

# Compassionate Communities in the Basque Country

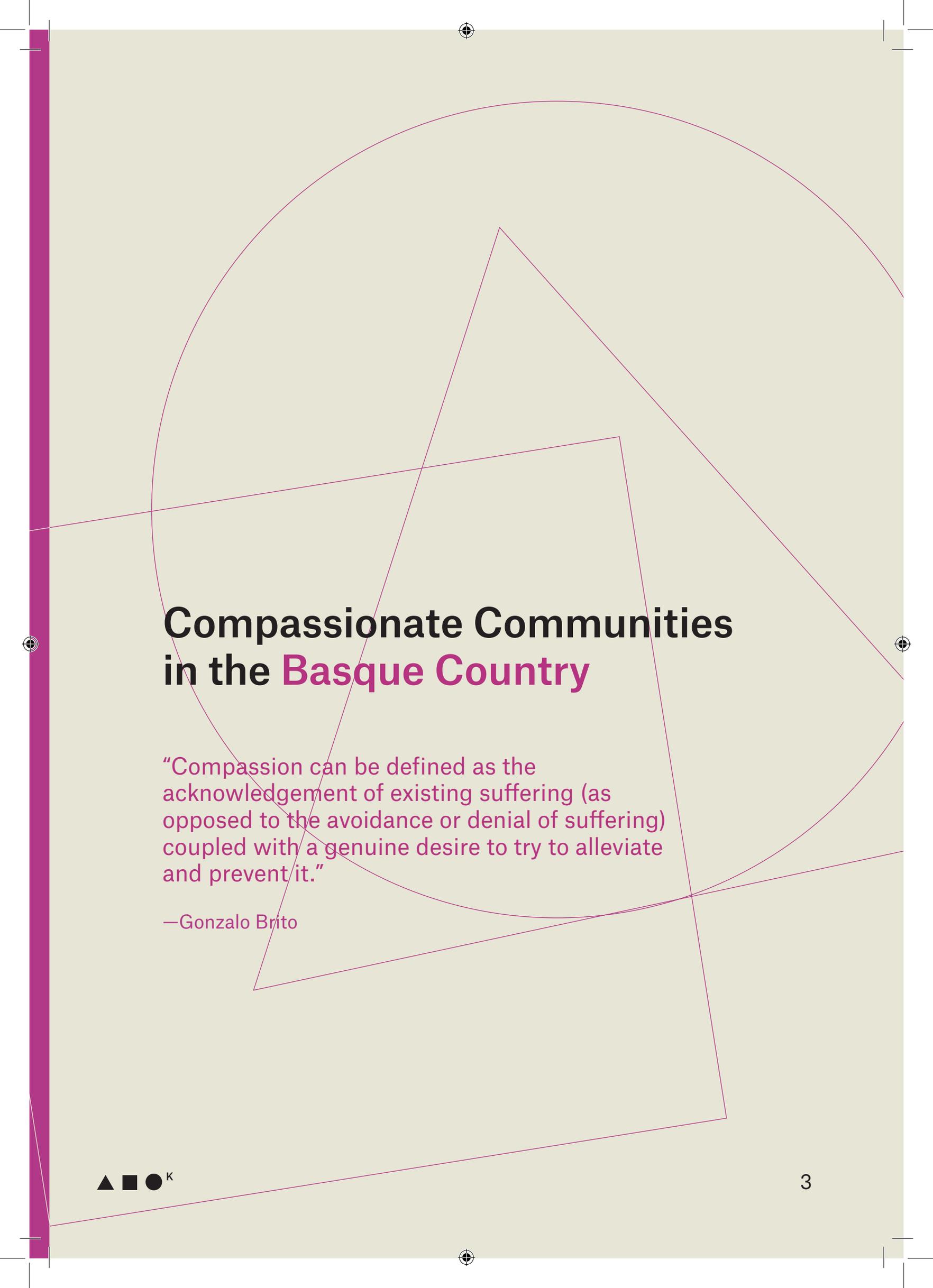


**DOBLE SONRISA**  
FUNDACIÓN

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AGIRRE LEHENDAKARIA CENTER  
for Social and Political Studies

 **Deusto**  
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# Compassionate Communities in the **Basque Country**

“Compassion can be defined as the acknowledgement of existing suffering (as opposed to the avoidance or denial of suffering) coupled with a genuine desire to try to alleviate and prevent it.”

—Gonzalo Brito

# 1/ Acknowledgements

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## 1/ Acknowledgements

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## 2/ Executive summary

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This research has corroborated that there are many people in the Basque Autonomous Community (CAV) who are alone, sick or with a very limited family and social network and find themselves in situations of dependency, palliative care, end of life, death and bereavement. These situations are made worse by the process of population ageing and the crisis caused by the COVID-19 pandemic. Given the complex nature of the problems related to advanced illness, loneliness and death, it is impossible to find a solution that is exclusively health-related or linked to existing public services. As an alternative, compassionate communities aim to build a system alongside existing services that is decentralised and self-organising.

This report has identified more than a hundred community initiatives that attempt to complement existing social services. These initiatives are highly valued by people and families who find themselves in situations of loneliness, advanced illness or death. There is extensive scientific evidence on the value of social support networks. For this reason, compassionate communities may become the new social network that accompanies lonely or sick people during the last stage of their lives.

The fundamental problem lies in the fact that public administrations, in most cases, do not know how to relate to these initiatives beyond subsidy programmes. There is no strategic reflection on the complementarity and possible joint action between social and health services, community actions and care companies. These emerging initiatives are not interconnected and there is no shared

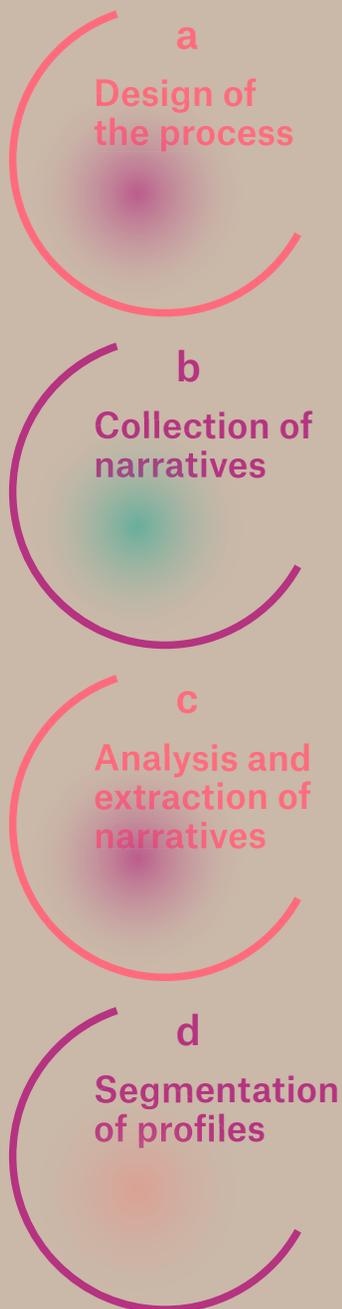
## 2/ Executive summary

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strategy for knowledge generation.

The report has focused on gaining a better understanding of the perceptions and motivations of the people who drive these communities and the individuals and families who call for their support. This information can be very useful to create a real connection between the efforts of the different administrations and social initiatives. Basque institutions have a wealth of quantitative and qualitative data on these issues at their disposal, but this report has tried to complement this information with the perceptions that we often do not voice but which condition the impact of public policies and community actions. These perceptions have been collectively analysed and have enabled us to identify a series of concrete actions that can help to empower these communities.

## The working process for the collection of narratives involved the following steps:



**a.** Design of the process for collecting and managing the narratives.

**b.** Collection of 90 in-depth narratives on compassionate communities in pilot municipalities in the Basque Country with different contexts, population levels and lifestyles in the historical territories of the CAV: Vitoria-Gasteiz, Amurrio, Donostia-San Sebastián, Zarautz, Orío, Mungia, Bilbao, Getxo and Bidasoa.

**c.** Analysis and extraction of narratives, challenges, opportunities, barriers and enablers.

**d.** Segmentation of information into profiles based on unified narrative patterns and behaviours. This information was used to better appreciate the different ways of understanding the same reality in the Basque Country and to propose a range of interconnected solutions.

These profiles correspond to multiple voices and represent patterns of narratives that have been repeated. If these narratives relate to caregiving, we have given them the character of a woman caregiver, given that caregiving usually has a woman's face, and it is specifically migrant women who carry out this type of work. If these narratives relate to the public sector at different levels, they have been attributed a similar profile. This does not mean that they represent the unified narrative of the public sector, young women or migrant women. They represent a functioning narrative, and the set of profiles aims to visualise the set of existing narratives concerning end-of-life care and compassionate communities in the Basque Country.

Once the **identified narratives (structured in profiles or archetypes) had been contrasted**, we moved on to a phase of co-creation of possible initiatives that could reinforce compassionate environments (while at the same time responding to the different perceptions and needs identified). Death Cafés, bereavement spaces, the possibility of supporting networks of 'community influencers', awareness programmes in educational institutions, 'super heroines' groups, community social brokers, the redesign of funeral services and other socio-health services, as well as a possible push for a palliative care law all form together a portfolio of interconnected initiatives (innovation portfolio) and a good starting point for providing content and an operational plan for the potential compassionate communities of the future in the Basque Autonomous Community.

## 2/ Executive summary

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These initiatives present a first experimental space that the Basque Government could support on an experimental basis in different localities of the territory. The combination of these and other similar initiatives could generate a shared strategy to foster this type of compassionate environment. Fundamentally different from a traditional approach, these initiatives are understood as interconnected prototypes. The fundamental objective is to learn as they develop and to analyse how they reinforce each other. These early communities could be identified as spaces of advanced experimentation.

The fundamental dilemma lies in how we understand the public services of the future. Looking at it from a more traditional perspective, we are tempted to differentiate between public service and community action. However, the most progressive international trends and emerging practices in Basque society described in this report talk of new models in which public services are naturally complemented at a community level. This interaction can help shape a new Basque model of “care” in its broadest sense, but it requires reinventing many of the existing structures, roles and regulations. This is a complex challenge, which no single institution or social entity can tackle alone. For these reasons, compassionate communities are a space for experimentation and the generation of shared knowledge that can help to weave together these new alliances.

There are two possible future scenarios. On the one hand, a scenario in which individualistic narratives take on greater importance and people try to resolve their own

## 2/ Executive summary

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personal or family situation themselves. Or on the other hand, a scenario in which collective narratives take on greater relevance, in which we value the collective effort to face the great challenges that confront us and in which the community regains a central role in everything we do.

Bearing in mind that no one has all the knowledge and that it is not possible to respond to this situation in isolation, the Basque society must create the necessary spaces to create a collective intelligence strategy. The role of institutions is changing. Nobody expects them to provide the solution to all the problems anymore. From now on, we will ask the institutions to generate the necessary meeting spaces so that, in close collaboration with social agents and citizens, we can develop this new form of collective intelligence.

# 3/ Forewords

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—Julian Abel & Allan Kellehear. **COMPASSIONATE COMMUNITIES UK**

End of life care is everybody's business – and responsibility! Remember that dying and grieving people spend less than 5% of their time with professional health services.

Most of the time – 95% of their time – is spent alone, or with friends, family, co-workers, parishioners, fellow students or worshippers, animal companions, or spending time with television or social media.

**What are we doing for the dying, bereaved and caregivers in this 95% space?**

The traditional answer is: *very little*. The time has come to address this omission and to begin promoting progress in support and compassion by the civic arena.

The phrase “*a good death*”, although expressing a wish that the last phase of life goes as well as it can, is difficult and hard to define. Part of the problem lies in some major gaps in the research literature on what is important to people, the person with the illness and their families, in the multiplicity of end-of-life settings – from home, workplaces, or schools, to hospices, hospitals and care homes. This is further complicated by the common focus of palliative care services on looking after people with a cancer diagnosis. And yet cancer accounts for only one quarter of the people who die. Crucially, the historical focus of palliative care has been on the use of professional services – on the 5% of time people spend dying, grieving, or caregiving. As a consequence, the larger part of dying, grieving, and caregiving has become publicly “*invisible*” and unsupported. The crucial need to genuinely address the challenges of quality and continuity of care at the end of life means that we can no longer accept this upside-down set of priorities in end-of-life care.

**The Getxo Zurekin** project aims to remedy some of this historical anachronism. By bringing everyone together, from citizens to key stakeholders such as health services and state bodies, a conversation can begin about what is most meaningful and most helpful to those undergoing the experiences of death, dying, loss and caregiving. We all undergo these experiences multiple times in our life, caring for and losing the people we love.

We do not want to repeat the mistakes of when things did not go well. This means that we need to discover, through a shared conversation, what is most important and meaningful at the end of life.

### 3/ Forewords

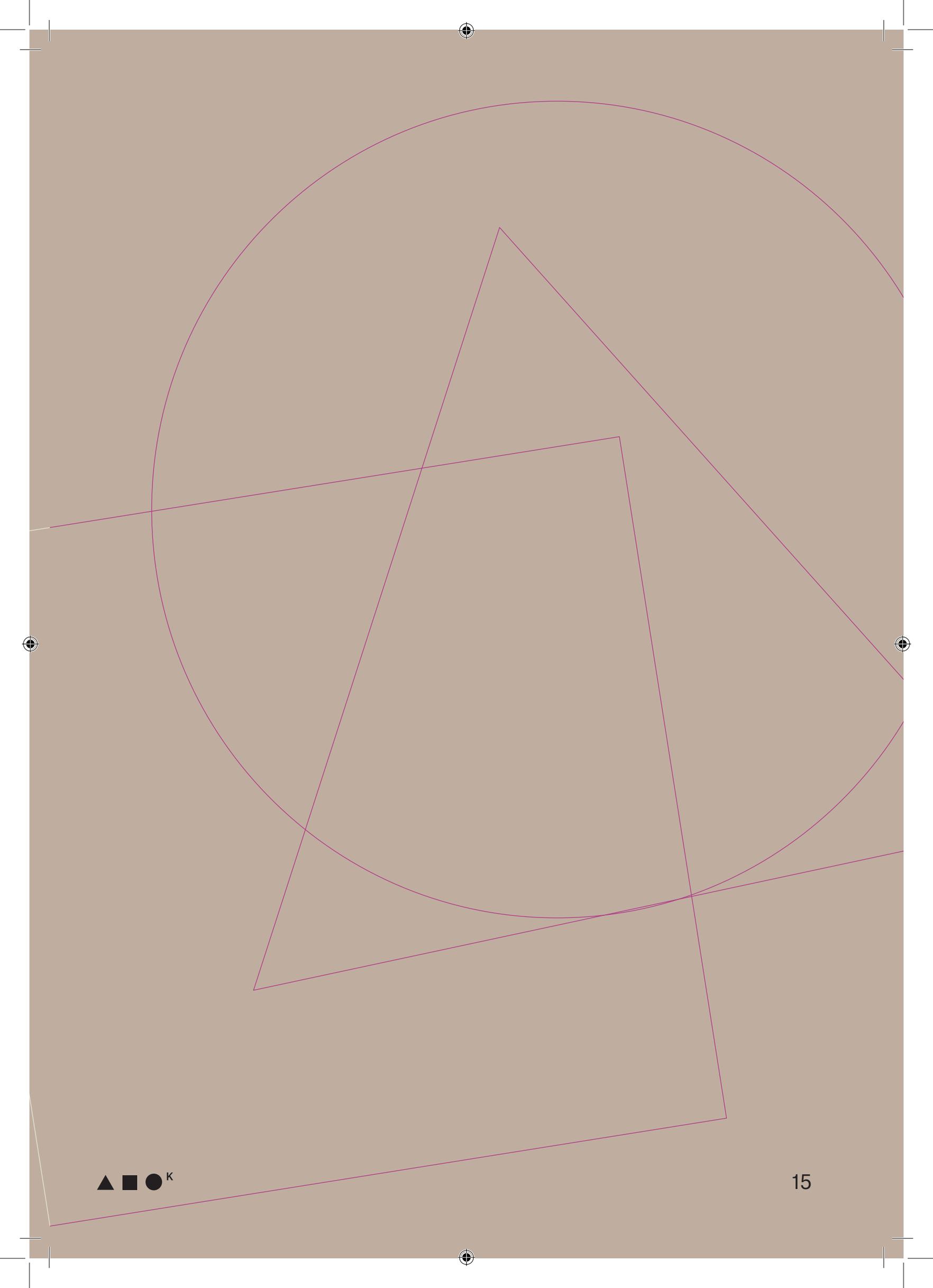
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**How can we support this priority with community action, public education, partnership with health services, social care services, and local state institutions - all working together?**

The Getxo Zurekin is the catalyst and the opportunity for us to answer this great contemporary question, so that the experiences of living with advanced ageing, life-limiting illness, caregiving and grief and bereavement, can be as meaningful and good as possible.



—Julian Abel & Allan Kellehear.  
COMPASSIONATE COMMUNITIES UK



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## “The feelings of cities”

—Doctor María Angeles Durán. Research Professor at the Spanish National Research Council (CSIC)

Compassion is a feeling of pity, tenderness and identification with someone’s ills. Compassion by itself does not entail action to lessen the pain of others; that happens at a later stage, and can be done individually or collectively, effectively or ineffectively.

Since cities are agglomerations of people living in the same territory, they lack feelings. However, people who live in cities transfer their feelings to the institutions that represent them, to those in charge of managing the city; even to the laws by which they are governed. Citizens can also express their feelings and organise their actions in parallel, in collaboration or in opposition to the city’s authorities.

Citizens of compassionate cities must decide towards whom they are compassionate and to whom they remain insensitive. Beyond well-meaning statements, resources

are limited and those in need of help are many: to name but a few, the rejected, the poor, the violent, the lonely, the sick, the dying.

Cities and institutions compete for material and other resources and are in constant conflict over how to prioritise objectives. Groups of citizens also organise themselves to compete for scarce resources; those in the last stage of the life cycle are in a poor position to make themselves heard, precisely because of their frailty. In Spain, eight out of every hundred people suffer from poor or very poor health. Among the over-75s, this proportion is one in four. Illness and poverty go hand in hand: the proportion of those suffering ill health among those living in households at the lowest income level is six times higher than at the highest income level. One fact that adds realism and brutality to this situation is that the real cost of a single night in the ICU in a public institution is close to two thousand euros, more than double the average monthly retirement pension for women. If it is an ICU for contagious patients, such as COVID-19, the real cost is even higher.

Unpaid care forms the enormous foundation on which the healthcare system and institutionalised care depend, but the fact that it is unpaid does not mean that it does not require effort, nor that it is inexhaustible. Increased longevity and changing family patterns make it foreseeable that care needs will increase while available carers will decrease. The journey from initial compassion to improving the situation that provoked it is a long one; in addition to goodwill, it requires large doses of social innovation and activism to overcome obstacles.

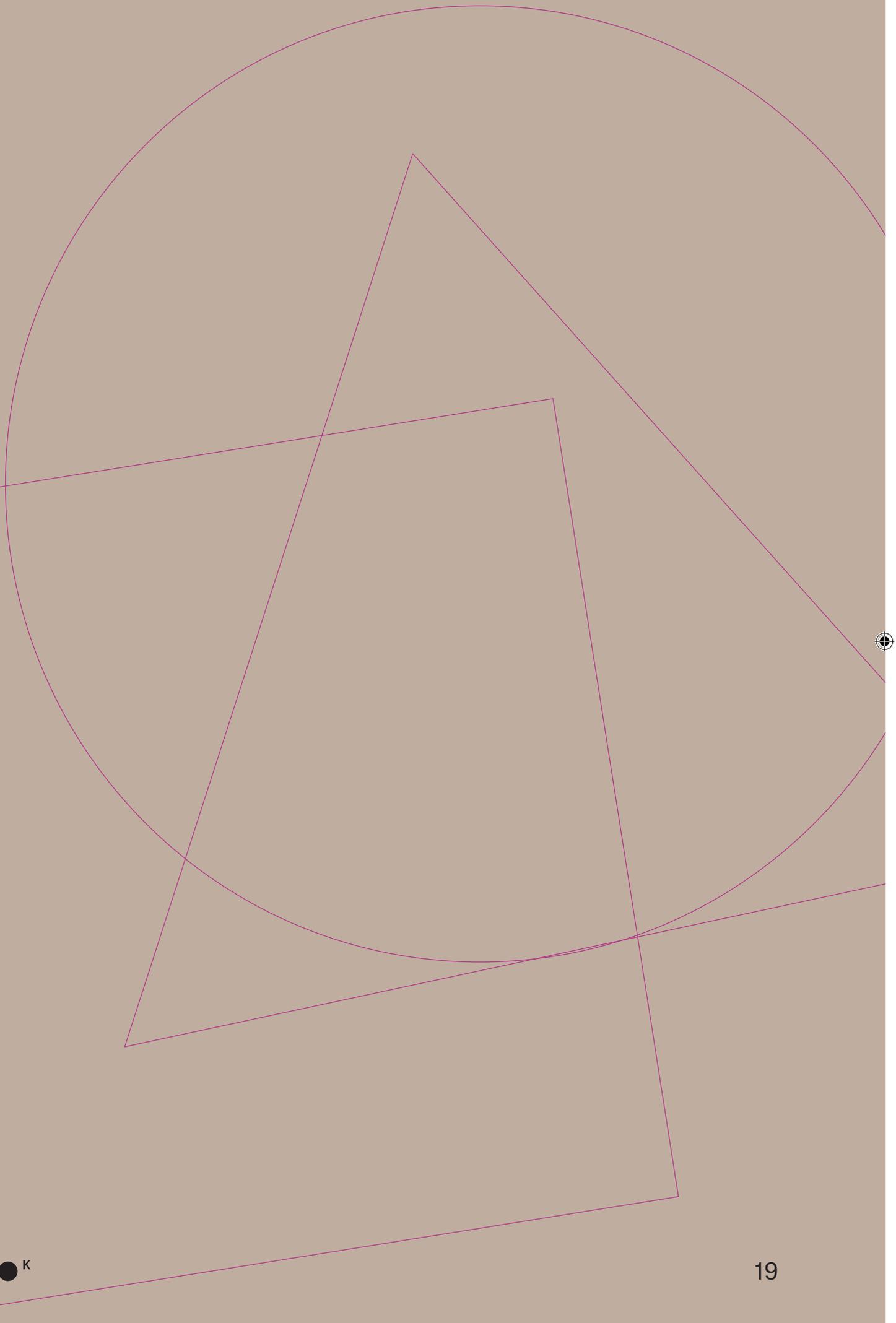
### 3/ Forewords

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I trust that these brief lines will contribute to making care during the last stage of life one of the priority objectives of cities as they take on the beautiful and difficult challenge of becoming caring and compassionate cities.



—Doctor María Angeles Durán. Research Professor at the Spanish National Research Council (CSIC)



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# 4/ Glossary

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## ///Co-creation

A process led by platform stakeholders with the participation of ILO constituents, their target groups and the community (in the broad sense) in which innovative solutions are formulated in a collaborative manner.

## ///Community<sup>1</sup>

An interconnected network of people who trust, care for and provide for each other's needs, and who have a sense of belonging to the network as well as a sense of common history. Communities may differ in relation to different geographical, socio-cultural or political aspects among others, and are formed and shaped by the current needs of the people involved. Apart from individuals, the community is also understood as the government, public institutions, companies, workers' organisations, employers' organisations, non-profit organisations (third sector), social enterprises, educational establishments, etc.

<sup>1</sup> David M. Chavis and Kien Lee. May 2015. "What is community anyway?". Stanford Social Innovation Review. Stanford University [Internet]. [Accessed 21/01/2020]. Available at [https://ssir.org/articles/entry/what\\_is\\_community\\_anyway#](https://ssir.org/articles/entry/what_is_community_anyway#)

### **///Collective interpretation space**

These are meeting and/or consultation spaces, e.g., events, meetings, or workshops, in which the listening group, including representatives of the target group, participate to compare the information gathered.

### **///Workgroup**

A set of people who participate in the process of putting the initiative into practice, made up of different profiles of people, both from the community (in a broad sense) and experts. Its composition can be modified and its number can be increased or decreased depending on the progress of the idea to be developed.

### **///Social innovation**

Social innovation is the development and implementation of new ideas and solutions that contribute positively to human development and empowerment. It responds to a variety of social, economic, environmental and institutional problems and challenges linked to exclusion, deprivation and lack of well-being. In this framework, from the ILO's perspective, this approach helps to respond to the needs, priorities and challenges of governments, employers' organisations and workers' organisations to advance social justice and promote fair and decent work.

### **///Narratives**

These are the target groups' perceptions of their own lives. They are subjective and have a decisive influence on the actions they believe possible or impossible.

### **///Ethnographic profile**

This is a simplified representation of the people, their main challenges and needs. It enables the information from the listening process to be converted into a simpler and more easily understandable form.

### **///Listening process**

It is a set of tools and activities to gain an in-depth understanding of the needs, challenges and opportunities of the target groups.

### **///Prototype**

It is the realisation of an idea or solution to test, learn, adjust, modify, or eventually discard it.

### **///Theory of change**

It is a hypothesis that describes the strategic vision of the desired change, carefully analysing and detailing the assumptions behind each stage, identifying the conditions that will enable or inhibit each of them, the activities that will produce the conditions and explaining how those activities might work.

# 5/ Table of contents

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## 1/ Acknowledgements

Page 04

## 2/ Executive summary

Page 06

## 3/ Forewords

Page 12

## 4/ Glossary

Page 20

## 5/ Table of contents

Page 24

## 6/ Introduction

Page 26

## 7/ The economic, political and social context of care. Theoretical framework

Page 32

## 8/ Compassionate communities

Page 40

## 9/ Study objectives

Page 50

### • 2019

Page 50

### • 2020

Page 51

## 10/ Process development

Page 54

## 11/ Thoughts on the future

Page 164

## 12/ Conclusions

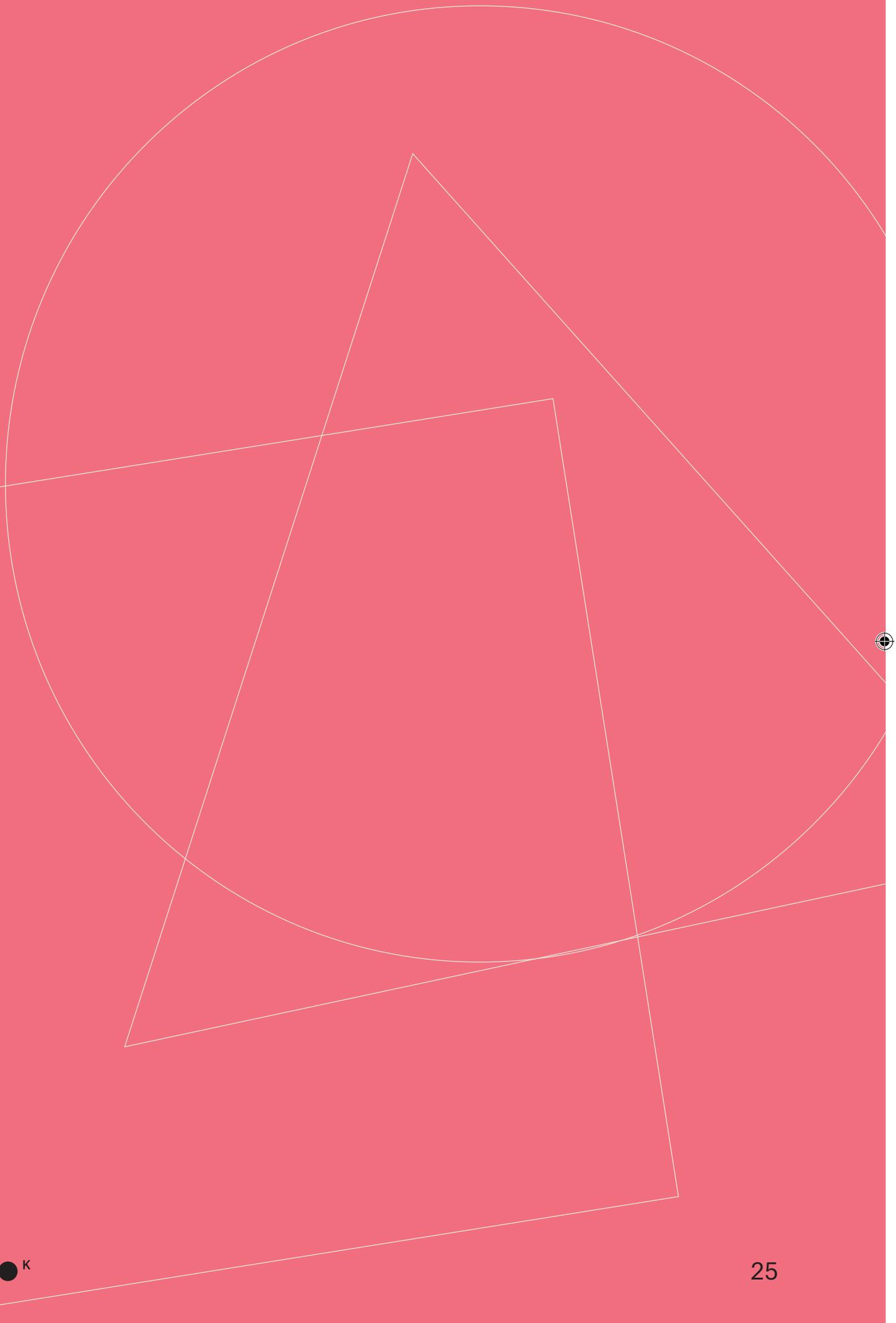
Page 180

## 13/ Reference

Page 188

## 14/ Annexes

Page 192



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# 6/ Introduction

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What is  
known so  
far?



• Demographic, epidemiological and social changes are leading to a paradigm shift in the care of people and families in dependency and end-of-life situations.



• Scientific evidence confirms that palliative care provides a benefit in terms of cost savings and increased efficiency, without compromising patient care.



• A public health approach to end-of-life care and the development of communities committed to supporting and empathising with people in these situations is an opportunity to improve the end-of-life experience of individuals, their families and citizens in general, as well as to address the unfair and inefficient nature of the current system.

///  
What does  
this project  
contribute?



• This study shows a practical example of the use of ethnographic research methodologies in end-of-life care and health.



• The results demonstrate that it is possible to create a community that is supportive and committed to the care and needs of people in dependant and end-of-life stages.



• The figure of the social promoter<sup>2</sup> is presented as an option to facilitate the connection between community resources and support for people and families in dependency, advanced illness or end-of-life situations.

<sup>2</sup> The social promoter or social broker is an individual or collective of people whose ultimate goal is to create resilient networks and communities linked to specific needs.

This work brings together two different projects that have been carried out in an essentially interconnected manner. The first project is called **Getxo Zurekin**.

**Getxo Zurekin** is a project led by Fundación Doble Sonrisa [Double Smile Foundation] with the collaboration of New Health Foundation (hereinafter, NHF), Agirre Lehendakaria Center and Deusto Business School Health. The project is a commitment by Doble Sonrisa to transfer the NHF's Todos Contigo® [All With You] methodology to the city of Getxo, with the support of the city council and public administrations.

**The Getxo Zurekin** initiative is a space for experimentation in what concerns compassionate communities.

**Getxo Zurekin** is conceived as a social awareness, training and research programme with the aim of transferring the importance of end-of-life care to the community. The project is intended to promote a new social movement in Getxo for the creation of a compassionate environment

for people at the end of their lives through the involvement and participation of the community. Rather than replacing existing palliative services and health and social care, the aim is to contribute to the well-being and improvement of the quality of life of people in dependency and end-of-life situations, capitalising on existing community strengths and networks.

This initiative embarked on research between 2017 and 2019 to gain an in-depth understanding of the challenges related to advanced illness, end-of-life and the bereavement process, as well as the existing capacities, resources and opportunities for the design and implementation of innovative and well-being, generating actions from a community perspective. Throughout this process of listening, network management and collective interpretation, focused on carers, care workers and their immediate environment (from care home staff to the public sector, including pharmacists, undertakers, cemetery workers and hairdressers for cancer patients), the programme was able to determine a series of challenges

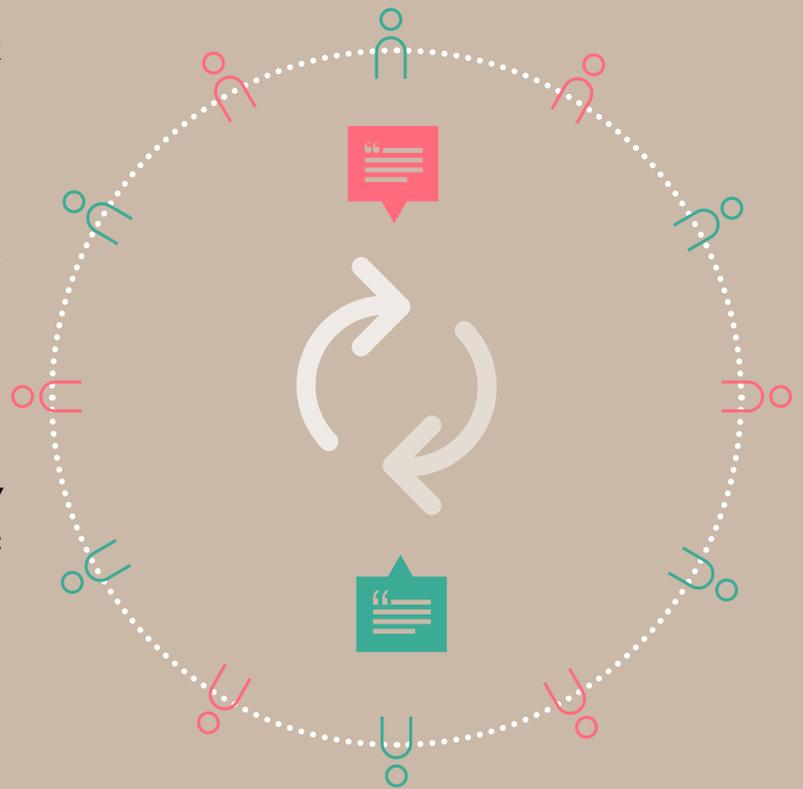
## 6/ Introduction

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and opportunities that can serve as a basis for work on compassionate environments in the Basque Country. This report is presented as an annex and background to the work that follows.

The second project is one that was requested by the Basque Government at the beginning of 2020 from the Fundación Doble Sonrisa (F2S). It involved an analysis of the so-called “*compassionate communities*” in the three historical territories of the Basque Autonomous Community. This would reinforce its main strategic objectives in this area:

- Harnessing the potential that older people offer in the life of towns and cities in the Basque Country as generators of well-being
- Creating and fostering community participation processes
- Creating a network of friendly initiatives in the Basque Country
- Facilitating the introduction of changes in these environments in order to improve the quality of life of its citizens

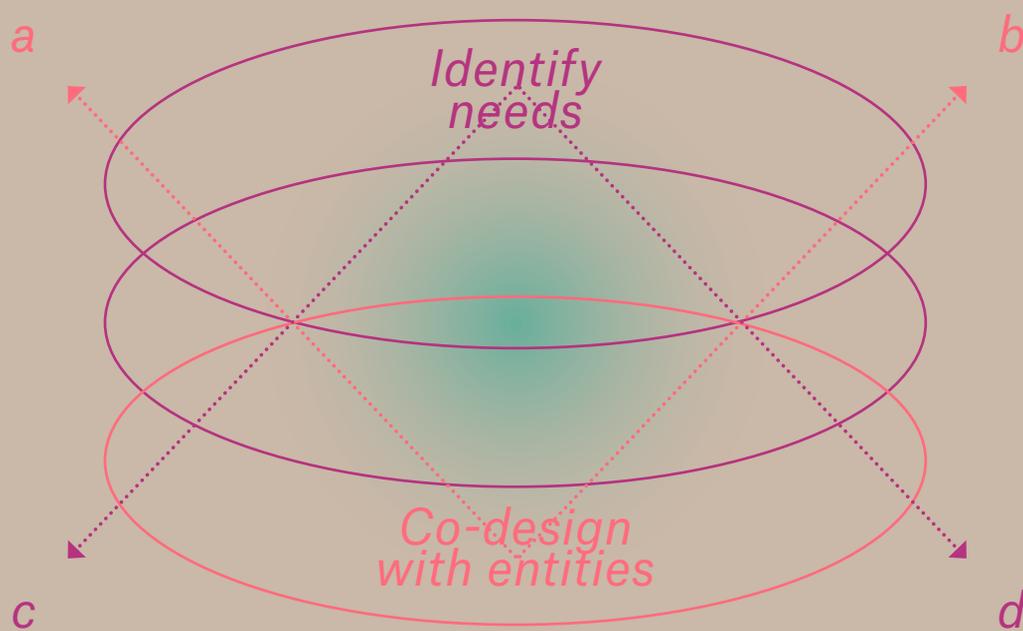


The main objectives of this second stage was to:

- (1) Determine what kind of specific needs compassionate environments require in the Basque Country (based on a mapping of the current situation and an ethnographic listening process);** and
- (2) Co-design with public, private, academic and civil society entities possible solutions to expand and scale up this type of initiative in all Basque territories.**

F2S has a solid base of information on which to work in this domain after several years of activity surrounding the loneliness and vulnerability of the elderly in the Basque Country, end of life and bereavement, as well as the prototyping of initiatives that can generate more compassionate communities, mainly through the Getxo Zurekin project. Thanks to this work, the foundation has a long history of community work and aims to create a model of integrated care (health, social and community) that improves the effectiveness and efficiency of organisations and the well-being of people in processes of advanced illness, situations of dependency or at the end of life.

The socio-health emergency created by COVID-19 has turned the process of drafting this report into a true *“living lab”* through which to reflect on community responses to the major socio-health challenges of the twenty-first century.



# 7/ The economic, political and social context of care. Theoretical framework

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End-of-life care is becoming increasingly relevant due to demographic and epidemiological changes. Population ageing and the consequent increase in chronic diseases is a global reality that is changing the care landscape (Zaman et al, 2017). The dying process is becoming increasingly protracted, entailing complex and varied needs of people in this situation. Our current social panorama and future prospects suggest a scenario in which health and social systems are unable to cope with existing demand, endangering their sustainability.

According to the WHO, there were 56.4 million deaths worldwide in 2016, more than a third of which could have benefited from palliative care (WHO 2018) . The main causes of death were ischaemic heart disease and stroke, which accounted for 15.2 million deaths, followed by chronic obstructive pulmonary disease (COPD), which accounted for

three million deaths. Lung cancer, along with tracheal and bronchial cancers, caused the deaths of 1.7 million people, and diabetes was the cause of death for 1.6 million people in 2016. Deaths attributable to dementia have also doubled in the last decade, making it one of the leading causes of death in the world (WHO 2018)<sup>3</sup>.

It is therefore estimated that chronic diseases account for 90% of the palliative care burden, with cardiovascular diseases, cancer, and chronic obstructive pulmonary disease representing the heaviest burden in this respect.

In Spain, the total number of deaths in 2016 amounted to 418,000, 91% of which were caused by chronic diseases. Cardiovascular diseases and cancer account for more than 60% of all deaths, and deaths from Alzheimer's disease and other dementias are increasing (in 2014 they were the

<sup>3</sup> Top 10 causes of death World Health Organisation. 24 May 2018. [Accessed 10/12/2018]. Available at <https://www.who.int/es/news-room/fact-sheets/detail/the-top-10-causes-of-death>

<sup>4</sup> Estrategia en Cuidados Paliativos del Sistema Nacional de Salud, 2007 [Spanish National Health System's Palliative Care Strategy, 2007]. Ministry of Health and Consumer Affairs. [Accessed 10/12/2018]. Available at [http://www.mscbs.gob.es/organizacion/sns/planCalidadSNS/pdf/excelencia/cuidadospaliativos-diabetes/CUIDADOS\\_PA-LIATIVOS/estrategiaCuidadosPaliativos.pdf](http://www.mscbs.gob.es/organizacion/sns/planCalidadSNS/pdf/excelencia/cuidadospaliativos-diabetes/CUIDADOS_PA-LIATIVOS/estrategiaCuidadosPaliativos.pdf) [In Spanish]

third leading cause of death). It is also worth noting the increase in Disability Adjusted Life Years (DALYs) associated with Alzheimer's disease (OECD 2017).

At the same time, the Spanish National Health System's 2007 Palliative Care Strategy already highlighted<sup>4</sup> the challenge of integrating palliative care into the National Health System to address the needs of people living in this situation. It was estimated that 50-60% of deaths require this type of end-of-life care. Other studies yield different data, estimating that in so-called "high-income" countries between 69% and 82% of deaths may require palliative care (Murtagh et al, 2014). There is currently a lack of consensus on objective estimates of people's palliative care needs. Existing methods vary in their approach, the tool employed for their identification and the data sources used. This creates a hurdle for the planning of palliative care services and resources.

In the Basque Country in 2020, the population over 65 years of age will already outnumber minors (Basque Statistical Office EUSTAT, 2020)<sup>5</sup>. The results of the indicators for the analysis of demographic phenomena prepared by EUSTAT show that life expectancy for men is over 80 years in the Basque Country, and 86.3 years for women. Both men and women have experienced a steady increase in life expectancy over the last 40 years. Few developed countries can boast such a high life expectancy, especially in the case of women (EUSTAT, 2020)<sup>6</sup>.

The birth rate in the Basque Country is low. It was 8.7 per 1,000 inhabitants in 2015, below the national average (9.0) and the European Union average (10.0) and has declined significantly in recent years. In 2019, it stood at a rate of 7 per 1,000 inhabitants (EUSTAT, 2020)<sup>7</sup>.

<sup>5</sup> EUSTAT. Estadística municipal de habitantes [Municipal Register of Inhabitants]. October 2020. [Internet]. [Accessed 23/11/2020]. Available at [www.eustat.eus/](http://www.eustat.eus/) [In Spanish]

<sup>6</sup> EUSTAT. Indicadores para el análisis de los fenómenos demográficos [Indicators for the analysis of demographic phenomena]. March 2020. [Internet]. [Accessed 23/11/2020]. [In Spanish]. Available at [www.eustat.eus/](http://www.eustat.eus/) [In Spanish]

<sup>7</sup> EUSTAT. Estadística de nacimientos [Birth statistics]. June 2020. [Internet]. [Accessed 23/11/2020]. Available at [www.eustat.eus/](http://www.eustat.eus/) [In Spanish]

## 7/ Theoretical framework

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Among the 28 EU countries, only Italy, Portugal and Greece have a lower rate than ours. This trend is unlikely to reverse, as the number of offspring that women under 40 expect to have in their lifetime barely exceeds 1.3 on average, with those born between 1996 and 2000 having only 1 offspring on average (EUSTAT, 2018)<sup>8</sup>.

The combined effect of both causes means that the relative proportion of older people in the population as a whole is increasing, something which in the case of the Basque Country is becoming more evident and accelerated.

Chronic diseases, mental health problems and physical disability increase in prevalence with age and reduce the quality of life of people suffering from these health conditions. The incidence and prevalence of chronic diseases has increased and will presumably increase much more in the coming years. Some 42% of men and 43% of women suffer from a chronic health problem, with the prevalence of chronicity in-

creasing with age.

It exceeds 80% for people aged 65 and over and reaches 90% for those aged 75 and over (Mateos M et al, 2018)<sup>9</sup>. These rates are also directly related to people's income and education levels.

It is precisely these pathologies that are the main causes of death in the population. Three out of four deaths are caused by the progression of one or more chronic health problems in Spain, and between 1 and 1.5% of the population suffers from complex chronic diseases in advanced stages with major care needs (Gómez-Bastiste X, 2015)<sup>10</sup>. In the Basque Country, the main causes of death in women are senile and presenile organic disorders (47 per 100,000 inhabitants), followed by cerebrovascular diseases (44 per 100,000 inhabitants). In men, the main causes are tracheal, bronchial and lung tumours (85 per 100,000 population) and ischaemic heart disease (79 per 100,000 population) (Audikana C, 2015)<sup>11</sup>.

<sup>8</sup> EUSTAT. Encuesta demográfica [Demographic survey]. February 2018. [Internet]. [Accessed 23/11/2020]. Available at [www.eustat.eus/](http://www.eustat.eus/) [In Spanish]

<sup>9</sup> Mateos M, de Diego M, Martín JA, Calvo M, Elorriaga E, Esnaola S. (2018) Datos relevantes de la Encuesta de Salud del País Vasco 2018 [Key data from the Basque Country Health Survey 2018]. Vitoria-Gasteiz: Department of Health, Health Studies and Research Service. [In Spanish].

## 7/ Theoretical framework

Population pyramids for the Basque Autonomous Community 2016-2031



Source: EUSTAT. Demographic projections 2031. Populations as of January 1.

Due to the prolonged and disabling nature of these pathologies, it is important to focus on life expectancy and good health beyond life expectancy per se. The first indicator provides information on the quality of life in terms of the health of an individual's life-year perspective. The absence of functional limitations or disability is considered to be a condition of good health.

There is also today considerable diversity in the degree of maturity and preparedness of health systems worldwide to provide palliative care. Differences in palliative care range from an informal family setting to isolated services for clinical care, to the integration of palliative care within the healthcare systems themselves.

<sup>10</sup> Gómez-Batiste X, Amblàs Novellas J, Lasmarías Martínez C, Calsina-Berna A. (2015) Manual de atención integral de personas con enfermedades crónicas avanzadas: aspectos clínicos [Handbook of comprehensive care for people with advanced chronic diseases: clinical aspects]. Madrid: Elsevier. [In Spanish]

<sup>11</sup> Audicana Uriarte C. (2018) Mortalidad en la Comunidad Autónoma del País Vasco [Mortality in the Basque Autonomous Community]. Registration and Health Information Service. Health Planning, Management and Evaluation Directorate Department of Health. [Internet]. [Accessed 23/11/2020]. Available at [https://www.euskadi.eus/contenidos/informacion/registros\\_mortalidad/es\\_def/adjuntos/Informe-Mortalidad-2017.pdf](https://www.euskadi.eus/contenidos/informacion/registros_mortalidad/es_def/adjuntos/Informe-Mortalidad-2017.pdf) [In Spanish].

## 7/ Theoretical framework

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This is compounded by the fact that there is a lack of consensus on questions of how we die and what a good death means, which is subjective and depends on the context, environment and cultures of the communities concerned

The particularities of the cultural, social and community contexts largely determine the approach and preferences for end-of-life care. Additionally, palliative care must be understood as an inter-subjective process in which different stakeholders involved in the affected person's life participate.

In addition to the above, new family structures are affecting how people are cared for and supported towards the end of life. In many cases, the family environment has been and remains the only source of security and protection for its members. Therefore, these new family models highlight the need to involve the whole community in the care and support of people facing the end of life. This

is all the more so when it is estimated that people with chronic diseases spend on average only three hours a year in contact with healthcare services and 8,757 hours in the community, which is less than 5% of caring time<sup>12</sup>.

Beyond the clinical conditions of the population, loneliness among the elderly is increasingly recognised as a major problem in today's modern society (Borsch-Supan A et al, 2019). Living in loneliness is not in itself a cause of ill health, as the negative effects of loneliness on health are a matter of a person's perception of loneliness (Borsch-Supan A et al, 2019)<sup>13</sup>. EU data show that 6% of the adult population have no one to talk to about personal matters<sup>14</sup>. In the Basque Country, data from the latest Basque Country Health Survey reveal a decrease in both confidential and affective self-perceived lack of support at all ages and more intensely in older age groups (ESCAV 2018) [Basque Autonomous Community Health Survey 2018].

<sup>12</sup> The Health Foundation. Co-creating health: evaluation of first phase. April 2012. [Accessed 16/12/2018]. Available at <https://www.health.org.uk/sites/default/files/CoCreatingHealthEvaluationOfFirstPhase.pdf>

<sup>13</sup> Axel Börsch-Supan, Johanna Bristle, Karen Andersen-Ranberg, Agar Brugiavini, Florence Jusot, Howard Litwin, Guglielmo Weber. (2019) A spotlight on health and life courses in Europe using SHARE Waves 6 and 7. De Gruyter; 1-32. <https://doi.org/10.1515/9783110617245-001>

Unwanted loneliness is the cause of various risk factors, not only physical and mental health, but also the result of the socio-cultural and environmental context, as well as aspects related to the psychological and cognitive situation of each person. The impact of loneliness reaches beyond the individual to the public and social sphere, triggering higher health and social costs, and resulting in the loss of human capital and experience, among others.

In response to these situations, new alternative models of palliative care have emerged that champion a paradigm shift, underlining the importance of involving and empowering society as a whole in end-of-life care, without this meaning that public health and social services neglect these people and their needs.

Along the same lines, previous studies have shown the negative effect on the health of people who lose a close loved one. Loneliness and depressive symptoms increase in sit-

uations of loss of a partner or close family member, and the affected person's satisfaction with his or her environment and social networks is undermined. This highlights the relationship between social connections and health, and the importance of promoting health measures and policies that address bereavement and death processes (Borsch-Supan A et al, 2019).

### The burden of public policy

Since the 70s and 80s, the ideas for a "new" public health, developed by the WHO (Awofeso N, 2004)<sup>15</sup>, have gained in approval for the shared responsibility of all sectors in the promotion of the health of individuals and populations. Therefore, various policies and measures to promote reproductive health, healthy lifestyle choices such as nutrition or exercise, and the promotion of safe working environments, among others, have gained prominence and involved different sectors and stakeholders besides the healthcare sector in their

<sup>14</sup> Healthy Loneliness. Manifesto for addressing and reducing older adults loneliness in Europe. Raising awareness and taking appropriate and timely actions to minimize the negative effects of loneliness on older adults. [Internet] [Accessed 30/11/2020]. Available at <https://www.healthy-loneliness.eu/>

<sup>15</sup> Awofeso N. (2004). What's new about the "new public health"?. *American journal of public health*, 94(5), 705-709. <https://doi.org/10.2105/ajph.94.5.705>

## 7/ Theoretical framework

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development (Kellehear, 2013)<sup>16</sup>. Today, the relevance of health promotion and prevention policies beyond the health sector is assumed to be key to improving health outcomes in populations.

It was not until the 1990s that this same public health approach was brought into the field of palliative care. It is well known that people facing life-limiting chronic diseases suffer from anxiety, depression, unwanted loneliness, social stigma, loss of employment, and economic hardship, which in turn determines their quality of life, that of their caregivers and family members of those close to them when they die.

Many of these social and psychological problems are not easily addressed by healthcare services, and therefore, once again, the support of other sectors, social spheres and the community as a whole is of vital importance. Moreover, these situations could be avoided with prevention approaches and measures introduced in other public health and communi-

ty-based initiatives, as well as with the involvement of different social, educational, media, corporate and local business stakeholders. This is all part of a twofold mission:

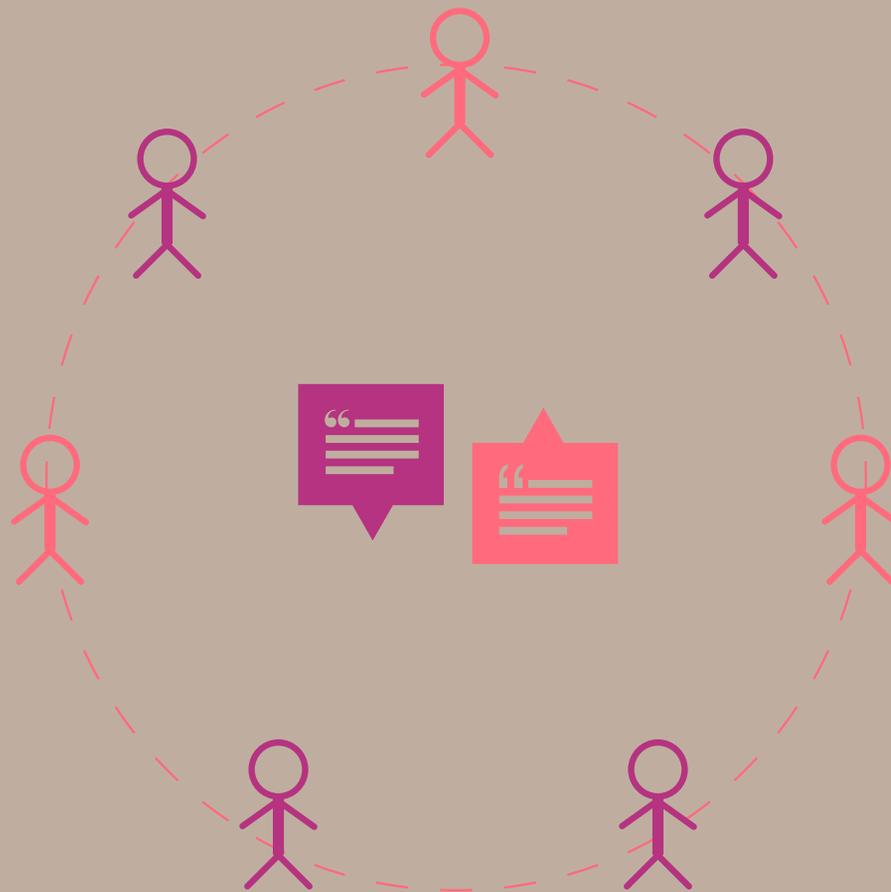
- 1) to improve care and meet the real needs of people in illness and end-of-life situations,
- 2) to free up resources in palliative care services for the management of the most complex and extreme cases (Kellehear A, 2013).

<sup>16</sup> Kellehear A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *Q J Med*; 106:1071-1075. doi:10.1093/qjmed/hct200

## 7/ Theoretical framework

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The care challenge we face is enormous. Our current social panorama and future prospects suggest a scenario in which health and social systems are unable to cope with existing demand, endangering their sustainability. Public health models and community-inclusive integrated care approaches are needed more than ever.



## 8/ Compassionate communities

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At the end of the twentieth century, Allan Kellehear coined a new approach to palliative care from the perspective of health promotion, whereby different stakeholders in the community (government, state administrations, social and health organisations, and the community as a whole) organise themselves to offer a range of resources and alternatives to improve the health and well-being of people at the end of life within the community itself. The idea is to change from doing initiatives “for” the community to doing them “with” the community. Building on this philosophy, it was this author who proposed the idea of “*Compassionate Communities*”, with the intention of changing the narrative within the communities themselves and highlighting the responsibility of the whole community to offer support and relief in the final stages of life to families in such situations, based on the principles of compassion and mutual aid (Kellehear, 1999)<sup>16</sup>.

In recent decades, the “*Compassionate Communities*”<sup>17</sup> movement has attracted international and local interest. From a public health approach, where health promotion is a general responsibility, but also includes end-of-life processes as part of a process in the life course of the human being, “*Compassionate Communities*” are positioned as a community solution that complements responses to people’s needs at the end of life.

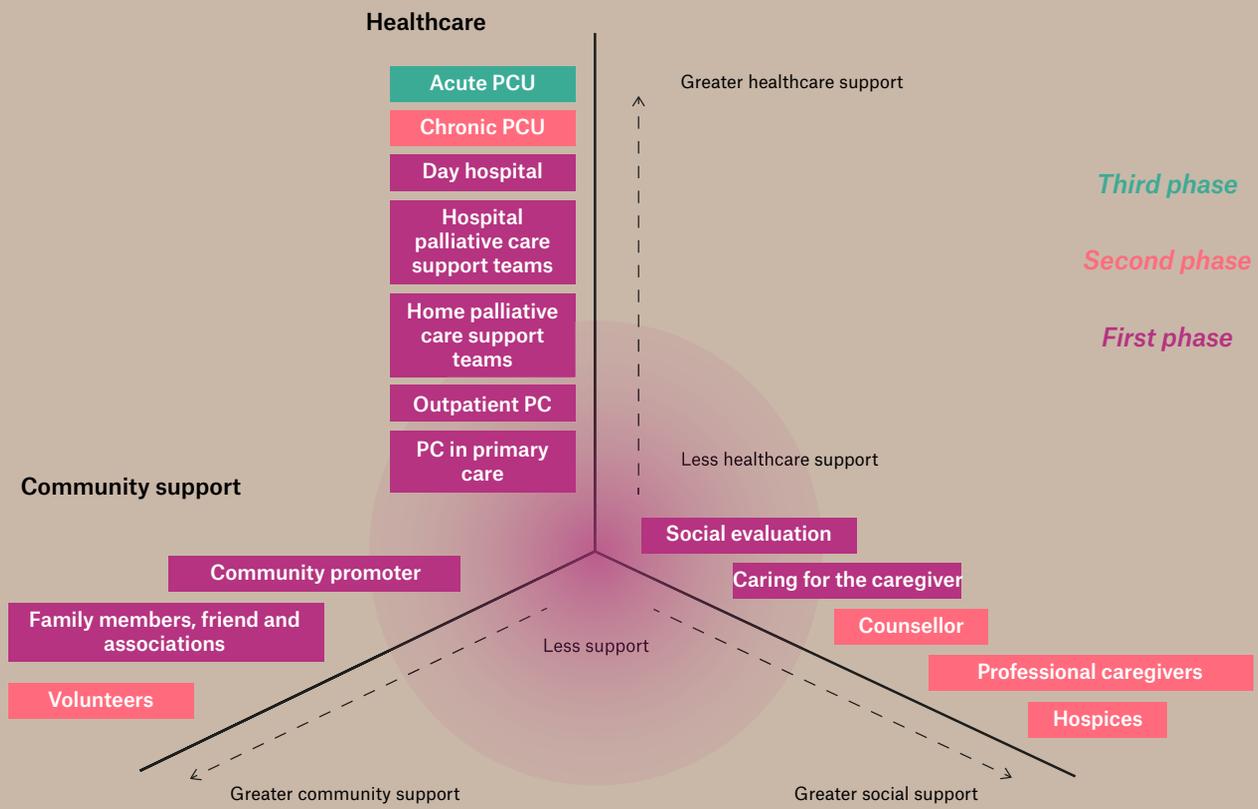
In 2013, the Public Health Palliative Care International (PHPCI) movement was founded in response to the need to create a partnership to communicate the importance of the public health approach to end-of-life palliative care worldwide. Since the first experiences in 2007 until today, various organisations in different countries have promoted the development of Compassionate Communities, showing a heterogeneity in their models and forms of implementation, although all of them have a number of core aspects in common.

<sup>16</sup> Kellehear A. (2013). Compassionate communities: end-of-life care as everyone’s responsibility. *Q J Med*; 106:1071-1075. doi:10.1093/qjmed/hct200

<sup>17</sup> Given the diversity in terminology for community-based movements to promote collective social and civic responsibility for improving end-of-life care, the term “Compassionate Communities” will be used in this document for ease and speed of reading only. However, other names for these movements are acknowledged and cited here: among others, “Caring Cities” or “Compassionate Cities”

## 8/ Compassionate communities

Integrated palliative care model. Fundación New Health



Zainketa Aringarrien Eredu Integratua. New Health Fundazioa

# “Compassionate Communities”

(Librada-Flores S et al, 2020)<sup>18</sup>

**1/** Are supported by health policies that recognise compassion and solidarity as a prevailing ethical issue

**3/** Recognise people’s cultural, spiritual and social differences

**5/** Offer a wide range of services and access to resources for communication and relationship building, as well as mutual support between people

<sup>18</sup> Librada-Flores S, Nabal-Vicuña M, Forero-Vega D, Muñoz-Mayorga I, Guerra-Martín MD. (2020). International Journal of Environmental Research and Public Health, 17, 6271; doi: 10.3390/ijerph17176271

## 8/ Compassionate communities

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**2/** Are geared towards meeting the needs of people at the end of life, the elderly and the bereaved

**4/** Take palliative services into account in local planning and public policies

**6/** They provide quick and easy access to palliative care and bereavement support services

## 8/ Compassionate communities

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*“Compassionate Communities”* is a social change approach to promote the social integration of the vision of palliative care, death and bereavement into the everyday life of individuals and communities; making the whole community feel a responsibility to support and care for the end-of-life process. This movement aims to raise awareness about the involvement of communities and individuals at the end of life, through their active participation in end-of-life care for people and their families. The aim is to create care networks, mobilising entire communities to provide emotional support (both professional and informal), and to develop capacities to respond to end-of-life situations.

Some evidence suggests the benefits of community involvement for people’s health and well-being. Along these lines, community involvement is increasingly acknowledged in policies and plans, as well as through various experiences worldwide. Several communities have launched initiatives within the framework of Kellehear’s compassionate cities,

including countries such as the UK, Ireland, India, Canada, Australia, Latin American countries and Spain.

The very paradigm of integrated care embraces the view that the integration of services and social and health organisations will not transform the reality of people with complex needs if they do not go hand in hand with and serve the family, neighbourhood and community networks, which are the ones that really share the life of the person concerned. Social and health systems sometimes fail to meet the basic needs of affection, love and accompaniment that can be provided by the person’s community support network. Studies have found that each death can affect up to 10 people, 10% of whom will experience grief with repercussions on their physical and mental health [8]. In Vizcaya, almost ten thousand people die every year, which means that a total of 50,000 people are in the process of mourning and accompaniment. Consequently, there are a substantial number of people who may need help to cope with their

<sup>19</sup> EUSTAT. Estadística de Defunciones [Death Statistics]. [Accessed 28/12/2018]. Available at [http://www.eustat.eus/elementos/ele0000000/Defunciones\\_y\\_tasas\\_de\\_mortalidad\\_de\\_la\\_CA\\_de\\_Euskadi\\_por\\_1000\\_habitantes\\_por\\_Territorio\\_Historico/tbl0000026\\_c.html](http://www.eustat.eus/elementos/ele0000000/Defunciones_y_tasas_de_mortalidad_de_la_CA_de_Euskadi_por_1000_habitantes_por_Territorio_Historico/tbl0000026_c.html) [In Spanish]

grief<sup>19</sup>.

In addition, there is evidence that a high percentage of people do not die in the place they would like to due to lack of support and family network. A survey by the Centro de Investigaciones Sociológicas [Centre for Sociological Research] (CIS) in 2009 found that 45% of Spaniards want their last moments to be spent at home and only 17.8% would choose a hospital. However, in 2008, 47.26% of deaths occurred in hospital (De Benito, 2010).

Furthermore, the current challenge of sustainability faced by the healthcare sector is exacerbating the need for a change in the way end-of-life needs are addressed, moving beyond the hospital setting to bring care closer to the patient's immediate environment. Several publications report the benefit of providing palliative care at home, which contributes to patients' preferences to die at home, as well as to hospitalisation cost savings (Sheow et al, 2018).

One independent study by Duke University in 2007 showed that hospices provide compassionate care to those

reaching the end of life and save an average of 2,300 dollars per patient in medical care (Taylor et al, 2007).

A 2008 report found that, in hospitals, spending on palliative care for patients resulted in a significant reduction in hospital costs compared to patients who did not receive palliative care (Morrison et al, 2008). The savings were made, in principle, through reduced hospital stays, more deaths at home and less use of hospital emergency facilities in complicated cases.

In Spain, palliative care was shown to result in significant cost savings and increased efficiency, without compromising patient care (Gomez-Batiste et al, 2006). Yet, in general, these studies still fail to include the impact and contribution of community initiatives on the health and well-being of the population as a whole.

Compassionate Communities do not emerge naturally. Their development and implementation are coupled

## 8/ Compassionate communities

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with a systematic process of community transformation, the involvement of supporting services in end-of-life care for individuals and families, and the development of policies that directly have an impact in this area.

The public health approach to end-of-life care and the development of *Compassionate Communities* offers an opportunity to address inefficiencies and inequities in palliative care. Since the publication of Kellehear's work on health promoting palliative care (Kellehear, 1999), the Compassionate Communities movement has gained international recognition and interest. Despite its short history, there is growing evidence to support the effectiveness of this approach to end-of-life care (Sallnow et al, 2016; Wegleitner et al, 2016).

Coordination and liaison between community and specialist palliative care services is key to the success of approaches such as this one. The former possesses the closeness and experience of the dying process that the latter do not. The latter have the opportunity to offer support in pro-

viding the necessary support and care in these final moments of life.

### Compassionate environments in the Basque Country

The launch of compassionate environment initiatives in the Basque Country has already taken its first steps in what is called Red de Comunidades Compasivas de Euskadi [Basque Country Compassionate Communities Network]. Among these municipalities are Gasteiz, Getxo, Santurtzi, Donostia-San Sebastián, Zarautz, Tolosa, Orío, Bidasoa, Elgoibar and Sopelana. The aim of these projects is to "*open spaces to make the invisible visible*", as well as to provide resources to the community to facilitate the accompaniment of people in the last stage of life, to encourage the creation of neighbourhood networks and to tackle unwanted loneliness. Recognising their value in today's society, the Provincial Council of Álava has proposed the creation of a network of compassionate communities at the provincial level, for future expansion throughout the Basque Autono-

<sup>20</sup> For more information, visit [euskadilagunkoia.net/](http://euskadilagunkoia.net/)

mous Community.

In addition to these initiatives, there are already several projects underway that focus on community participation. One example is Euskadi Lagunkoia [Age-friendly Basque Country], promoted by the Department of Employment and Social Policies of the Basque Government, in collaboration with Fundación Matia. The initiative stems from the WHO's "Age-friendly Environments Programme" and is being developed under the paradigm of Healthy Ageing. It promotes improvement actions in different areas such as urban planning, transportation, social participation, employment, health and social services, as well as management of open-air spaces.

In recent months, due to the emergency created by the pandemic situation, a number of initiatives and resources related to friendliness have also flourished. From home services for the elderly (shopping, meals, medicines, etc); physical and cognitive health programmes; other

programmes to combat loneliness (support letters or telephone support); initiatives to share experiences (stories written by the elderly during their confinement or a radio space for talking); recommendations to get through quarantine (for people who live with someone with dementia); to engagement and fun programmes (producing the municipal magazine together or reproducing works of art, among others)<sup>21</sup>.

### Development, implementation and evaluation of compassionate environments

Evidence published to date highlights as key elements in the development and implementation of "Compassionate Communities" citizen awareness and education about grief and death (through schools and workplaces, among others)<sup>21</sup> (Abel J et al, 2011; De Zulueta P, 2014), recognition and support for caregiving and caregivers (Lown B, 2014), the value of compassion and social joint responsibility for healthcare (Lown B

<sup>21</sup> Euskadi Lagunkoia COVID-19. [Internet]. [accedido el 30/11/2020]. Disponible en: <https://www.euskadilagunkoia.net/es/component/content/article/145-entrevistas-covid19/2135-euskadi-lagunkoia-estrena-la-seccion-covid-19?Itemid=367>

<sup>22</sup> Abel, J.; Bowra, J.; Howarth, G. (2011) Compassionate community networks: Supporting home dying. *BMJ Support. Palliat. Care*; 1, 129-133

## 8/ Compassionate communities

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2014), in addition to leadership<sup>23</sup>,<sup>24</sup>in the healthcare field, involving the community and promoting alliances and networking between these sectors and research personnel in improving the quality of life in situations of death and bereavement (Lown B, 2014; De Zulueta P, 2014; <sup>25</sup>Chou WY et al, 2008; Sallnow L et al, 2010).

In terms of evaluation, there is a need to collect information on caregiver satisfaction, the experience of professionals and patients, along with community development in this area through education and the creation of care networks (Sallnow L et al, 2010). Carers are asked about the information provided, suitability, timing and financial aspects of Compassionate Community experiences compared to conventional care. For professionals, accessibility to resources and community support is evaluated, as well as any obstacles in the recommendation and referral of

potential beneficiary sectors<sup>26</sup> (Williams AM, 2010).

Other evaluation frameworks have focused on collecting indicators related to *“structure (person- and family-centred care); values (empathy, respect, collaboration); process (communication, shared decision-making); and outcomes (satisfaction and organisational development of the Compassionate Community)”*<sup>27</sup> (Pfaff K et al, 2017).

<sup>23</sup> Lown, B. (2014) Seven guiding commitments: Making the U.S. healthcare system more compassionate. *J. Patient. Exp;* 1, 6-

<sup>24</sup> De Zulueta, P. (2016) Developing compassionate leadership in health care: An integrative review. *J. Health Leadersh*

<sup>25</sup> Chou WY, Stokes S, Citko J, Davies B. (2008) Improving end-of-life care through community-based grassroots collaboration: Development of the Chinese-American Coalition for Compassionate Care. *J. Palliat. Care;* 24, 31-40.  
Sallnow, L.; Kumar, S.; Numpeli, M. (2010) Home-based palliative care in Kerala, India: The Neighbourhood Network in Palliative Care. *Prog. Palliat. Care;* 18, 14-17

## 8/ Compassionate communities

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Other approaches have also evaluated the visibility of programmes and initiatives within the framework of the Compassionate Community (websites, awareness campaigns, dissemination material), citizen participation (through workshops, volunteering, community groups), and the model of care (encompassing caregivers and mentoring in the community, trained volunteers and the adequacy of services provided)<sup>28</sup> (McLoughlin K, 2013).

<sup>26</sup> Williams, A.M. (2010) Evaluating Canada's Compassionate Care Benefit using a utilization-focused evaluation framework: Successful strategies and prerequisite conditions. *Eval. Progr. Plann*; 91-97

<sup>27</sup> Pfaff K, Markaki A. (2017) Compassionate collaborative care: An integrative review of quality indicators in end-of-life care. *BMC Palliat. Care*; 16, 65

<sup>28</sup> McLoughlin, K. Compassionate Communities Project Evaluation Report. 2013.[Internet]. Available at [www.lenus.ie/handle/10147/621066](http://www.lenus.ie/handle/10147/621066) (Accessed 28/11/2020)

# 9/ Study objectives

## 9.1. in 2019

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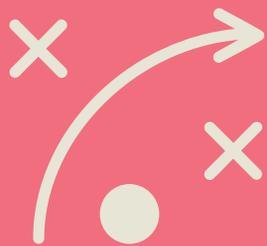
**Getxo Zurekin** is an initiative to create a model of integrated health, social and community care that improves the effectiveness and efficiency of organisations and the well-being of people in processes of advanced illness, situations of dependency or at the end of life.

Along these lines, the following specific objectives are proposed:

- a) Raise awareness among the citizens of Getxo about the importance of community care and support for people in situations of dependency and end of life.
- b) Normalise the discourse in the community around death
- c) Train residents in the area of palliative care and end-of-life support.

## 9.1. Study Objectives in 2019

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d) Promote research through a community innovation platform on community support at the end of life

e) Design and set up a local observatory to monitor community support needs in real time

f) Develop a collaborative methodology that incorporates the community, encouraging the participation of citizens, local partners and international institutions, aiming at their involvement in the development of a compassionate community.

g) Study the cultural dimension of an innovation process, including the cultural perspective gathered from the users' perspective (beyond the experts' perspective).

# 9/ Study Objectives

## 9.2. in 2020

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The Basque Government intends to promote a model of integrated health, social and community care that improves the wellbeing of people in processes of advanced illness, situations of dependency or at the end of life.

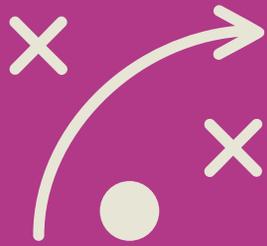
This study has attempted to make a contribution to this objective through the following actions:

- a) Determine what kind of specific needs compassionate environments require in the Basque Country (based on a mapping of the current situation and an ethnographic listening process) to complement (not replace) existing strategies.
- b) Co-design with public, private, academic and civil society entities possible solutions to expand and scale up this type of initiative in all Basque territories.

The objectives of the second project are in line with the study objectives of the 2019 project, continuing in this second project along different lines initiated in the 2019 project.

## 9.2. Study Objectives in 2020

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So, the specific objectives of the study in 2020 are as follows:

- a) Envision the existing network and the main responses and key agents around the existing compassionate communities in the Basque Country.
- b) Create an extensive database on compassionate communities in the Basque Country (institutions, organisations, companies, individuals).
- c) Identify narratives, challenges, opportunities, barriers and enablers for compassionate communities in the Basque Country.
- d) Segment the information in order to understand the different ways of understanding this reality.
- e) Collectively validate and correct the analysis and profiles identified.
- f) Envision new solutions through participatory processes.

# 10/ Process Development

The initiative is located in the town of Getxo, on the right bank of the Bilbao estuary, forming part of the Greater Bilbao region and the metropolitan area of Bilbao (14 kilometres from the city of Bilbao). The city has 78,276 inhabitants (**53.2% women; 23.4% over 65 years of age**)<sup>29</sup> and it is known for the large number of mansions and houses built by the gentry during industrialisation.

Some demographic and socio-economic data that characterise the municipality are given below, although it is true that the data correspond to previous years, and a more recent study is needed to update the information.

Item	Getxo
<b>Births (2014)</b>	<b>621</b>
<b>Deaths (2014)</b>	<b>677</b>
<b>Net migration (2014)</b>	
Men	-257
Women	-136
<b>Place of Birth (2011) (%)</b>	
Vizcaya	58.655 (73,5)
Rest of BAC	1.835 (2,3)
Spain	11.920 (14,9)
Other countries	7.405 (9,3)
<b>Family type (2001) (%)</b>	
Single person	4.347 (16,1)
Compound	738 (2,7)

<sup>29</sup> National Institute of Statistics. Official population figures resulting from the revision of the Municipal Register on 1 January 2018. [Accessed 7/01/2019]. [In Spanish]. Available at <https://www.ine.es/jaxiT3/Datos.htm?t=2905>

## 10/ Scope of the study

Nucleus without children	3.767 (13,9)
Nucleus with children	12.545 (46,4)
Single parent	3.022 (11,2)
Extended	2.115 (7,8)
Polynuclear	485 (1,8)
<b>Level of education (2011) (%)</b>	
Illiterate or uneducated	608 (0,8)
Primary education	13.483 (18,4)
Vocational training	8.674 (11,9)
Secondary or medium-to higher education	26.487 (36,1)
Higher education	23.934 (32,7)
<b>Personal income (2013)</b>	
Total Income	26.505
Disposable income	21.047
<b>Population in Relation to Activity (Men/Women; %) (2011)</b>	
Active population	51,6/43,5
Employed	44,5/37,1
Unemployed	7,1/6,4
Inactive	48,4/56,5
<b>Unemployed population (men/women; %) (2015)</b>	
<b>45,9/54,1</b>	
<b>Gross Value Added by Sector (2012) (%)</b>	
Services	88,9
Construction	6,8
Industry	4,2
Primary sector	0,1
<b>Employment by branch of activity (2011) (%)</b>	
Agriculture, livestock and fisheries	133 (0,4)
Industry and energy	3.550 (11,0)
Construction	1.768 (5,5)
Trading and repairs	4.597 (14,2)
Hospitality industry	1.812 (5,6)
Transport and communications	2.527 (7,8)
Financial intermediation	1.646 (5,1)
Professional and business services	13.872 (42,9)
Other service activities	2.461 (7,6)

Table 1. Prepared by the authors based on the 2015 socio-economic report on the municipality of Getxo.

## 10/ Scope of the study

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The ageing of the population is a reality in the municipality of Getxo, in addition to the negative natural increase recorded in 2014, because of the fact that deaths (677) were higher than births (621).

In terms of family structure, most of the families are couples with children, the nuclear family, although its importance has diminished. At the other extreme, there has been an increase in the single-person family type, due to the ageing of the population.

The population's educational level has increased in the number of people with vocational education (+14.1%, +1,073), secondary education (+4.2%, +718), and higher education (+7.0%, +1,576). In comparison with Vizcaya and the BAC, higher levels of education (secondary, medium-higher and higher) represent substantially higher percentage weightings in Getxo.

Despite the decline since the crisis years, the average personal and household income of people aged 18 and over in Getxo is higher (by just over €7,000) than in Vizcaya or in the CAV as a whole.

The unemployment rate in the municipality of Getxo continues to be significantly lower than that recorded for the BAC (14.1) and Vizcaya (15.3), although the female unemployment rate is higher than the male rate.

## 10/ Scope of the study

The most recent accessible data<sup>30</sup> reflect the following situation:

Item	Algorta	Las Arenas	Andra Mari	Getxo
Population (%)	38.926 (48,8%)	26.866 (33,7%)	14.023 (17,6%)	
Men	18.261 (46,9%)	12.426 (46,3%)	6.759 (48,2%)	
Women	20.665 (53,1%)	14.440 (53,7%)	7.264 (51,8%)	
0-19 (%)	18,1%	15,8%	18,9%	17,4%
20-64 (%)	63,4%	61,3%	66,2%	63,2%
65+ (%)	18,5%	22,9%	14,8%	19,4%

**Table 2.** Source: Prepared by the authors based on the 2015 socio-economic report on the municipality of Getxo.

On the one hand, as can be seen from the table, almost 50% of the population of the municipality of Getxo is located in the territory of Algorta, where women outnumber men, as in the rest of the municipalities.

On the other hand, looking at the distribution by age group, the ageing of the population is particularly significant. In Areeta/Las Arenas, 22.9% of the population is 65 years of age or older, and in contrast, it is the area with the lowest percentage of population under 20 years of age, 15.8%. For its part, Andra Mari is the youngest, with less than 15% of the population aged 65 or over, while almost 19% is under the age of 20.

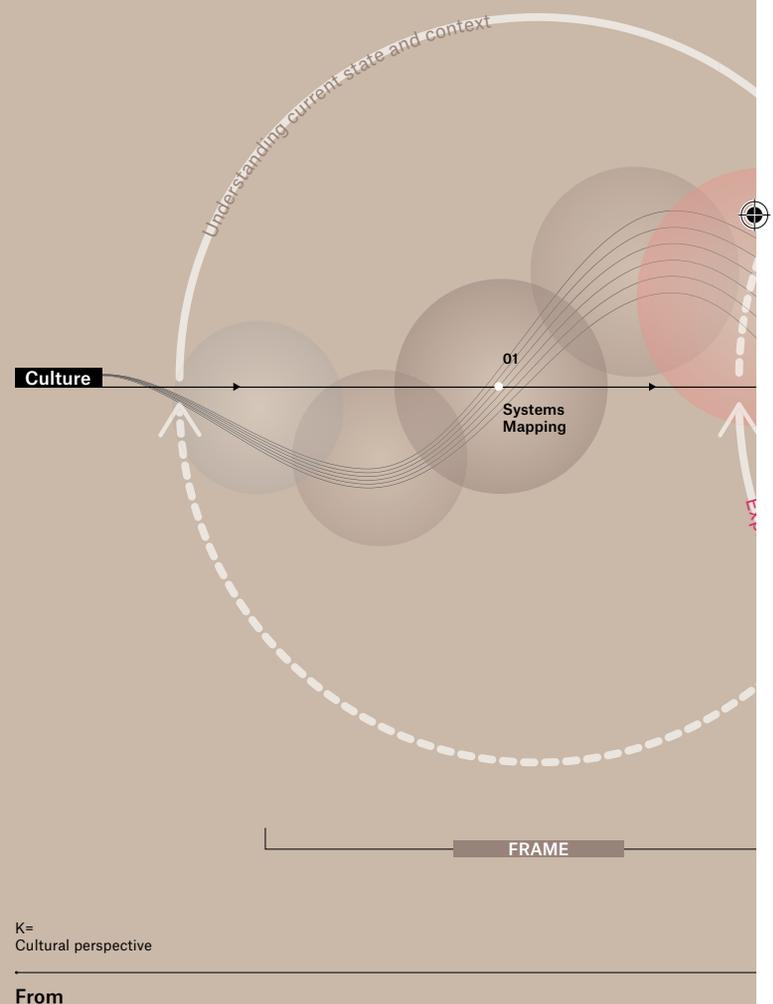
<sup>30</sup> EUSTAT. Censo de población y Viviendas 2011.  
[Population and Housing Census 2011]

# 10/ Process design and methodology

Different agents from the Getxo community are involved in the project (representatives of public administrations, social and healthcare professionals, neighbourhood associations, local business people, patient associations and individual citizens, among others) and their forms of participation vary depending on the person (from occasional participation at some stage, to a more extensive participation over the course and development of the project). To recruit the first participants, the focus has been on the main local associations, as well as health and social centres. Subsequently, the network of new contacts has expanded through the snowball effect.

**The project is structured in four work phases: listening and collective interpretation, co-creation, implementation, and evaluation.**

It must be understood that these phases are interconnected and part of a continuous process.



# 10/ Participants and project phases



Systemic Transformation

Towards

## 10/ Participants and project phases

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Phase	Objectives	Methodology used
<b>ANALYSIS AND LISTENING</b>	<ul style="list-style-type: none"><li>• Collect testimonies of people with advanced disease and their families, social services, healthcare providers, institutional authorities, companies and neighbours.</li><li>• Generate insight into how the end-of-life phase is being approached.</li><li>• Create networks on which to promote the project and build future initiatives.</li><li>• Generate new ideas, projects and services that provide tangible and different responses to the needs of the community.</li></ul>	<ul style="list-style-type: none"><li>• It incorporates qualitative methodology with ethnographic observation, interviews and other community listening activities.</li><li>• Contrast sessions for the validation of the conclusions generated.</li></ul>
<b>CO-CREATION</b>	<ul style="list-style-type: none"><li>• Develop sustainable interventions based on citizens' proposals.</li></ul>	<ul style="list-style-type: none"><li>• Contrast sessions to encourage dialogue and discussion between the multidisciplinary group of community agents and residents.</li></ul>
<b>IMPLEMENTATION</b>	<ul style="list-style-type: none"><li>• Develop the selected interventions in collaboration with all community agents. As a first step on a small and medium scale, to later move on to large-scale actions.</li></ul>	

## 10/ Participants and project phases

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Phase	Objectives	Methodology used
<b>EVALUATION</b>	<ul style="list-style-type: none"><li>• Introduce improvements and adapt to new narratives as they are generated.</li><li>• Create a permanent public narrative.</li></ul>	<ul style="list-style-type: none"><li>• Piloting the “Super heroines” WhatsApp group and a meEting for family caregivers and a new grieving space</li><li>• Developmental evaluation</li></ul>

# 10/ Added value of the process

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## 1. It facilitates work on public policies

This methodological approach begins by a listening process, which generates qualitative information and knowledge and allows for a shared analysis of the neighbourhood in order to detect possible lines of work to be explored in greater depth. It starts by gathering the perception that communities have of a specific territory, in order to find concrete solutions to the challenges detected. It is therefore a system that makes it possible to tackle public policies, not just public projects, with citizens. It makes it possible to go beyond the tangible, to get an overview of the neighbourhood from different points of view, and to detect issues of a more strategic nature.

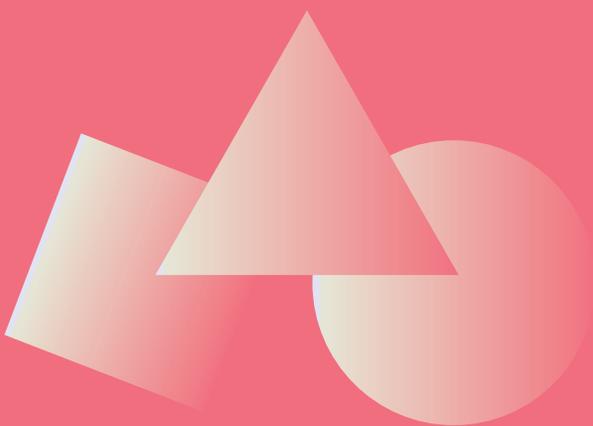
## 2. It detects discursive diversity

A wide range of voices is desired in the area of participation. In other words, the success of a participatory process depends more on giving space to all the sensitivities that may exist around the issue to be addressed than on being able to mobilise a large number of participants, so that all points of view have their place. The methodology proposed by this project has the quality of detecting the discursive diversity that can exist in the same territory. It begins at the outset by detecting what different narratives the inhabitants have about their neighbourhood, which, as well as helping us to identify the issues of greatest interest or that may give rise to conflict, gives us an insight into the different sensitivities that we may

encounter when exploring a topic in depth and therefore have as diverse a participation as possible.

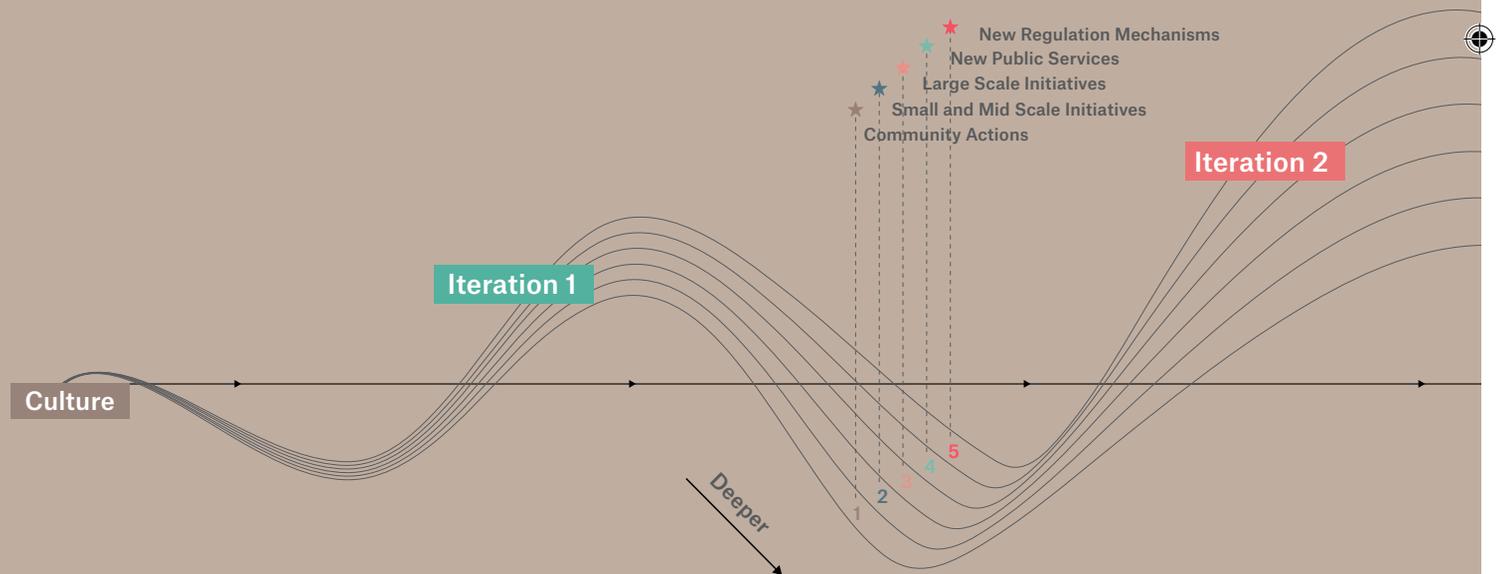
### **3. It fosters public-social collaboration and community work**

Irrespective of how good or new the information obtained in this way may be, it is how it has been obtained that matters. It is as important in this project to obtain information as it is to promote a horizontal relationship between public administration and citizens. Public-social collaboration spaces and projects that favour community work should be promoted. It is important to consider that this way of working is based on interaction and collaboration between citizens, agents and institutions. It is about overcoming transaction-based logic-demand/projects and services.



## 4. It aims for systemic transformation

The ultimate goal of this approach is a transformation to meet the challenges posed, in this case loneliness and palliative care. Transformative responses require systemic approaches and collaboration between different people – harnessing the energy of collaboration to create solutions. For this reason, during the process, the aim is to collaboratively generate ideas that can later be translated into concrete actions that respond to five potential project categories:

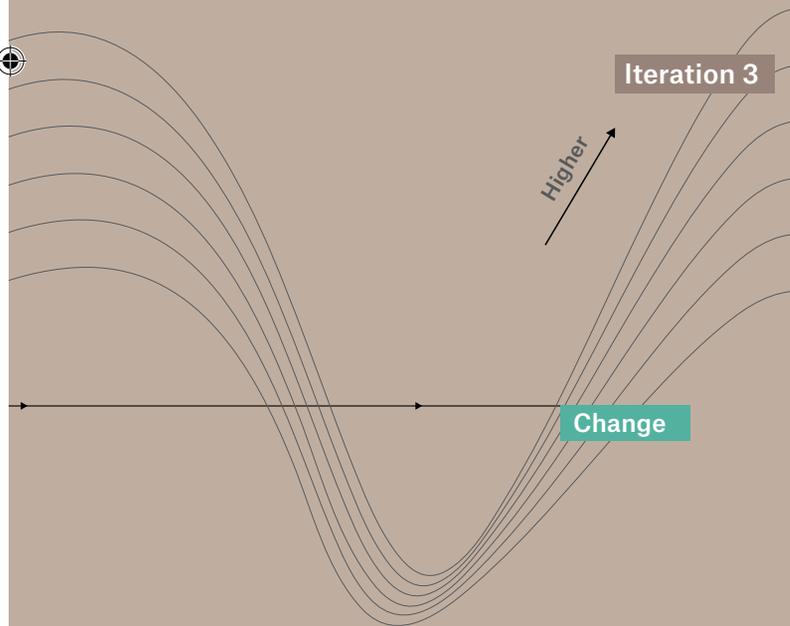


## 10/ Added value of the process

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(1) community initiatives; (2) small- and medium-scale initiatives; (3) large-scale initiatives; (4) new services; (5) new regulations.

The implementation of different categories of projects consolidates the transformation and public-social collaboration makes it possible to approach the challenge from different positions that anchor the transformation in the neighbourhood.



# 10.1/ Process development in 2019

## 10.1.1. Phase 1: Analysis and community listening process

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The first part of this phase involves collecting narratives on how families, institutions and professionals in Getxo are coping with the end-of-life phase.

The desired information on the end-of-life ecosystem is as follows:

- **WHAT ARE THE EXISTING NARRATIVES**

and who is part of them?

- **WHAT ARE THE CHALLENGES** concerning the end of life at different levels?

- **WHAT ARE THE OPPORTUNITIES** concerning the end of life at different levels?

- **WHO WINS AND WHO LOSES FROM ALL OF THIS**

and through which mechanisms?

### Interviews

This work was compiled through the collection of more than 70 testimonies and 90 narratives. The semi-structured interviews were conducted with the consent of the interviewees. The interview script was reviewed and approved by a group of experts in the fields of sociology, political science and ethnographic research methods. The questions were open-ended and adapted to the profile of each interviewee. Some of the interviewees were interviewed several times, due to their different profiles (for example, a healthcare professional who was also in bereavement). A total of 90 narratives have been collected through interviews to date.

## 10.1.1. Phase 1: Analysis and community listening process

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- **PUBLIC ADMINISTRATIONS**  
At different levels



- **SERVICES: PUBLIC AND PRIVATE**  
Hospitals, care homes, funeral homes.

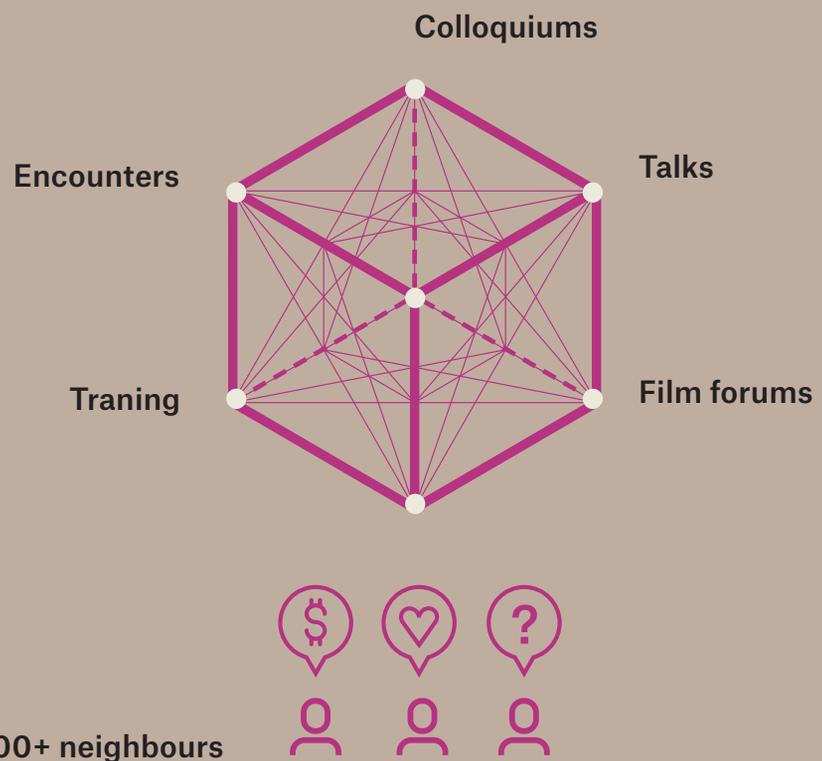


- **THE COMMUNITY AND CIVIL SOCIETY**  
Families, educators, volunteers, etc.

## 10.1.1. Phase 1: Analysis and community listening process

### Community listening process

All this work was supplemented with colloquiums and talks, film forums, as well as other community meetings, in which more than 900 Getxo residents took part. The listening actions have not only made it possible to gather the knowledge and perception of Getxo's residents but have also contributed to raising awareness and socialisation of suffering, death and grief in the municipality.



### 10.1.1. Phase 1: Analysis and community listening process

Intervention	Objective	Target audience	Reach
Death Cafés	<ul style="list-style-type: none"> <li>• Awareness</li> </ul>	<ul style="list-style-type: none"> <li>• Community of Getxo and Vizcaya</li> </ul>	<ul style="list-style-type: none"> <li>• 443 people</li> </ul>
Formal caregiver training	<ul style="list-style-type: none"> <li>• Palliative care training</li> <li>• Empowering caregivers for better care</li> </ul>	<ul style="list-style-type: none"> <li>• Community of women and men at risk of exclusion, both local and from abroad</li> </ul>	<ul style="list-style-type: none"> <li>• 430 people</li> </ul>
Talks and colloquiums	<ul style="list-style-type: none"> <li>• Awareness</li> </ul>	<ul style="list-style-type: none"> <li>• Community of Getxo and Vizcaya</li> </ul>	<ul style="list-style-type: none"> <li>• 1950 people</li> </ul>
Film forums	<ul style="list-style-type: none"> <li>• Awareness</li> </ul>	<ul style="list-style-type: none"> <li>• Community of Getxo and Vizcaya</li> </ul>	<ul style="list-style-type: none"> <li>• 257 people</li> </ul>

## 10.1.1. Phase 1: Analysis and community listening process

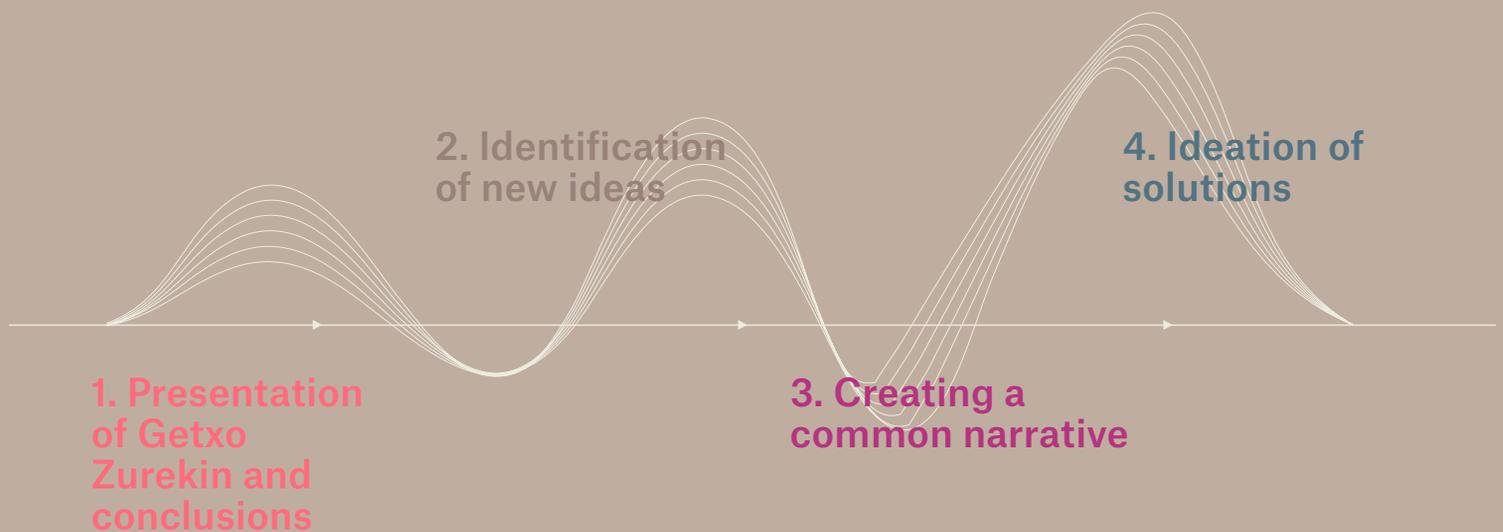
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### Collective contrast

This phase was completed with three sessions to contrast the conclusions generated from the interviews and community listening forums. The sessions were attended by a multi-disciplinary representation of local institutions, social services, representatives of local associations and municipal residences, volunteers and the organisations involved in the development of the project.

These contrast sessions took place between February 2018 and December 2019 and had the following structure: presentation of the conclusions of the interviews, identification of

other opposing or complementary ideas, generation of a common narrative on the main challenges and opportunities in the community, and a search for solutions.



## 10.1.1. Phase 1: Analysis and community listening process

Themes for discussion	Associated Question(s)	First-person Sentences	Main insights Gained
<p>★ Overall perception of services and care in the municipality at the end of life.</p>	<p><i>Is there anything you strongly disagree with? In your experience, does it reflect the reality of life in Getxo?</i></p>	<p><i>"This is a situation that we see on a day-to-day basis in our practices." "They are no isolated events, but repeated situations and sensations." "In these narratives, a majority view can be identified."</i></p>	<p><i>The first two contrast sessions led to the conclusion that the information from the interviews to a large extent reflects the real situation. The participants' narratives and perceptions show that:</i></p> <p><i>People in situations of advanced illness or bereavement feel largely abandoned by public institutions, as well as the community as a whole. There is a lack of knowledge on how to manage these situations. This generates neglect. There are examples of success where the network of friends manages to organise itself to support individuals and families in situations of suffering and bereavement.</i></p>

### 10.1.1. Phase 1: Analysis and community listening process

Themes for discussion	Associated Question(s)	First-person Sentences	Main insights Gained
<p>★ Identification of profiles and situations to be incorporated into the project, and specifically, into the listening process.</p>	<p><i>Do you consider there to be profiles that have not yet been identified and incorporated into the listening phase? Which ones?</i></p>	<p><i>“It would be interesting to include the voice of professional caregivers, who are, in many cases, the ones who experience and accompany the entire final process.”</i></p> <p><i>“The situations of people living in care homes is also a common profile, and they ought to be included.”</i></p> <p><i>“The role of teachers and schools is key in bereavement processes involving minors. It would be necessary to hear how these are experienced by the schools.”</i></p>	<p>After the first contrast session, the following profiles were incorporated into the listening process:</p> <ul style="list-style-type: none"> <li>• Middle-aged woman in paid work with a sick family member.</li> <li>• Single mother caring for sick family member. Professional caregiver.</li> <li>• People with palliative care needs.</li> <li>• Minor who has lost mother/father. Person living in a situation of a sudden family death.</li> <li>• Elderly woman, without resources for home care and support.</li> <li>• Mother/father living through the death of a descendant.</li> <li>• Professionals in educational institutions with students in bereavement.</li> <li>• Management professionals in the health sector.</li> <li>• Person accompanying a family member in a care home. People in residential nursing homes in situations of dependency and end of life.</li> <li>• Neighbourhood associations and property administrators in the municipality.</li> </ul>

## 10.1.1. Phase 1: Analysis and community listening process

Themes for discussion	Associated Question(s)	First-person Sentences	Main insights Gained
<p>★ Identification of needs to improve coping with end-of-life situations.</p>	<p><i>Based on the conclusions drawn from the interviews and community forums, what needs did we identify among individuals and families living in end-of-life and/or advanced illness situations in Getxo?</i></p>	<p><i>“The community must be educated about death. It has to be understood as something natural, without hiding anything.”</i></p> <p><i>“Schools and teachers play a very important role in the way minors experience death and bereavement. They need tools to know what to do and how to do it.”</i></p> <p><i>“Administrations, banking services, etc. should help and give advice on what to do in these cases. We don’t know about the paperwork and processes that have to be followed when a family member dies. There needs to be a community-wide sensitisation so that the whole community knows how to care for and treat people going through these end-of-life and bereavement situations.”</i></p>	<p>Needs are identified in three different areas:</p> <ul style="list-style-type: none"> <li>• <u>Education</u> <i>Institutional limitations for specialised training of professionals in the field of palliative care and bereavement (socio-health professionals, education professionals, home hospitalisation services). This would lead to an under-diagnosis of situations of loneliness and bereavement, and to greater medicalisation; education in schools on death and bereavement.</i></li> <li>• <u>Resources and support</u> <i>Lack of knowledge about the resources available on the part of the families, and among the support resources themselves: lack of specialised support and guidance; lack of knowledge on legal aspects.</i></li> <li>• <u>Avoidance of grief processes</u> <i>Coordination of agents involved in the care of these people and their families (volunteers, social-health professionals and home hospitalisation and palliative care services, local associations).</i></li> </ul>

## 10.1.1. Phase 1: Analysis and community listening process

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### Analysis of the narratives

“I can remember how when I was young, I believed death to be a phenomenon of the body; now I know it to be merely a function of the mind – and that of the minds who suffer the bereavement. The nihilists say it is the end; the fundamentalists, the beginning; when it is no more than a single tenant or family moving out of a tenement or a town.”

—William Faulkner,  
As I Lay Dying, 1930

which tend to be inherently more technology-driven than human. On a personal level, however, the predisposition is clear: *“I personally would like to create a network of compassionate Basque municipalities.”*

“A care home is very much like a hospital.”

### Government and provincial councils

- Some things are being accomplished in end-of-life care.

*“We know we need to focus more attention on care. Gipúzkoa is now a good place to develop social intervention programs”.*

- But we need to do something urgently.

*“Even when we have all the services in the world, when we have Nordic services or Swedish resources, it won’t matter, because we will still want someone to be with us at the end of life, we need it.”*

- Institutions want to play a greater

## ★ Before Life Ends



### PUBLIC ADMINISTRATION Government, provincial and town councils

Public administrations generally and by consensus recognise the need for urgent action on end-of-life care in the face of a changing society and a future that is more immediate than could be imagined. They attribute their inaction to resource constraints,

## 10.1.1. Phase 1: Analysis and community listening process

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**role but do not know how to address this issue.**

*“Issues such as compassionate cities have become very, very important in the immediate future, but to tell you the truth I don’t know how we can support initiatives in this area and work together. (...) It is important to see whether or not we are needed to coordinate these efforts, and if so, how to coordinate a joint working plan.”*

**• Until now, the administration has failed to get it right.**

*“You have to choose, manage what you collect through taxes, administer and deliver. Traditionally, due to inertia, we have focused on technology, and for us it has always been more important than other factors, such as support, human treatment or the social aspect. In order to take steps forward we have tried to copy other systems that seemed better, with more technology, more institutional... we have tended towards hyper-institutionalisation, hyper-technologisation and hyper-sanitisation of social services. As a result, we realise that a care home is very much like a hos-*

*pital.”*

**• Social services in the Basque Country do not currently consider the relational and human dimension as a central factor.**

*“Support, the relational, which is the core element in social services should have its own space, and we don’t have it. We have to start reflecting on this.”*

**• Home care services are still undeveloped.**

*“A society that wants to grow old at home, and even die at home (which is a very important cultural factor), is now in danger of going in the opposite direction... In Vizcaya, home care services are still underdeveloped.”*

### **Town councils**

The feeling from a more local level of administration is that those who are involved at an institutional level from the beginning of an end-of-life process, both for those affected and for their families, are the ones who consider that the options for change or innovation are diminishing.

## 10.1.1. Phase 1: Analysis and community listening process

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*“Services continue to be designed based on institutional slogans and never on the basis of citizens’ needs... You can open a centre in a village, but if the people feel they don’t need it, it doesn’t matter – invest the money in what they really need.”*

• **Information does not reach us. That is what a city council social services worker has to say.**

*“They give you a report and from that report we get information about the situation so we can access the service we can provide. It’s quite a long process and there’s still a significant information gap about the illness itself.”*

• **We don’t have enough resources.**

*“There is a need to raise awareness at the local level, at the initial, very basic level. If you know that this person lives alone, see if that person has the basics covered, shopping, teleassistance; sometimes those things slip through the cracks and the welfare needs are in that initial part.”*

• **People don’t use what is available because they just don’t know.**

*“When a situation of illness affects a home, a family, it comes as a cold shower, and from the outset there is little knowledge of the steps to be taken.”*

*“There are free courses for families. (...) There is also psychological support for people in training (...) But there is a lot of ignorance; people sign up through word of mouth and people arrive dejected, like it’s the last shot they have.”*

• **They are stigmatised.**

*“When people go to social services in a municipality like Getxo, it is understood to be for immigrants, for people in poverty, for people who don’t have resources.”*



### **PUBLIC SERVICES**

**Hospitals, centres, and care homes (palliative doctors and psychologists)**

*“Birth and death are two transcendental moments in life, and yet one is as transcendental as the other. If you*

### 10.1.1. Phase 1: Analysis and community listening process

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*live your life right and you are well accompanied and you do things properly, you come out of it enriched: grief is easier, situations are more comfortable, and your family always remembers you."*

- **The problem is not knowledge but time.**

*"Most employees at centres feel relatively well prepared to deal with a palliative person."*

- **The loneliness of patients in this type of situation is the main problem we encounter.**

*"The most complicated cases are when there are few family members or the patient lives alone. The other day we admitted a woman with pancreatic cancer and in the end it's not symptom control, it's that she lives alone and her friends were helping her with the shopping, but most of her suffering had to do with thinking she was taking advantage of people and she didn't feel OK about it."*

- **We need well-prepared palliative care units.**

*"Not all patients can die at home, it is as clear as that. Palliative care is essential. The problem is that at the moment people do not die at home, they die in hospital, so our contribution to palliative care is not so easy."*

- **Most workers believe that it is not their job.**

*"Many workers in the centre consider that their role is not that of a psychologist and shy away from it, but this is partly due to a lack of training. I believe that everyone in a hospital should be trained in palliative care... Palliative care is not only for the palliative care professionals, it is for everyone – the surgeon, the internist..."*

- **Care homes are the very last option for most of them because they are not affordable.**

*"Being sick is a rich person's thing, because supporting a person at home with care services involves a disproportionate cost – and the same goes for care homes."*

### 10.1.1. Phase 1: Analysis and community listening process

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*“At the hospital in Gornitz, they had something beautiful that I haven’t seen anywhere else, the ‘Hill’. That’s what they called the morning meeting because they did it just like in the series Hill Street Blues. They changed from the night to the morning shift and there was a meeting with coffee and pastries with nurses, assistants, the cleaning ladies, and they went over all the patients and commented on how they seemed to be doing, if they were sad, alone or with others... The collaboration was very good, because it was very human.”*



#### EDUCATIONAL SYSTEM

##### Universities, schools and formal training

There is no strong emphasis on the end of life in the educational curriculum. Although death is studied in schools as an academic subject (biology, science, literature, etc.), it is not approached from an emotional point of view.

At the secondary school level, educators report that “philosophy has

lost ground in the schools”. On an academic level, the end of life from an emotional point of view is not included in a multidisciplinary way in medicine or nursing studies, nor in teaching.

Similarly, key people who are involved at the end of life (during and after), such as social services specialists in municipalities, people who work directly with families in funeral homes, or cemetery workers who work at funerals, do not receive any specific support or training in this regard.

#### Academia

- **Medical schools do not provide multidisciplinary end-of-life training.**

*“We have to start at university and make it an important subject along with ethics.”*

- **The end-of-life training in Nursing faculties is not multidisciplinary.**

*“Some of us feel we have the ability to support someone, others do not. We also don’t talk about death with fami-*

## 10.1.1. Phase 1: Analysis and community listening process

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*ly or friends – it's taboo."*

- **There is no specific training for pedagogues or psychologists.**

*"Among those of us who work in children's oncology, hardly anyone made a conscious choice. Life leads you to it."*

- **There is a huge void in teaching faculties regarding the end of life.**

*"It is interesting to note that in teacher training at university level, many special circumstances in the development of students are addressed. You explore what to do if there are developmental problems, illnesses, cognitive problems, and things like that, but never scenarios around death."*

### **Primary education (3-12 years old)**

- **Educators prefer not to deal with illness or grief directly**

*"There is a taboo because the teacher does not want to deal with a subject that other children who may not be close to it may find upsetting."*

- **Children need to deal directly with any situations of illness or bereavement that they notice.**

*"As a mother and educator, I believe that we have to take advantage of all the daily situations of death to make the group understand that death is part of life and it is there. Children at the age of five have already developed emotional tools with which to gradually build a construct of death."*

### **Secondary education (13-18 years old)**

- **The attitude towards grief in secondary schools is passive.**

*"I insist a lot on training courses to empower teachers, so that when someone dies, they can go into the classroom and talk. It is very noticeable in schools when there is a bereavement and they don't want to talk about it, they think, we are going to hurt them... But it is better to get the damage out now, that's what is needed, so that it doesn't become engrained."*

## 10.1.1. Phase 1: Analysis and community listening process

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- **Educators choose to distance themselves.**

*"I think it's because there's a lot of fear of failing to address these issues on the part of the teachers, and they sometimes choose to keep a bit of distance – it's easier."*



### CULTURE

#### Society and the end of life

If there is one thing on which there is total consensus among public and private institutions, educators and individuals, it is that Basque society is afraid of death.

- **Society is afraid of death.**

*"Society must be transformed. People are so scared. There are real pacts of silence."*

*"Death is a neglected reality. We need an open debate on how and even when to die."*

*"People have an atrocious fear of*

*death. Sometimes families actually call us (funeral homes) to remove the body even before death, almost at the last breath."*

*"There are whole families paying insurance like Santa Lucia and Ocaso all their lives and then it's like they're kind of surprised when it happens and they have to actually show up for the funeral."*

- **Family units have changed but the end-of-life system has not.**

*"Many elderly people are alone and don't understand what is happening to them."*

- **Support systems related to life and death are stigmatised.**

#### Local administration employees

*"For some people, reaching out to social services is seen as a sign of failure."*

*"The group psychological support we offer has quite a negative connotation, if the title were changed more people would come."*

### Individuals and families

*"If you take them to a care home it's wrong, it's associated with guilt and failure - I can't do it... I've thrown in the towel."*

## ★ During the End of Life



### PUBLIC ADMINISTRATION

Government, provincial and town councils

- We do not want to explain what happens concerning death, care homes and the end of life because of cultural roots.

*"In Vizcaya, 27% of residents die in care homes. We don't want to share this information because it scares us. We prefer to die in hospital, which seems to be more upscale, and if you die at home even if it's in a chosen way it seems almost as if you were abandoned, all of that is very culturally ingrained and realities are evolving*

*a great deal. They don't prepare us for death; we don't even like to be with people when they die, and all this generates this kind of inertia."*

- People have too high expectations of care homes.

*"We have poorly defined the expectations we have of care homes. I'm grieved by the ratings that people make, like it's a park or a car park... Because you try not to make it so, but obviously there are bad practices."*

- At a certain age, an earlier death is a better death.

*"Perhaps we should help people to die earlier because we have statistical data and an analysis that a person with the same age, the same pathology and the same level of dependency lives longer in a care home than at home. Which I don't know if it is good for people, because you have to ask yourself if it is a case of therapeutic obstinacy (...) When the doctor tells you to cure at all costs a flu in someone 103 years old with cancer... It's an anecdote, but look, he doesn't have the flu, he is 103 years old (...)*

### 10.1.1. Phase 1: Analysis and community listening process

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*But of course, that's very hard."*

- **Citizens do not know what steps to take in an end-of-life situation.**

*"A situation of illness affects a home, a family; it's like a bucket of cold water, and from the outset, there is little knowledge of the steps to be taken by the person who provides accompaniment. Then you go home and there is a void. And later is when people go to social services."*

- **Care home employees do not receive the training and information about patients that their work requires.**

*"I've been here 17 months and I haven't had any training. We require more information in general about the person's situation, from the beginning to the end."*



#### **PUBLIC SERVICES**

##### **Hospitals, centres and care homes**

- **The healthcare system does not**

**need so many resources to ensure that people die well.**

*"The analysis of narratives shows that there is a perceived general void in the human and emotional part of the end of life in hospitals, centres and care homes."*

- **Physicians believe that the processes are sometimes overly sanitised.**

*"The social and emotional part is not spoken, not understood, not transmitted."*

- **They believe that instead that resources should be invested in technologies.**

*"Technology is a tool at the service of the professional. The problem occurs when technology replaces the professional. Its price must be weighed up against the benefit it provides. The healthcare system does not need so many resources to ensure that people die well."*

##### **Care homes and palliative care centres**

### 10.1.1. Phase 1: Analysis and community listening process

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- **Family members do not want the person to die in hospital but prefer that he/she dies in a care home**

*“Some relatives sign to say that they do not want us to send their relatives to hospital under any circumstances because if someone has to die, it should be here, but we cannot guarantee that. If I am not there and a doctor comes on call to cover for me, he is the one who decides.... What happens is that if we present them with a signed piece of paper it gives them peace of mind.”*

- **Physicians are not there long enough to interact with family members, so nurses are the ones who deal directly with families:**

*“Usually, the families engage with the nurses, because I (physician) am here for just a few hours.”*

- **Care homes do not deal with bereavement in a straightforward manner either.**

*“When it is foreseen that a person is going to die, he/she is moved to a single room, whether palliative or not, that person does not share death di-*

*rectly with his/her roommate... in a place where the family can stay for a longer period of time without interruption. Once the person has died, an attempt is made to arrange for the corpse to be taken out when no one is there or when everyone is in the dining room, or an activity is arranged for them so that the stretcher can be taken out. Despite this, it is explained to those who are usually with the person and the psychologist is more attentive.”*

- **There is too much difference between one care home and another.**

*“There is too much difference between one care home and another. I remember being in hospital and someone from a certain care home arriving and hearing someone say, ‘Pff, they haven’t even looked at him; they don’t even know why he’s here; he doesn’t even have a medical history’.”*



#### **CAREGIVERS** **Relatives and contract workers**

### 10.1.1. Phase 1: Analysis and community listening process

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In general, the profile of carers is overwhelmingly female: those who care for close relatives and the workers that families contract to care for the sick at the end of their lives, or to accompany them at times when they are unable to do so, are women. The latter, moreover, are mostly immigrants from the Philippines and Latin America.

This is the first step taken in an end-of-life situation. The decision pathway followed is (1) first try care within the family; if this is not sufficient, (2) contract a home carer; and as a last resort, (3) make the decision to contact a care home. As well as being a progressive path, from the easiest to the most difficult, pragmatically and emotionally, guilt seems to play a large role in this predetermined roadmap.

• **The burden of care in families falls on women.**

*"It's like it is ingrained in a woman's genes. These days, women are doing social and physical work that the family does not undertake. If the family had to pay taxes and social securi-*

*ty contributions for her... She is a free servant in the home. No wonder they get depressed."*

• **Caregivers are not emotionally equipped to care alone: they are the major dependants.**

*"I think that caregivers decide to provide support without knowing what is to come. The decision is made out of love, from the bond, and we work our fingers to the bone (...), but it seems that you have to be a nurse, a psychologist, a mother, a sister, and that is too much responsibility."*

• **The roadmap is: family care, then external care and finally the care home.**

*"I have looked after 18 people. I stopped caring for them because they died, or they were put in a care home."*

• **Immigrant women are the majority in care work and do a job that nobody wants to do.**

*"In most cases the people who come to provide home care are immigrant*

## 10.1.1. Phase 1: Analysis and community listening process

women who have no training, and many are unaware of illnesses such as dementia.”



### FAMILIES

#### Close and other relatives

- **Professional treatment is too impersonal.**

“You arrive home, you open the door, and suddenly you see a doctor and he says to you, ‘Shall we sedate her or are you going to say goodbye to her?’ I say, ‘What do you mean?’ And he answers me, ‘Yes, yes, didn’t they tell you that she’s dying? You have to decide now, either I sedate her or we sedate or intubate her’. And I tell him that I can’t make this decision right now... I start to call my brother and then the guy comes back after 30 seconds and says, since you didn’t say anything I intubated her. And I was freaking out; they intubated her and sent her to the ICU. And in the ICU, they just wanted to get rid of the problem, saying that this was the decision of those at the bottom, that it was up to us to keep

her alive... And then she was lucky, in inverted commas, to last 12 hours”.

“The nurses were very good – the best ones were the ones in pink. I don’t know what they’re called. I think they’re auxiliary nurses. They’re amazing, because on top of that it’s really hard work, and they’re lovely. But the ones upstairs are like robots. You see a lot of misery, their behaviour... I really thought they were psychopaths, with some kind of problem. The way they treat people is not normal.”

“To die you need silence; you need people not to cry because it stops them from being able to finally go. And imagine you’re trying to say goodbye to the family and in the next bed they’re talking about an Athletic Bilbao football match... It’s totally bizarre.”

- **The cases of people without close family are not properly managed.**

“The problem comes when you’re not a son, but a nephew. All the information you are given is drip-fed to you – you don’t get it.”

## 10.1.1. Phase 1: Analysis and community listening process



### CULTURE

#### Society at the end of life

*“Once the person has died, an attempt is made to arrange for the corpse to be taken out when no one is there or when everyone is in the dining room, or an activity is arranged for them so that the stretcher can be taken out.”*

- **People are reduced to their illness.**

*“The scale of values is all mixed up – everybody values youth, so you have to be young. The elderly have lost respect in society, in the family, as wise people; they are reduced to their illness.”*

- **Death is also taboo for those who are soon to die.**

*“Just yesterday, talking to a resident in a wheelchair, I said to him, ‘Don’t they give you a password at the bank in case something happens to you and you need money, so that someone else can go?’ And well, he asked how*

*I could even talk about such things.”*

*“Once the person has died, an attempt is made to arrange for the corpse to be taken out when no one is there or when everyone is in the dining room, or an activity is arranged for them so that the stretcher can be taken out.”*

- **Basque culture does not encourage open conversation about the end of our own and other people’s lives.**

*“There is something cultural about saying that everything is fine; we are secretive. It’s very difficult to interfere.”*

- **Health professionals are ill-equipped to manage the impact of social changes at the end of life.**

*“Recently a black person was admitted and some of the elderly people did not want him to be in the dining room. They said to me ‘Throw him out, throw him out’... Then they get used to it. User profiles are changing a lot. In Getxo we used to have widows with a certain status, a certain quality of life, and that has gradually changed.”*

## ★ After the End of Life



### PUBLIC ADMINISTRATION Government, provincial and town councils

- There is a complete lack of knowledge about legal procedures after death.

*“People get lost in all the paperwork: notaries, lawyers, judiciary, public prosecutor’s office.”*

*“Suddenly you’re faced with a lot of decisions to make, and you don’t quite know what to do.”*

*“We did the obituary with the undertaker and everything was fine. Then, of course, it was time to pay, and as she didn’t have insurance, she told me that I should use the money she had in the account for the funeral. So I go to the bank and say that I want to update the bankbook. They ask me if the bankbook is mine and I tell them no, that it belongs to my aunt who has*

*passed away, and that we want to use the money to pay for the funeral, and they tell me, well, the account has to be frozen.*

*I told them that she just died after two months in hospital, and I came there just to update the bankbook and I’ve come there, and from then on they could do whatever they want.”*



### SERVICES Funeral homes, burials, legal aspects

- Dying is expensive.

*“The cheapest is 1,800 euros for the removal of the body and cremation. A small obituary costs around 300 euros and up to 3,000 euros in El Correo newspaper.”*

*“Most people have insurance for death but some don’t and it can be a problem – they don’t realise how expensive it is to die.”*

### 10.1.1. Phase 1: Analysis and community listening process

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*“Getxo is among the places with the cheapest cemetery, it only costs 50 euros to dig the hole, but it also depends on the services offered.”*

- **Services after death tend to be impersonal.**

*“We try to be invisible and work with a lot of empathy. People come here in very, very bad shape. They usually come to the funeral with the undertaker. The undertakers organise more or less everything... They do their job well, but in general they are big companies that end up taking over the small ones and it becomes much more impersonal.”*

*“In Vizcaya it was agreed that masses must be celebrated without any body present and without flowers, but there are parishes that do not respect the rule. From an anthropological point of view, the presence of the body has its function, but even so, due to hygienic regulations, it is not always feasible to do so the day after death. In this parish, for example, due to a lack of priests, there is no mass on Mondays, Wednesdays, and Fridays, which is difficult to manage.”*



#### **FAMILIES** **In the face of grief**

- **Families are not prepared for bereavement.**

*“I think we were in shock for a long time. I stopped sleeping. I would wake up at about 4 a.m. with a feeling, with something inside, you feel a little bit responsible, each of us in a different way.”*

*“I went to a psychologist because I didn't know what was happening to me. I don't know if I've got over it or not yet, but what happened to me was that I was in bed asleep trying to sleep in silence and a memory of my dad came to me. Suddenly it hit me that I wasn't going to see him anymore and this destroyed me... I was anxious and overwhelmed with loads of anger inside – I was in a terrible state. The psychologist told me that it was because I was grieving.”*

*“When I went to the psychologist, I*

### 10.1.1. Phase 1: Analysis and community listening process

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*was out of my mind. If you'd have seen me, you would have said that it wasn't normal. I had this anger inside and it was like something bubbling inside and I wanted to argue about anything. When I went to the psychologist and he asked me what had happened, I couldn't even manage to say that he had died."*

• **Society is more tolerant of grieving for older generations, fathers and mothers.**

*"I take Lorazepam; it's hard for me to leave the house and I have panic attacks. It's also very difficult at my age to start making new friends again."*

*"We were avid readers and since he passed away, I can't open a book."*

*"His sisters made me clean up the flat very quickly to sell it and I think that hurt me a lot, I wasn't prepared."*

*"Christmas is horrible – I'd like to stick my head under the covers and not go out, but I can't because of the kids. My daughter and granddaughter come. But I don't feel like decorating the house or buying presents – I just*

*do it for them."*

• **The social and educational environments do not respond to the needs of bereaved adolescents and young people.**

*"One absurd thing they ask you, because that's what we've been taught, is to ask how you're doing out of politeness, and you know perfectly well that I'm going to tell you that I'm doing OK when I'm not doing OK – I think it's unnecessary. Well, how else should I be? Not OK, but I'll say that I'm fine so that you don't have to worry."*

*"They're all over you with questions about what you want to do. I don't care – I want to do what I always did. And I should get on with my life, because my life is going to fly by if you don't do anything... Then you try to explain but they don't understand. It doesn't matter how much you explain to them. Then they say yes, it's like when my granddad died, but it's not the same."*

*"What am I going to do? My dad has died. Do I have to go out dressed in black and cry every day and stop*

## 10.1.1. Phase 1: Analysis and community listening process

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*studying? But how should I do that when I'm 16 years old."*



### EDUCATIONAL SYSTEM

#### Universities, schools and formal training

- Educational institutions do not believe that the responsibility for student bereavement lies with them.

*"They have no experience and as they are exceptional cases, they think that solutions will be offered outside the institution."*

*"In schools they only care about the academic side they even told me, 'Look, since the death of your dad you are doing better academically...'. They only focus on academic aspects. It may even be that studying has helped me to disconnect from everything. If I had to study two history subjects, I studied them and at that moment I wasn't thinking about my dad. Instead of seeing that, they just noticed that my marks had got better."*

- Municipal cemetery workers lack some training in bereavement counselling.

*When people break down, we tell them to be calm, we let the person cry and show emotion. We've never been offered training on how to provide support in the 14 years I've have been here and we could certainly do with it."*

- Funeral homes that work directly with bereaved families believe it is not necessary.

*"We've never been trained in issues related to support and bereavement, but I don't think we need it either, as we do it well. You get used to this job. It's like anything else, and we don't feel that every death is special."*



### CULTURE

#### Society and bereavement

- Death is a private affair.

### 10.1.1. Phase 1: Analysis and community listening process

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*“From a religious point of view, funerals should be communal and not individual, but people want them to be individual.”*

- **People are often emotionally unprepared to cope with bereavement.**

*“I’ve never talked about this with anyone, and it happened a few years ago. I didn’t do it because deep down people don’t want to listen, because they don’t know how to be with you, they don’t know how to treat you, they don’t know how to look at you... I always thought it was my fault, that I shouldn’t have let him get on the motorbike. I’ve had a hard time coping with it.”*

*“Grief is cumulative. As a psychologist, I believe that you have to cry when you have to cry because if you don’t, it wells up inside you and in the end, you end up with such a burden of grief that you can’t manage what you are doing in your life.”*

*“Grieving takes time. There are people who then avoid it and there are others who spend their lives stuck in*

*it and live their lives through it.”*

- **The taboo about the end of life is culturally ingrained from childhood.**

*“Here children are kept away from death. Death should be discussed in families long before the end of life, not 10 days before death.”*

*“My Mexican family knows what I want... to be cremated – they can cry as much as they need to until they are at peace. In Mexico I tell them not to be overwhelmed by emotion, but here it’s the other way round – let yourself feel, don’t think so much.”*

- **A paradigm shift is taking place with regard to end-of-life rites and perspectives.**

*“The rites remain those of the Catholic tradition, although changes are beginning to be seen. For example, Getxo town council is trying to create a space in the cemetery for people who do not want to hold the ceremony in the church, but they still don’t know how to do it.”*

*“In the past, people used to say that*

## 10.1.1. Phase 1: Analysis and community listening process

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*they wouldn't have peace of mind until they had bought their villa in La Galea, and they were referring to the pantheon in the cemetery – even poor people too. Not anymore. Things are going to change; they are already changing.”*

### ★ Beyond Hospital

#### Other end-of-life companions

Throughout the study of the end-of-life ecosystem in Getxo, from institutions, public administrations, and public and private services, including educational services, more unusual protagonists have been identified who play a vital role in supporting people at the end of life and yet often go unnoticed.

#### Gravedigger at Getxo cemetery

*“The man in Getxo who started the first funeral parlour was much more approachable. He wore a beret and visited people when they were already ill. It was the way they used to measure the body beforehand to be sure about the size of the coffin – that’s how he prepared it. But they don’t work like that anymore.”*

*“My mother is dead. She was old and not ill, but she was 95 years old and one day she told the family that she was going to die and started to say goodbye to everyone, one by one. Our family doctor couldn’t believe it, and we, well, we had to accompany her. She didn’t want to eat; she drank very little and in 10 days she died.”*

*“There are still some beautiful pantheons with a lot of history and guided tours are available. But more space is needed. In the future... I don’t know, the ashes could even fit into a capsule! I don’t know what the cemeteries of the future will be like, but today this is still a meeting point to visit loved ones who are no longer here, and it is part of their lives.”*

#### Personalised wigs for sick people

*“Four years ago, I came from working in another salon, and suddenly they put me here to teach me how to be with the customers. It was a major change for me, but the team took to me from the very first minute as if I had known them all my life. At first, I panicked when I went in there, I said, ‘What is this’”.*

### 10.1.1. Phase 1: Analysis and community listening process

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“It was Maria Luisa’s idea to personalise them; she’s a researcher and a perfectionist too. You put on a wig and you can’t see the outline, like a swimming pool cap... It wasn’t done in other places.”

“The simplest wig costs about 700 euros, because then they are trimmed with products with other things. Sometimes wigs are donated to us for people who can’t afford to pay. We can’t collect wigs, but we call the AECC association or give them the phone number and they take it themselves.”

“We close the shutter, take out the wigs that most closely resemble the hair and they select one. It takes an hour and a bit to look and decide for one. And then when it’s time to put it on for another hour or so, we give them a massage and teach them all the tricks we can, how to be at home and how to sleep, how to put the stickers on the inside... everything we can.”

#### Neighbourhood shops

“There’s a group of cancer patients

who come to the herbalist’s shop regularly.”

Normally they don’t tell you about their lives, but depending on what they say, you can see the diet they are on, how they are physically... their progress.”

*“It creates a connection with those people; it creates familiarity and a bond. This kind of place is good for them and I think they appreciate it.”*

#### Auzoko dendak

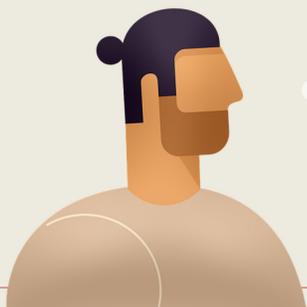
*“Minbizidun talde bat dago belar-dendara eskuarki etorri ohi dena.”*

*“Normalean ez dizute euren bizitza kontatzen, baina esaten dutenaren arabera ikusten zoaz zer dieta egiten duten, fisikoki nola dauden... Euren bilakaera.”*

*“Konexio bat sortzen da pertsona horiekin, etxekotasuna eta lotura bat sortzen da. Ondo etortzen zaizkie mota honetako espazioak, eta uste dut baloratzen dutela.”*

# Main Profiles in the End-of-life Ecosystem

Who is around people at risk of loneliness and palliative care and how do they relate to each other?



**XABIER**

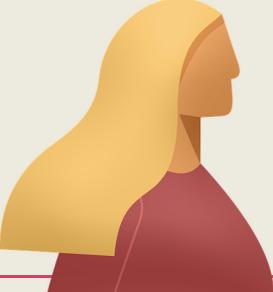
**Age\_** 46  
**Studies\_** Business administration and management  
**Occupation\_** Social services institutional officer

**CONCERNS**

- ★ Social services in Vizcaya do not currently consider the relational and human dimension as a central factor.
- ★ Home care services are still undeveloped.
- ★ People have too high expectations of care homes.

“We have moved towards the hyper-institutionalisation, hyper-technologisation and hyper-sanitisation of social services. As a result, we realise that a care home is very much like a hospital.”

## 10.1.1. Phase 1: Analysis and community listening process



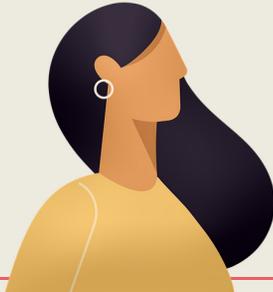
**MAIALEN**

"Familiarrak nirekin eta nire lankideekin dituzte hartu-emanak, medikuak oso ordu gutxi daudelako hemen".  
Erabiltzaile bat hiltzen denean, gorpua inor ez dagoenean edo guztiak jantokian daudenean ateratzeko antolatzen saiatzen gara".

**Age\_ 46**  
**Studies\_ Eritzaintzako laguntzailea**  
**Occupation\_ Laguntzailea getxoko egoitza batean**

**CONCERNS**

- ★ Family members prefer the person to die in hospital, not in the care home.
- ★ There is a lot of difference between one care home and another.
- ★ Care homes do not deal with bereavement in a straightforward manner either.



**ANA MARÍA**

"Since I've been here, I've looked after 18 people. I stopped caring for them because they died, or they were put in a care home."

**Age\_ 36**  
**Studies\_ No specific training**  
**Occupation\_ Caregiver for a man of 86 in getxo**

**CONCERNS**

- ★ Uncertain working conditions and immediate future.
- ★ Poor preparation for the job: "I have no training in dementia".

## 10.1.1. Phase 1: Analysis and community listening process



**BEGOÑA**

“The most complicated cases are when there are few family members and the patient lives alone. The other day we admitted a woman with pancreatic cancer and in the end it’s not symptom control, it’s that she lives alone, and her friends were helping her with the shopping, but her suffering had to do with thinking she was taking advantage of people.”

**Age\_ 47**  
**Studies\_ Physician**  
**Occupation\_ Palliative care physician**

**CONCERNS**

- ★ We need better-prepared palliative care units.
- ★ Processes are overly sanitised: resources are invested in technology.
- ★ The loneliness of patients in this type of situation is the main problem we encounter.



**BELÉN**

“I think that in most cases, caregivers decide to provide support without knowing what is to come. The decision is made from love, but it seems that you have to be a nurse, a psychologist, a mother, a sister... It’s too much responsibility.”

**Age\_ 50**  
**Studies\_ Shop worker**  
**►► Cares for her mother at home**

**CONCERNS**

- ★ Balancing her work outside the home with caring for her mother at home.
- ★ The guilt of not caring enough.
- ★ Not emotionally prepared to provide care alone.
- ★ The burden of care in families always falls on women.

## 10.1.1. Phase 1: Analysis and community listening process



**ISABEL**

“At times it was humiliating. He couldn’t speak because he had a brain tumour, but he was still aware of everything.... People told me that he had to be admitted, but I wanted to keep him at home. He was my son and I wanted him to be at home until the end.”

**Age\_ 70**  
**Studies\_** No specific training  
▶▶ Her son died two years ago, her husband, last year

**CONCERNS**

- ★ Lack of specialised support.
- ★ Lack of information on palliative care (her son had very poorly controlled symptoms and was in pain until he came to know San Juan de Dios homecare team.
- ★ Confusion about subsequent paperwork.
- ★ General and confusing treatment by doctors and healthcare staff (“giving false hope”).



**KONTXI**

“We don’t know how to help... People are afraid of social services coming to their house because it sounds terrible.”

**Age\_ 75**  
**Studies\_** No specific training  
**Occupation\_** Community caregiver

**CONCERNS**

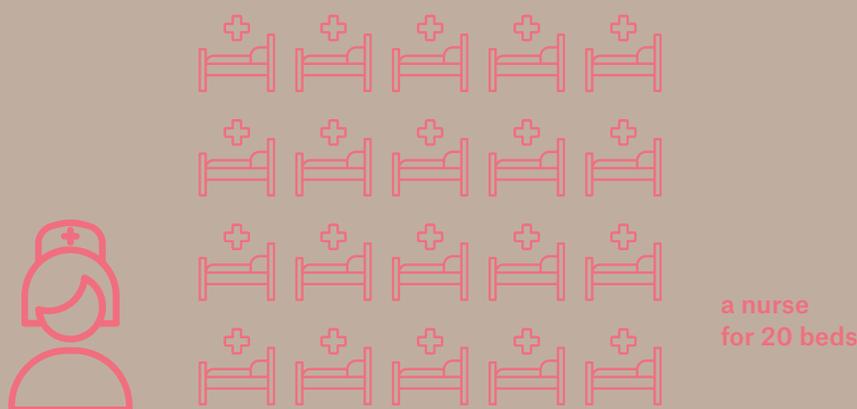
- ★ Mentality. “It’s a very closed society and we don’t want to bring strangers into the home.”
- ★ Gaps in the system. “There’s a good primary care service, but when the weekend comes around, who takes care of the elderly?”
- ★ Inequality. “In Getxo, families with a good economic standing can afford to accompany people at home.”

## Identified Needs and Challenges

### a. Resources

*"It is not easy to apply for and obtain resources for dependant people. The processes are long and bureaucratic, and often do not arrive in time."*

Prioritisation of palliative care in order to obtain more resources and more effective management are the main needs right now. Hospitals are understaffed (one nurse for 20 beds). In addition, 83% of carers are women between 50 and 55 years old who do not pay taxes or social security contributions: they care for people but do not expect to be cared for.



# Specific needs

- More resources to enable people to stay at home for as long as possible. Palliative Care workers. There is now greater awareness of the need and there are people who specialise in accompaniment.
  - Medical and social services specialists who are able to work in homes.
  - Physical and emotional accompaniment, communication and approaching death as an inherent part of life.
  - Medical equipment to be able to go through this phase at home with the necessary technical support.
  - A space to express own experiences, sharing spaces for listening.
  - Support for the main carer, with breaks at least one weekend a month.
  - Training for families to be able to provide support and care in a better way.
- Prior training for external carers, especially for immigrants who carry out this activity in an unofficial way.
  - Hospital accompaniment.
  - Municipal home-based care.
  - Fostering the relationship and communication within the families, with the aim of creating a circle of care so that the family can obtain leave of absence from work.
  - Facilitate the discussion of advance directives – a municipal service should be developed to be able to manage advance directives.



## **b. Integrating and coordinating existing resources**

***“What we need is an umbrella organisation of guilds, like when we do a construction project!”***

“One of the reflections that has emerged most strongly from this listening process is the sense that there are resources available, even if they are limited, yet these services operate on a very individual basis. They are not integrated and are unknown resources for most families: “There has to be a better integration and use of the resources that exist in the community. They are key to providing support in situations where, due to the family situation, carers cannot count on other support (lack of economic resources, family networks, etc.)”

***“There’s a need for someone to act as a link between the services, associations and resources that are available. So far, many of them don’t know each other.”***

During the process of listening and comparing the needs identified, the participants made special mention of the fact that the current requirements of the Spanish Act on Dependency limit the number of families who can access these services.

They also stress that there is “a lack of information about home hospitalisation services in relation to Palliative Care”.

## c. Communication and information on existing resources

*“You often don’t know where to go, not even what paperwork has to be filled in.”*

After the loss of a loved one, most people are lost in the paperwork: notaries, lawyers, the judiciary, the public prosecutor’s office... The conversation about advance directives is also a need that has been identified to facilitate this process.

There is also a lack of information on what support is available and how to get training, as well as how to accompany someone. When people decide to provide accompaniment, they need to know what they have to do, what the roadmap is and what resources are available to them.

## d. Training

*“There should be training for family members in these situations. We often want to offer our best care, but we can’t or don’t know how.”*

As described in the narratives drawn from the listening process, there is very little training for people and professionals working in the field of end-of-life care and accompaniment. At the hospital level, they feel that more doctors are needed who are sensitive to the emotional needs of the people admitted to their care (especially in

### 10.1.1. Phase 1: Analysis and community listening process

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university hospitals).

It is also worth mentioning the existing institutional limitations (lack of material support or time) for professionals in the field of healthcare, social services or education to be trained, and therefore to be able to do things differently. Specifically, a lack of trained professionals in home-based care in both health and social palliative care can be observed. From an educational point of view, the need to start working on these issues in primary and secondary schools was identified, enabling families to approach the possibility of formalising advance directives more naturally.

## e. Diagnosis and listening

Loneliness and grief are generally under-diagnosed – the focus is on caring for the sick and the few services that exist are not integrated. There is no real picture of loneliness, care, volunteers and existing associations in Getxo. Talking about death is avoided and there are insufficient resources for the diagnosis and treatment of grieving processes.

## f. Raising social awareness

***“Let’s talk naturally and without fear about how we go through the whole process.”***

Identifikatutako beharrei buruzko entzute eta kontraste prozesuan zehar, parte-hartzaileek gizarte- eta kultura-sentsibilizazioa azpimarratzen dute heriotzaren inguruko tabu kulturala eraisteko, heriotzari eta doluari buruzko dibulgazioa eta sozializazioa sustatuz.

## Specific needs

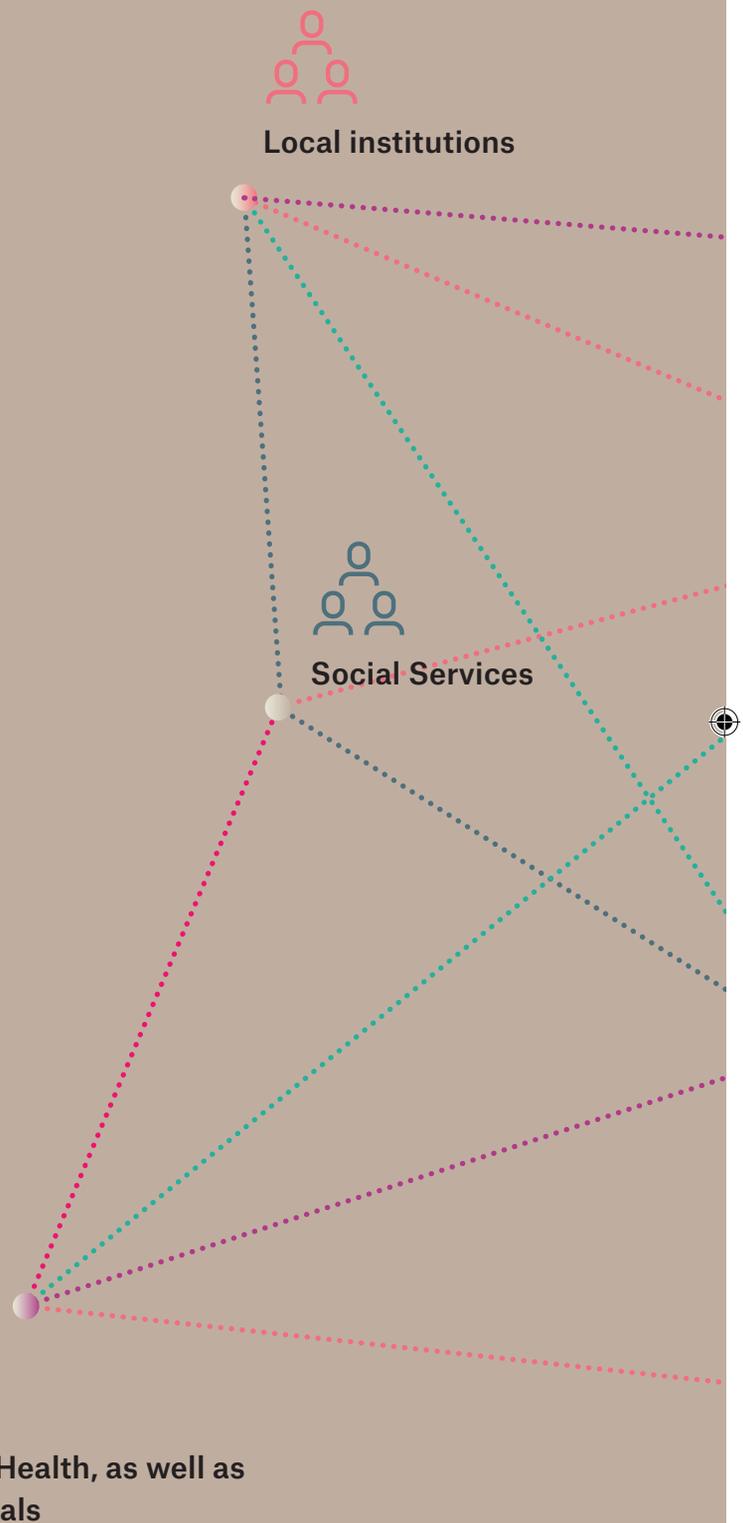


- The need for safe spaces, respect, and a place where it is possible to talk about death, life and things that are important to everyone.
- The participants suggest specific campaigns on how situations of suffering are being experienced in Getxo in order to raise awareness and bring the experiences closer to the community as a whole.
- Working on and promoting social and health aspects.
- Networking.
- Encouraging open meeting spaces with people to facilitate and invigorate them.
- Talks, courses, awareness-raising and sensitisation workshops.
- Increasing knowledge about death and bereavement.

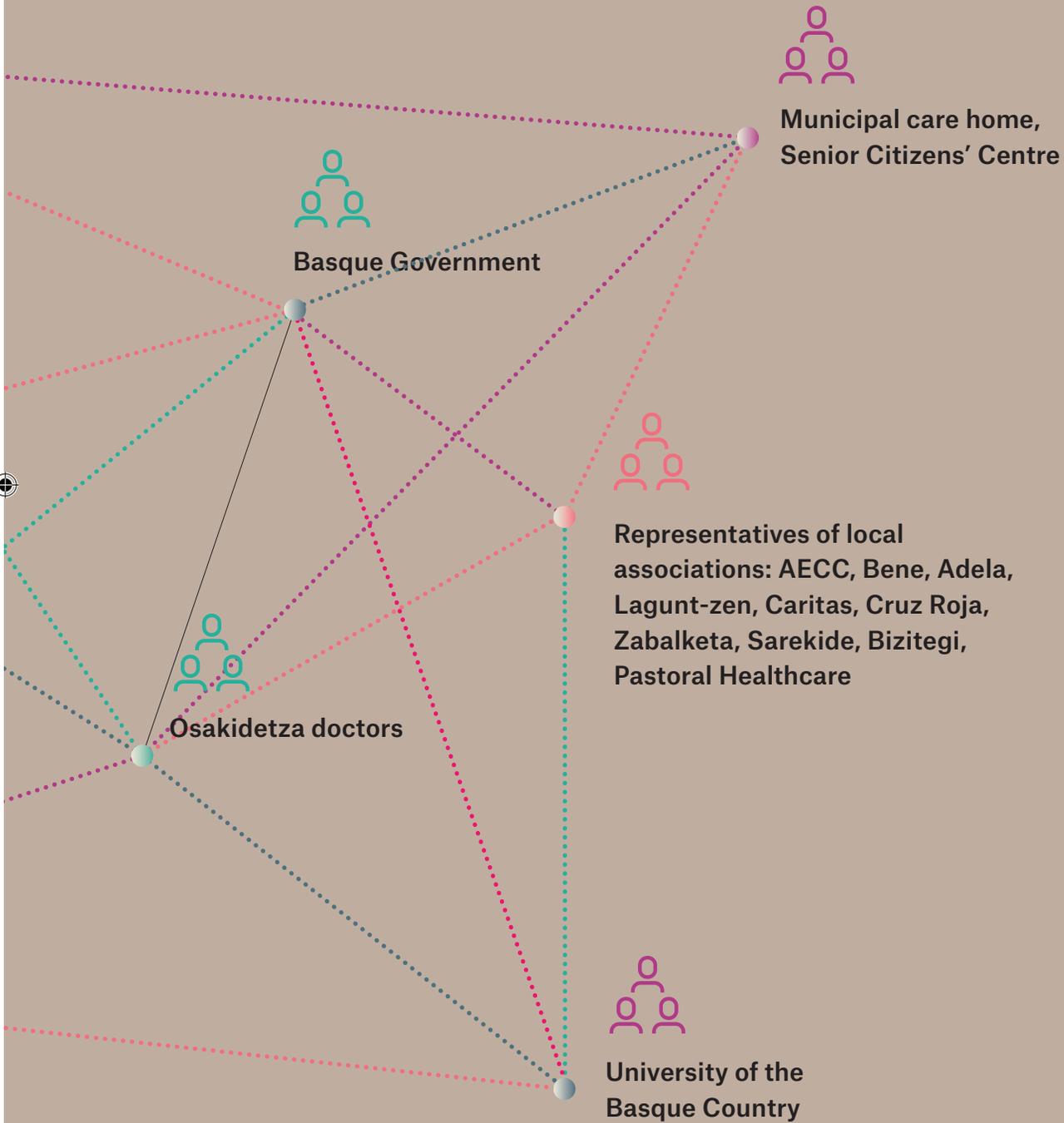
## 10.1.2. Phase 2: Collaborative co-creation

The community listening processes were followed by the generation of new ideas, solutions and services that would contribute to addressing the challenges and needs identified in the first phase. The comparison sessions have contributed to this (demonstrating the interaction between phases) and have made it possible to involve citizens in the design process from the outset, without waiting for the listening process to be completed. This method helps to drive initiatives with the input of the people they target, with the aim of achieving sustainability in the medium and long term.

On the basis of the needs identified in the listening phase, a process of co-creation is set in motion with a variety of participants:



## 10.1.2. Phase 2: Collaborative co-creation



## Opportunities identified at Different levels

### ★ Community initiatives

#### ★ DEATH CAFÉS

In a death café the participants drink coffee, eat cakes and talk about death. The main objective is to raise awareness about death in order to help people make the most of their lives.



#### ★ GRIEF SPACES

These spaces provide participants with the opportunity to address issues that, like bereavement or death, are often culturally stigmatised.

#### ★ COMMUNITY INFLUENCERS: The “activa tu comunidad” [activate your community] project

Compassionate Communities in the Basque Country

#### brought to Getxo

*“The worst thing that happened to us was the lift. Before, at least we used to bump into each other on the stairs.”*

These spaces provide participants with the opportunity to address issues that, like bereavement or death, are often culturally stigmatised.

**The need to generate, in a society that tends towards individualism, initiatives that boost the day-to-day life of neighbourhood communities.**

#### 1. Facilitating day-to-day situations

*“My husband fell down on the floor and it took hours for the ambulance to arrive.”*

#### 2. The need to recover community networks in Vizcaya (Auzolan) [Neighbourhood work]

*“There’s something cultural about saying that everything is fine; we are secretive. It’s very difficult to interfere.”*



## 10.1.2. Phase 2: Collaborative co-creation

### ★ Getxo ZUrt!

This is an ambitious initiative aimed at all the citizens of Getxo, and is a necessary continuation of the Strategy for the Prevention of Suicide in the Basque Country.

Getxo ZUrt! is based on the premise that suicide is not a disease, but rather something that can happen during a person's life and the resolution of conflicts, and that it is associated with multiple and complex risk factors (sometimes depression or other mental illnesses are among the associated factors). This initiative helps to raise awareness about the causes of emotional pain and provides training for citizens in the prevention, approach and postvention (care for people who suffer the loss of a loved one through suicide) of suicide in Getxo. This is all undertaken from a public health perspective and with a community approach, addressing a reality that has been kept in silence until now.



## 10.1.2. Phase 2: Collaborative co-creation

### ★ RUMBO DESCONOCIDO [DESTINATION UNKNOWN] documentary play

This is a theatrical work which depicts the experiences of the people from the municipality of Getxo in terms of life, care and death.

It involves people from the municipality together with two professional actors who play the game of the goose in order to simulate the numerous situations identified in Getxo.

It is part of the Getxo Zurekin project – a project to create a compassionate community. In 2017, a community listening process was initiated to respond to how people in the municipality cope with illness, dependency, death and bereavement. This work is intended to be a new media channel to give visibility to all the information collected, based on collective participation and interpretation.



## 10.1.2. Phase 2: Collaborative co-creation

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### ★ Small- and medium-scale initiatives

#### ★ SOCIAL BROKERS

New social contexts and innovative methodologies bring with them the creation of new roles and the inclusion of new stakeholders. This is the case of the “Social Broker” (SB) mentioned above. This is a vital figure for the success of this project, which is already well established in countries such as the Netherlands and the United Kingdom. The SB works to ensure inclusion and promote social cohesion in a specific territory in a multidisciplinary way in the projects carried out, always working on different scales and dimensions: the community, social services, public and private stakeholders and institutions. The ultimate goal is to create resilient networks and communities linked to specific needs.

A social broker, also known as an “innovation broker”, must be on the

ground, helping to transition from theory to practice, from the abstract to the concrete. The social broker should serve as a pivot point between the community and public administrations. The role of this person is to create and empower social networks to support and respond to the perceived and internalised narratives of the community, which is the most “internal” work of this role.

At the same time, the social broker must operate outwardly, creating synergies with projects already existing in the territory, in neighbouring territories or even in other countries, importing and exporting projects, ideas, methodologies and ways of doing things.

In short, the social broker works from the outside in to create resilient social networks and communities; from the inside out to create synergies with other networks and thereby strengthen the internal network. From the bottom up, starting from the needs and narratives of the community to reach out to public,

## 10.1.2. Phase 2: Collaborative co-creation

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private and institutional stakeholders. And from the top down so that public (and private) stakeholders can really deliver to the community.

In time, some large-scale initiatives such as the creation of alternative funeral homes or new public services could be launched

on different scales (the creation of resource guides so that primary care doctors and Social Services personnel are aware of them and can pass them on, a municipal service to manage advance directives, or even the redesign of hospitals and palliative care centres by the users themselves). Even at the regulatory level, more and more project participants see the need for a palliative law.

## 10.1.3. Phase 3: Implementation of the first opportunities

This phase involves a process of adjustment and adaptation of the proposed initiatives to the local situation. As with the previous phases, this is not an isolated phase, insofar as it will follow on from the suggestions and proposals developed. In an initial wave, the selected initiatives and actions need to be deployed on a small scale, and then scaled up to a larger outreach level.

### ★ Death Cafés

Between 2018 and 2019, awareness-raising sessions have been carried out in different places in Getxo, reaching more than 440 people. Since then, it has been expanded to other municipalities in Vizcaya and Guipuzcoa, and Álava, such as Orduña, Amurrio, Portugalete, Bilbao, Zumaia, Zarautz, Santurce, Bermeo, Gatika, Mungia, Sopelana, and has become a social movement.



### ★ Designing the role of the Social Broker

#### ADDED VALUE AND DESCRIPTION

- 24 h/day availability – integrating the three cornerstones – social, health, community. A comprehensive care service. Support in psychological/emotional processes.

### 10.1.3. Phase 3: Implementation of the first opportunities

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- Lead the initiative as a community movement for greater community involvement.

- Must have the time, availability and compassion to support the needs of the family/caregivers.

- Promote greater coordination and cohesion between institutions and the community.

- People specialised in palliative care, accompaniment and bereavement who provide comprehensive help with different types of tools.

- Have a direct relationship with the family, creating links and accompanying people. At the same time, by creating networks, getting to know and contacting the social fabric of the community and institutions, giving a greater response to identified needs and following up with the family, without forgetting accompaniment in bereavement. Promote greater coordination and efficiency.

- Guide, support, accompany, propose spaces to connect services and people, spaces where people can

express themselves, multi-family groups...

- Provide training on how to care for a person in a situation of PC and bereavement.

#### KEY PARTNERS

- City Council... Provincial Council of Vizcaya

- Social Services, public institutions

- Existing social partnerships with some kind of connection

- Social organisations in general Federations/associations

- Health centres/social work/home-based care teams/care homes/volunteer networks

- Funeral homes, insurance companies

- Directly affected families and individuals

- Municipal public institutions, all cross-cutting areas

- ICT company to create a platform, an APP

### 10.1.3. Phase 3: Implementation of the first opportunities

#### QUESTION 3: HOW COULD IT BE FINANCED?

- Tax changes in Vizcaya
- Public-private resources – models to demonstrate costs
- Example of a social action movement – Fair Saturday – Crowd funding
- Corporate/bank welfare projects
- Funding subsidies local councils provincial councils
- Approach it as part of an existing programme eg: Euskadi Lagunkoia
- Support resources, spaces for training/awareness raising
- Setting up a cooperative

We understand that there should be a person in charge of overseeing the social and psychological aspects of palliative care, dependency, advanced illness and bereavement in order to identify cases of vulnerability and give an early warning that enables us to anticipate complex situations and provide a response. In this way, we can support the person and his or her family by reducing the resulting impact – promoting good quality of life and saving costs for institutions.



### 10.1.3. Phase 3: Implementation of the first opportunities

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#### What is its added value?

- Leadership of the citizens' movement/initiative
- Proximity, friendliness, compassion and
- Availability 24 hours a day
- Health-social-community connection
- Knowledge of the environment and personalisation

#### What activities does it carry out?

- End-of-life care training
- Search and identification of assets
- Resource coordination and referral between resources
- Supports, listens and attends to the process
- From the social to the relational level

#### Who are the key partners?

- Municipal institutions (all areas in a cross-cutting manner)
- The town council as a promoting partner and channel with the other institutions
- Local businesses and trade for awareness-raising/socialisation activities

#### How could it be financed?

- Through other existing budget lines ((euskadi lagunkoia)



### 10.1.3. Phase 3: Implementation of the first opportunities

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## ★ From community radar to neighbourhood radar

On 12 December 2019, at the Romo Cultural Centre, Getxo Zurekin brought together around twenty participants with different profiles and ages (retired people, young people, doctors, palliative care nurses, sociologists, public institutions, lawyers, civil society...). The main objective of the session was to co-design the implementation of this initiative in Getxo.

### STEP BY STEP GUIDE

#### Step 0. Become part of the network

- Contact Getxo Zurekin and tell us why you want to set up this project in your community.

#### Step 1. Identify the community influencer

- Should act as a bridge between neighbours.
- Must be able to identify existing needs and opportunities.

- Has to be able to create new opportunities: for example, talk to the greengrocer, so that if they see someone who could benefit from having their groceries brought to them, they can tell them.

- Must be able to appreciate the limits of each neighbour in order to be balanced.

- Must have leadership skills.

- Must have patience and energy.

- Should be a discreet person.

- Should be a problem-solver.

#### Step 2. Create the necessary conditions

- First. In our culture, this project can work best if it first starts working privately, creating prior connections and the necessary conditions to make it public.

- Second. Mention it at a community of neighbours meeting or discuss it with neighbours one by one.

### 10.1.3. Phase 3: Implementation of the first opportunities

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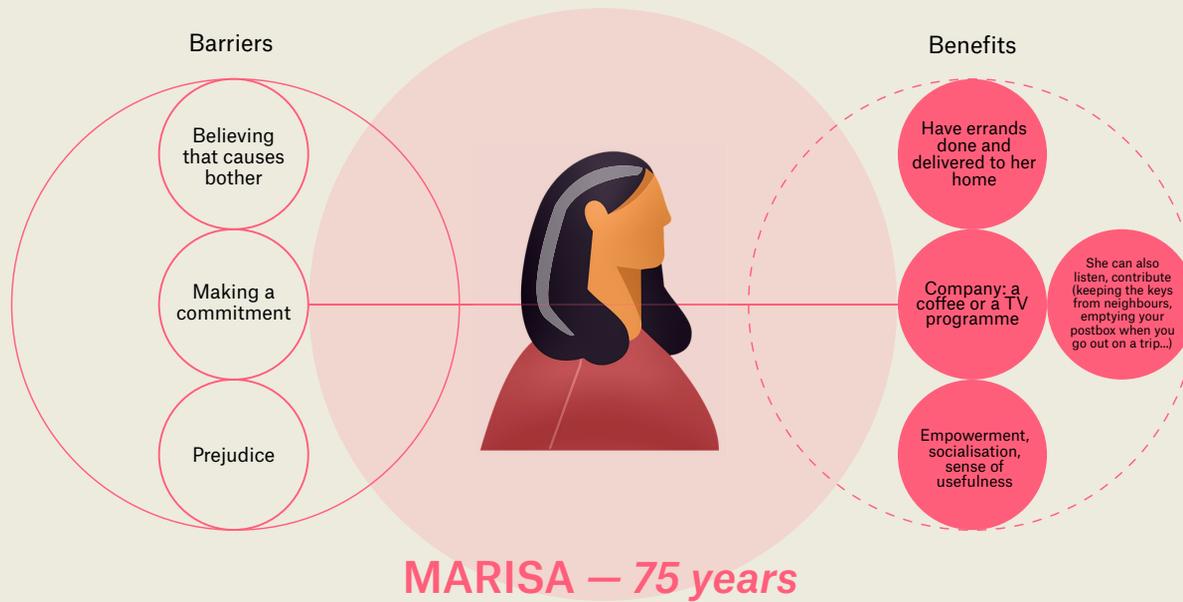
- Third. Put up the poster and leave out the stickers. Another alternative is to install a corkboard as a notice board.

#### **Step 3. Approach neighbours in your community**

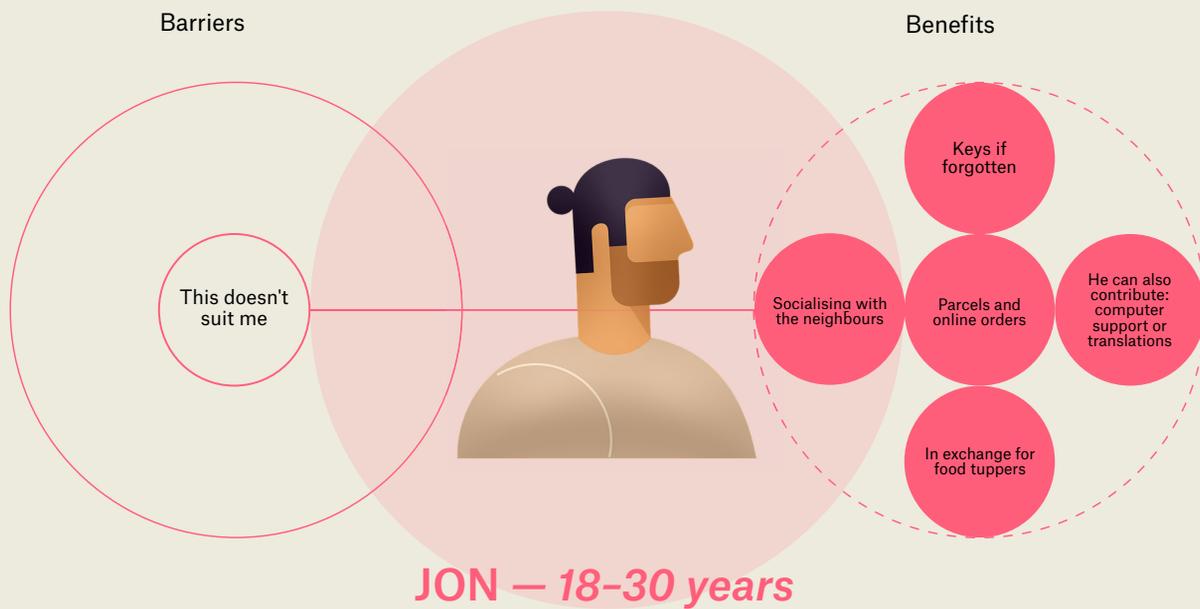
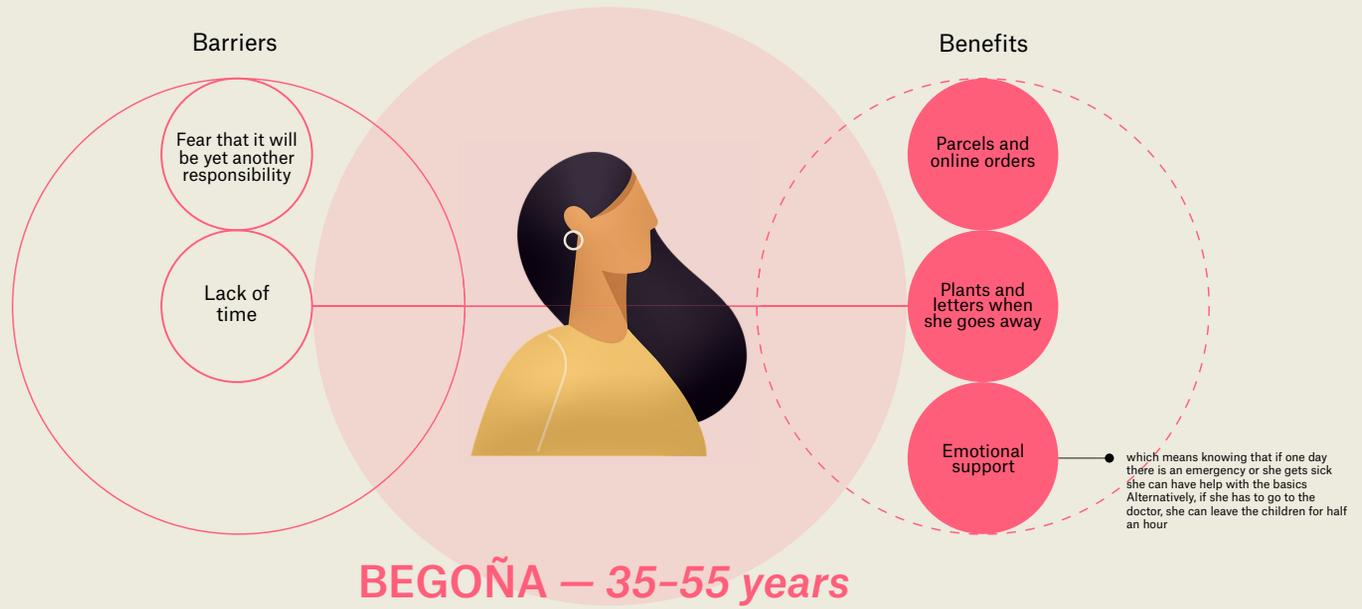
Sometimes the most difficult part of this kind of project is getting it off the ground. Approaching neighbours by conveying the benefits they can gain from this type of initiative and taking into account the prejudices they may have is a first step.

### 10.1.3. Phase 3: Implementation of the first opportunities

As this is an initiative linked to care and loneliness, the designers have divided the different people into three different profiles based on their ages:



### 10.1.3. Phase 3: Implementation of the first opportunities



### 10.1.3. Phase 3: Implementation of the first opportunities

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#### Step 4. Create the right stickers for your community

These are the stickers that the participants of the session chose to adapt the stickers of the “La Escalera” [The Staircase] project to the situation of Getxo. They can be used as a starting point or as inspiration to create stickers that best suit your community.

I bring you up your shopping	I treat you to a coffee	I water your plants
I look after your Christmas presents	I pick up your parcels	I look after your kids for 20 mins
I lend you chairs for christmas	I can help you with computers	I take your dog out with mine
I bring out your rubbish	I take you to hospital	I lend you a book
I listen to you for a while	I bring you a newspaper	I give you my phone number in case of emergency
Call me if you fall down	I go for you to the chemists	I call you a taxi
I lend you a drill	Other	

#### WHAT IF I DON'T LIVE IN FLATS WITH A STAIRWELL?

If instead of Getxo you live in a town or in a more rural environment, you can promote this initiative among your neighbours by using focal points of neighbourhood activity, especially those related to care and loneliness: shops, bars, clinics, chemists, public libraries...

#### HOW DO WE SYSTEMATISE THIS AT THE TERRITORIAL LEVEL?

##### Plant the seeds

- The Town Council and public institutions should promote it: "It should be advertised in the town with provocative questions, such as 'What would happen if you fell down and no one was around?'"
- Institutional promotion: "a prize could be created for the best auzolan".
- Create materials that interested parties can request guide, stickers and posters.

##### Organise

- Direct distribution of materials through letterboxes.
- Create spaces to identify community influencers: "e.g. village civic centres".
- Spaces for sharing experiences among the leaders of each community.

## 10.1.4. Phase 4: Evaluation, adjustment and communication

In this phase, it is necessary to compare the different actions developed and the evolution of the project with similar initiatives in other contexts, in order to improve their approach.

This phase also enables the results and work carried out to be showcased elsewhere. Public and permanent communication of the project's progress and results allows for a

broader involvement of the community.

The initiative's pilot group was responsible for the communication and dissemination of the event. To this end, the following communication actions were carried out.

Action	Objective	Description	Reach
<b>Scientific communication</b>	Publicise the name of the project and preliminary results	Oral and poster presentation at the International Congress on Integrated Care	International
<b>Exchange days</b>	Present the framework of the compassionate cities and the Getxo Zurekin project	Formal presentation at the University of Deusto as part of the visit of a group of young entrepreneurs from different European countries	International
<b>Network campaigns</b>	Publicise the project and connect with more stakeholders	Campaign to upload photos endorsing the initiative	International

### Donostia-San Sebastián

In addition, the listening and co-creation process developed by Getxo Zurekin has collected 10 narratives in Donostialdea [area of Donostia-San Sebastián] and has established a space for collaboration with various agents who have promoted the “Community Listening Platform” in the Egia neighbourhood. Getxo Zurekin, through ALC [Agirre Lehendakaria Center], has shared the progress of the project and has been able to learn about the methodologies being applied in Donostia-San Sebastián. Specifically, the process of collecting narratives, spaces for collective interpretation and the design of the co-creation process. ALC is currently exploring spaces for collaboration with the Donostia-San Sebastián City Council regarding participatory processes in Egia.

The narratives collected focused on three areas:

- **Education:** It must be addressed from childhood onwards. The issue needs to be discussed at school. There is no need to wait for some-

thing to happen at school to work on it. It must be incorporated into the educational curriculum, adapting it to different ages, different ways of understanding things and, of course, different ways of dealing with them.

- **Family:** we should encourage families to talk about this issue. Together with schools, the family is a key factor in ensuring that children begin to talk about this issue in a natural way.

- **Training for professionals:** there are so many professions that are related to this topic and we could say that all of them are related in one way or another. There is a need to prioritise and start training students: doctors, nurses, social workers, ambulance drivers, care home staff.

Although the volume of narratives collected in Donostialdea is not representative of the size of the city, the results obtained to date do not show significant differences with those obtained in Getxo. However, it is recommended that the sample be expanded to complete the study and meaningful results be obtained.

#### 10.1.4. Phase 4: Evaluation, adjustment and communication

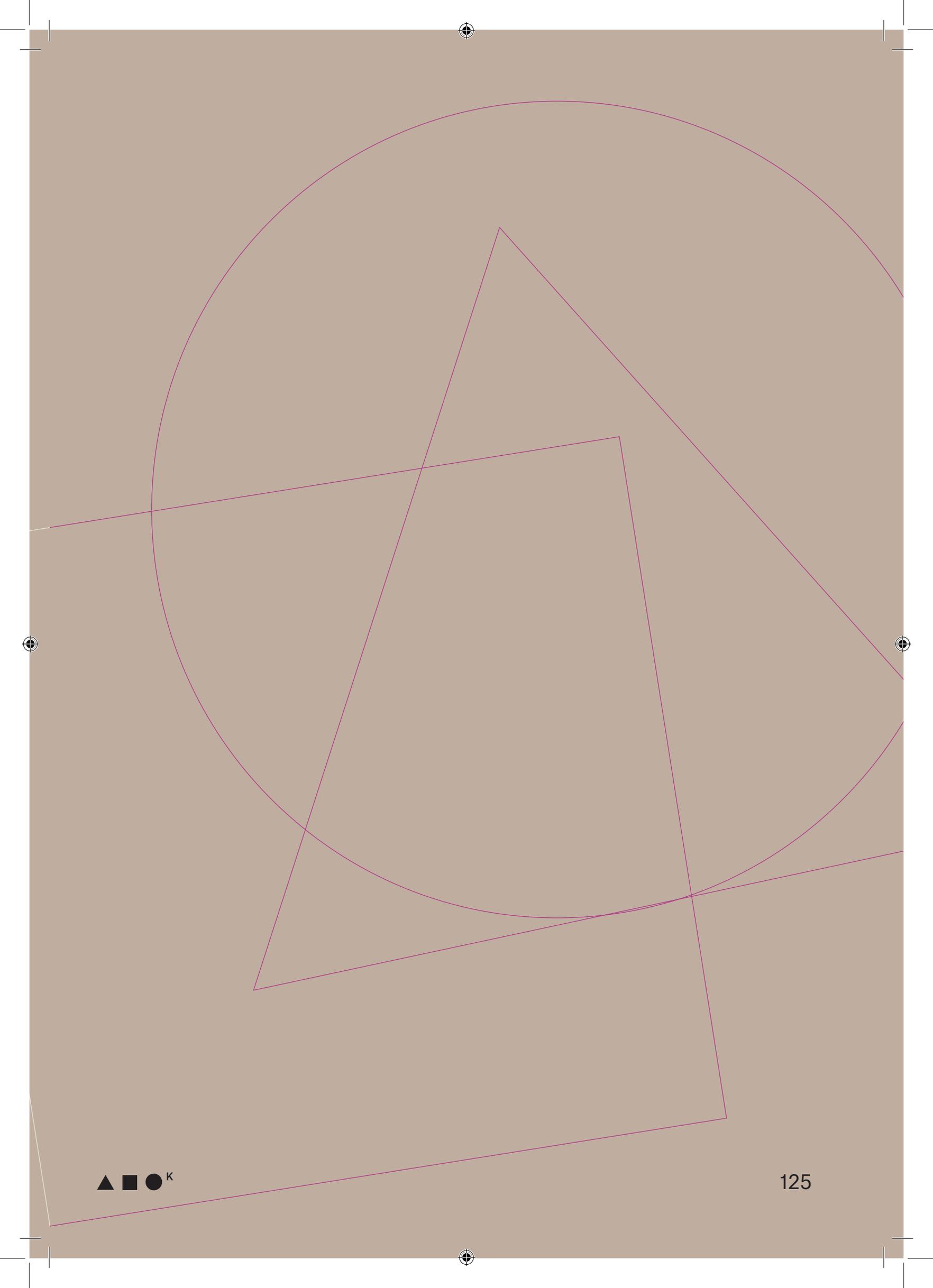
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### Next steps

Getxo Zurekin aspires to continuity. In the next phase, we will try to delve deeper into the hidden narratives and meta-narratives that are active in Getxo regarding loneliness, the end of life and bereavement. This information will enable us to (1) continue to increase the spaces for community debate on these issues, (2) systematise the processes of co-creation of new solutions and (3) begin the prototyping phase. The socio-health emergency created by COVID-19 positions Getxo Zurekin as a real living lab in which to address priority issues within the priorities of the new political agenda.

This work will be progressively extended to include other municipalities. To this end, an analysis will be carried out together with the Basque Government under the title "Report on the development of compassionate environments for the Basque

Country", in which, in addition to Getxo, six municipalities interested in promoting this type of process will participate: (1. Zarautz, 2. Donostia-San Sebastián, 3. Amurrio, 4. Vitoria-Gasteiz, 5. Mungia, 6. Bilbao.



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## 10.2/ Process development in 2020

### 10.2.1. Phase 1: Mapping of compassionate environments in the basque country

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During 2020, the project team formed by F2S and the Agirre Lehendakaria Center performed a mapping of the most relevant initiatives that were launched in the different municipalities of the Basque Autonomous Community. In total, more than 100 pandemic response initiatives related to compassionate networks were mapped.

Most of these initiatives are community-based, undertaken by citizens, although there are also initiatives undertaken by institutions (local, provincial and regional) and initiatives by private associations and even public-private initiatives. We contacted each of them in order to gather more information on each initiative. This report therefore contains two levels of information:

**1) Mapping of some of the initiatives identified at the Basque Autonomous Community level.**

**2) The result of the questionnaire which was sent out and answered by 31 community care networks**

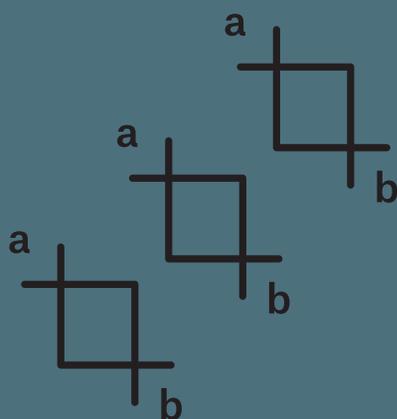
**and solidarity initiatives. Among them, 29 are community initiatives and two are public services.**

The mapping carried out has sought to maintain territorial balance and to compile initiatives from all the territories and all the districts of the BAC. For this purpose, searches were carried out through social organisations, institutions, people working in the socio-healthcare sector and on the internet (general newspapers and local media) and social networks. Below is a list of the community initiatives and services mapped by territories (Vizcaya, Álava and Guipúzcoa) and districts. In addition to the list presented, a map by province is included so that all the initiatives can be visualised, created using Google Maps. The mapping includes, for the most part, community initiatives, but also the launch of some services by some municipalities.

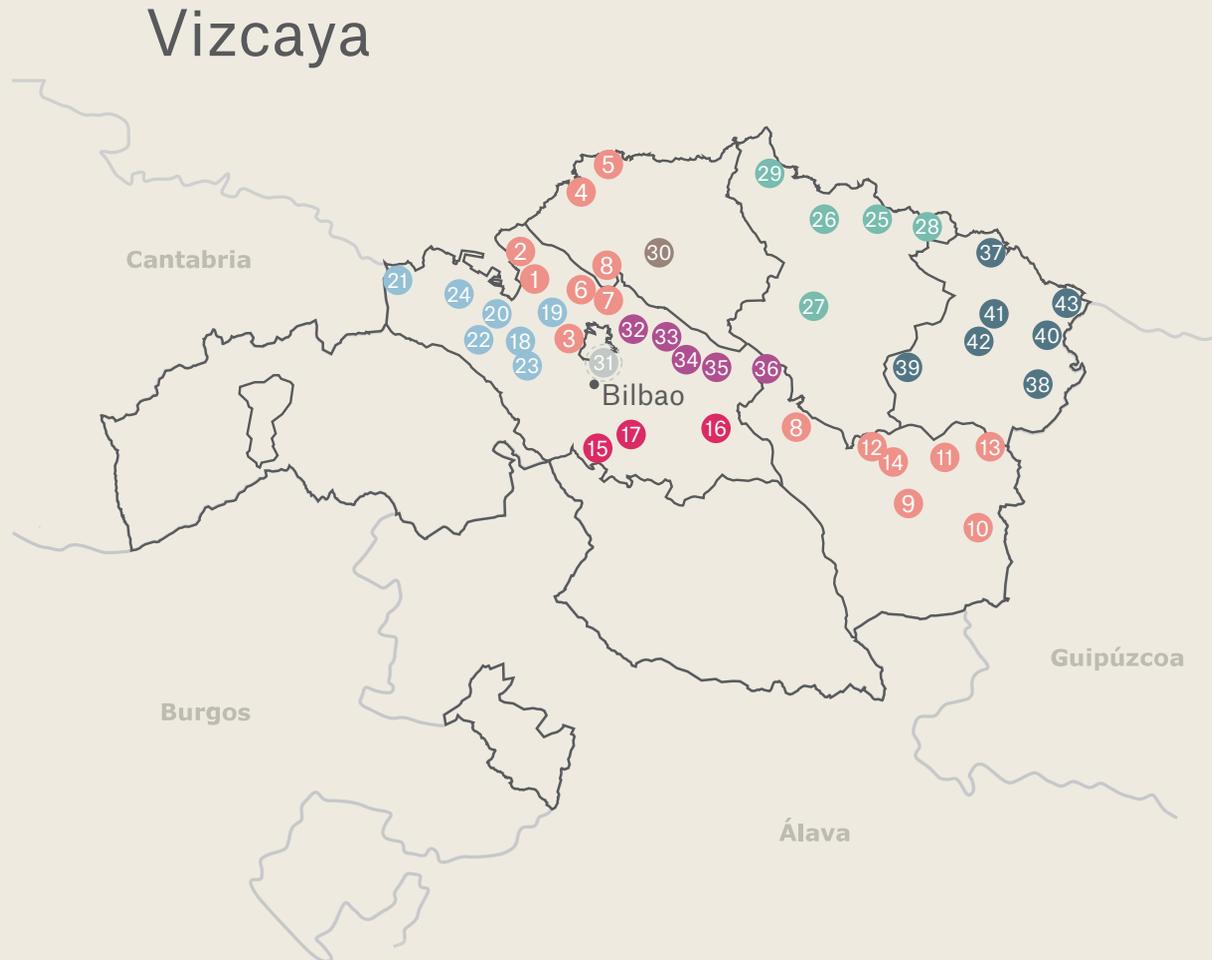
## Conclusions from the mapping process

The mapping process over the last few months has shown that:

- There is a wide variety of community initiatives that intend to complement existing social services.
- These initiatives are highly valued by people and families who find themselves in situations of loneliness, advanced illness or death.
- Public administrations, in most cases, do not know how to relate to these initiatives beyond subsidy programmes. There is no strategic reflection on the complementarity and possible joint action between social and health services, community actions and care companies.
- Although there are numerous public and citizen initiatives, most of them are not systematically interconnected and there is no shared strategy for knowledge generation.



## 10.2.1. Phase 1: Mapping of compassionate environments in the Basque Country



### Uribe Kosta

- 1 Getxo-Itzulbaltzeta (Erromo)
- 2 Getxo-Algotarrok Zaintzen
- 3 Erandio Gaitezen
- 4 Sopela Zaintzen  
↓  
Sopelana Zurekin
- 5 Ari du Elkartasun Sarea (Plentzia/Gorliz/Lemoiz)
- 6 Zaindu Leioa
- 7 Asociación Epi y Blas (Leioa)
- 8 Pausoz Pauso
- 9 Zornotza
- 10 Abadiño Zaindu
- 11 Elorrio
- 12 Berriz
- 13 Iurreta
- 14 Zaldibarko zaintza sare herritarra

### Hego Uribe

- 15 Arrigorriaga
- 16 Galdakaoko elkarlaguntza sarea
- 17 Zaratamoko Zaintza Sarea

### Ezkerraldea/Meatzaldea

- 18 Barakaldo: Red de cuidados comunitarios
- 19 Sestao Zaintza Taldea
- 20 Portugaleta Zaintzen
- 21 Muskiz
- 22 Trapagaran
- 23 Barakaldo: Banco del tiempo
- 24 Santurce Ciudad Cuidadora

### Urdaibai/Busturialdea

- 25 Ibarregelu
- 26 Urdaibai
- 27 Gernika-Lumoko zaintza sarea
- 28 Ea
- 29 Bermeo

### Mungialdea

- 30 Mungia

### Bilbao (City)

- 31 Arangoitiko laguntza sarea
- Bilbi (Bilbao La Vieja)
- Alde Zaharreko elkartasun sarea
- Deustuko jai-batzordea
- Erribera
- Irala
- Indautxu eta Basurtu
- Santutxu
- Otxarkoagako elkartasun sarea
- Uribarri
- San Adrian/Miribilla
- San Inazio
- Zorrotza
- Bilbo: Elkartasun sareak (coordinadora de las redes vecinales)
- Getxo Zurekin

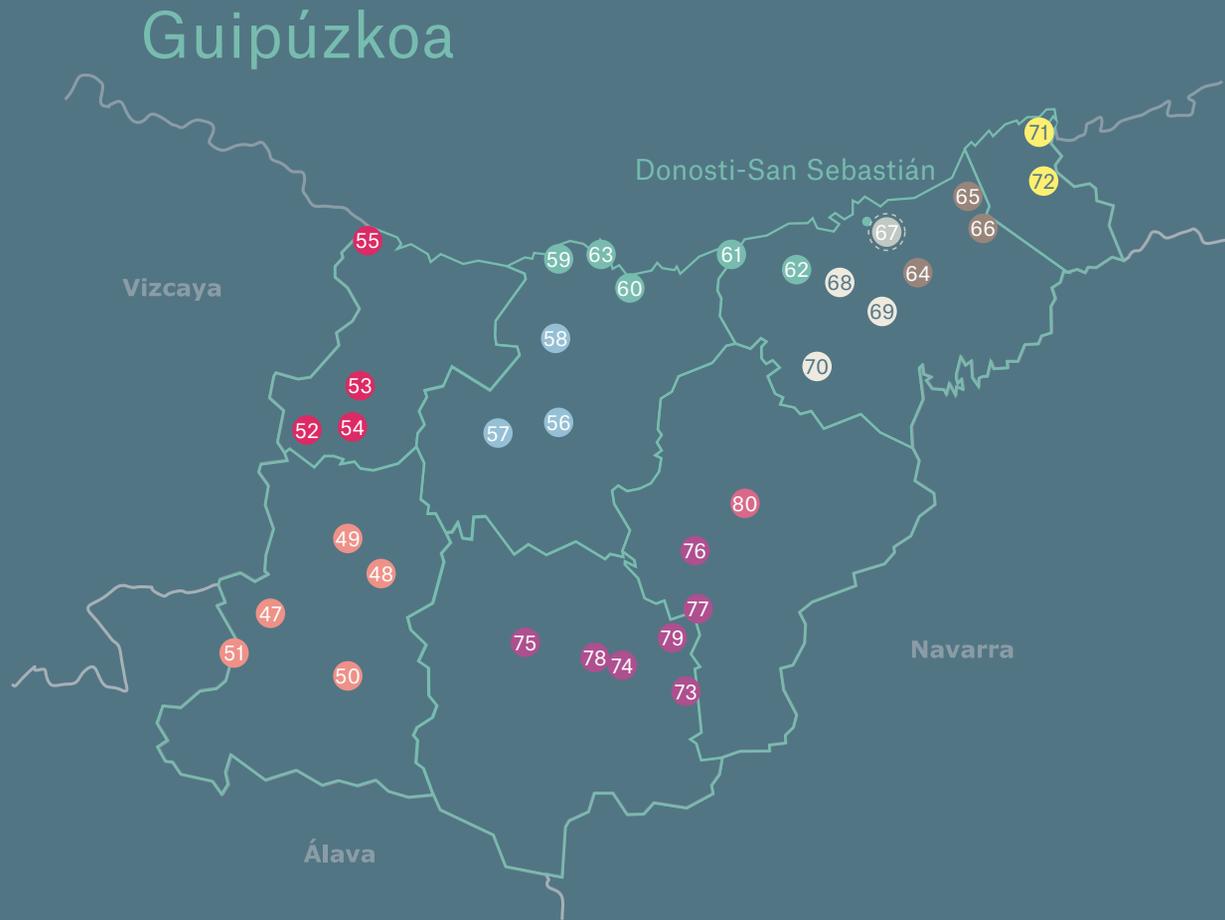
### Txorierrri

- 32 Sondika (Ayuntamiento)
- 33 Derio (Ayuntamiento)
- 34 Zamudio (Ayuntamiento)
- 35 Lezama (Ayuntamiento)
- 36 Larrabetzu

### Lea-Artibai

- 37 Lekeitio
- 38 Markina-Xemein
- 39 Munitibar
- 40 Berriatua
- 41 Amoroto
- 42 Aulesti
- 43 Ondarru

## 10.2.1. Phase 1: Mapping of compassionate environments in the Basque Country



### Debagoiena

- 47 Arrasate zaintza sarea
- 48 Aramaioko zaintza sarea
- 49 Bergara
- 50 Oñati
- 51 Antzuola

### Debarrena

- 52 Eibar
- 53 Elgoibar
- 54 Amalur - Elgoibar
- 54 Soraluze
- 55 Mutriku

### Urola Garaia

- 56 Azpeitia
- 57 Azkoitia
- 58 Zestoa

### Urola Kosta

- 59 Zumaiaiko Torreberri Gaztetxea y el Ayuntamiento
- 60 Zarautz
- 60 ZarautzOn
- 60 Zarautz Herri Zaintzailea
- 60 Biziraun
- 61 Orio
- 61 Mandalara Taldea Orio

- 62 Usurbil herritarren babes sarea
- 63 Getaria

### Oarsoaldea

- 64 Astigarrako udalak bultzatutako zaintza sarea
- 65 Antxoko Zaintza Sarea (Pasai Antxo)
- 66 Errenteriako udala eta zaintza sare komunitario

### Donostia (City)

- 67 Añorga
- 67 Bidebieta, Herrera, Jolastokieta, Larratxo, Altza
- 67 Bidegin-Zurekin

### Donostialdea

- 68 Lasarte-oriako babes-sarea
- 69 Hernaniko zaintza talde iraunkorra
- 70 Andoain

### Bidasoa

- 71 Hondarribia
- 72 Irun

### Goierri

- 73 Ataun
- 74 Lazkao
- 75 Legazpi
- 76 Legorreta
- 77 Zaldibia
- 78 Beasain
- 79 Ordizia

### Tolosaldea

- 80 Auzolanean Tolosa
- 80 Betirako

## 10.2.1. Phase 1: Mapping of compassionate environments in the Basque Country



### Vitoria-Gasteiz (capital)

- 43 Batera Zaindu
- Gasteizko Alde Zaharra (Goian)
- Programa Estamos Contigo (Ayto. Vitoria-Gasteiz)
- Centros Socio Culturales de Mayores (Ayto. Vitoria Gasteiz)
- Hilo de Plata - Nagusian
- Betirako
- Cuidate. Cuidale - nos quedamos en casa - AFA ARABA
- Cruz Roja Responde
- Asociación Kokuk
- Etxean Zurekin IFBS
- Azalapean - IFBS
- Vivir con voz propia

### Aiaraldea

- 44 Laudio, Amurrio, Aiara y Okondo

### Agurain comarca

- 45 Agurain

### Gorbeialdea

- 46 Zuia



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## 10.2.2. Phase 2: Active listening

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This phase consisted of collecting community narratives on how families, institutions and professionals in the Basque Country perceive end-of-life issues, care and the need to promote more compassionate communities. Basque institutions have a wealth of quantitative and qualitative data on these issues at their disposal. This report has tried to complement this information with the perceptions that we often do not voice but which condition the impact of public policies. These perceptions have been collectively analysed and have enabled us to identify a series of concrete actions that can respond to the various existing perceptions. The working process for the collection of narratives involved the following steps:

- **Design of the process for collecting and managing the narratives.**
- **Collection of 90 in-depth narratives on compassionate communities in municipalities in the Basque Country with different contexts, population levels and lifestyles in**

**the historical territories of the BAC: Vitoria-Gasteiz, Amurrio, Donostia-San Sebastián, Zarautz, Orío, Mungia, Bilbao, Getxo and Bidasoa.**

- **Analysis and extraction of narratives, challenges, opportunities, barriers and enablers.**
- **Segmentation of information into profiles on the basis of unified narrative patterns and behaviours. This information was used to better appreciate the different ways of understanding the same reality in the Basque Country and to propose a range of interconnected solutions.**

### Interviews

This work was compiled through the collection of **more than 70 testimonies and 90 narratives**. The semi-structured interviews were conducted with the prior consent of the interviewees. The interview script was reviewed and approved by a group of experts in the fields of sociology, political science and eth-

## 10.2.2. Phase 2: Active listening

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nographic research methods. The questions were open-ended and adapted to the profile of each interviewee. Some of the interviewees were interviewed several times, due to their different profiles (for example, a healthcare professional who was also in bereavement).

### Groups of interviewees:



- **PUBLIC ADMINISTRATIONS**  
At different levels



- **SERVICES: PUBLIC AND PRIVATE**  
Hospitals, care homes, funeral homes, health-care workers



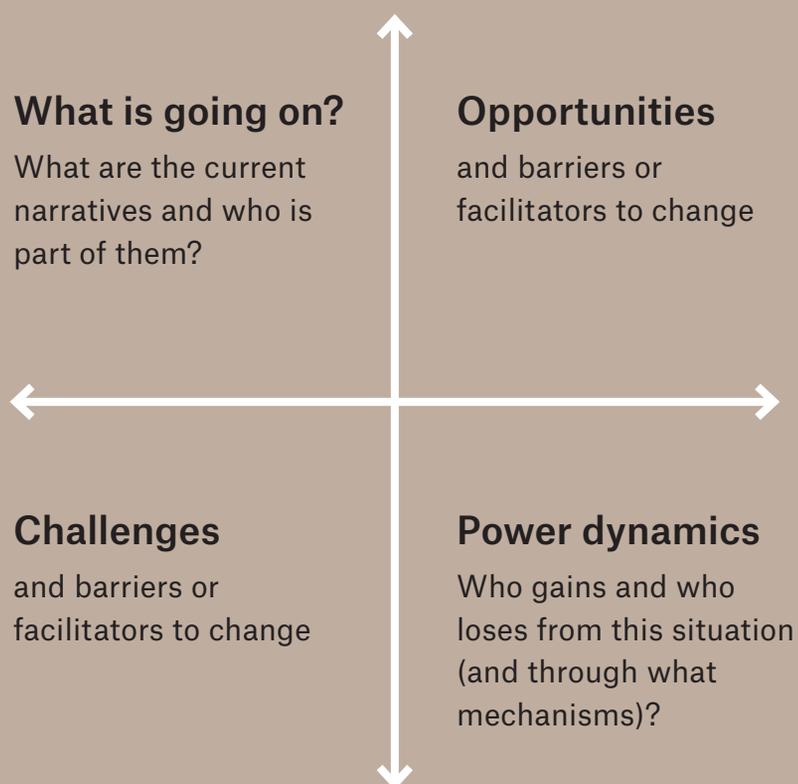
- **THE COMMUNITY AND CIVIL SOCIETY**  
Families, educators...

## 10.2.2. Phase 2: Active listening

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The desired information on the end-of-life ecosystem is as follows:

- **WHAT ARE THE EXISTING NARRATIVES** about loneliness, advanced illness, end of life, death and bereavement?
- **WHAT ARE THE CHALLENGES** concerning the end of life at different levels?
- **WHAT OPPORTUNITIES** should be explored?



### Analysis of the narratives

What follows is a summary of the narratives identified, arranged into the various groups with whom we were able to talk. The combination of statistical information (quantitative and qualitative) together with these perceptions gives us a much more realistic picture of this problem and its possible solutions (new compassionate environments).



#### ADMINISTRATION AND SOCIAL SERVICES

There is a widespread perception that social services do not necessarily reach everyone and that the sheer workload, coupled with increasing demand, leads to a certain “defeatism” about the possibilities of creating more compassionate community environments.

- **Social services fail to reach the whole of civil society.**

*“In the Basque Country, the organisation of services of this type is based on a law that was created to provide the best possible services, but we are not achieving this... We have been thinking for years about how to do it better.”*

*“Social services fail to reach the whole population and we have to recognise these weaknesses – I think it’s difficult for us.”*

*“In my town, we are fortunate that neither political allegiances nor stories of this kind have taken precedence. It has been important for the people to be OK and form a team – we are like a football team in that respect.”*

*“The management of social services is too complicated, not integrated and inflexible.”*

*“It is very complicated at the management level for frontline professionals... The one who is shoulder to shoulder with the families.”*

*“Inter-institutionality is like a jigsaw puzzle.”*

## 10.2.2. Phase 2: Active listening

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*"From time to time they call us from the Provincial Council to see how we are doing in the town councils, but they are not really forthcoming. There's no close contact or deeper understanding of the reality."*

*"The town authorities are doing a lot of things, but they are not coordinated – they are all scattered all over the place."*

*"Everything should be coherent."*

*"We work as separate groups. The town councils feel that they should call us or write to us and send us all the available information so that we can reach the people."*

*"Many activities are organised just for the sake of organising something, without a specific purpose."*

*"There's a certain amount of conformism within the administrations."*

*"There's a lot of arrogance in the authorities. There are a lot of clear messages about how well we are doing*

*things and how good we are, and we are not."*

*"The quality of socio-health care depends too much on the individual people themselves."*

*"In the areas and neighbourhoods in which there are named leaders, more progress has been made."*

*"There has to be a person, someone specific... If not, it's very difficult to get it right."*

*"The support is there, but there has to be someone local to somehow set the wheels in motion, otherwise it doesn't work."*

*"It's thanks to the new mayoress that there is institutional support, otherwise it wouldn't be possible."*

*"The authorities are focused on administration and completely disconnected from reality."*

*"The authorities are departmentalised, with a very stagnant culture: this*

## 10.2.2. Phase 2: Active listening

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*concerns me, and this doesn't. Therefore, what is not in the structure of a department and is mainstream ends up being spread out and what goes ahead is done by specific people."*

*"More and more childless couples in this kind of situation are in great need of emotional support. The other day a man was telling me that he wasn't complaining that nobody was going to help him at home, but that he needed a place to talk, where he could see that they cared at least a little about him."*

*"I have the feeling that we work with only one type of profile, simply by opening that up, by considering more possibilities, more dimensions, we can move forward."*

*"We don't take into account demographic changes, and we have a very hard time identifying people."*

*"We have to be consistent in what we say, and there's something we are not doing right. We talk about citizen participation as a value, and it is true that*

*there are older people participating, but not those who are in a precarious or vulnerable situation. We are not including these people, and that just can't be."*

*"The provincial councils are the institutions that are most removed from the people; they are not at all involved in day-to-day life."*

*"The local councils have to be close to the users and lead this, but it costs money and the money is in the hands of the provincial councils."*



### HEALTHCARE

*"The issue of loneliness and end-of-life care is being addressed by private initiatives. Those who can afford it have better services."*

### Public narratives

- **The healthcare system in the**

## 10.2.2. Phase 2: Active listening

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**Basque Country does not reach everyone.**

*“There are such things as mental healthcare units, but they are scarce... And in terms of suicide figures, Vizcaya is leading the way and they are rather alarming.”*

*“I’ve had three episodes of illness and I’ve not been offered psychological support during any of them. The same as the support I get with chemo or surgery, I miss that.”*

*“Doctors don’t engage enough with this type of patient”.*

- **The challenges of home-based care**

*“As much as they want to convince us that caring for a person at home is much cheaper, it’s just not true. It actually costs a lot more.”*

*“This calls into question the model of family-based care, where the family cares, and within the family, we know exactly who does the caring.”*

- **The professionals who attend to**

**people in palliative care situations lack specialised training.**

*“The doctors and nurses are so afraid then they go on home visits... Some don’t want to give the necessary medication because they don’t know how to use it and they’re afraid that they’re going to harm them. If you don’t have training, you can’t help.”*

*“End-of-life care training for healthcare workers does not exist.”*

*“How difficult it is when we do some awareness-raising in the hospital, like a talk... It’s really hard to get colleagues other than the usual ones to come.”*

*“The medical reports don’t reflect the realities of the person at all. How can that be possible? They don’t reflect the social situation or anything, only if the patient deteriorates badly or dies, without detailing how it happened... The families read that and they’ll say...”*

- **Palliative care, the last stage of life and bereavement are not priorities for the authorities.**

## 10.2.2. Phase 2: Active listening

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*"The Basque Government has not taken the right approach to home help."*

*"No value is placed on support services for vulnerable people. During the lockdown, our services were dispensed with, and we were furloughed."*

*"It would be great to be able to take some time off for training."*

*"We give a lot of support to education and leisure. Priority is given to the usual things because the feeling is that everything related to bereavement, death and suffering is of no interest, but then you organise a workshop on vulnerability, accompaniment, death and bereavement and you get more than 80 people coming..."*

*"Building community through housing or cultural policies is a shared responsibility – in the end, we all benefit."*

### **• Change should start with tax policies**

*"Everyone knows that improving the*

*system requires that we as a society have to be more supportive, and that starts with our tax policies."*

*"We are talking about huge buildings, terrible ratios and huge problems, but I don't want them to touch my assets to be able to pay for a place in these services..."*

*"We need to rethink healthcare services, to look at them from a system perspective, because I'm worried about young people not being able to become independent. But of course, it's all interrelated – it's all the same package."*

### **• The quality of socio-health care depends too much on the individual people themselves.**

*"In our view, the key is that there must be people who are leaders with the strength and energy and the will to bring more people on board to make communities work."*

*"There is a need for someone knowledgeable about vulnerability and end-of-life issues – a professional,*

## 10.2.2. Phase 2: Active listening

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*with training, flexibility and a strategic vision.”*

*“Doctors and nurses have different ways of seeing things. A hospital liaison figure, with nurses and the community, would be a good thing.”*

• **Social services are a stopgap: economic inequality is the key factor.**

*“With money you can do anything... I get a lawyer to fight to prove my degree of dependency, etc. I can do a lot of things.”*

*“As soon as my mother turned 65, she changed from being disabled to being a senior citizen, and with that the homecare service became much more expensive. It makes no sense.”*

*“Private homes are not set up for this kind of care, and the costs are very high... If you don't have the money, you're financially ruined.”*

• **Socio-health interaction is not agile.**

*“Doing things with associations is much more agile... as a doctor, like*

*getting materials, adjustable beds, psychological care... a lot of things. In the end, we end up doing all the social stuff with the AECC – the town council's social services are always slower.”*

*“I have colleagues who have clearly told me that social issues are not part of their remit.”*

*“We must try to break away from the doctors and their power, often their interests are different from those of the patients.”*

*“Healthcare and social issues fall into separate boxes... that can't be.”*



### EDUCATION

• **End of life, care and bereavement have no place in the school curriculum and teachers are not prepared to deal with such situations.**

• **Teachers are unprepared for end-of-life situations**

## 10.2.2. Phase 2: Active listening

*"At the moment there is some sensitivity, but it is not enough, and the problem is the lack of training." We have brought up our children in a society where we only want them to be happy, to feel happy and satisfied, joyful... And life is not just about that."*

*"Our hope is to introduce this in schools. Many teachers have this concern, but we also know that they are very overwhelmed and sometimes they can't cope."*

- **The education staff themselves are fully aware of their lack of tools.**

*"What do I do if someone is going to fall to pieces? As a teacher, what do I do if someone cries?"*

*"There are protocols for everything, but not for this – there's nothing set up. The topic is going to come up and we know it, but it is not addressed as a pedagogical aspect."*

*"It happens all the time, and you have to call in a specialist when it does."*

- **This situation is directly linked to school failure.**

*"I am an example. I was a school failure because I didn't deal with the loss of my mother. When my father could start talking about my mother at home, I stopped getting 'Fs' and started getting 'As'." "If you don't work on your grief in life, you can't move forward."*



### CULTURE AND SOCIETY

Existing structures prevent the development of more compassionate communities.

#### Public narratives

- **The support that exists at the moment is functional but cold.**

*"When you talk to a person on the phone, sometimes just by listening for half an hour, you can sense that the person's anxiety level decreases, because the person doesn't feel so lonely."*

- **Society is unfamiliar with existing**

## 10.2.2. Phase 2: Active listening

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### services.

*“Often we do not know whether the last will and testament is carried out by the City Council or the Provincial Council.”*

*“People don't know which institution handles what, and who to call.”*

*“The over-60s should be contacted and talked directly about the things that already exist.”*

*“The system is not going to be able to cope with everything. People also miss having access to friendly treatment; they feel invisible and miss community networks.”*

*“I've clearly realised that my neighbours who have this kind of problem need someone's attention – it's obvious.”*

*“Many needs were identified during COVID-19 in the shops. If you compare the needs, you have met or solved thanks to a neighbour or the family or the home deliveries they did*

*for us, then you notice more subsistence needs in the neighbourhood – for food, to pay the rent... Plus huge confusion – they don't know what's available out there or where to go.”*

*“Socio-health coordination has not worked, but communities have.”*

**• Existing structures hamper the advancement of compassionate communities.**

*“The Spanish Act on Voluntary Work is an example of a structure that does not provide for interaction. It's quite tough, very secretive with a very particular vision.”*

*“More nuances are needed in the Spanish Act on Dependency; the questions are closed (age range, disability...)” “Lagunkoia is very instrumental. When you ask them something or try to contribute something of your own, they don't give you much of a chance, apart from workshops once a week.”*

*“I've felt bad. I don't mind because I'm*

## 10.2.2. Phase 2: Active listening

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*fine. I want to do things and live life, but it shouldn't be like that. I've felt a bit cornered, pushed to one side."*

*"Depending on the municipality, many people don't really know what a social welfare department is, and so they call other departments..."*

*"Welfare officials are amazed that they don't call them. They are called more about financial issues and aid."*

- **For this work to be effective, it needs to be linked to actions and therefore properly resourced.**

*"In order to be able to start initiatives at the community level, we need resources... Because if we don't, we have created a very powerful network, but there are no resources to do anything."*

*"There have to be action plans, otherwise there's no point. "We make a lot of plans that are not given a budget – even if it's only small, we need a minimum number of resources."*

- **The system fails to take advantage**

**of the people there are.**

*"The Spanish Act on Volunteering is designed to ensure that volunteers do not become moonlighters, which is what people have traditionally used volunteering for. The laws are made that way for a reason... Otherwise, since we are tremendously exploitative as a society, someone would take advantage of this loophole to recruit undocumented people."*

*"The social protection system treats older people like children. There are many pensioners with free time, health and enthusiasm, but the system is ironclad and does not allow for participation, nor does it allow for collaboration between people, which results in an impressive waste of human capital."*

*"So many people in the sector are retiring and disengaging from everything, just like it was like any sort of company! If they were offered a bit of structure, which is what a volunteer or an altruistic person needs, money is not much in exchange for knowledge."*

## 10.2.2. Phase 2: Active listening

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- **Many people find themselves at a complete loss after years of caregiving.**

*“There is a profile of women over sixty-something who have been taking care of their families, their parents, their children all their lives. Then when their children get older, they don't know what to do because they have never had time for themselves, and they drop out of the picture.”*

- **Assistance of this kind is stigmatised.**

*“One interesting thing that has been shared with me by several welfare workers is that many people are offered help and do not accept it.”*

*“I also think that there are people who perhaps haven't dared to ask for help.”*

*“There are a lot of people who don't ask for help; they don't come to us.”*

- **Community work needs to be used not to substitute services, but rather to complement them.**

*“This is of course not the job of the neighbours either. It is not the job of one neighbour to take care of another's needs, no matter how much the neighbour wants to or is able to. Isn't it supposed to be the local social services?”*

*“There is less and less active volunteering. Before, there used to be much more, but this cannot be sustained by volunteers, people have to be able to feed themselves.”*

*“I am from the neighbourhood of San Francisco in Bilbao and we have a life expectancy ten years less than in Getxo, which is next door... In 2019, I devoted two hours a month to militancy in the neighbourhood, and in the pandemic, it was two hours a day. I also think that the closeness, but also the sense of solidarity and neighbourhood identity help that.”*

*“Society participates and gives something to you when it receives something in return.”*

- **This human capital is squandered in competing associations and**

## 10.2.2. Phase 2: Active listening

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**comes to nothing.**

“There is no political interest in promoting these things, and it is a pity because I think the country is losing wonderful resources. Moreover, in the more community-based associations and movements, competitive attitudes prevail, and when there is a new one, it is seen as just another one on the receiving end.”

“There are some associations that have, quote unquote, more privileges than others, and it’s not known why that is. It depends on whether or not you’re friends with whoever is involved.”

“It’s important to stress that town councils handle our money, which we pay for with our taxes. They have an institutional obligation to help us.”

### Intersectionality

In the care setting, it is important to consider the different contexts and the unique experiences of people in their daily lives, so that an intersectional perspective takes on a central role in this regard. By intersections we refer to the different axes (gender, race, class and a long etcetera) of oppression that interconnect with each other and that are experienced by individuals and groups (Gandarias et al. 2019; Henne 2018; Parent et al. 2013). Intersectionality is the perspective that identifies the different identities and oppressions experienced by people in different societies that are interconnected with each other (Shields 2008 in Parent et al., 2013, 640). These identities and inequalities function in relation to socio-cultural authority and privilege and then materialise in people's experiences and identities (Parent et al., 2013, 639). As a result, intersectionality aims to criticise the homogenisation of categories in a way that exposes the multiplicity of axes of oppression (Gandarias et al., 2019,

41; Shields, 2008 in Parent et al., 2013, 640). By identifying multiple and interconnected inequalities, intersectionality aims to abolish and transform situations of subordination (Henne, 2018, 2).

This intersectional perspective was emphasised by the participants in this project, especially in the co-creation sessions, since, as the participants emphasised, the different axes of inequality can influence care practices in a multidimensional way.

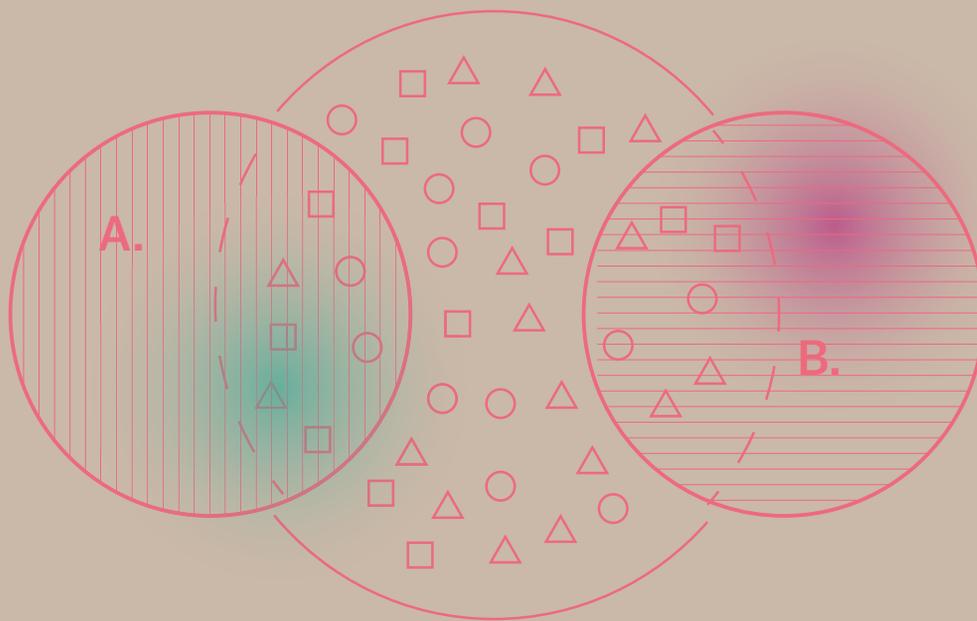
*"I would add another point to this idea, and that is intersectionality. There are many axes of inequality that condition health, quality of life and ways of living. This is what we should aspire to evaluate and consider in order to achieve a more compassionate and equitable community."*

*"I'm a real pain when it comes to work on equality. What I tell them is that if they don't do it, they are generating more inequality and here if you don't bring in care, you are making it more difficult. In other words, it's not that*

## 10.2.2. Phase 2: Active listening

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*you are not doing something well,  
but that you are doing badly and as a  
public policy there is a responsibility."*



## 10.2.3. Phase 3: Collective contrast

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- **Collective contrast of the narratives and the segmented profiles in one or two general sessions in which the analysis carried out will be validated.**
- **Analysis of the contributions and enrichment of the conclusions of the listening phase.**

This phase was completed with three sessions to contrast the narratives identified. In these sessions, which took place between October and November 2020, the analysis carried out by the F2S team was compared. The aim of these sessions was to gradually reinforce and correct the conclusions of the listening analysis, as well as to add new focuses in order to, if necessary, rework these conclusions through new interviews or new approaches. These sessions also helped to strengthen the network of participants. The sessions were attended by a multidisciplinary representation of local institutions, social services, representatives of

local associations and municipal residences, volunteers and the organisations involved in the development of the project (see participant profiles annex). The information was presented in the form of profiles or archetypes:

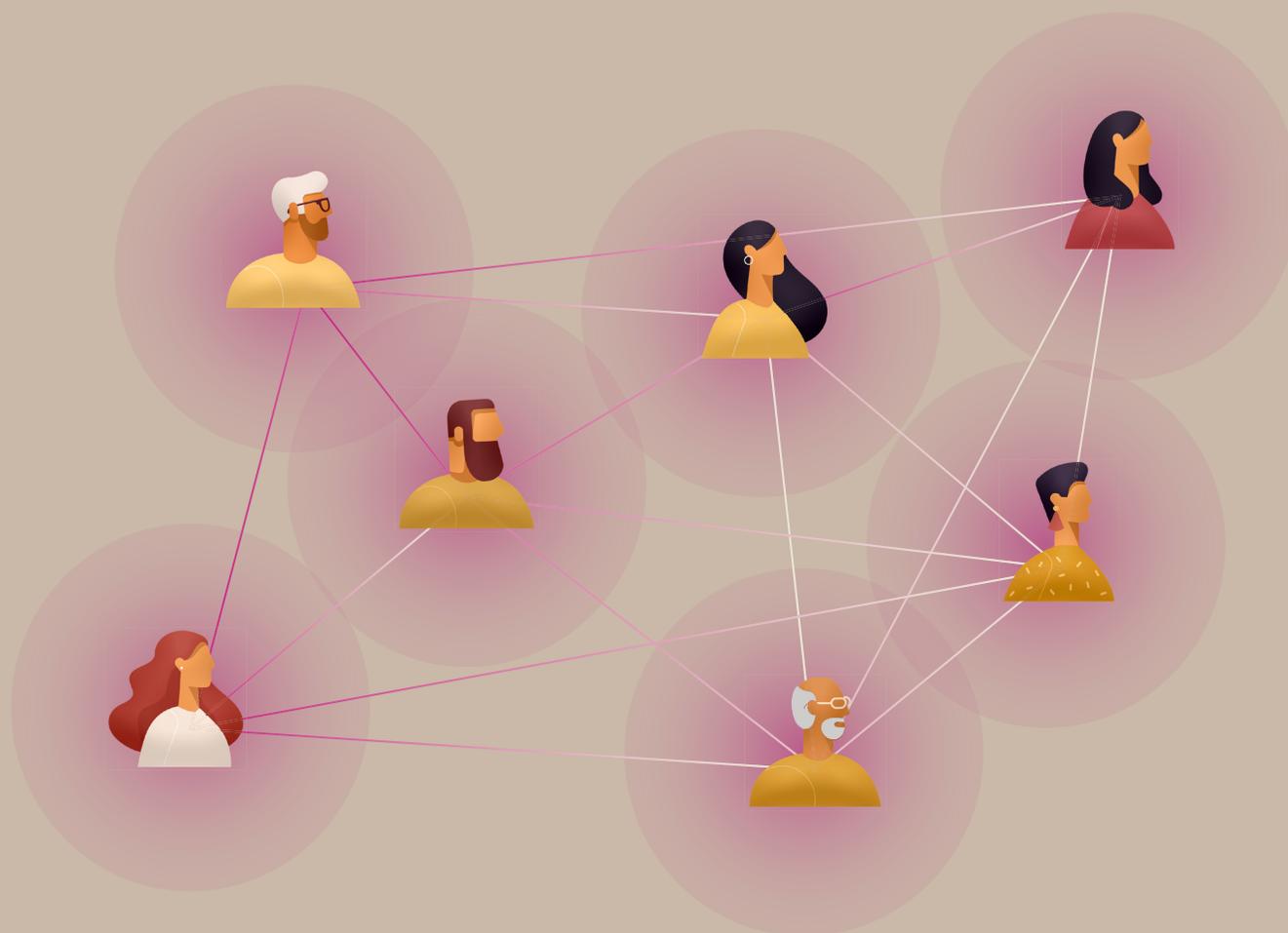
- 1) These profiles correspond to multiple voices and represent patterns of narratives that have been repeated. If these narratives relate to caregiving, we have given them the character of a woman caregiver. If these narratives relate to the public sector at different levels, they have been attributed a similar profile.**
- 2) This does not mean that they represent the unified narrative of the public sector, young women or immigrant women. They represent a functioning narrative, and the set of profiles aims to visualise the set of existing narratives concerning end-of-life care and compassionate communities in the Basque Country.**
- 3) These profiles complement the more social, healthcare and public sector part of the end-of-life work**

launched by Getxo Zurekin.

## Main profiles of the end-of-life ecosystem

Who is around people in situations of dependency, palliative care, end of life, bereavement and risk of loneliness? How do they relate to each other?

Here are the seven profiles for the Getxo Zurekin 2020 project.



### 10.2.3. Phase 3: Collective contrast



"From time to time they call us from the Provincial Council to see how we are doing in the town councils, but they are not really forthcoming. There's no close contact or deeper understanding of the reality."

**ARANTZA**

Age\_ 45  
Occupation\_ Municipal Social Services Technician  
Municipality\_ Orio



**VISIBLE NARRATIVE**  
Social services in the Basque Country fail to reach the whole of the population.  
*"We have to recognise these weaknesses - I think it's difficult for us."*

**METANARRATIVE**  
The quality of services depends too much on the individual people themselves.  
*"The support is there, but there has to be someone to somehow set the wheels in motion, otherwise it doesn't work."*

**HIDDEN NARRATIVE**  
Management is complicated, not integrated and inflexible.  
*"It is very complicated at the management level for frontline professionals who are with the families."*

 **CHALLENGES**

- ▲ **Disconnection.** "The town authorities are doing a lot of things, but they are not coordinated - they are all scattered all over the place... Everything should be coherent."
- ▲ **Poor adaptability:** "Many activities are organised just for the sake of organising something, without a specific purpose."

 **OPPORTUNITIES**

- **Inter-institutional body for general coordination.** "To coordinate and integrate the different administrations".
- **New liaison officers at district and local level.** "In the areas and neighbourhoods in which there are named leaders, more progress has been made."

### 10.2.3. Phase 3: Collective contrast



**LEIRE**

**Age\_ 36**  
**Occupation\_ Palliative care nurse**  
**Municipality\_ Donostia-San Sebastián**

**CHALLENGES**

- ▲ **We don't have any training.** "As doctors and nurses, we are sometimes so afraid... Some don't want to give the necessary medication because they don't know how to use it properly and they're afraid that they're going to kill someone."
- ▲ **Collective contrast.** "The system is not going to be able to cope with everything. People also miss having access to friendly treatment; they feel invisible and miss community networks."

**OPPORTUNITIES**

- **Caregiver care programmes.** "If we are able to develop good care programmes for carers, to complement what is already there, it would be a great approach."

**Metanarrative:** Social services are a stopgap: money is still the key. "As soon as my mother turned 65, she changed from being disabled to being a senior citizen, and with that the homecare service became much more expensive. It makes no sense."

**Visible Narrative:** Home-based care is prioritised. "As much as they want to convince us that caring for a person at home is much cheaper, it's just not true. It actually costs a lot more."

**Hidden Narrative:** The quality of care depends too much on the individual people themselves. "It depends very much on the person you have in your municipality whether things are easier or not."



**MIGUEL**

**Age\_ 71**  
**Occupation\_ Retired, volunteer association**  
**Municipality\_ Getxo**

**CHALLENGES**

- ▲ **Raise people's collective awareness.** "Population ageing is already here, it is a challenge of the first magnitude".
- ▲ **Existing structures do not allow compassionate communities to move forward.** "This decree that was made 7, 8 years ago, dead as a doornail, would be the ideal umbrella for all community initiatives."

**OPPORTUNITIES**

- **Identify new tools for mutual aid in the communities.** "During Covid we have had the balconies or the Whatsapp groups, digital spaces for mutual help. There have to be intermediate elements that connect people."

**Metanarrative:** Community work cannot replace services, but should complement them. "There is less and less active volunteering, there used to be a lot more, but this is not sustainable with volunteers".

**Visible Narrative:** Society wants community work to be strengthened. "The system will not be able to cope with everything, people also miss friendly treatment, they feel invisible, they miss community networks".

**Hidden Narrative:** For this work to be effective it needs to be linked to actions and therefore resourced. "To be able to set up initiatives at the community level we need resources... Because if not, we have created a very powerful network, but there are no resources".

### 10.2.3. Phase 3: Collective contrast



**“Healthcare and social issues fall into separate boxes... that can’t be... Many of my colleagues think that social issues are not up to them, and they’ve told me that it’s just not possible on a day-to-day basis.”**

**IÑAKI**

Age\_ 43  
Occupation\_ Palliative Care Physician  
Municipality\_ Zarautz



**METANARRATIVE**  
Gizarte Social issues do not fall within the competencies of the healthcare team.  
“Many of my colleagues think like that and they’ve told me that it’s just not possible on a day-to-day basis.”

**VISIBLE NARRATIVE**  
There appears to be little interest among medical staff in the social aspect of our work:  
“It’s always the same people who go to the meetings.”

**HIDDEN NARRATIVE**  
We don’t connect with the patients:  
“Our reports don’t reflect the social situation, only if the patient deteriorates badly or dies, without detailing how it happened... What would the families think?”

 CHALLENGES

- ▲ **We need more training, but there are no resources:** “It would be great to be able to take some time off for training.”
- ▲ **Public healthcare is not agile.** “It’s much easier to get materials, adjustable beds or psychological care from associations. In the end, we end up doing all the social stuff with the AECC.”

 OPPORTUNITIES

- **Intergenerational spaces.** “In small districts, it would be easy to foster the idea that the end of life is not only concerned with the elderly. Joining together is all about sharing, the elderly have experience they can share and young people and other generations can bring offer them new things.”



**“Usually, the general approach is that the family takes care because it is supposed to be cheaper, but within the family we know who does the caring because they don’t all provide the same care, far from it...”**

**BEGOÑA**

Age\_ 71  
Occupation\_ Former caregiver, widow  
Municipality\_ Amurrio



**METANARRATIVE**  
Many people find themselves at a complete loss after years of caregiving:  
“There is a profile of women of fifty-something who have been taking care of their families, their parents, their children all their lives. Then when their children get older, they don’t know what to do, and they drop out of the picture.”

**VISIBLE NARRATIVE**  
Support from the administration is very cold.  
“There are things that work, but many people feel that they are not being heard. Even things that are functional... “Many people don’t know whether the last will and testament is carried out by the City Council or the Provincial Council.”

**HIDDEN NARRATIVE**  
Caring and being cared for means for the administration putting that person aside:  
“I’ve felt bad. I don’t mind because I’m fine. I want to do things and live life, but it shouldn’t be like that. I’ve felt a bit cornered, pushed to one side.”

 CHALLENGES

- ▲ **Gender bias.** “We should also talk about joint responsibility for care, beyond the conditions in which care is provided. Also, women’s right not to provide care.”
- ▲ **Systematising community listening.** “A total cultural change is needed to move from individuals grieving in privacy to creating another ecosystem.”

 OPPORTUNITIES

- **Profile segmentation.** “It would be possible to identify the variety of existing profiles and their complexity so that resources can reach them more efficiently. Everyone needs different care, as we are not all the same.”

### 10.2.3. Phase 3: Collective contrast



**ISABEL**

Age\_ 29  
Occupation\_ Caregiver/Household worker  
Municipality\_ Mungia

**CHALLENGES**

- ▲ **We lack training.** "There are many things we don't know; we learn about things like dementia on the job... It's like that for a lot of caregivers. Nobody looks after the caregivers – maybe there should be a programme for that."
- ▲ **Poor working conditions.** "We can't get any dole money. It depends on how much you've paid in contributions and I've only been paying them for a short time. Working conditions for us home-based caregivers are bad."

**OPPORTUNITIES**

- **Community listening process.** "A lot of things are done, but the things that are done are often not what patients, caregivers, nurses, etc. need at the time... In the end it gets lost."
- **Cultural change.** "I've noticed that Basque people are afraid to talk about death, maybe, especially after COVID-19, it would be good to work on that."

**VISIBLE NARRATIVE**  
The profile of caregivers is clear.  
"It's not just that we're all women, it's that most of us are from abroad. We emigrated all the way here and it's difficult."

**HIDDEN NARRATIVE**  
The working conditions are bad.  
"Especially with COVID-19, we have less and less stability and security. Besides being a caregiver, I try to find some other things to earn extra income."

**METANARRATIVE**  
The working conditions are worse for immigrants. We are not appreciated.  
"People are not very sensitive. Now OK, but in general it's bad. There was a house where they were renovating and I carried all the rubble down on my back (...) and I had to clean the paint off the floor on my knees and my trousers were ruined (...) You don't get any thanks."



**PEDRO**

Age\_ 51  
Occupation\_ Social Services  
Municipality\_ Province

**CHALLENGES**

- ▲ **Disconnection.** "The town authorities are doing a lot of things, but they are not coordinated – they are all scattered all over the place. Everything should be coherent."
- ▲ **Poor adaptability.** "Many activities are organised just for the sake of organising something, without a specific purpose."

**OPPORTUNITIES**

- **Inter-institutional body for general coordination.** "To coordinate and integrate the different administrations".
- **New liaison officers at district and local level.** "In the areas and neighbourhoods in which there are named leaders, more progress has been made."

**VISIBLE NARRATIVE**  
Services work best where welfare takes precedence over political preferences: "We have to recognise these weaknesses – I think it's difficult for us."

**HIDDEN NARRATIVE**  
There's a certain amount of conformism within the administrations.  
"Sometimes we tend to look more at what we do well, and we don't stop to look at the shortcomings!"

**METANARRATIVE**  
There is a disconnection from reality.  
"I have the feeling that we work with only one type of profile, simply by opening that up, by considering more possibilities, more dimensions, we can move forward."

## 10.2.4. Phase 4: Collaborative co-creation of the project portfolio

Level of impact	Narrative to which it responds						
Persona							
IZENA	Arantza	Leire	Miguel	Iñaki	Begoña	Isabel	Pedro
Community							
Small- and medium-scale							
Large-scale							
New services							
Regulations							

- Design and implementation through two co-creation sessions of new solutions at five levels (community, small- and medium-scale, large-scale, services, regulatory) related to compassionate communities in the Basque Country.

- Synthesis and conceptualisation of each of the solutions on the basis of profiles.

Once the identified narratives (structured in profiles or archetypes) had been contrasted, we moved on to a phase of co-creation of possible initiatives that could reinforce compassionate environments (while at the same time responding to the different perceptions and needs identified). These initiatives present a first experimental space that the Basque Government could support on an experimental basis in different localities of the territory. The combination of these and other similar initiatives could generate a shared strategy to foster this type of compassionate environment. Fundamentally different from a traditional approach, these initiatives are understood as intercon-

## 10.2.4. Phase 4: Collaborative co-creation of the project portfolio

nected prototypes. The fundamental objective is to learn as they develop and to analyse how they reinforce each other. These early communities could be identified as spaces of advanced experimentation.

These initiatives are ongoing or proposed for launch, classified according to their type. The initiatives we are developing at the moment are set out below.



#### 10.2.4. Phase 4: Collaborative co-creation of the project portfolio

### ★ Death cafés

Death Cafés are one of the first initiatives identified to be promoted at the community level. In a death café, the participants drink coffee and talk normally about advanced illness, loneliness and death. The aim is to create spaces for dialogue on this issue that are open to all citizens. These initiatives began in Vitoria-Gasteiz and are now held in more than 30 towns and cities in the BAC.

[hospice.org.uk/news\\_posts/bereavement-cafe-online-communities-to-support-bereaved-locals-during-lockdown/](https://hospice.org.uk/news_posts/bereavement-cafe-online-communities-to-support-bereaved-locals-during-lockdown/)

### ★ Community influencers: “La escalera” project

One of the most interesting initiatives in this area is the “La Escalera” project. Its aim is to build a system of mutual aid and support for people in situations of vulnerability, loneliness or advanced illness in the same neighbourhood community

### ★ Grief spaces

The collective interpretation sessions identified the need to create spaces for grief at the community level. These spaces are usually professionally managed and are limited to those who can afford to pay for these services. A compassionate community should offer spaces for the management of grief processes to the whole population.

<http://www.proyectolaescalera.org/>



<https://www.thegoodgrieftrust.org/need-know-info/from-us-to-you/pop-up-good-grief-cafes/>

*“Ilogailua da gertatu zaigun okerre-na. Lehen, behintzat, eskaileran elkar topo egiten genuen”.*

St. Claire hospice: <https://stclare->

## 10.2.4. Phase 4: Collaborative co-creation of the project portfolio

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### ★ Awareness programmes in educational centres

The co-creation workshop generated ideas for building awareness programmes on compassionate environments in schools in the municipality in which work is being carried out.

Raising awareness in educational centres: <https://www.vivirconvozpropia.com/acciones-comunitarias/sensibilizacion-en-centros-educativos/>

### ★ Super heroine groups – Weavers Project

This type of community groups allows for the identification of situations of loneliness experienced by people who care for their loved ones at home, with the aim of proposing solutions from the community itself. Similar initiatives are currently underway in Australia, the United Kingdom, the United States and Canada. Those who participate in these programmes receive specific training in this field. Super heroines is a WhatsApp mutual help group with

fortnightly meetings to strengthen the bonds between carers.

A peer to peer program: <https://www.tacsi.org.au/work/weavers-peer-to-peer-carer-support/>

Coaching for carers: <https://www.stchristophers.org.uk/coaching-for-carers>

### ★ Talking Cafés

Talking Cafés is an initiative that creates spaces to connect people who have some kind of need related to situations of loneliness, advanced illness or end of life.

Talking Cafés: <https://somesetagents.org/talking-cafes/>

### ★ LOKARRIA. (Humanitarian Association) COMMUNITY SOCIAL BROKERS

New social contexts and innovative methodologies bring with them the creation of new roles and the inclusion of new stakeholders. This is the case of the “Social Broker” men-

#### 10.2.4. Phase 4: Collaborative co-creation of the project portfolio

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tioned above. This is a vital figure for the success of this project, which is already well established in countries such as the Netherlands and the United Kingdom. The SB works to ensure inclusion and promote social cohesion in a specific territory in a cross-cutting way in the projects carried out, always working on different scales and in different dimensions: the community, social services, public and private agents and institutions. The ultimate goal is to create resilient networks and communities linked to specific needs. A social broker, also known as an “innovation broker”, has to be on the ground, helping to transition from theory to practice, from the abstract to the concrete. The social broker should serve as a pivot point between the community and public administrations. The role of this person is to create and empower social networks to support and respond to the perceived and internalised narratives of the community. This the most “internal” work of this role.

**Community connectors:**  
<https://healthconnections.mendip.org/lets-connect/training/community-connectors/>  
**Community outreach programme:**

<http://www.msal.gob.ar/index.php/component/content/article/46-ministerio/521-programa-promocion-comunitaria>

#### ★ New funeral services

Another proposed initiative is the redesign of existing funeral services from a community perspective in collaboration with a company from the sector. This initiative would make it possible to detect and manage many complex bereavement situations.

#### ★ Redesigning socio-health services

Using the same community-based approach, new compassionate environments could trigger a process that would redesign existing services from the users’ perspective. Although these methodologies are common in the redesign of other public services, they have not been sufficiently developed in the context of loneliness, advanced illness and end of life. More specifically, the following issues could be addressed:

#### 10.2.4. Phase 4: Collaborative co-creation of the project portfolio

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- Creation of resource guides so that primary care doctors and the social services team personnel are aware of them and can pass them on to people.
- A municipal service to manage advance directives.
- Redesign of hospitals and palliative care centres by the users themselves.
- Palliative care training: immigrants, special support; health workers; social workers; bereavement counselling services.
- Restructuring/redesign of home-care support – very different casuistry (e.g. when you turn 65, home help costs twice as much).
- Lead campaigns through mass messaging to address community behaviour change and access to information (SMS, WhatsApp, videos, social media).

### ★ Need for a Palliative Care Act and reform of the law on voluntary work)

Compassionate communities under-

line the importance of palliative care and society awareness as a universal right. This domain of action is linked to a potentially more active and skilled type of volunteering in issues related to the last stages of life.

## 10.2.4. Phase 4: Collaborative co-creation of the project portfolio

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### Overview of the interlinked initiatives

This graph represents how, with people as the focus, the different interlinked initiatives operate and the levels at which they operate. The colours assigned to the initiatives correspond to the levels or areas in which these initiatives operate.

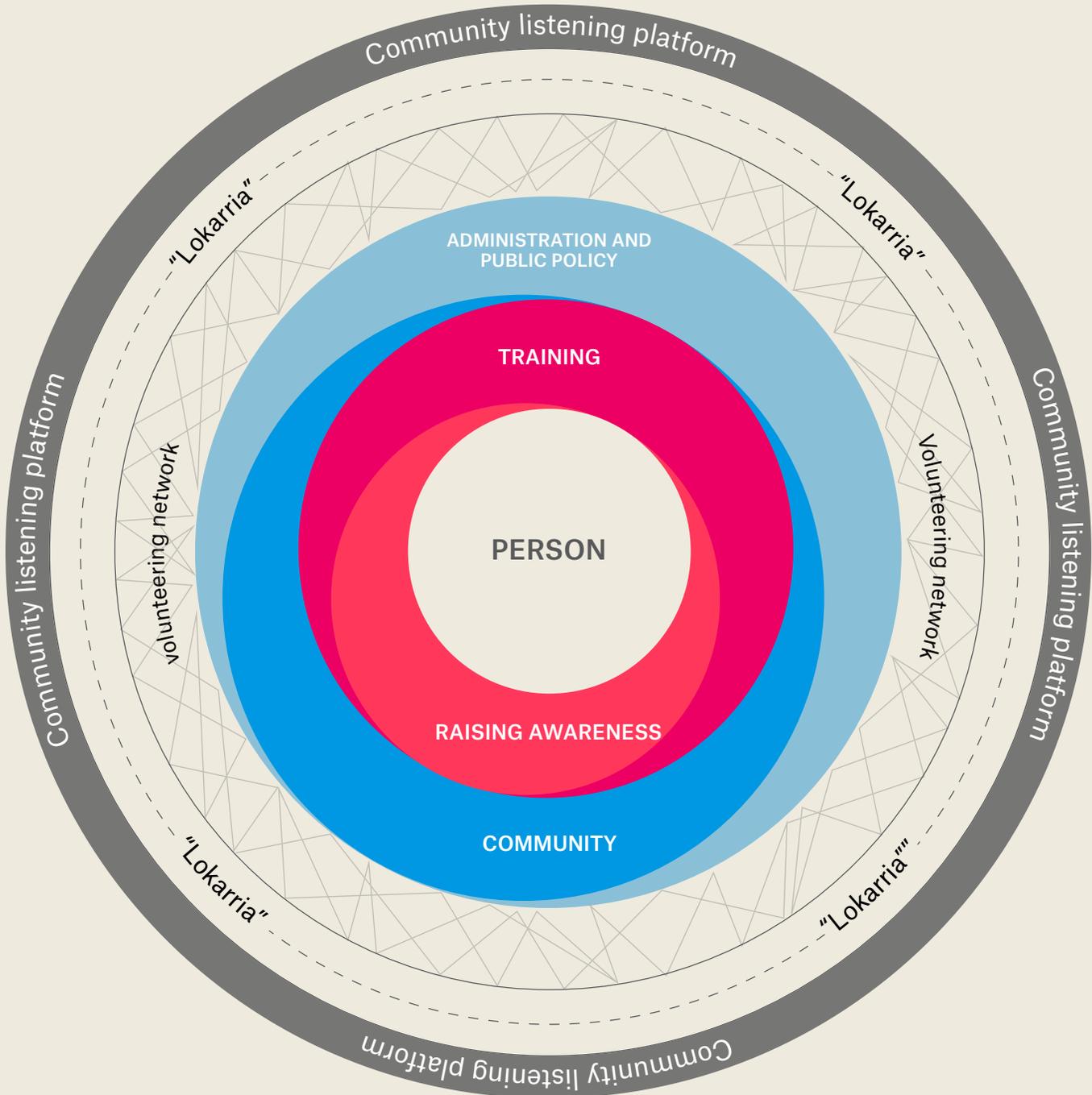
- Talking Cafés
- Death Cafés
- Community training
- Theatrical play
- Grief Group

- "Activa tu Comunidad"
- Weavers
- Super Heroines

- Getxo ZUrt
- Training for volunteering network

- Third party volunteer training
- Training for caregivers
- Training for people at risk of exclusion
- Forum theatre

## 10.2.4. Phase 4: Collaborative co-creation of the project portfolio



## 10.2.5. Phase 5: Designing the Basque compassionate environment

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The identified narratives (needs and opportunities) as well as the initiatives that emerged from the co-creation process provide us with the necessary information to be able to initiate a compassionate environment. In other words, a compassionate environment in which to integrate, to interlink all those initiatives and roles mentioned earlier in the report. To this end, last November, and with the limitations of the digital environment, a joint design session was held with the aim of taking the first steps towards the creation of a possible Basque model of a compassionate environment. The participants highlighted the necessary characteristics to make this adjustment, as well as the barriers and obstacles to overcome and the main opportunities in our environment. The ideas presented below reflect the proposals put forward by the participants during the different sessions.

### Main features of the potential Basque compassionate environment

#### 1) Clear-Cut Objective

Compassionate environments should aim for long-term citizen engagement, an engagement that is based on inclusivity, friendliness and humanity, and that has care at the core of the practices and considerations of citizens. In this way, the aim should be to cater for the various care needs of different individuals and social groups.

## 10.2.5. Phase 5: Designing the basque compassionate environment

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Given the fickleness of public administrations, compassionate environments should be established on the basis of long-term citizen participation. However, this does not mean that compassionate environments have to be based on volunteering, but rather that the proposal would be to establish a partnership between public administrations and citizen participation, based on public resources.

*“Compassionate spaces, compassionate communities must, in my view, be born from the grassroots, because administrations are changeable. We all know that we have to go to vote every X amount of time and there are towns that change more or those that change less, but the public administration is still a changing thing. And (...) citizenship persists over time. Trying to promote it from the grassroots.”*

### **2) Collaborations and synergies between and within environments. Importance of the auzolana. [Neighbourhood work]**

The use of community collaboration systems, such as auzolana, could stimulate the creation of new spaces for interaction in situations of loneliness, advanced illness and end of life. Practices such as auzolana could stimulate the coordination and involvement of citizens and administrations, establishing better coordination and promoting citizen action.

*“The analysis of the traditions of each environment will give us clues as to what to build in that specific environment. Although the final outcome may be shared by many different places and settings... Going back to cultural tra-*

## 10.2.5. Phase 5: Designing the basque compassionate environment

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*ditions and building on and drawing from them can make it easier for us."*

*"Taking a step back (to the past) might be a good answer."*

### 3) Public institutions as process facilitators

The role of public institutions is among the most relevant in this type of projects. Given the importance of public institutions, facilitating shared leadership in compassionate environment projects would promote real interaction between different stakeholders, empowering the community and enabling citizens to engage with the system, thereby facilitating a holistic perspective of what is happening to local public institutions.

*"Where do we build it from? From the top down? Or from the bottom up? This is going to determine how all this is understood, and also the pace, the timing, the dynamics..."*

*"I wouldn't make this division between public and private but rather talk about the common good, which is something that unites us much more." "It's empathy in action and we can all have it regardless of our ideology and we must take it forward."*

### 4) Roles, scale and gender in compassionate environments

Given the proposal that compassionate environments are based on a partnership between citizens and public administrations that are supported by public resources, there is a need for a figure who is independent of the

### 10.2.5. Phase 5: Designing the basque compassionate environment

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public administration and who acts as an intermediary. This figure could be a “lokarría”, a connecting group with social and administrative recognition that coordinates different projects and links public administrations with citizen initiatives. *“Connecting together, building together and not reinventing things.”*

Although it would be ambitious to establish a compassionate environment on a large scale, the opinions gathered are in favour of promoting this type of project at the village, or neighbourhood level in the case of large cities.

Considering gender and intersectionality in compassionate environments is relevant when taking into account the different realities and difficulties that people may experience in their daily lives. Consequently, by incorporating these perspectives, compassionate environments will lead to more compassionate, inclusive and equitable communities.

#### 5) The term “compassionate”

Participants question the appropriateness of the term compassionate. In their opinion, this term is associated with piety or charity, so it could limit the participation of a wider public. An alternative may be to replace it with friendly environments or community care, caring community or “your community and you”.

## 10.2.5. Phase 5: Designing the basque compassionate environment

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### Barriers

Barriers that compassionate environments may encounter are as follows:

- Resistance to change and to carrying out activities in a different way;
- Lack of coordination between projects and interests, and how this can influence the people intended to be helped;
- Failure to consider the socio-cultural and individual context of the people to whom the project applies;
- Lack of real involvement of the administrations;
- Lack of reflection on the vulnerability of individuals.

*“The institutions already exist (...), everything already exists, we have a lot of resources, we have a lot of things, we have a lot of people who are very willing to do things. There is a lot of enthusiasm (...) As facilitators we have everything, we just need a little bit of a way to bring it all together.”*

### Enablers

Enablers that could help the development of compassionate environments include the following:

- Institutions and resources available to partner in projects;
- People as the driving force, and their desire and motivation to drive the project forward;
- The technological resources available, which can bring us closer to the people or facilitate the collective creation of projects;
- A clearly defined shared objective, such as an umbrella framework for initiatives;
- Training in networking dynamics and ways of working;
- The impetus given by the pandemic to people to make a difference and help the most vulnerable.

*“It’s a very significant moment. With what we have experienced with the pandemic, the COVID-19 situation, lockdown... we are more and more aware of our individual vulnerability, our own vulnerability and the vulnerability of society as a whole. And I believe that this has rekindled a series of latent forces that we have to take full advantage of.”*

# 11. Thoughts on the future

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In this section, we have collected the views of people with extensive experience in the field of care, with the aim of looking to the future and contemplating the challenges, opportunities and visions that from their perspectives are important to consider for the functioning and development of compassionate communities.



– Emilio Sola

Provincial Councillor for Social Policies in Álava

At the outset, I see the need to differentiate the future of compassionate communities from what the term “compassion” can hope to achieve.

Let's start with the latter: It is said that when a question, rule, proposal... is not understood by the people to whom it is addressed or lends itself to different interpretations, it is most likely not well formulated. I don't think that this is the case with compassion, although it is no less true that those of us who are in favour of the use of this term are continually obliged to explain that compassion should not be understood as a synonym for pity, charity, sorrow... But rather, from a psychological point of view, it should be interpreted as the capacity to become aware of the suffering of other people, based on the knowledge of one's own suffering. Added to this is the commitment to try to reduce that suffering as far as possible, but at the same time, because it is not a matter of alleviating other people's suffering at the expense of one's own. This suggests that compassion involves empathy and is similar to

## 11. Thoughts on the future

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what is necessary to be able to empathise with suffering, since both terms imply identification with the feelings of others. Yet it goes beyond that, since in the case of compassion, there is the added intention to put an end to the suffering of the other.

Another thing is that the RAE [Royal Spanish Academy] dictionary defines compassion as “a feeling of pity, tenderness and identification with someone’s ills”. It includes pity along with the necessary identification and understanding of suffering. It does not regard it as an action between equals, nor does it include one’s own suffering. I believe, therefore, that this definition should be revised because it is the one that generates confusion, since compassion is not feeling pity or looking at others with pity from a feeling of superiority.

In short, I think that the word “compassion” needs to be changed in the dictionary and in collective thinking if we want to ensure that it is used widely in the future and does not have to undergo continual clarification every time we use it. Therefore, the sobering work of those of us who are committed to its use is indispensable, given that it is a genuine and irreplaceable word.

Let me now turn briefly to the future I foresee for compassionate communities.

In my opinion, the issue of community participation is key to ensuring societies characterised by social cohesion and the commitment of citizenship, of each citizen towards others.

For many years now in the UK, most palliative care services have prioritised “community engagement” initiatives, most commonly adopting a “compassionate community” model. To my mind, it is something that

## 11. Thoughts on the future

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should also be encouraged in the Basque Country, that it is established that there is a growing acceptance of compassionate communities by palliative care services. This implies new end-of-life care policies and practices. A new approach that encourages community involvement in supporting people and their loved ones throughout the course of the disease, through efforts in prevention, education, community support and advocacy, especially for the most vulnerable. After all, we are part of an interpersonal community of inherently fragile and suffering beings in need of mutual help.

And from my area of involvement, social services, I firmly believe in the imperative need to create a model of compassionate communities at the level of the Basque Country and each of its historical territories. Particularly with regard to Álava, we are setting up the ARABA VECINDARIO COMPASIVO network [ÁLAVA COMPASSIONATE NEIGHBOURHOOD network]. This network will be developed using the “bottom-up model”, i.e. from citizens and neighbourhoods committed to others, with institutional support, which should act as a decisive driving force for the network to become a reality.

It is the duty of political leaders to make a serious commitment to ensure that these networks that we are creating achieve considerable deployment in the future, involving the various social agents, combining efforts and providing them with the necessary sustainability (social and economic) over time.

We still have a long way to go, but at the same time, I would like to encourage everyone to appreciate how much has been done in our land in support of the deployment of Compassionate Communities. Its consolidation is everyone's responsibility. Let's make it happen!



—Eva Salaberria

**Head of the Donostia-San Sebastián Lagunkoia Citizen Plan. Donostia-San Sebastián City Council**

### **Compassionate environments in the Basque Country**

I'd like to begin these lines by thanking the Compassionate Cities movement, and in particular Naomi and Maider, for the meeting spaces that they are promoting in the Basque Country to share reflections and learn about care and the role of the community in end-of-life processes. Their work and perspective are a source of inspiration for people who, as is the case with Donostia Lagunkoia, think of care as a public value which, in a democratic society, defines the exercise of citizenship, and which, as a common good that spans the entire life cycle, must be recognised as a shared responsibility.

Donostia Lagunkoia is a city strategy promoted by Donostia-San Sebastián City Council to face the challenges and opportunities posed by the increase in life expectancy and the ageing of the population from a multifaceted and multidimensional perspective. We have structured the complexity that this perspective entails by grouping the challenges that we have considered unique and specific to our city into four axes. Specifically, with regard to care, in "A community that cares", the third of the axes, we developed a community action strategy that aims to promote dynamics that enable us to maintain links with the community to which we belong, and from there generate networks that facilitate the provision of support and

## 11. Thoughts on the future

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care when there are situations of isolation, frailty or lack of energy.

Given that our society is witnessing a change in family structures and the traditional model of organising care, previously provided in the family setting (specifically by women), and in which there are high levels of individual freedom and personal autonomy that we surely do not want to give up, at Donostia Lagunkoia we ask ourselves the following questions:

- How do we collectively formulate responses to the challenges posed by care, which is such an essential, ordinary and permanent dimension of our lives?
- How do we organise the provision of care and support when realities surface, such as loneliness, illness, lack of energy, or the risk of isolation and disengagement?
- What are the needs, desires and expectations of the people living in these situations?
- What is the role of the community and community-based approaches in improving the quality of life and well-being of older people when these realities occur?
- How can we build a realistic model that responds to the widespread desire and will to grow old and be cared for in normal surroundings, avoiding institutionalisation as far as possible?

I think there are some challenges in addressing these questions that I believe can be shared with the Compassionate Cities movement, in particular with regard to the need to define what we mean when we talk about the community. Community issues are increasingly on the agenda. We use the word, the concept, but with different meanings, not only in different projects, but also often

## 11. Thoughts on the future

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between people and agents working in the same ecosystem or initiative, with the resulting difficulties when interacting or developing joint initiatives.

It is clear that there are different ways of understanding the community, and community issues, and that these viewpoints are sometimes even relatively opposed to one another. However, it is also true that we don't tend to find "pure models", but more links, or mixtures between different visions. In any case, I think it is important to define, within the framework of any initiative that is to be developed in this field, exactly how it is understood by those who advocate it, on what basis this approach is founded and from where we drive the acknowledgement and acceptance of this collective dimension of society, which is required for the promotion of these collective practices.

Here at Donostia Lagunkoia, we believe that facing many of the social challenges (cohesion in a diverse society, organising care, interacting and coexisting in the public space, strengthening social capital, fighting poverty and social exclusion, committing to the sustainability of systems...) requires the development of collective responses (in collaboration!!), and overcoming the polarisation that has sometimes characterised the design and development of public policies. We therefore believe that community action must have a clear cross-cutting and multi-actor vocation, and that for this development to be possible and coherent, it requires the definition of a conceptual, strategic and values framework to guide and inspire all activities in this field.

Imbued with that challenge, I think that joining with other movements, such as Compassionate Cities, would give us all more strength and certainly a wider reach.

## 11. Thoughts on the future

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This is because we should not forget that incorporating this community perspective into policies and projects brings with it the idea that it is often not a question of having more resources but of doing things differently or doing other sorts of things. Putting community issues on the agenda offers us the opportunity to rethink together what we do and how we do it, to reflect on what is a priority, on what we should not stop doing and what we could do without. In short, an opportunity to rethink strategies, connect initiatives, join forces and complement actions. By basing the relationship and shared work between agents on principles of collaboration, interdependence, recognition, and reciprocity, we can undoubtedly gain in coherence and have a greater impact on improving people's quality of life and well-being.

A common and shared framework on the role of the community in the care system, generating alliances and complicities with other "components" of this system so that the dynamics of support that are created from different areas in local and daily life environments are also compassionate and recognise and interact with people in advanced illness and end-of-life situations, and their families and carers, are all in my opinion key to strengthening the community, developing citizenship and fostering social transformation.

Understanding the needs and desires of the people who are going through these situations and designing mechanisms that offer tangible responses and favour co-responsibility and empowerment, undoubtedly contribute to the achievement of the common good. I've found that it is worth exploring ways to make visible the strengths of people in need of ongoing care and support, and to promote, in accordance with their wishes and capacities,

## 11. Thoughts on the future

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their participation in developing responses to the challenges we face in relation to caregiving and caring for the vulnerable. We also need to know the motivations and interests of the communities in which these people live in order to identify together how we can (re)build supportive relationships today, and to devise, from these different perspectives, solutions that improve everyday life scenarios for everyone.

Ultimately, it's a matter of valuing the power of vulnerability and building care systems that recognise that it is an inherent fact of life and that we can all face this type of situation at any time in our lives. We need to generate images and narratives that enable us to recognise, accept, dare to show, and practise our own vulnerability. Accepting vulnerability as part of our condition as human beings, recognising the need we have for others, to be connected, to be accepted and understood by others makes us, as paradoxical as it may seem, stronger, resilient, empathetic, closer and more committed to ourselves and to the people around us.

Furthermore, I am convinced that working with this community perspective enables us to progress in a conception of public and common things as the shared wealth and responsibility of all, and to favour the confluence and interaction of the agents that share the spaces and environments of people's daily lives on the basis of interdependence and daily reciprocity. It makes it possible to overcome monopolies and rigid hierarchies, and to generate alliances for action based on the mutual recognition of capacities and limits. Local public services, associative structures, social organisations, private entities, commercial and economic agents, neighbours, technicians and professionals who share objectives and

## 11. Thoughts on the future

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act in a specific environment, with different roles and responsibilities... The community dimension as a strategy that can be used as a lever to overcome the silos and fragmentation that occur in the environments of people's local daily lives.

Through their reflections, the people who grow old in Donostia-San Sebastián show us every day that the community can be a real alternative in our twenty-first century society. Addressing these challenges requires raising the profile of vulnerability, claiming the importance of care in the sustainability of life, and imbuing public policies with actions that make the city a place that cares and allows for care at any time or in any situation of the life cycle.

Today, society is changing so radically and rapidly that we often do not know, nor do we really imagine, what kind of society will result from the social, economic and technological changes that we as individuals and society will have to manage. What role do we as a society want to give to care? Are we willing to channel the benefits of accepting and recognising the vulnerability of life, to put care at the centre of our actions and from there to weave community and contribute to social cohesion and inclusion?



—Roberto Nuño

Director of Deusto Business Health School

Basque society is ageing and family care is changing, creating scenarios of need and opportunity to give rise to emerging models of care, accompaniment and support based on visions of solidarity and compassion. This report represents a formidable effort to listen to citizens in order to make the invisible visible and to promote the advancement, integration and consolidation of compassionate environments in the Basque Country. The social fabric and network that sustains these compassionate spaces is not delocalisable and represents a unique human and relational capital for the emergence of social innovations that contribute to individual and collective well-being. Let's keep up the momentum in this direction.



—Patxi del Campo

Vivir con Voz Propia [Living with a Voice of Your Own],  
Vitoria-Gasteiz Compassionate Community

### **BASQUE COUNTRY COMPASSIONATE COMMUNITIES NETWORK**

When the different compassionate communities in the Basque Country met for the first time, it was clear to us

## 11. Thoughts on the future

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that the first step was to accompany each other in order to provide accompaniment. We found ourselves in compassionate conversations that gave strength to each of the experiences we shared.

Our compassionate communities undertake projects that aim to become involved in the care and accompaniment of people in situations of suffering and vulnerability (advanced illness, loneliness, end-of-life processes, etc.). The key is to recognise the importance of community-led action. Our network's task is based on the search for each community's own strengths and ideas in order to generate local credibility and awareness, building emotionally intelligent relationships (from the inside out), being compassionate, helpful and approachable.

The intention is to use a natural language, familiar to the experiences of each individual, with easy and accessible actions so that any member of the community can get involved in actions that make it possible to provide accompaniment and to be accompanied.

We propose a social change of the care model based on compassion and space where the synergy between each of the community initiatives amplifies its effect. As Gonzalo Brito notes: Making an analogy between communities of neurons and communities of people, between neural connections and social links, and between individual minds and culture, I would propose the term compassionate socioplasticity...The influence of change in some people's mindset, behaviour and ways in which they relate to each other generates local change that can be translated into changes in the collective mind (the culture) of organisations and communities, which in turn can shape compassionate change in other organisations and communities.

## 11. Thoughts on the future

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We want to strengthen and create a collaborative community culture that is safe, enabling as many people as possible to participate while fostering a sense of community ownership. We see the need to value shared humanity so as to generate solutions based on shared wisdom.

Our aim with compassionate communities is not to create services but to create activities in which people meet other people and generate an interdependent network to sustain ourselves.

We want the initiatives of the Compassionate Communities to be places of contact, where loneliness, suffering and vulnerability enable words, looks, gestures and silences to be exchanged in order to alleviate our own and other people's suffering.



—**Silvia Librada Flores**

**Director of New Health Foundation's Compassionate Communities Programme**

**Developing compassionate communities begins with each and every one of us.**

In terms of the development of Compassionate Cities, especially those that have successfully implemented community intervention processes and have demonstrated the benefits of these interventions in improving the quality of life and well-being of people with advanced illness and end of life, reducing loneliness, increasing care networks, reducing caregiver overload and increas-

## 11. Thoughts on the future

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ing the satisfaction of family members, there are still many aspects that need to continue to demonstrate results.

The future of Compassionate Communities will come from a real social change that involves citizens in their relationship with care, compassion and the community and healthcare systems that manage to establish an integrated model of health, social and community care to improve the quality of life and well-being of people with advanced illness and at the end of life, as well as their families.

Finally, there are two fundamental aspects to think about when developing Compassionate Communities and Cities Programmes:

Making progress in the conceptual delimitation of what should be the role of public and private institutions in the organisation, management, implementation and evaluation of Compassionate Communities.

Making progress in community intervention processes and further measuring their impact in terms of clinical effectiveness, loneliness, satisfaction, community involvement and cost-efficiency for the healthcare system: effective reduction of hospital admissions, hospital stays, emergencies and other hospital-related expenditure.

## 11. Thoughts on the future

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—Joan Berenguer

Director, Fundació Mémora

—Francesc Rillo

Project Coordinator, Fundació Mémora

At Fundació Mémora, we have worked on the development of a city model that prioritises the care of people, which we have called “Ciudades que Cuidan” [Caring Cities].

These are friendly, compassionate, smart and healthy cities, where at the heart of the model is the concept of “caring” as the soul of the new city.

In this context, we have promoted a forum for debate in different fields of knowledge, reflecting on the idea of a caring city, focusing on a caring society [www.ciudades-quecuidan.com](http://www.ciudades-quecuidan.com). Our “Ciudades que Cuidan” initiative aims to facilitate the paradigm shift from producing to serving and from competing to caring. Now is the time for deep reflection and action.

## 11. Thoughts on the future

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—Teresa García Oviedo

Asociación Ecivis Getxo. Association for the Promotion of Active Citizenship

### **Compassionate environments, empathy in action.**

Although it does not appear in the RAE, the definition of compassion that I love the most is empathy in action. These two words together and combined seem to me to be like “a shot” full of change, of dynamism, of actually doing something. Putting compassionate empathy into action is like the executive intelligence that José Antonio Marina, one of the people I most admire, talks about, enriching it even more by adding empathy towards other people.

That definition, empathy in action, was made by another of the people I also admire on a personal level. A few days ago, I invited eCivis to the online meeting where the results of the project “Compassionate environments in the Basque Country”, 2017-2019, were presented. It is a project that has been undertaken with the collaboration of the Agirre Center and the UPV with its very evocative and empathetic title. So, there we were engaged in the listening process – the same process used to develop the project. Empathetic, assertive listening. That methodology was applied in care-related ecosystems and resulted in 60 narratives in seven localities in three territories. It was also clearly identified that the same person can have several narratives.

Just because it is obvious, it should not be overlooked

## 11. Thoughts on the future

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– it should be mentioned and emphasised. Care still has a woman's name – until when? This is why it has been proven that the same person, a woman, can have several narratives. A doctor has a narrative on a professional level and as a caregiver on a personal level. After all, if you look at it from another angle, it's not two, it's just one prolonged narrative – care and more care.

Now, two years into the project, the new challenge is to actually build compassionate environments through concrete actions. Right there, where the action begins, is where I love being involved. The first phase was a diagnosis, a photo, the existing landscape. The second is, perhaps, that in the process of building, something has to be deconstructed. This demolition could include eliminating the current connotation of compassion associated with charity. That's where it'll start. It will continue with the definition of specific actions. This society has yet to respond to people, especially those who are lonely. Empathy in action, por favor!

# 12. Conclusions

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The objectives of this report were to determine what kind of specific needs compassionate environments require in the Basque Country and to co-design with public, private and academic entities and civil society agents possible solutions to expand and scale up this type of initiative in all Basque territories. As detailed in the report, an exhaustive mapping of the current situation was developed, complemented by a listening process among the most relevant agents.

This report has identified more than a hundred community initiatives that attempt to complement existing social services. These initiatives are highly valued by people and families who find themselves in situations of loneliness, advanced illness or death. There is extensive scientific evidence on the value of social support networks. For this reason, compassionate communities may become the new social network that accompanies lonely or sick people during the last stage of their lives.

There are many people in the Basque Autonomous Community who are alone, sick or with a very limited family and social network and find themselves in situations of dependency, palliative care, end of life, death and bereavement. These situations are amplified by the process of population ageing and the crisis situation caused by the COVID-19 pandemic. Given the complex nature of the problems related to advanced illness, loneliness and death, it is impossible to find a solution that is exclusively health-related or linked to existing public services. As an alternative, compassionate communities aim to build a system alongside existing services that is decentralised and self-organising.

There is extensive scientific evidence on the value of social support networks. For this reason, compassionate

## 12. Conclusions

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communities may become the new social network that accompanies lonely or sick people during the last stage of their lives.

The report has focused on gaining a better understanding of the perceptions and motivations of the people who drive these communities and the individuals and families who call for their support. This information can be very useful to create a real connection between the efforts of the different administrations and social initiatives. Basque institutions have a wealth of quantitative and qualitative data on these issues at their disposal, but this report has tried to complement this information with the perceptions that we often do not voice but which condition the impact of public policies and community actions. These perceptions have been collectively analysed and have enabled us to identify a series of concrete actions that can help to empower these communities.

The working process for the collection of narratives involved the following steps:

- Design of the process for collecting and managing narratives.
- Collection of 90 in-depth narratives on compassionate communities in pilot municipalities in the Basque Country with different contexts, population levels and lifestyles in the historical territories of the BAC: Vitoria-Gasteiz, Amurrio, Donostia-San Sebastián, Zarautz, Orío, Mungia, Bilbao, Getxo, Bidasoa.
- Analysis and extraction of narratives, challenges, opportunities, barriers and enablers.
- Segmentation of information into profiles on the basis of unified narrative patterns and behaviours. This infor-

## 12. Conclusions

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mation was used to better appreciate the different ways of understanding the same reality in the Basque Country and to propose a range of interconnected solutions.

These profiles correspond to multiple voices and represent patterns of narratives that have been repeated. If these narratives relate to caregiving, we have given them the character of a woman caregiver. If these narratives relate to the public sector at different levels, they have been attributed a similar profile. This does not mean that they represent the unified narrative of the public sector, young women or migrant women. They represent a functioning narrative, and the set of profiles aims to visualise the set of existing narratives concerning end-of-life care and compassionate communities in the Basque Country.

Once the identified narratives (structured in profiles or archetypes) had been contrasted, we moved on to a phase of co-creation of possible initiatives that could reinforce compassionate environments (while at the same time responding to the different perceptions and needs identified). Death Cafés, grief spaces, the possibility of supporting networks of “community influencers”, awareness-raising programmes in educational centres, groups of “super heroines”, community social brokers, the redesign of funeral services and other socio-health services, as well as the possibility of promoting a palliative care law form a portfolio of interconnected initiatives (innovation portfolio) that is a good starting point for providing content and an operational plan for the potential compassionate communities of the future in the Basque Autonomous Community.

These initiatives present a first experimental space that the Basque Government could support on an experimental basis in different localities of the territory. The combi-

## 12. Conclusions

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nation of these and other similar initiatives could generate a shared strategy to foster this type of compassionate environment. Fundamentally different from a traditional approach, these initiatives are understood as interconnected prototypes. The fundamental objective is to learn as they develop and to analyse how they reinforce each other. These early communities could be identified as spaces of advanced experimentation.

The fundamental dilemma lies in how we understand the public services of the future. Looking at it from a more traditional perspective, we are tempted to differentiate between public service and community action. However, the most progressive international trends and emerging practices in Basque society described in this report speak of new models in which public services are naturally complemented by the community sphere. This interaction can help shape a new Basque model of “care” in its broadest sense, but it requires reinventing many of the existing structures, roles and regulations. This is a complex challenge, which no single institution or social entity can tackle alone. For these reasons, compassionate communities are a space for experimentation and the generation of shared knowledge that can help to weave together these new alliances.

The people, organisations, companies and institutions we have spoken to have suggested very specific actions: establishing early warning systems, creating systems in neighbourhood communities so that these people feel accompanied (that their neighbours take an interest in them), providing support in basic domestic tasks (shopping, recycling, etc.) or taking advantage of tools such as WhatsApp groups to send direct messages, specific to a particular area and in real time to citizens. All these ini-

## 12. Conclusions

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tiatives are aimed at increasing the feeling that people in your community care about you all the time, not about an inundated phone line.

The messages are clear:

*“population ageing is already here; it’s a major challenge”, “the system is not going to be able to cope with everything; people also miss having access to friendly treatment; they feel invisible and miss community networks.” “If we are able to develop good care programmes for carers, to complement what is already there, it would be a great approach.”*

The main problems we have identified concern shortcomings in the flexibility of legal structures to combine public response and community action.

*“Joining together is all about sharing, we have experience that we can share and they can bring us new things.” “I think it would be the most effective thing to do, and I think it will eventually happen. But it takes time, you have to give it time. This is a total cultural change, a very powerful one, to move from individuals grieving in privacy to creating another ecosystem. “I think a lot of things are seen from the public side as different competences, but they are interrelated. We have to go to the Basque Government and talk to them, work with them as they see fit, and we need resources.” “We need community partners. The aim is not just about doing, it’s about engaging, encouraging participation... But that requires taking some risks and changing some ways of doing things.” “It has to be revolutionary in the sense that it will have to break the mould*

## 12. Conclusions

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*and fight precisely against some of the structures of the administration.”*

In the co-creation sessions, we identified the need for an entity that coordinates the different agents, both social and administrative, so that there is a better relationship between them and so that they can see the real needs of each person. It is therefore essential to identify the variety of existing profiles so that resources can reach them more efficiently.

“There is a profile of women of sixty-something who have been taking care of their families, their parents, their children all their lives. Then when their children get older, they don't know what to do because they have never had time for themselves, and they drop out of the picture.” “I have the feeling that we work with only one type of profile, simply by opening that up, by considering more possibilities, more dimensions, we can move forward.”

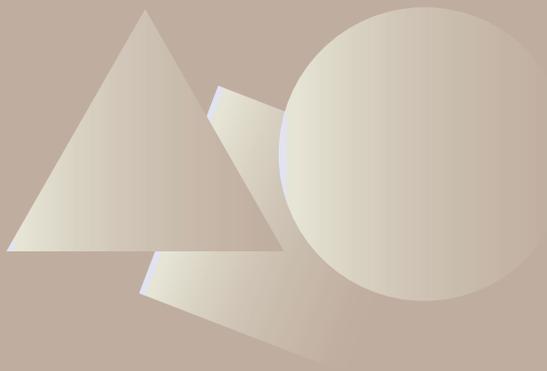
There are two possible future scenarios. On the one hand, a scenario in which individualistic narratives take on greater importance and people try to resolve their own personal or family situation. Or on the other hand, a scenario in which collective narratives take on greater relevance, in which we value the collective effort to face the great challenges that confront us and in which the community regains a central role in everything we do.

Bearing in mind that no one has all the knowledge and that it is not possible to respond to this situation in isolation, Basque society must create the necessary spaces to create a collective intelligence strategy. The role of

## 12. Conclusions

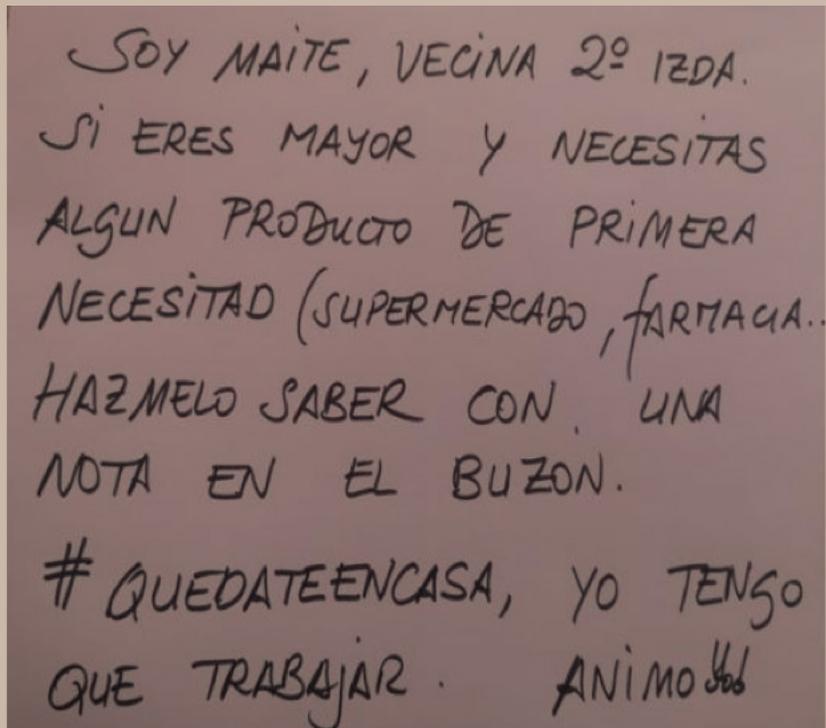
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institutions is changing. Nobody expects them to provide the solution to all the problems any more. From now on, we will ask the institutions to generate the necessary meeting spaces so that, in close collaboration with social partners and citizens, we can develop this new collective intelligence.



## 12. Conclusions

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SOY MAITE, VECINA 2º IZDA.  
SI ERES MAYOR Y NECESITAS  
ALGUN PRODUCTO DE PRIMERA  
NECESIDAD (SUPERMERCADO, FARMACIA..  
HAZMELO SABER CON UNA  
NOTA EN EL BUZON.  
# QUEDATE EN CASA, YO TENGO  
QUE TRABAJAR. ANIMO <sup>👏</sup>

*I'm Maite, the neighbour from the 2nd floor on the left.  
If you are elderly and you need some basic necessities  
(supermarket, chemists, etc.), please leave a note in my  
mailbox. # STAY AT HOME. I have to work. Chin up!*

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# 14. Annexes

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## 1) Mapping

In addition to the mapping, a questionnaire was sent to the different care networks and solidarity initiatives, with special emphasis on community initiatives promoted by the municipalities. The questionnaire was sent in Basque and Spanish, using Google Forms, and included the following content and questions (11):

### **Mapping of COVID-19 solidarity initiatives and community networks**

There have been hundreds of community initiatives to help citizens during the COVID-19 pandemic. The aim of this questionnaire is to map the care initiatives and networks that have emerged in the Basque Autonomous Community, regardless of who instigated them (citizens, city council, Gaztetxe, Asociación Tiempo Libre [Free Time Association], foundations, neighbourhood associations, NGOs, collaborative city council-citizen initiative...).

Thank you in advance for answering this questionnaire,

- Name of the municipality/neighbourhood
- Name of the community initiative
- How did citizens get in touch with you? (Please write down the email or phone number that you made public so that citizens could contact you.)
- Why did you start the initiative and what needs did you identify?
- How many citizens got in touch with you?

- How many people were involved in the community care network or initiative?
- Do you intend to continue the initiative once COVID-19 is over?
- What were the obstacles and difficulties you encountered, and where did these difficulties originate?
- Did you have support, for what, and where did that support come from?
- Do you know of similar initiatives in your environment, if so, which ones?
- Other information of interest.

From among the 31 initiatives that completed the questionnaire sent out, 29 are community-based and only two initiatives can be defined as services. By contrast, there are no small-, medium- or large-scale initiatives, nor have we found that any of the initiatives have led to new legislation.

Among the information that can be seen in the table that compiles the answers to the questionnaire, it is reflected which agents (civil society, private sector, public sector, associations...) participated in the initiative, as well as whose initiative it was. In some cases, the initiative was undertaken by more than one agent.

## 14. Annexes

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### 2) Getxo Zurekin network: Key Agents and Resources

#### • ASSOCIATION

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##### **AECC Bizkaia**

##### **Sarekide**

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##### **Esclerosis Múltiple**

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## 14. Annexes

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#### **Igurco. Aiboa**

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#### **Igurco Estartetxe**

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