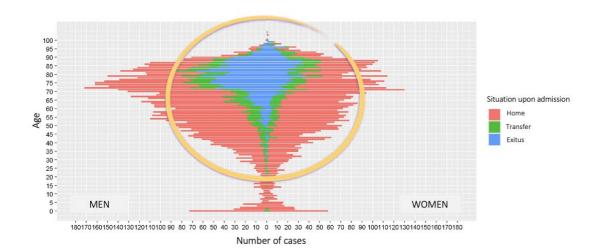


Figure 37. Distribution of suspected cases of COVID-19 from 1/03/2020 to 16/04/2020 by age and sex.

Source: MUSSCAT.

Need for individualised decision-making: *The case of intensive care units (ICU)*

Thus, for example, the increase in the needs for intensive care and the limitations on resources has brought the **clinical and ethical debate** on the allocation of resources and the prioritisation of people front and centre. In order to respond to it, a recently published consensus document offered a series of recommendations, especially in 3 areas: 1) related to the organisation, availability of resources and alternatives; 2) related to the person's characteristics and overall situation; and 3) related to the ethics of decisions.²³²

In all of them, particular emphasis was placed on the need to stratify and make a good situational diagnosis/multidimensional assessment and individualisation of the care plans—ideally in advance, and with the availability of shared information among the professionals providing care. That is: **an individualised model of care is needed**—like the one developed in this document.

Repercussions of COVID-19

It is estimated that 90% of the deaths from COVID-19 were in people over the age of 65²³³(Figure 38), and that 85% of them had a moderate or high AMG (Figure 39). At least half of all these deaths took place at nursing homes.^{234,235}

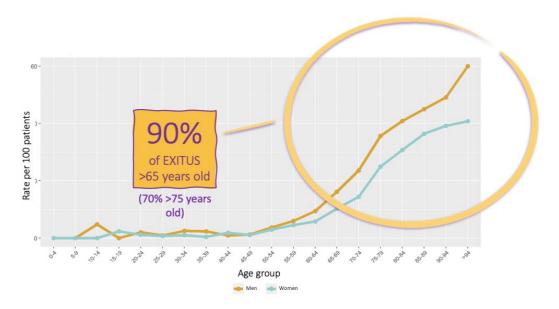


Figure 38. Mortality among hospitalised COVID-19 cases from 1/03/2020 to 29/04/2020 according to age and sex.

Source: MUSSCAT.

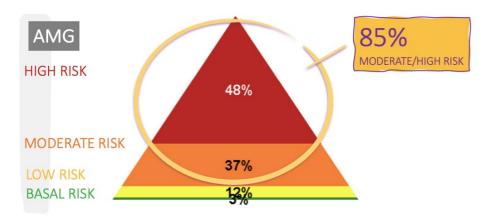


Figure 39. Mortality among hospitalised COVID-19 cases from 1/03/2020 to 29/04/2020 according to AMG.

Source: MUSSCAT.

Indeed, in the specific case of **nursing homes**, the profile of the typical resident is a female (in 72% of the cases, compared to 28% males) of advanced age (an average of 87) with major multimorbidity (with a predominance of dementia: 46%), with high complexity (51% of people with high-risk adjusted morbidity (AMG)), probably in end-of-life situations (54% are NECPAL positive). ^{145,236} In this environment, where the annual death rate is close to 20%, ²³⁶ infection with SARS-COV-2 is extremely lethal: at least one out of every four people infected in geriatric residences died (far above the lethality rate in the general population, which is 4%). ²³⁴ Even though we do not yet have definitive data, the percentage of deaths in nursing homes over total deaths may be around 35% if we only take into account cases confirmed by a PCR test, and up to 70% if we include all cases with symptoms suggesting COVID-19). ²³⁷

Yet beyond the horror of the mortality rates, we also have to take into account the **other repercussions**, both physical and social and emotional, that this crisis has caused.²³⁸ Loneliness, fear, the difficulty taking shared decisions or the impossibility of being with a family member at their death have had a major impact which may be equally or even more catastrophic than the illness itself.²³⁹⁻²⁴² In the case of professionals, the emotional impact stemming from the rawness of the situations they have experienced is magnified by the risk to their own lives stemming from the lack of personal protective equipment (PPE), especially in the early phases.^{243,244}

Likewise, in nursing homes it has become essential to develop consensus on recommendations with the goal of providing ethical and clinical support to the decision-making process, especially in situations involving more complexity. In the context of the pandemic as well, individualised care models are the cornerstone of guaranteeing good practice as the guarantors of authentic person-centred care.

Lessons learned and model of care

Now that we have (more or less) overcome the first onslaught of this pandemic, we are facing a second challenge that is equally or even more difficult: being able to learn the lessons that this situation has offered.

From an **individual perspective**, one of the main lessons to be learned is the need to have an individualised model of care like the one developed in this document, which includes the identification of people—especially those with advanced chronic disease, multidimensional assessment, the consensus of a single individualised care plan—which includes planning decisions in advance, and sharing this plan with other providers who may participate in caring for the person at some point in the crisis.

From a **population/systemic perspective**, the application of a personalised model of care should facilitate planning the response to future crises based on a specific definition of the circuits, referral criteria and management of the flows of people, as well as the evaluation of the care received.

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