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List of Abbreviations

ACS	Acute Coronary Syndromes
ADI	Assistenza Domiciliare Integrata
ADL	Activities of Daily Living
ASP	Azienda Pubblica Servizi all Persona – Public Company for Services to the Person
AUSL	Azienda Unità Sanitaria Locale
BOTs	Brussels Thuis Overleg (Belgium)
CGA	Comprehensive Geriatric Assessment
CHD	Chronic Heart Disease
CHF	Congestive Heart Failure
CNS	Clinical Nurse Specialist
COPD	Chronic Obstructive Pulmonary Disease
CreG	Chronic Related Group project
CSO	Central Statistics Office
CSSDs	Centres de Coordination de Soins et de Services à Domicile (Belgium)
ED	Emergency Department
EIP-AHA	European Innovation Partnership on Active and Healthy Ageing
ESD	Whole System Demonstrator
ESF	Electronic Health Record (Italy)
EU	European Union
FSE	“Fascicolo Sanitario Elettronico” (Electronic Personal Health Record)
GC	Guided Care
GP	General Practitioner
HISC	Home Instead Senior Care
HSE	Health Service Executive (Ireland)
ICPs	Integrated Care Programmes
ICT-AT	Information Communication Technology – Assistive Technology
IHCA	Integrated Home Care Assistance project (Italy)
INPS	National Institute of Social Security (Italy)
ISHC	Integrated Services for Home Care (Belgium)
KCE	Federaal Kenniscentrum voor de gezondheidszorg



LHTs	Local Health Trusts (Italy)
MAB	Maximum billing system
MDT	Multidisciplinary team
NHP	National Health Plan (Italy)
NHS NICE	National Health Service National Institute for Clinical Excellence
NHS	National Health Service (Italy)
NKP	Vlaams-Nederlands Netwerk Klinische Paden
OT	Occupational Therapist
PAI	Personalised Care Programme (Italy)
PCAP	Community based Sanitary Primary Care Team (Italy)
PCCC	Primary, Community and Continuing Care (services)
PCT	Primary Care Team
PDTA	Percorsi Diagnostici Terapeutici Assistenziali (Diagnostic Therapeutic Assistive Pathways)
PwD	Persons with dementia
QA	Quality Assistant (Home Instead Senior Care staff, Ireland)
QoL	Quality of life
RCT	Randomised controlled trial
SAD	Servizio di Assistenza Domiciliare
SELS	Cooperation Initiatives in front-line health care (Belgium)
SGS	Specialist Geriatric Services
SOLE	“Sanità On Line” (“Health Care On Line”)
TILDA	The Irish Longitudinal Study on Ageing
UASS	Social-Sanitary Units at District level (Italy)
US	United States
USSI	Integrated Social-Sanitary Units (Italy)
UVM	Multidimensional Assessment Unit (Italy)
WHO	World Health Organisation
WIV-ISP	Belgian Scientific Institute of Public Health



Executive Summary

The overall aim of ProACT is to develop an open web application programming interface (API) ecosystem to integrate a wide variety of new and existing technologies to pull, aggregate and analyse data for the purposes of higher order inference, to improve and advance integrated care for multimorbidity (including associated comorbidities). The ecosystem will connect four key care and support models central to understanding and implementing effective, continued and coordinated patient centric care (including self-management). **These models are:** 1) homecare (including informal care) 2) hospital care 3) community and social care and 4) social support networks. The **objectives** of this deliverable are to:

- *Identify the **key stakeholders** to engage with during the requirements gathering phase;*
- *Identify and understand **care pathways** of the patient with multimorbidity; and*
- *Understand the **challenges** in supporting patients with multimorbidity along these pathways*

This deliverable describes the process undertaken to meet these objectives across 2 EU countries in which ProACT pilots will take place – Ireland and Belgium, as well as in the Emilia-Romagna Region of Italy, where at a later stage a small pilot will occur in the framework of a transferability study. The methodology included desk-based research as well as interviews and focus groups with some of the identified key stakeholders.

Key Findings

1. Current level of integration of healthcare services (both horizontal and vertical) and of healthcare and social care is limited, though it is a priority for health care systems and governments across all 3 countries.
2. The GP is apparently the most obvious and accessible primary source of care coordination for people with multimorbidity living in the community. However, short consultation times, the complexity of multimorbidity management and limited guidelines on treating people with multimorbidity can prevent effective case management and a thorough review of treatment plans, medications etc.
3. Geriatricians and/or multidisciplinary specialist teams, where they exist, are thus a key referral for those older adults with complex needs (including multimorbidity) across all 3 countries.
4. Development (and updating) of a personalised care plan is also a critical component of the pathway for a person with multimorbidity. It should take into account the person's full medical history (including co-morbidities), their social / environmental situation, patient choices and preferences for treatment and patient goals. However, there is often no single care plan developed for and with patients that is accessible by all relevant stakeholders.

5. The development of a digital platform for integrated care has the potential not only to support existing practice, but also to improve the management of a complex and integrated care plan, introducing new ways of collaboration between key actors.

We have begun to identify the network of, and determine the connections, collaborations and alignment between stakeholders involved in caring for older people with multimorbidity. Understanding the care pathways and challenges in achieving the key milestones in care, will support us in building an integrated care ecosystem to support individuals living with multimorbidities. This deliverable document will be updated as our scoping and requirements gathering phase continues.



1 Background - Integrated Care Systems for Multimorbidity

The European Union (EU) faces strong concerns over the sustainability of health services due to the increase in healthcare expenditure, as well as disparities in the number of practising health professionals. 70-80% of healthcare costs are spent on chronic diseases, which corresponds to €700 billion in the EU, while an estimated 50 million people in the EU live with multiple chronic diseases, which deeply impact quality of life (Rijken et al., 2013).

Presently health systems across the EU focus on supporting a single disease framework of care; the primary challenge is to create a patient centric integrated care ecosystem to understand and manage multimorbidity (defined as the presence of two or more disorders and associated comorbidities) (Rijken et al., 2013). For patients with multimorbidity services are often repetitive (multiple appointments), inconvenient, inefficient (patients may see different clinicians who give conflicting advice), burdensome and potentially unsafe due to poorly integrated and coordinated care (Starsfield et al, 2005). This significantly impacts on reducing patient quality of life (QoL). In addition these patients may take a large number of medications, which can be difficult to remember with some combinations potentially dangerous. There is a need to improve best practice around the provision of continued, well-coordinated, person-centred care for individuals with multimorbidity. Another key challenge in achieving this is to empower the home dyad of the individual with multimorbidity and their primary informal carers to play an active role in self-management and care practices to improve quality of life for both.

Frailty is an issue that is central to ageing, transcending specific diseases and compromising quality of life (Rockwood & Mitnitski, 2007). By the age of 80, approximately 40% of older adults have some degree of functional decline, and 6% to 11% of older people are considered frail (Bandein-Roche *et al.*, 2006). The prevalence of frailty in community-dwelling older Europeans (aged >65) varies between 5.8% and 27.3%, and is about 22% in community-dwelling older Americans (aged >60); in addition, between 34.6% and 50.9% are classified as 'pre-frail' in Europe (Santos-Eggiman *et al.*, 2009), and 28% in the US (Smit *et al.*, 2013). In 2012, the European Innovation Partnership on Active and Healthy Aging (EIP AHA) launched its action plan '*Prevention and diagnosis of frailty and functional decline, both physical and cognitive, in older people*'¹. This action plan highlights frailty and the ensuing vulnerability of frail older adults as a growing multidimensional health and social care challenge across the EU, associated with increasing health care costs, and increased risk of physical, cognitive, and functional decline and adverse health outcomes. It discusses how frail older adults are at high risk of increased use of community resources, hospital, and long-term care institutions, and that attention should be paid to "prevention, screening and early diagnosis". A systematic review by Ryan et al (2015) examined 37 studies on multimorbidity and found evidence that indicates multimorbidity predicts frailty and functional decline. Patients with higher numbers of diseases and greater severity experience greater decline. Thus it is important to target function, and not only disease, in older adults with multimorbidity.

¹ http://ec.europa.eu/research/innovation-union/pdf/active-healthy-ageing/a3_action_plan.pdf



1.1 Integrated Care

The World Health Organization (WHO, 2011), describes integrated healthcare systems as designed to manage and deliver health services so that 'clients' receive and perceive a continuum of health promotion, protection and disease prevention services, as well as diagnosis, treatment of long-term care, rehabilitation and palliative care services, through different levels and sites of care within the health system according to their needs. Traditionally, integrated care has been fragmented. An analysis by Frost & Sullivan (2014) identified the key elements of traditional healthcare systems, indicating how these need to evolve to become integrated. This includes moving from: a provider-centred to patient-centred model of healthcare; individual expertise to collaborative or multidisciplinary approaches; one-size fits all care to personalised care; hospital-based to community-based care; disease treatment to prevention and; healthcare professional expertise to data-analytics driven care.

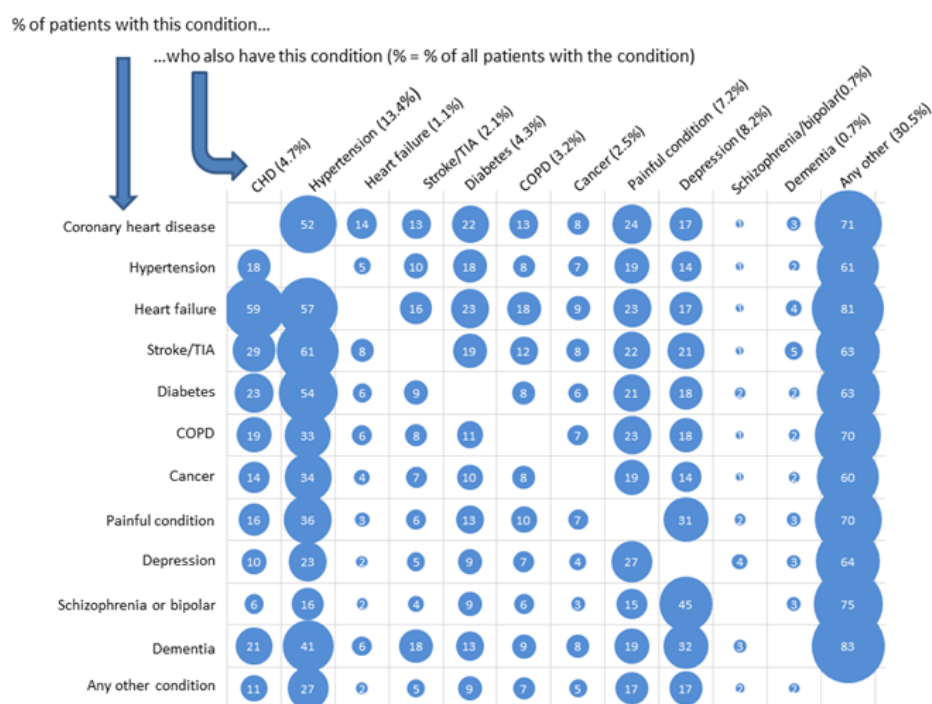


Figure 1.1: Correlation matrix of disease conditions (Barnet et al., 2012)

There are limited studies on effective models to manage and support integrated multi/comorbid disease care. Those available focus on self-report by older people or hospital populations and indicate that multimorbidity is correlated with increased age (Salisbury, 2011), reduced function (Kadam, 2007), increased inpatient admissions (Salisbury, 2011) and reduced socio-economic status (Marmot 2005; Walker 2007; Salisbury, 2011). Figure 1.1 shows key outcomes from a recent multimorbidity study (Barnet et al, 2012) with data collected from 1,751,841 people in 314 medical practices in Scotland, complimenting WHO (2011) findings to show Chronic Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD) and Diabetes as significantly linked disease conditions with related comorbidities (e.g. hypertension). The 2013-2016 ICARE4EU project

(<http://www.icare4eu.org>) seeks to address understanding of EU research being conducted into integrated multimorbidity care and has analysed innovative approaches in 30 multidisciplinary test projects. The programme supports the EIP AHA programme and was co-funded by the Health Programme of the EU 2008-2013².

ICARE4EU states the following two urgent EU key challenges, which need to be addressed:

(i) Most current care delivery models are disease-specific and not adapted to the needs of the growing number of people with multimorbidity and (ii) Chronic illness care places a high burden on financial and human resources. The programme recommends that to tackle these challenges innovation is needed to provide “good quality care with limited resources”. Care should be patient centric, integrate health and social care, use new technologies, support self-management, improve collaboration with family carers, meet the complex needs of multimorbidity, and prioritise and integrate treatment across a range of care and services.

Most progressive integrated care approaches have been developed in the United States (US) to incorporate new models of healthcare with management responsibilities divided between administrators, third party providers and health professionals. The EU however is seeing change, with greater emerging public-private sector collaborations on integrated care being developed. Recent EU integrated care programmes include;

‘Polypathology (Spain)’ (Rijken et al, 2013): Highlighted that care for multimorbidity is difficult to plan and coordinate as a result of exacerbations and additional comorbidities. The programme led to **organizational re-design** in which patients manage their care in collaboration with internal medicine specialists, family physicians and nurses to improve continuity of care, workflows and best clinical practice supported by an Information-Communication Technology – Assistive Technology (ICT-AT) system.

‘CasCo (Netherlands)’ (Versnel et al, 2011): Developed for patients with comorbidities linked to Type 2 diabetes, adopting the **Guided Care (GC) model** to design a case management care programme for primary care settings with practice nurses acting as case managers, who aim to coordinate all care for patients enrolled in different single-disease management programmes, drawing on evidence based optimal care to systematically manage all of the patient’s conditions, tailored to the patient’s preferences. Unfortunately results are yet to conclude effectiveness.

‘Whole System Demonstrator’ (WSD) trial (UK) (UK Department of Health, 2011): The world’s largest randomized controlled trial (RCT) of telehealth and telecare, involving 6,000 patients and 238 General Practitioner (GP) practices and patients with CHF, diabetes and COPD. Findings indicated a 45% reduction in mortality and 20% reduction in emergency admissions, with a 15% reduction in accident and emergency visits, elective admissions and bed days. Their model involved a hospital In-Reach team consisting of nurses who plan the return home for patients and identify the support they may need, who can be discharged early and supported at home using telehealth. The two main levels of support are (1) those with complex needs have a set top box to send readings, complete questionnaires and watch videos; (2) those with simpler needs use “Flo Simple Telehealth”³ whereby mobile phones are used to text message and collect patient observational data with advice and guidance. The **aim was to find a cheap, simple, easy to learn solution to help engage,**

² <http://ec.europa.eu/health/programme/policy/2008-2013/>

³ <http://www.getflorence.co.uk>

educate and empower patients to manage their own care. However the WSD **was limited by the closed nature of the system, which was not flexible to business transformations in the health service.**

1.2 ProACT Approach

Barriers to integration are not only clinical and technical, but include cultural and organisational resistance to change. Therefore research on new models of care should include understanding of organisations that respond to the complexities of multimorbidity care (within cultural contexts) effectively and efficiently.

To this end, one of the primary objectives of ProACT is to identify the network of, and determine the connections, collaborations and alignment between stakeholders (individuals and organisations) within an integrated care ecosystem to support individuals living with multimorbidities. An understanding of these issues within the ProACT trial sites is essential, as is an understanding of how they relate to the wider EU context. The authors of this report undertook desk-based research to investigate individual country contexts, and held meetings, interviews and/or focus groups with key stakeholders where a more thorough insight was required. The focus was to:

1. Identify the key stakeholders of ProACT in order to engage with them as part of the requirements gathering process, and gain an initial understanding of their role in the care ecosystem, their values and how they may benefit from ProACT.
2. Understand the care pathways of patients with multimorbidity and associated complex health needs between home, primary care and hospital/specialist care; communication amongst relevant stakeholders along these pathways; barriers to access of care; inefficiencies within the system; critical information and decision points.
3. Understand the key challenges faced by stakeholders along these pathways.

The remainder of this document is structured as follows. The following section highlights the common methodology employed across all three pilot countries (Ireland, Belgium and Italy). Sections 3-5 outline the healthcare context of these countries, including a health status overview as well as a description of the respective healthcare systems and policies relevant to ProACT. Sections 6-8 present our findings regarding stakeholder mapping, care pathway mapping and key challenges respectively. Finally Section 9 discusses the implications of our findings for creating the ProACT ecosystem.

2 Methodology Overview

The methodology used in producing this deliverable is outlined in Figure 2.1 We began with desk-based research to review the literature on multimorbidity (including co-morbidities e.g. indicators around frailty) and integrated care for older adults. An analysis of healthcare policy in each pilot country relevant to these issues was performed, as well as a review of national documents describing general care pathways for older adults as well as pathways for the chronic diseases of relevance to ProACT. These steps helped to identify the primary stakeholders of ProACT and their role along the patient's care pathway. Given the limited focus of national policy across all three countries on integrated care pathways for multimorbidity, interviews with relevant stakeholders were held to gain further insight into challenges experienced along the existing pathways, in terms of caring for those with multimorbidity and complex needs. These will be augmented as part of ProACT's specific requirements gathering task (T1.2 Months 1-9).

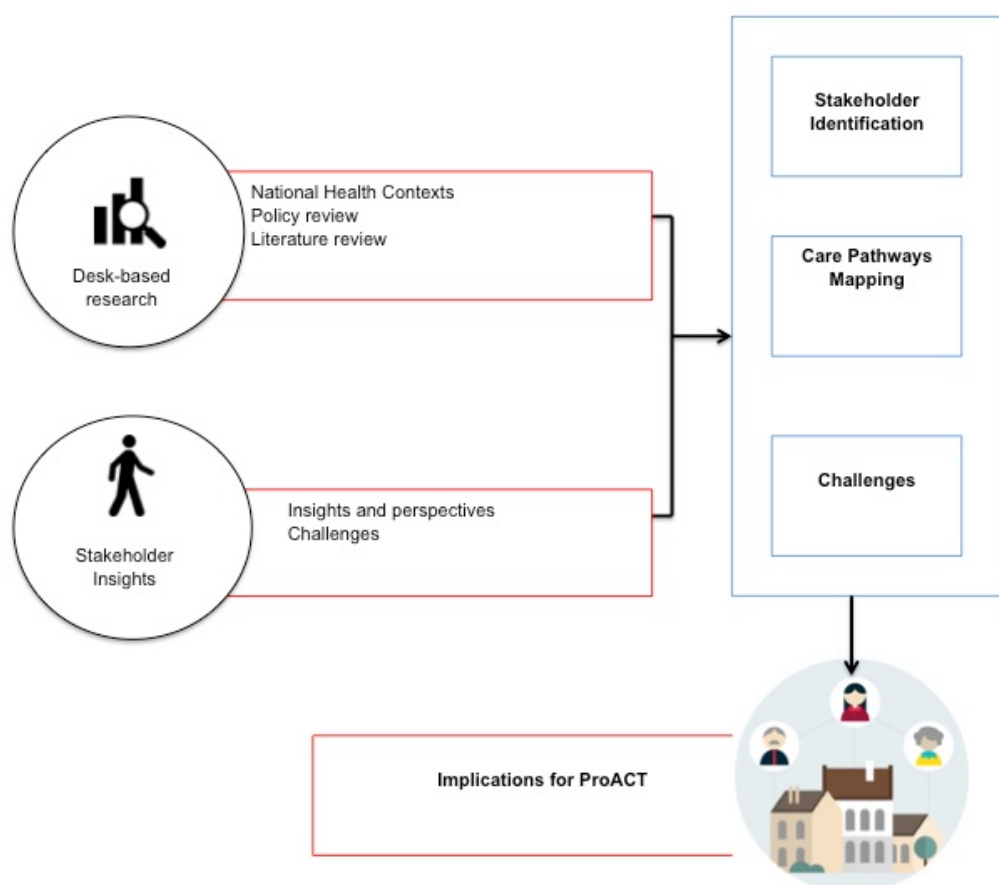


Figure 2.1: Overview of methodology across pilot partners

This research is presented in the following sections.

3 Healthcare Context – Ireland

3.1 Health Status Overview

In Ireland, the number of people aged 65 and over grows by 20,000 each year. Ireland's ageing population growth is much higher than the EU average (Figure 3.1). Between 2011 and 2025, the over-65 population will increase by approximately 54%, while the number of over-85s will double. A 2013 Census report by the Central Statistics Office (CSO) projects that the number of people aged 65 and over in Ireland will increase from 532,000 in 2011 to between 850,000 and 860,700 by 2026 and will be close to 1.4 million by 2046 (CSO Ireland, 2013). A more dramatic increase is expected in the number of people aged 80 and over, increasing from 128,000 in 2011 to between 484,000 and 470,000 in 2046. This will result in a significant change in the structure of the Irish population (Figure 3.2). From 2006 to 2026, within the 65 and over age group, the dependency ratio is expected to increase from 16.4% to 25.1% for Ireland (CSO Report, 2007). The health statistics released by the Irish Department of Health indicate that average life expectancy of the Irish population has grown by 10 years over the past 50 years (Dept. Health, 2005) and is now above the EU average. Life expectancy for men is 83 years, while it is 85 years for women (Dept. of Health 2013). Healthy life years at age 65 is 11 for men and 12 for women (Figure 3.3).

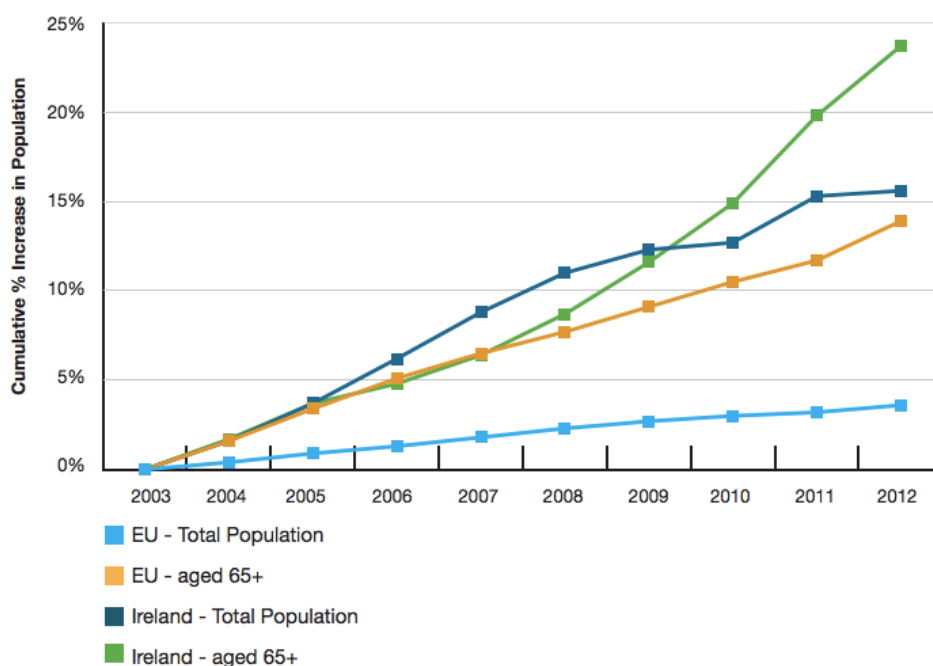


Figure 3.1: Cumulative percentage increase in population, all ages and aged 65+, Ireland and EU, 2003 - 2012 (Source: Eurostat)

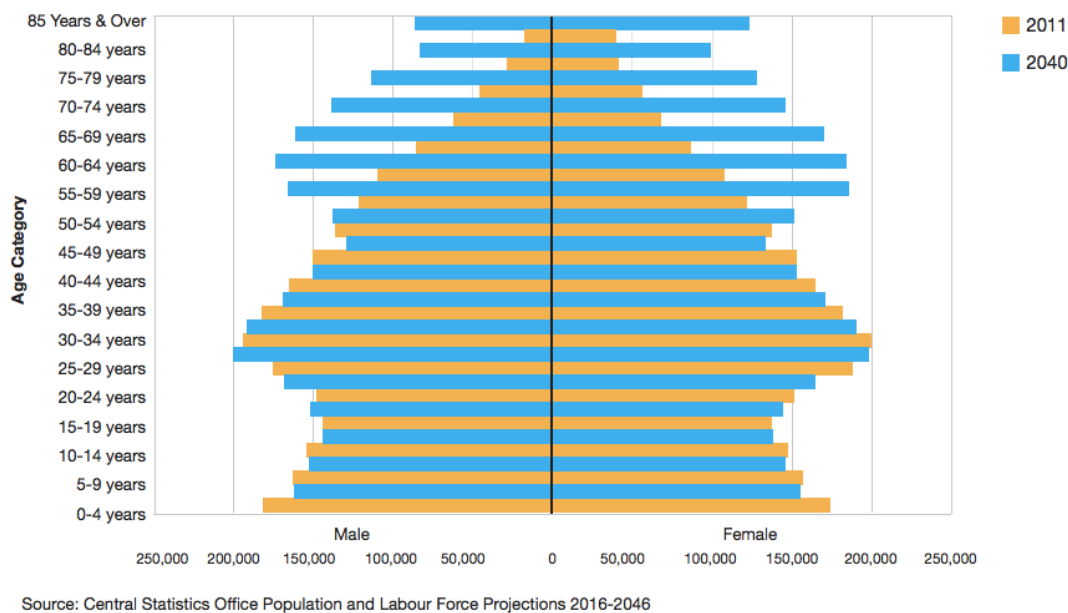


Figure 3.2: Ireland actual population 2011 and project population 2040 by gender and age group

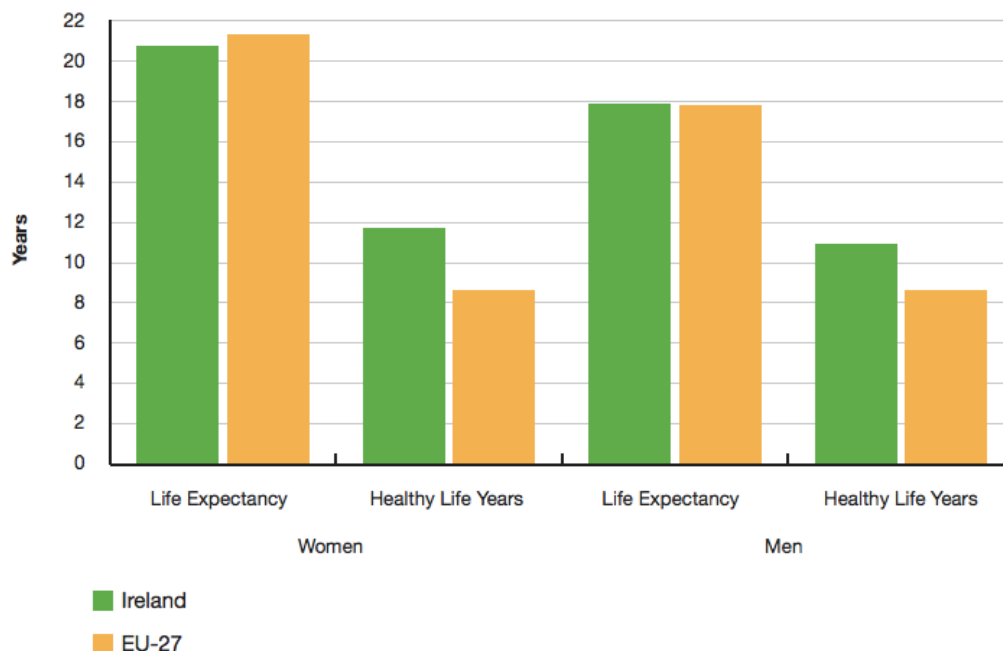


Figure 3.3: Life expectancy and healthy life years at age 65, male and female, Ireland and EU, 2011 (Source: Eurostat)

There has also been significant growth in the number of people living with chronic illness – between 2007 and 2020, incidences of chronic disease are expected to rise by around 40% (Balanda et al., 2011). According to Ireland's Health Service Executive (HSE), 38% of the

Irish population report having a chronic disease and half of all people over 50 have at least one chronic disease. This rises to 62% for those over 65. Chronic diseases are responsible for about 76% of deaths in Ireland. In 2011, 2 out of 5 hospitalisations were due to the four main chronic diseases – cancer, cardiovascular disease, respiratory disease and diabetes. Chronic disease accounts for approximately 80% of GP consultations. It is estimated that 40% of the adult population in Ireland will have one or more chronic conditions by 2020. Chronic diseases are associated with 86% of mortality and 77% of overall disease burden, with patients utilizing around 70% of healthcare resources.

Balanda et al. (2011) examined prevalence rates of four chronic conditions (hypertension, angina, stroke and diabetes type 1 and 2 combined) in the Republic of Ireland and Northern Ireland. Their data indicates that there will be a dramatic increase in prevalence rates by 2020 (Table 3.1). For example, in relation to chronic heart disease (CHD), there will be an additional 65,000 adults (a 50% increase) with the disease, in the space of 15 years. The study by Balanda et al. also found that a person is more likely to be living with chronic disease if they live in a deprived area and prevalence of chronic disease is generally higher in males.

Table 3.1: Number of cases and prevalence rates in 2007, 2015 and 2020 in the Republic of Ireland and Northern Ireland (Source: Balanda et al., 2011)

	2007		2015		2020	
	n	%	n	%	n	%
Hypertension						
Northern Ireland	395,529	28.7%	448,011	30.3%	481,867	31.7%
Republic of Ireland	851,658	25.1%	1,050,591	26.8%	1,192,415	28.3%
Angina and heart attack (CHD)						
Northern Ireland	75,158	5.4%	87,848	5.9%	97,255	6.4%
Republic of Ireland	130,703	3.8%	166,985	4.3%	195,243	4.6%
Stroke						
Northern Ireland	32,941	2.4%	38,405	2.6%	42,457	2.8%
Republic of Ireland	58,778	1.7%	74,493	1.9%	86,845	2.1%
Diabetes (Type 1 and Type 2 combined)						
Northern Ireland	67,262	5.3%	82,970	6.0%	94,219	6.6%
Republic of Ireland	143,618	4.5%	193,240	5.2%	232,644	5.9%

Prevalence of multimorbidity in Ireland is less well studied. Glynn et al. (2011) studied a sample of 3309 community-dwelling patients in the West of Ireland and found that prevalence in those over 50 years of age was 66.2%. Healthcare cost and utilisation was also significantly increased for this population. The study found that the addition of each chronic condition led to an increase in primary care consultations, hospital outpatient visits, hospital admissions and total healthcare costs over the previous 12 month period. Glynn et al. state that this is the first study on multimorbidity prevalence and burden to be conducted in Ireland.

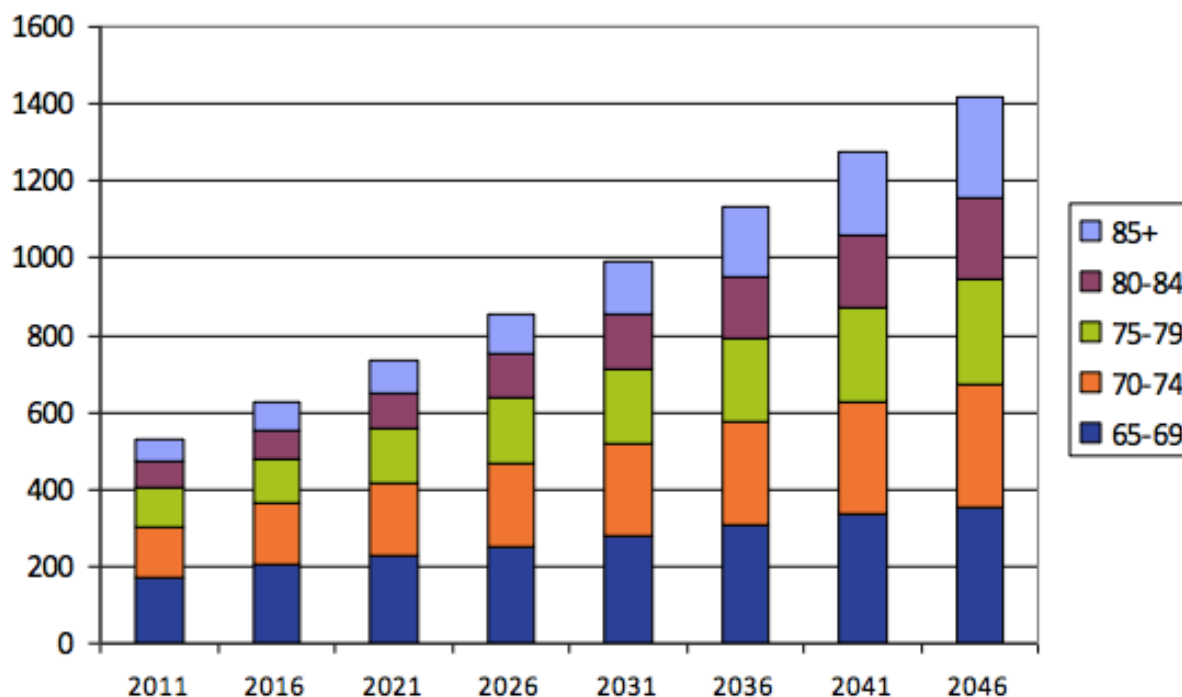
Another study by Savva et al. (2011) found that multimorbidity is around twice as common in the over-75s as those aged 50-64. Data was taken from the Survey of Lifestyle, Attitudes and Nutrition carried out by the Department of Health and Children in 2008 and sampled 4,255 people over the age of 50. The study examined prevalence of 8 chronic diseases (heart attack, angina, stroke, diabetes, asthma, COPD, musculoskeletal pain, cancer). In Ireland, 11% of those over 50 suffered from two or more of these conditions. Musculoskeletal pain was the most widely reported condition with a prevalence of 40%, followed by diabetes (7%) and angina (6%). The study also revealed that those in higher socio-economic groups were more protected from the effects of chronic disease than those in lower socio-economic groups and that those with 2 or more chronic conditions are almost 20 times more likely to report having a disability than those with no chronic conditions.

A report by Pierce, Cahill and O'Shea (2014) provides detailed estimates, based on census data and EuroCoDe dementia prevalence rates, of the projected growth of dementia in Ireland in between 2011 and 2046. Table 3.2 outlines the estimated prevalence of dementia in Ireland in 2011, indicating that 47,849 people suffered with dementia, of which approximately two-thirds were women. The largest prevalence of dementia was seen in the 80-84 age group. A total of 63% of those with dementia were estimated to be living in the community, 60% of which were over 65, and 3% under 65.

In terms of projections, Pierce et al. found that the number of people living with dementia in Ireland is estimated to double over the next 20 years, with an estimated 94,000 people suffering from dementia in 2031 (Figure 3.4). Of these 94,000 it is estimated that approximately 60,000 will be living in the community (Figure 3.5).

Table 3.2: Estimates of number of people with dementia in Ireland, 2011 (Source Pierce et al., 2014)

Age groups	Total Population (Census 2011)		Persons with dementia (estimated using EuroCoDe (2009) age/gender-related dementia prevalence rates)		
	Men	Women	Men	Women	Total
30-59 years	953,715	959,396	1907 ¹	959 ¹	2,866
60-64 years	109,869	108,917	220	980	1,200
65-69 years	86,298	87,340	1,553	1,223	2,776
70-74 years	63,476	67,714	2,031	2,573	4,604
75-79 years	46,631	55,405	3,264	4,211	7,475
80-84 years	28,423	41,690	4,121	6,837	10,958
85-89 years	13,591	26,296	2,841	7,494	10,335
90-94 years	4,155	10,722	1,213	4,761	5,974
95+	740	2,912	240	1,421	1,661
Total	1,306,898	1,360,392	17,390	30,459	47,849



Source: CSO (2013)

Figure 3.4: Actual and projected population of older people by age group in Ireland (in thousands), 2011-2046 (Source: Pierce et al., 2014)

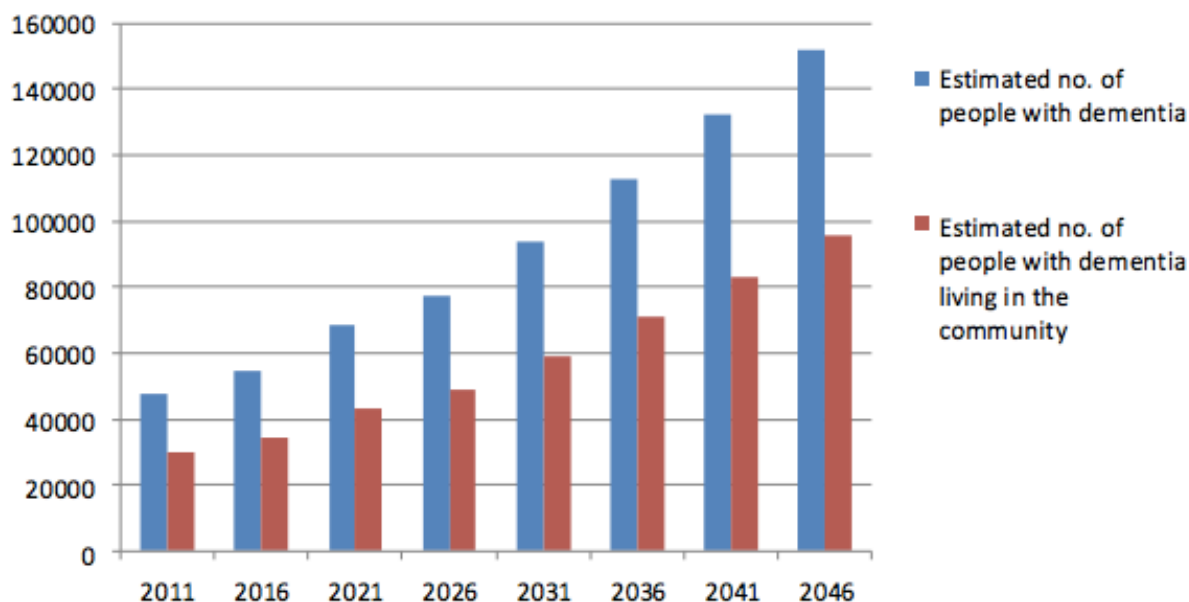


Figure 3.5: Estimated and projected number of people living with dementia in Ireland in the community, 2011-2046 (Source: Pierce et al., 2014)

With the projected increases both in the ageing population and the incidence of chronic diseases in Ireland comes increased costs for both the health service and patients. The total cost of hospitalisations related to COPD is estimated at €70,813,040⁴ ⁵. The total cost of diabetes in Ireland is estimated at €731,580,993, with a cost per patient of €3,982⁶. While little data exists on the cost of multimorbidity in Ireland, the study by Glynn et al. (2011) outlined above found that within their sample of people aged over 50, of which 66.2% were found to have multimorbidity, over the previous 12 months the addition of each chronic condition led to an increase in:

- Primary care visits (11.9 versus 3.7 for 4 or more conditions versus 0 conditions)
- Hospital out-patient visits (3.6 versus 0.6)
- Hospital admissions (adjusted odds ratio of 4.51)
- Total healthcare costs (€4096.86 versus €760.20 for 4 or more conditions versus 0 conditions)

Darker, Whiston & O'Shea (2015) found that private patients with chronic diseases delay facing primary care services due to cost, while both public and private patients found paying for medications and other related expenses to be difficult.

3.2 The Irish Health Care System

In Ireland, the Government, Minister for Health and Department of Health are responsible for the development of health policy. The Health Service Executive (HSE) is the national body responsible for strategic planning, implementation and management of health and social services. Policy and guidelines are developed for national use to ensure quality in service, however the implementation of these at local level is open to interpretation and is very much dependent on local area budgets. The structure of the HSE can be seen in Figure 3.6. According to the HSE:

- **Acute Hospitals** work closely with the hospitals division in Figure 3.6 to deliver hospital services throughout Ireland, including inpatient care, emergency care, maternity, diagnostic and outpatient services.
- **Primary Care** is all of the health or social care services that can be found in the community outside of the hospital/acute setting. A **Primary Care Team (PCT)** is a team of healthcare professionals who work together to meet the needs of people living in the community, providing a single point of contact to the health service. This includes GPs and GP nurses, Public Health Nurses (PHNs), Occupational Therapists, Physiotherapists and home help / support staff. The PCT also links with speech and language therapy, dieticians, mental health services, social workers, psychologists, podiatrists, dental and ophthalmic services. GP out of hours services are also part of primary care.
- **Social Care** supports the needs of older people, as well as people with disabilities, with the aim of supporting people to live at home, independently within their community. Some of the services for older people include home care packages⁷,

⁴ <http://www.chronic-disease.ie/#/copd/all-ireland>

⁵ <http://www.hse.ie/eng/services/list/1/schemes/cbd/Ready%20Reckoner.pdf>

⁶ http://www.idf.org/sites/default/files/EN_6E_Atlas_Full_0.pdf

⁷ <http://www.hse.ie/eng/services/list/4/olderpeople/homecarepackages/>

older person primary care and community services⁸, benefits and financial entitlements⁹, nursing home support scheme¹⁰ and residential care¹¹.

Social and Continuing Care in Ireland is provided to meet physical and or mental health needs arising from disability, frailty, accident or illness, and can be provided over an extended period of time in a multitude of settings, including a person's home, day hospitals, health centres as well as nursing homes and hospices. Social and Continuing Care in Ireland is currently fragmented, differs across regions and is lacking integration with other healthcare services. A number of new Integrated Care Programmes (see below) are currently under development and are designed to more closely integrate health and social care delivery. However, this development is still at a very early stage.

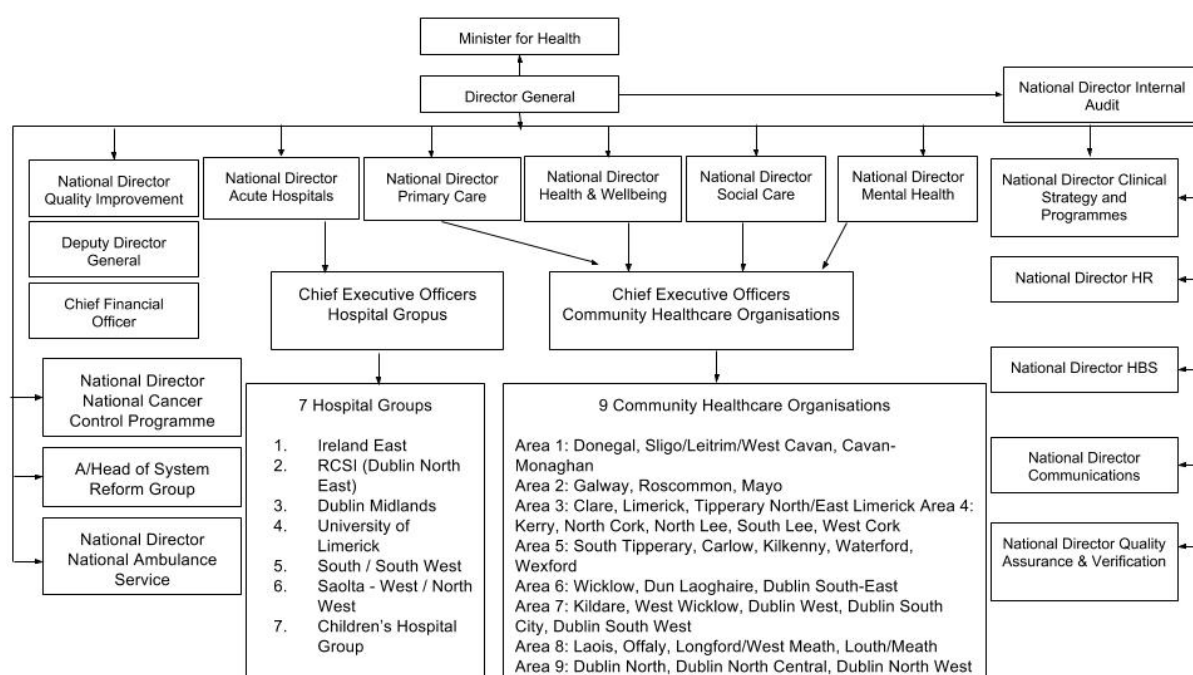


Figure 3.6: HSE organisational structure (source: HSE)

In Ireland, free primary care and medications are available at the point of care for those deemed eligible based on their socio-economic status. These individuals are registered to a single GP. Those who are responsible for paying for their own healthcare largely tend to be registered to a single GP, but this may not necessarily be the case. However, as of 2015, all those over 70 are entitled to free GP care and can apply for a GP Visit Card.

Data from the Irish longitudinal study ageing (TILDA) highlights that people with multimorbidity utilise all of the different health services (GPs, emergency department, outpatient departments and hospital stays) significantly more often than those without

⁸ http://www.hse.ie/eng/services/list/4/olderpeople/mao_older.html

⁹ <http://www.hse.ie/eng/services/list/1/schemes/>

¹⁰ <http://www.hse.ie/eng/services/list/4/olderpeople/nhss/>

¹¹ <http://www.hse.ie/eng/services/list/4/olderpeople/residentialcare/>

chronic illnesses (McNamara, 2013). For example, those with three or more chronic conditions report visiting their GP six times annually, in comparison to two visits for those without chronic conditions (McNamara, 2013).

According to OECD figures the total health spending in Ireland accounted for 8.9% of GDP in 2012, which is slightly more than the EU average of 8.7% (OECD, 2014). Recent figures from the HSE financial statements show the total HSE expenditure in 2014 was €13.33 billion. Total expenditure on acute services was €5.3 billion (39.52%), on primary care €3.4bn (25.85%), social care €2.6bn (19.92%) and mental health €716m (5.42%).

Even though research highlights that the preference of the majority of Irish people is to remain living independently in their own home for as long as possible, a larger proportion of money spent on care for older people goes to residential care rather than community supports (CARDI, 2011). In 2009 the Irish government established the Nursing Homes Support Scheme (also referred to as the Fair Deal Scheme) giving financial assistance to older people entering into residential care. In 2014 22,360 people were supported under the Nursing Homes Support Scheme for long-term residential care (HSE, 2012). As this scheme does not fund home care or home help, it has been criticised for creating a situation where remaining living independently in the home could prove more expensive than entering a nursing home (CARDI, 2011).

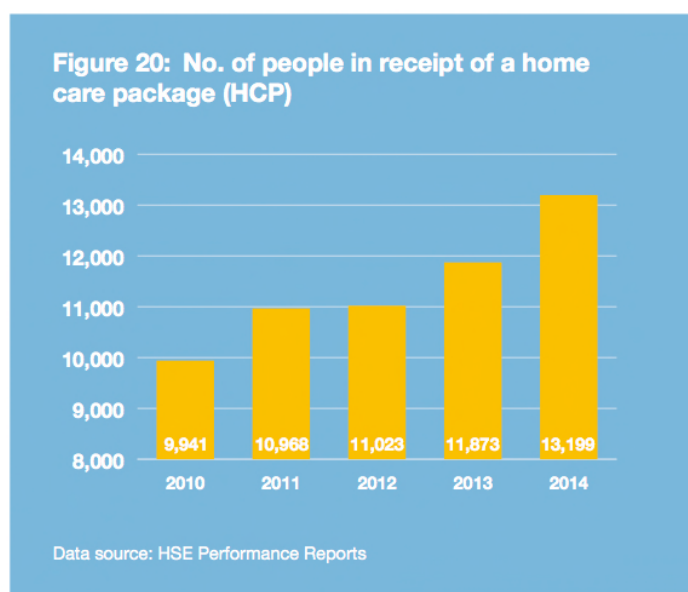


Figure 3.7: Number of People in Ireland in receipt of a home care package from 2010 to 2014 (source: HSE, 2012)

The demand for home care packages (HCPs) to enable people to remain in their community has been rising steadily (see Figure 3.7). According to HSE figures, in 2014 a total of 13,199 persons received home care packages, which was an increase of 11% on 2013. Nearly 10.3 million home help hours were delivered, with 47,061 persons in receipt of home help services in 2014 and this is predicted to rise (Table 3.3).

Table 3.3: Projected home help hours and home care packages 2016 to 2021 (source: HSE, 2012)

	2011	2012	2013	2014	2015	2016†	2021
Pop >65 years	531,560	549,010	567,160	585,825	604,830	624,183	731,860
Home Help Hours (million)	11.98	9.83	9.74	10.3	10.6	10.97	12.9
Home Help clients (excl HCP)*	54,000	44,387	46,454	47,061	48,390	49,934	58,550
% Pop over 65 yrs with HH	10.1%	8.1%	8.2%	8.0%	8.0%	8.0%	8.0%

† Extrapolated from 2014 figures assuming the same level of population coverage and model of care

*home care package

From the HSE service plan in 2015 there was a provision of €25m for an initiative to address patients whose discharge from acute hospitals is delayed due a lack of capacity (HSE, 2015). The breakdown of the funds is presented in Table 3.4 which highlights that the proportion of spending on acute long and short stay care is much higher than that of home care packages and supports.

Table 3.4: Proportion of funds spent on residential care, short stay, home care and community intervention teams (Source: HSE, 2015)

Service Area	Programme for Government €	Expected Delivery 2015
NHSS (long stay residential care)	€10m	300 places
Short stay beds in Dublin area	€8m	115 beds
Home care packages	€5m	600 additional people
Community Intervention Teams	€2m	4 teams
Total	€25m	

3.3 Relevant National Policies and Research

Recent years have seen a number of developments within the Irish healthcare context, with the overall aim of improving the Irish health system and patient care. A number of programmes / policy documents have been developed which are of relevance to ProACT. These include:

- **The National Clinical Programme for Older People**¹². This programme is to support older people to live in the community, independently and with dignity.
- The policy document '**Healthy Ireland – A Framework for Improved Health and Wellbeing 2013-2025**'¹³. Currently the overarching policy on health promotion and prevention in Ireland, with an aim to ensure cooperation and collaboration across the government, the health service and all of society.

¹² <http://www.hse.ie/eng/about/Who/clinical/natclinprog/olderpeopleprogramme/about/>

¹³ <http://health.gov.ie/blog/publications/healthy-ireland-a-framework-for-improved-health-and-wellbeing-2013-2025/>

- The policy document, **'Future Health – A Strategic Framework for Reform of the Health Service (2012-2015)'**¹⁴ Has the goal of implementing 'large-scale change that delivers fundamental reform'.
- **Ireland's e-Health Strategy**¹⁵. Established in 2013, this strategy outlines a set of objectives to be achieved in implementing e-health in Ireland, and provides a roadmap to achieve these.
- **Integrated Care Programmes**¹⁶, launched in 2014, aim to join up health and social care, focussing on programmes for chronic disease management, older persons, patient flow, maternity and children.
- A number of **policies on chronic disease management**. However these focus on single disease treatment, for example, the **Policy Framework for the Management of Chronic Diseases in the Republic of Ireland (ROI)**¹⁷.

Those programmes and policies most relevant to ProACT are discussed in more detail below.

3.3.1 The National Clinical Programme for Older People

The main goal of this programme is to support older people to live in the community, independently and with dignity. It is recognised that while many older people live healthy, independent lives, an increasing number suffer from frailty, multimorbidity and polypharmacy. The specific aims are outlined in Table 3.5. One of the main policy documents emerging from this programme, published by the HSE and the Royal College of Physicians in Ireland, is the **Specialist Geriatric Services Model of Care Part 1: Acute Service Provision (2012)**. This document states that the core responsibility of care for community-dwelling frail older people is with the GP and primary care team. It outlines the care pathways of older people through the healthcare system as well as the key stakeholders involved in their care. This is discussed further in sections 6 and 7. While the document primarily deals with older adult care in acute services, it states that Part 2 will address community care. However, as of yet, Part 2 has not been published.

¹⁴ <http://health.gov.ie/blog/publications/future-health-a-strategic-framework-for-reform-of-the-health-service-2012-2015/>

¹⁵ <http://health.gov.ie/blog/publications/ehealth-strategy-for-ireland/>

¹⁶ <http://www.hse.ie/eng/about/Who/clinical/integratedcare/programmes/>

¹⁷ http://health.gov.ie/wp-content/uploads/2014/03/tackling_chronic_disease.pdf

Table 3.5: Aims of the National Clinical Programme for Older People

Aim	Every older person should have access to the right care and support
Quality	➤ Support the planning and delivery of health and social services for older people. ➤ Support older people to remain at home by optimising independence and clinical outcomes. ➤ Support the provision of services across all settings to optimise patient outcomes and independence by the provision of appropriate alternatives of care eg. day hospitals for older people. ➤ Improve the management of ill older adults across all health and social care settings
Access	➤ Every patient should have quick access to the right care in the right place at the right time including timely access to community and home care support services. ➤ Regardless of the setting, the health system will identify those older people that are at risk and address their health and social care needs appropriately early in the disease process to optimise outcomes. ➤ Improve the integration of services for older people across the continuum of health and social care.
Value	Overall improvement in patient flow through the health and social care system by: ➤ Reduce delayed discharges in the acute hospital system Decrease AVLOS for > 65 years, > 75 yrs, > 85 yrs ➤ Development of community health and social services to meet population needs. ➤ Reduce risk of inappropriate re-admission following discharge. ➤ Decrease risk of re-attendance at ED ➤ Reduce % of inappropriate admissions to acute and long term care

3.3.2 Future Health

Future Health (2012) is a Department of Health policy document outlining a strategic reform of the Irish healthcare system. It recognises that the current system is “unfair to patients; often fails to meet their needs fast enough; and does not deliver value for money”. At its core is the development of a single-tier health service that will be supported by the implementation of Universal Health Insurance.

Future Health has four pillars of reform, two of which are of particular relevance to ProACT:

1. **Health and Wellbeing** – focusing on a move away from treatment of ill people to keeping people healthy. This principle underlies many of the reforms outlined in Future Health.
2. **Service Reform** – focusing on a move away from hospital-centric care towards ‘a new model of integrated care that treats patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible. The Future Health

strategy recognizes the importance of such service reform in dealing with the growing number of people managing chronic illness as well as those with two or more disorders. It views primary care as critical and essential in developing a new model of integrated care.

Future Health's vision of reform includes integrated primary and acute care systems. Plans for reform in primary care includes GP-lead teams of primary care professionals, working from dedicated primary healthcare facilities, providing care for health and social needs. Primary care should meet 90%-95% of people's healthcare needs. Only those patients with highly complex needs will be referred from primary care. In terms of reform of Social and Continuing Care, this includes a reform of the Fair Deal scheme (discussed in Section 3.2)¹⁸, to support more people in living at home.

A new model of care for chronic disease management is also proposed in Future Health, shifting care from hospital to the community. In addition to community-based prevention and early diagnosis, a large part of the model will involve patient empowerment, managing conditions and preventing exacerbations. The models of chronic disease management will outline the key stakeholders and their roles and responsibilities in shared care. This will include clinical protocols and guidelines, as well as specific programmes of self-management. Such reforms are expected to result in benefits to the population, including:

- Helping people to manage their health, improve their health and get diagnosed earlier.
- Access to chronic disease management programmes.
- Supporting people to be cared for in their own homes, through improvements in social care.

The following section discusses specific programmes of integrated care.

3.3.3 Integrated Care

More recently, in 2015, the HSE launched 5 integrated care programmes (ICPs) with the overall objective of "integrating health and social care services as part of a long-term programme to improve and streamline care for Irish citizens" (HSE, 2015). The ICPs aim to "join up health and social care, and put good patient and service user outcomes at the centre". The 5 ICPs, to be introduced over a 2 to 5 year period, are listed in Table 3.6.

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http://www.citizensinformation.ie/en/health/health_services_for_older_people/nursing_homes_support_scheme_1.html

Table 3.6: Overview of Integrated Care Programmes, Principles and Aims (Source HSE)

New Integrated Care Programmes	• Prevention and management of chronic disease • Older Persons • Patient Flow • Children • Maternity
Key Principles of Programmes	• Patient perspective • Illness prevention • Patient empowerment • Multidisciplinary, cross-service planning and delivery (across health and social care); responsive to changing needs of patients and their families
Aims of the Programmes	• Empower those with chronic disease, including older people, to manage their needs with support, and to live independently for longer in their own homes. • Empower and enable clinicians to deliver the right care at the right time, in a joined up manner, to improve the patient's experience of health and social care. • Design and develop integrated and sustainable health and social care services.

The ICPs of relevance to ProACT are described in more detail below.

3.3.3.1 Integrated Care Programme on Chronic Disease Prevention and Management

The primary objective of this programme is to provide access to integrated care and support for people with chronic disease, that is planned around their needs and preferences, and that will improve quality of life and independence. The programme aims to provide individuals with chronic disease with:

- Access to support and management programmes for primary and secondary prevention.
- Care and support as close to home as is required.
- Access to condition specific specialist advice and support.
- A seamless transition between primary and community settings.

There are 5 key deliverables associated with the plan of integrating care for those managing chronic diseases. These include:

- Develop an integrated model of care
- Develop integrated care patient pathways
- Development of disease registries and risk stratification
- Improve supported self-management

- Improve patient engagement within the model of care and pathways

3.3.3.2 Integrated Care Programme for Older Persons

The objective of this programme is to provide older people with a continuum of services, including home care, day care and residential care, to avoid unnecessary acute hospitalisations and where possible, have treatment delivered within the community and primary care. The following have been identified as enablers to providing integrated care for older persons:

- Development of an integrated model of care
- Proactive approaches to the needs of the older person
- Develop clinical care programmes where gaps exist
- Technology and ICT for self-management and support
- Inter-sectoral collaboration (between primary, secondary and tertiary care)

3.3.3.3 Integrated Care Programme for Patient Flow

Effective patient flow within a health system is critical to ensure safety. Lack of integration across services, including hospital, primary and social care, as well as between hospital departments, can have a negative impact on, and often prevent, patient flow. The key enablers to improving patient flow have been identified as:

- Clinical leadership, governance and standards. This requires service reconfiguration to build enhanced and scalable models of care.
- Patient flow planning and pathway management, requiring integrated clinical networks.
- Patient information, comprising a whole systems approach across performance and reporting.
- Improved resource allocation.
- Information and ICT

Together, the Integrated Care Programmes aim to improve patient care and to facilitate access to care that appears seamlessly integrated to the patient. It is anticipated that these models will also contribute to increased efficiency within the health service. However, they are at a very early stage of development, there is little information on how the above points will be achieved, and they have yet to be implemented.

3.3.4 E-Health

Ireland's e-health strategy defines e-health as "the integration of all information and knowledge sources involved in the delivery of healthcare via information technology-based systems. This includes patients and their records, caregivers and their systems, monitoring devices and sensors, management and administrative functions. It is a fully integrated digital supply chain and involves high levels of automation and information sharing". The strategy outlines a set of objectives to be achieved in implementing e-health in Ireland, and provides a roadmap to achieve these. Priority areas for development have been identified as e-prescribing, online referrals and scheduling, telehealth (with a focus on chronic disease management) and patient summary records. Recently, the development of an electronic patient identifier has received priority and the HSE have made plans to roll this out, with

access to records provided to those with a “legitimate relationship” to the patient, including the patient themselves¹⁹.

The e-health strategy notes that a number of legacy healthcare ICT systems exist throughout Ireland, some of which offer ‘pockets’ of integration, and that this will make national integration a challenge. The document outlines 5 levers of change necessary to drive momentum for change in healthcare systems, as well as the potential level of impact on different stakeholders, including patients (Table 3.7).

Table 3.7: Levers of change (Source: E-Health Strategy Ireland)

Stakeholder Group	My data, my decisions	Liberate this data	Revolutionise health	Connect up everything	Include everyone
	Patients and institutions share their data, flexible consent mechanisms	Health outcomes and performance data freely published with full transparency	Technology and information management drives the pace of change	Link lifestyle data with health data, lots of new apps and tools from entrepreneurs	Contribution to and benefit from eHealth for all
Citizens and patients	High	High	High	High	High
Regulators and policy makers	Medium	High	Medium	Medium	Medium
Clinicians and care professionals	Medium	High	High	High	High
Payers and insurers	Medium	High	High	Medium	Low
Service providers and managers	Low	High	High	High	High
Researchers	High	High	Medium	High	High
High – If the preconditions were met and this lever utilised, there would be a high-level impact on the stakeholder group; Medium – If the preconditions were met and this lever utilised, there would be a medium-level impact on the stakeholder group; Low – If the preconditions were met and this lever utilised, there would be a low-level impact on the stakeholder group					

3.4 Summary and Challenges

There is a mandate to reform the Irish health system, and to improve integrated care within the Irish healthcare context. However, the level of implementation of policies is fragmented and varies within regions. Timelines for change have not always been met. There are still serious challenges including reduced budgets, long waiting lists, large numbers of people on hospital trolleys and capacity deficits. While there are specific programmes that address chronic disease management and older persons, there isn’t a focus on multimorbidity. However, Primary, Community and Continuing Care (PCCC) services have been identified as the path to optimal care and cost-effectiveness, and this may be important in caring for those with multimorbidity. In parallel, Ireland’s e-health strategy will be key in delivering ICT infrastructures to support such reforms, including integrating care across various stakeholders, ultimately resulting in enhanced patient-centred care.

¹⁹ <http://www.irishexaminer.com/ireland/hse-to-spend-875m-on-health-records-system-388741.html>

4 Healthcare Context – Belgium

This section gives an overview of the Belgian health status related to ProACT, the Belgian healthcare context, its main organizational structure and impact on the ProACT solution and the relevant policy framework for ProACT. This section is based on desk research and interviews with key stakeholders in Health and Social Care in Belgium.

4.1 Health Status Overview

In 2013 there were 1,783,308 people over 65 years old in Belgium²⁰. The amount of people aged over 65 is expected to increase by 60% between 2014 and 2060: the dependency ratio is estimated to increase by 51% (which reflects the ratio between people over 65 years old and people aged 15 to 64) (Federaal Planbureau, 2015). In 2012 Belgium spent €40.9 billion on healthcare, which is 10.9% of the gross domestic product. 75.2% of these costs are financed by the Belgian government, while the remaining cost is accounted for by the private sector (Assurinfo, 2015). Generally, about 70% to 80% of healthcare costs are spent on chronic diseases (European Union Health Policy Forum, 2012).

Every five years, The Belgian Scientific Institute of Public Health (WIV-ISP)²¹ performs a National Health Survey to obtain an overview of the status of health of Belgian citizens (Van der Heyden & Charafeddine, 2013). The health survey is subsidised by the federal and regional governments with the aim of identifying national health problems, describing the health needs of the Belgian population, estimating the prevalence and distribution of health indicators, analysing social inequality and studying health consumption.

ProACT focuses on the prevalence of two or more diseases, and only focuses on the following chronic diseases: Congestive Heart Failure (CHF), (which may be linked to Chronic Heart Disease (CHD)), COPD, dementia and diabetes. The prevalence of these diseases in Belgium in 2013 are shown in Table 4.1. There are currently no up-to-date figures for CHF.

Table 4.1 Prevalence of ProACT focus diseases in Belgium

	2013	
	Men (65+)	Women (65+)
Diabetes ²²	14.6%	12.4%
COPD ²³	7.7%	2.8%
Coronary Heart Disease ²⁴	6%	4.3%
Dementia ²⁵	8.3%	8.3%

²⁰ <http://statbel.fgov.be/nl/statistieken/cijfers/bevolking/structuur/leeftijdgeslacht/piramide/>

²¹ www.wiv-isp.be

²² (Van der Heyden & Charafeddine, 2013)

²³ (Van der Heyden & Charafeddine, 2013)

²⁴ (Van der Heyden & Charafeddine, 2013)

²⁵ (Berr et al., 2005)

In its research, WIV-ISP defines multimorbidity as the occurrence of two of the following six chronic diseases: heart diseases, chronic lung disease, diabetes, cancer, arthritis and hypertension.

In Belgium; 64.4% of the total population above 15 years old has **none** of the above stated diseases, 22.1% has one disease, 9.4% has two and 4.1% has three or more. In Belgium, 13.5% of the population aged over 15 years suffers from multimorbid diseases.

The percentage occurrence of multimorbidity is strongly correlated with age; 2% amongst 25-34 year olds, 39% with 75 and older. Women are more frequently diagnosed with multimorbidity than men. Figure 4.1 shows the distribution of multimorbidity according to age and sex in Belgium.

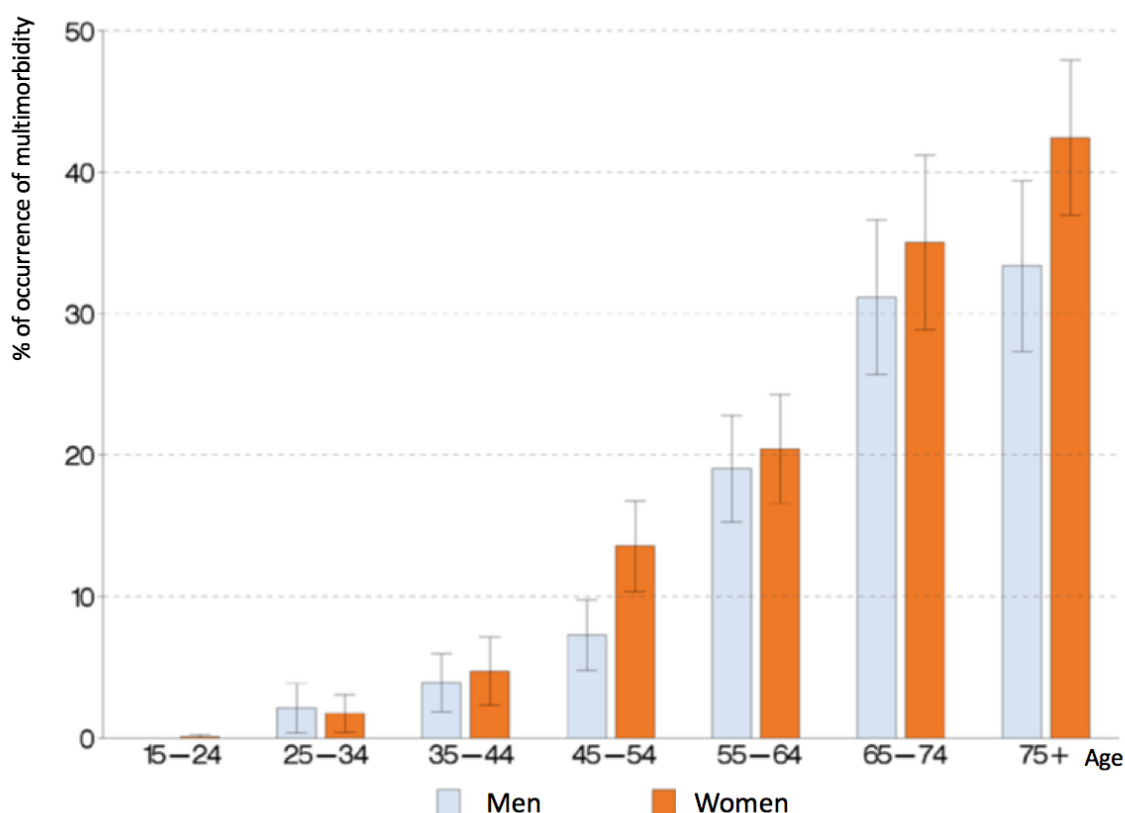


Figure 4.1: Distribution of multimorbidity according to age and sex in Belgium (Van der Heyden & Charafeddine, 2013)

When looking at socio-economic characteristics of multimorbidity in Belgium, there is a strong correlation with education. The rate of multimorbidity occurrence is 1.6 times higher among citizens who did not follow higher education (University and college education). There is no significant effect of the level of urbanisation of the area where citizens live to the prevalence of multimorbidity (Van der Heyden & Charafeddine, 2013).

From 1997 to 2013 the prevalence of multimorbidity in Belgium increased from 8.9% to 13.5%. Causes for this increase are mainly due to a rise in the older population over this period. However, after the age correction, there is still a significant increase in multimorbidity. Overall there is no significant difference in multimorbidity prevalence across the three Belgian regions (Flanders, Brussels, Wallonia). Figure 4.2 gives the occurrence of multimorbidity over time in Belgium and its three regions (Van der Heyden & Charafeddine, 2013).

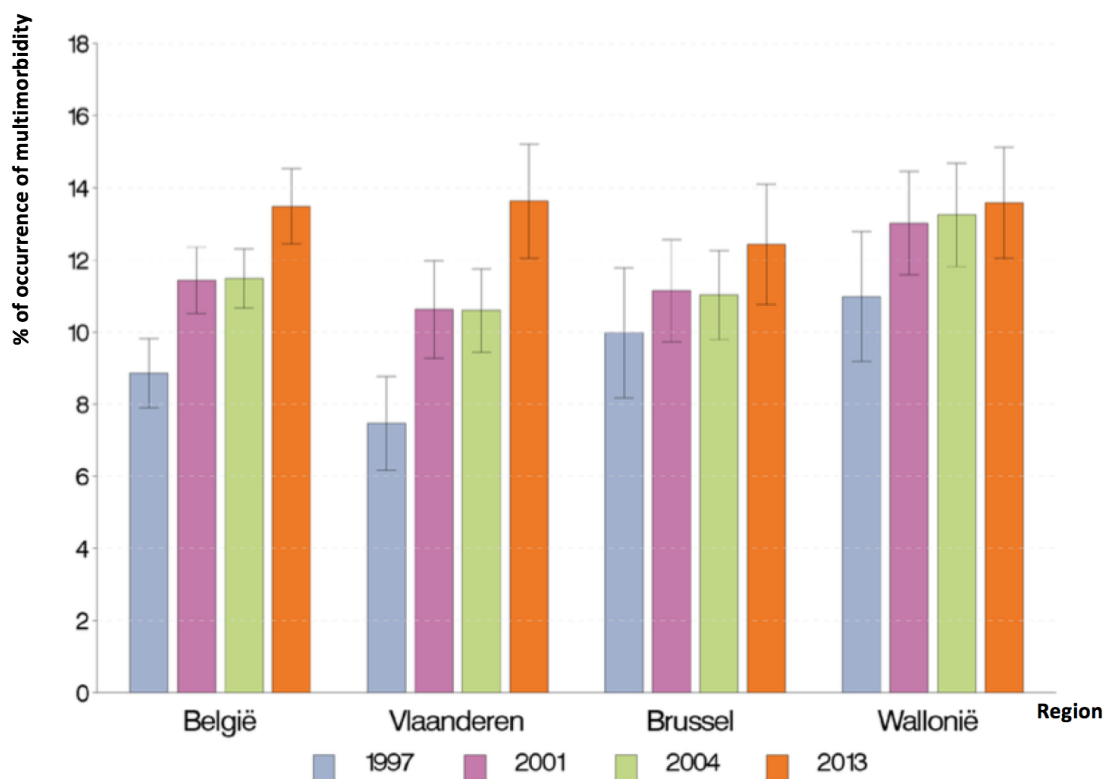


Figure 4.2: Occurrence of mutimorbidity over time in Belgium and its three regions (Van der Heyden & Charafeddine, 2013)

4.2 The Belgian Health Care System

The Belgian health system is based on a social insurance system, characterized by the principles of therapeutic freedom for physicians, freedom of choice for patients and remuneration based on fee-for-service payments.

As health insurance is compulsory, almost the whole population (99%) is covered by a very broad health insurance package. All services that are being reimbursed (8000+) are described in the nationally established fee schedule (nomenclatuur/nomenclature²⁶). Services not included in the nomenclature are not reimbursable. Around 20% of total health expenditures are paid by the patient through non-reimbursed medical acts (goods or services), co-payments and supplements. The reimbursement of services depends on the income and social status of the patient (preferential reimbursement or not), the type of service provided, as well as the accumulated amount of co-payments already paid for that year. For more vulnerable population groups, several measures were taken to ensure their access to high-quality care (OMNIO, maximum billing (MAB) system, etc.).

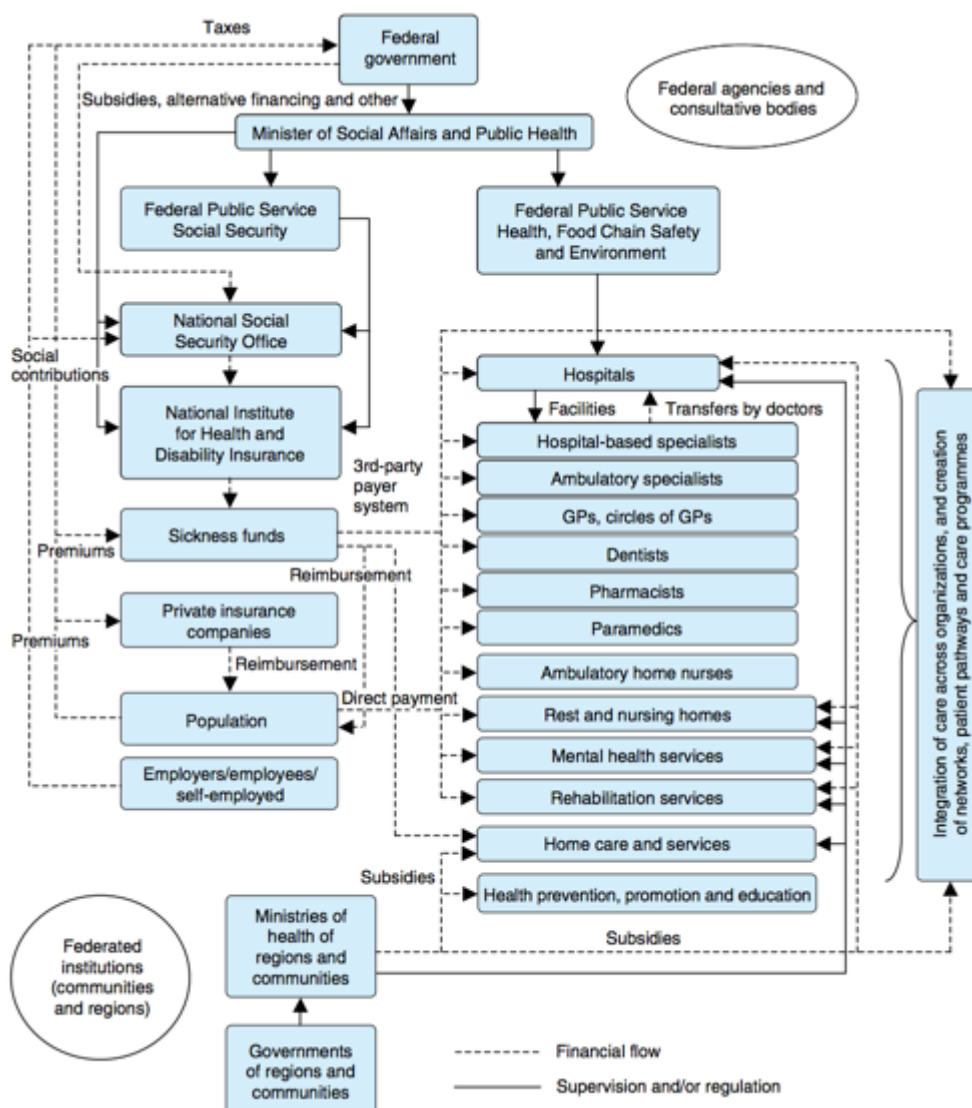


Figure 4.3: Overview chart of the Belgian health system (Gerken & Merkur, 2010)

²⁶ Full list of Belgian nomenclature is given on the website of the Belgian National Social Security Office <http://www.inami.fgov.be/nl/nomenclatuur/Paginas/default.aspx>

Figure 4.3 gives an overview of the Belgian healthcare system through its main actors, financial and supervision/regulation flows. Financing is based on proportional social security contributions related to income, progressive direct taxation and value added tax (financing related to consumption of services and goods).

Responsibilities for health policy are shared between the federal government and the regional governments. The federal level is in charge of the organisation and financing of compulsory health insurance, financing of hospital budgets, determination of accreditation criteria, healthcare legislation and pharmaceutical price controls. At the regional level, governments are responsible for health promotion and prevention, elderly care, home care, maternity and child services, coordination and collaboration in primary and palliative healthcare and the financing of hospital investments (i.e. Infrastructure investments). To facilitate cooperation between the federal level and regional governments, inter-ministerial conferences are regularly organised. Note that, for the ProACT solution, a collaborative approach between the federal level (financing, IT & eHealth services, legislation & regulatory framework) and regional level (elderly care, home care, healthcare coordination) is needed.

Several measures have been undertaken to increase accountability of Belgian health care providers. New policy objectives include the integration of care and multidisciplinary cooperation. More information follows in the next section.

4.3 Relevant National Policies and Research

In 2008 the federal government launched the national programme 'Prioriteit aan de Chronisch Zieken'²⁷. In this project the focus was on improving the quality, affordability and accessibility of care for patients with chronic illnesses. Also, the 'Observatorium voor de Chronische Ziekten' was founded: an advisory body consisting of all of the different stakeholders involved in improvement of chronic care (Paulus, van den Heede & Mertens, 2012).

In October 2010, during its presidency of the Council of the European Union, Belgium held an inter-ministerial conference on 'Innovative Approaches for Chronic Illnesses in Public Health and Healthcare Systems'. The conclusions from the European Council in December 2010, urged member states to 'further develop patient-centred policies for health promotion, primary prevention and secondary prevention, treatment and care of chronic diseases, in cooperation with the relevant stakeholders, especially patients' organisations'. In addition, the Council recommended a reflection process aimed at identifying the best options to respond to the challenges of chronic diseases. These included; scope for action on health promotion and prevention of chronic diseases, the sharing of good practices in healthcare to enable (i) patients to maximize their autonomy and quality of life and (ii) how to base practical implementations of prevention, early interventions and care on the existing scientific knowledge (Council of the European Union, 2010).

Building on these conclusions, the Minister assigned the Federaal Kenniscentrum voor de gezondheidszorg (KCE) to write a 'position paper' on chronic care in Belgium, which was

²⁷http://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/20151019_imc_p lan_geintegreerde_zorg_chronisch_zieken.pdf

published in December 2010 (Paulus et al., 2012). The paper theoretically relies on the 'Chronic Care Model' which aims to transform care for patients with chronic illnesses from acute and reactive to proactive, planned and population-based. This is to be achieved through effective team care and the stimulation of self-management with the use of community resources, patient registries and supportive information technology (Coleman, Austin, Brach & Wagner, 2009). The KCE-paper states that the care for patients with chronic illnesses should offer 'a coordinated whole that is based on the needs of the patients, personalized, goal-orientated, planned, with professionally supported routine and acute care. This care is to be provided in a high quality, evidence-based, efficient, sustainable, accessible, culturally competent and patient empowering way in the least complex setting that is clinically acceptable. The goal is to improve the quality of life of the beneficiaries and to help them function better both at home and school/work as in the society (Paulus et al., 2012).

Focus groups with field-experts were composed to formulate points of action, which led to the creation of an inter-cabinet workgroup 'Chronic Illnesses' developed to come to concrete policy proposals. Their efforts led to the orientation nota 'Een geïntegreerde visie op de zorg voor de chronisch zieken in België'. This nota follows the direction of the earlier mentioned KCE-paper and adds the need to simplify, be flexible regarding the needs and level of autonomy of the patient, digitalise and share information and keep an eye on the equity (Nationale Conferentie Zorg voor Chronisch Zieken, 2013). Following this, the federal and regional governments underlined the need for integrated care in their coalition agreements (2014), and signed a common declaration to work together on the integrated care of the chronically ill. This 'Gemeenschappelijke Plan voor chronisch zieken: Geïntegreerde zorg voor een betere gezondheid' (2015), which is based on the orientation nota, has the mission 'to strive towards an improvement of the quality of life of the population, in particular the people with one or more chronic conditions, so that they are able to live in their own environment (family, school, work) and society as best as possible and control the care-process in an active manner' (Paulus et al., 2009).

This plan states that in order to achieve these goals, the health care system has to change according to the Triple Aim principle: improving the health of the population and chronically ill in particular, improve the quality of care and use the allocated means more efficiently. Integrated care that is patient-centred and has attention for the self-reliance of the patient and the satisfaction of the patient and healthcare professionals about the provided care is required. In the plan, 18 components are identified that need to be implemented in order to evolve towards integrated care. Four lines of action are established to achieve this: (i) integrated care pilot projects, (ii) methodological, scientific and technical support of these projects and the plan as a whole, (iii) establishing cooperation between and engagement of the different levels of policymakers, (iv) defining specific initiatives for the different governments that exist in Belgium²⁸.

In 2012 a policy brief was written on the vision for Flanders on integrated care by the Strategische Raad Welzijn Gezondheid Gezin. This brief emphasizes the importance of a person-centred approach to improve quality of life and states that prevention and strengthening the access to the first line of healthcare (all care that is directly accessible by

²⁸http://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/20151019_imc_plan_geintegreerde_zorg_chronisch_zieken.pdf

the patient in which the GP is the central figure) is key. Self-care, informal and formal care are all on the same continuum of care, and formal care should support and guide self-care and informal care from a preventive point of view. The principle of staged care should be implemented: start with self-care and informal care and move on up (Strategische Adviesraad Welzijn Gezondheid Gezin, 2012).

The latest federal policy document, which is also signed by the regional governments, is the 'Actieplan e-Gezondheid 2015-2018'. This plan contains 20 objectives that are to be finalized by 2019. These objectives all mainly contribute to the realization and improvement of the electronic exchange of information and communication. The action plan involves several objectives to improve and guarantee privacy by using different types of electronic records and filters in these records for the different stakeholders that are involved (patients, GP's, pharmacists, health insurance). The goal is to lower the administrative burden, and improve the quality of care; especially the multidisciplinary care. Incentives for the use of eHealth are included, as well as an educational programme for healthcare professionals. Some positive results in the use of e-health since the emergence of the action plan are notable. For instance, at the end of 2015 almost 2 million Belgian citizens had given their consent for the digital exchange of their medical details between caregivers, opposed to 352,000 at the end of 2014. The amount of sent messages via eHealthBox, a secured electronic mailbox, had increased from 2.5 million to 11 million between July 2014 and July 2015. However, there is still a lot of room for improvement when it comes to the involvement of all different caregivers and organizations and the extent of the data that is electronically exchanged.²⁹

²⁹ <http://www.plan-egezondheid.be>



5 Health and Social Care Context – Emilia-Romagna, Italy

The following section is based on desk research and interviews with key stakeholders in Health and Social Care in Emilia-Romagna, predominately decision makers in the Local Health Trust of Bologna and the Municipality of Bologna. The reason for this is that it is the intention of AIAS and ASP Città di Bologna, the two Italian partners, to involve the Local Health Trust of Bologna, the capital of Emilia Romagna, directly in the transferability study of ProACT and the future pilot, and to assess the potential importance of ProACT for both the Health and the Social care sector, as well as for the integration between the two. As a consequence, the stakeholder analysis and the description of pathways refer to the Bolognese context and build on what is already achieved in integrating both sectors. Being a well-integrated part of the Regional Health Care system which responds to national legislation it is nevertheless believed that the results have a wider validity than just the Bolognese context.

5.1 Health Status Overview

The demographic picture of Europe shows that the population is rapidly ageing and that as a consequence the proportion of the population over 65 is becoming an increasingly large part of the whole population. The graph depicted in Figure 5.1 shows how the percentage of population over 65 has increased over the last 10 years.

The Italian demographic trends reflect these European trends. Among the 60.8 million Italian inhabitants in 2014, 21.4% were aged 65 and older (compared to 18.5% of Europe). Emilia Romagna (4.45 million inhabitants) is one of the Italian regions most affected by this trend and statistics reveal that the percentage of persons aged over 65 is 2 points higher than the national data in 2014, namely 23.4%. Furthermore, in Emilia Romagna there is a high number of people over 75 years old, 553,017, representing 12.4% of the population (11.9% in 2012) and over 80 years old, 330,054, 7.6% of the total number of residents (7.3 % in 2012). There are 167,683 over 85 years old, 3.8% of the population (163,133, 3.6% in 2012)³⁰.

Closely related to the ageing trend are the conditions of frailty and multimorbidity: data analysis and studies demonstrate the impact of multimorbidity and frailty on the increasing demand for multidisciplinary care. In Italy 52.4% of the persons over 65 report having at least two long-standing illnesses or health problems, while this number related to the whole Italian population is estimated to be around 24% (see Figure 5.2). This evidence poses new challenges to the health services, in terms of professionals' skills, resources and organizational aspects.

³⁰ ISTAT Emilia romagna 2015, Retrieved from <http://www.istat.it/it/emilia-romagna>

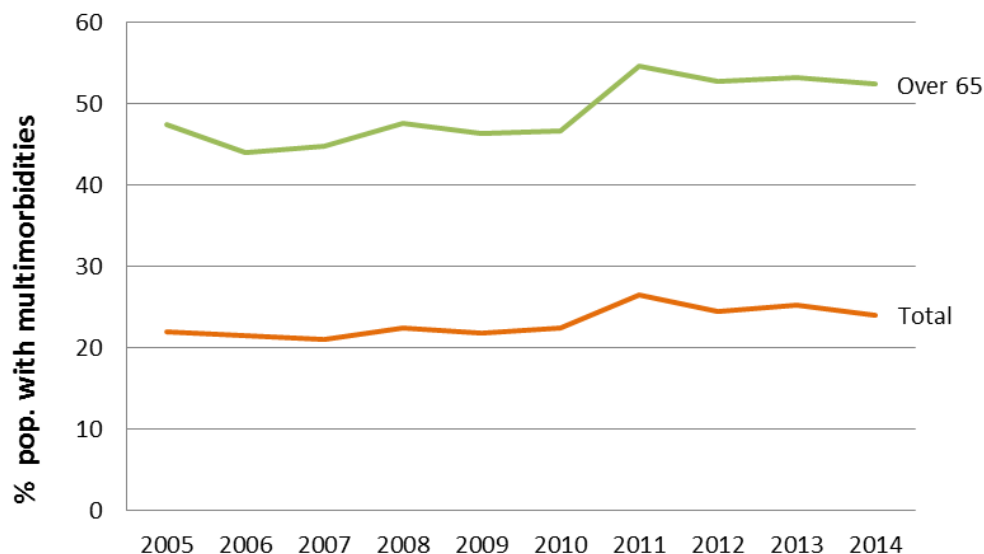


Figure 5.1: Prevalence of people over 65y in Emilia-Romagna compared to Italy and Europe as of 2014 (Source: Eurostat³¹; Istat³²)

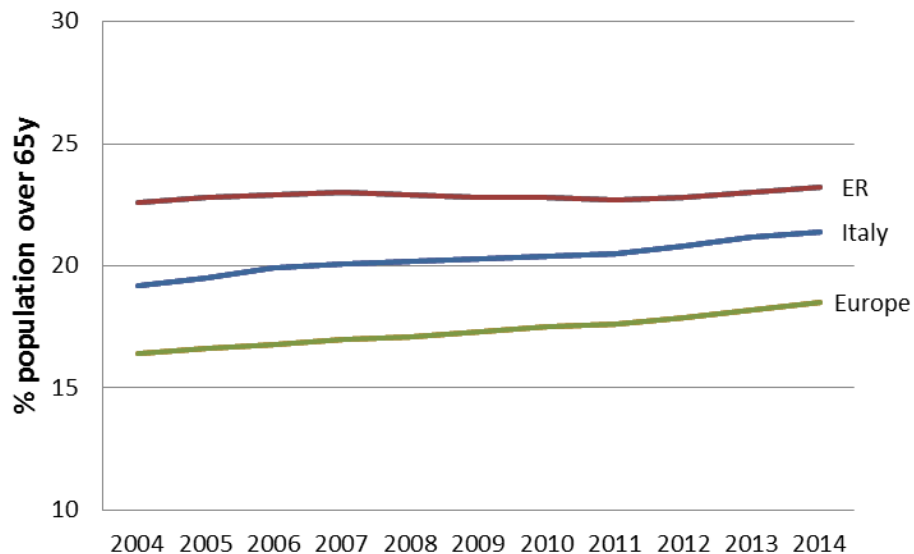


Figure 5.2: Prevalence of people over 65y reporting multimorbidity compared to the rest of the Italian population³³

³¹ Eurostat 2015, Retrieved from <http://ec.europa.eu/eurostat/data/database>

³² ISTAT, Annuario Statistico 2015, Retrieved from <http://www.istat.it/it/archivio/171864>

³³ Eurostat 2015, Retrieved from <http://ec.europa.eu/eurostat/data/database>

Table 5.1 provides an overview of the prevalence of three chronic diseases for the age groups 65-74 and 75+, as well as for the total population. What is striking is that particularly for the 75+ population there appears to be a positive trend – with a decreasing percentage of individuals suffering from the specific pathologies.

Table 5.1: Prevalence of chronic diseases in Italy 2013-2015. Source: ISTAT

Italy 2013 Prevalence of chronic diseases

Age	65-74			75+			Total population		
	M	F	M & F	M	F	M & F	M	F	M & F
Diabetes	16	14,3	15,1	20,7	20,1	20,4	5,6	5,3	5,4
COPD	11,4	10,3	10,8	21,8	18,1	19,5	5,9	5,9	5,9
Heart Diseases	11,6	6,7	9	19,8	14,3	16,6	4,2	3,2	3,7

Source: ISTAT (National Institute for Statistics), Annuario statistico italiano 2013, Cap. 3 Sanità e Salute, page 96.
http://www.istat.it/files/2013/12/Cap_3.pdf

Italy 2015 Prevalence of chronic diseases

Age	65-74			75+			Total population		
	M	F	M & F	M	F	M & F	M	F	M & F
Diabetes	16,6	13,9	15,2	20,2	19,5	19,8	5,4	5,4	5,4
COPD	10,4	8,5	9,4	19,4	16	17,4	5,6	5,6	5,6
Heart Diseases	11,6	6,7	9	18,2	14,1	15,8	4,5	3,4	3,9

ISTAT (National Institute for Statistics), Annuario statistico italiano 2015, Cap. 4 Sanità e Salute, page 148.
<http://www.istat.it/files/2015/12/C04.pdf>

Italy Prevalence of chronic diseases - Trend 2013-2015

Age	65-74			75+			Total population		
	M	F	M & F	M	F	M & F	M	F	M & F
Diabetes	0,6	-0,4	0,1	-0,5	-0,6	-0,6	-0,2	0,1	0
COPD	-1	-1,8	-1,4	-2,4	-2,1	-2,1	-0,3	-0,3	-0,3
Heart Diseases	0	0	0	-1,6	-0,2	-0,8	0,3	0,2	0,2

5.1.1 Emilia-Romagna

The demographic picture of the Emilia-Romagna Region is characterized by a high number of older adults (almost one out of four inhabitants are over 65), mostly resident in the province of Bologna (242,233)³⁴. Recent studies estimate that the group of so-called “older-old” (over 80 years old) in 2030 will form more than 10% of the population³⁵. The group is not homogenous and it is possible to identify 4 groups: persons with good health and low risk of health problems, persons with good health but with high risk of health problems, persons with some frailty and persons with disabilities. These numbers change when we analyse the population aged over 74: frailty increases and the number of persons with low risk of health problems almost halves (Figure 5.3).³⁶

³⁴ ISTAT Emilia romagna 2015, Retrieved from <http://www.istat.it/it/emilia-romagna>

³⁵ Comune di Bologna, Scenari demografici a Bologna nel periodo 2015-2030, Retrieved from http://www.comune.bologna.it/iperbole/piancont/scenari20152030/PRES_scenari2030versioneULTIMA.pdf

³⁶ Emilia Romagna Istituzional website, Retrieved from <http://sociale.regione.emilia-romagna.it/anziani>

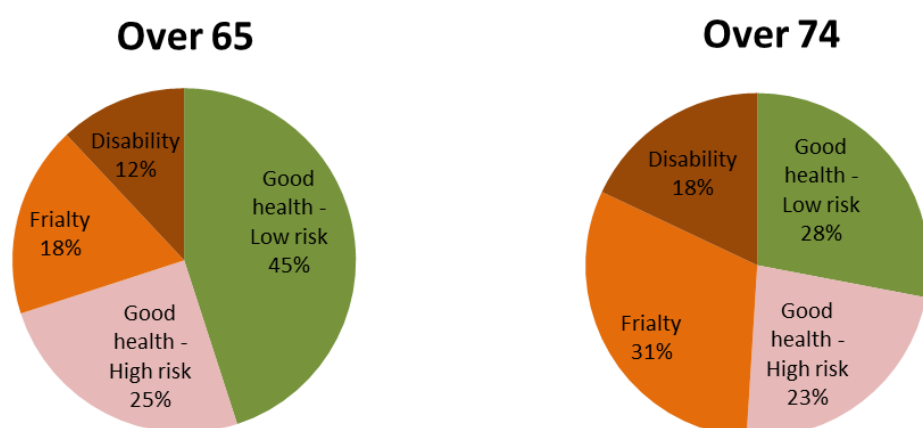


Figure 5.3: Distribution of elderly subgroups in Emilia-Romagna according to age

Frailty does not correspond to disability, but it is a direct precursor as it connects biological dimensions with the subjective loss of strength and adaptability to negative events and factors of change. Addressing frailty early means preventing loss of independence and postponing the development of long-term care needs.

Considering the sole municipal area of Bologna, the data presented above underlines the impact of frailty on the older population³⁷.

Table 5.2: Characteristics of elderly groups living in the municipality of Bologna in 2012

Elderly +65	95.368 (22.5%)
Elderly +74	54.547 (14%)
People living alone + 65	34.050 (9%)
Persons with at least 2 chronic diseases	72.300 (18%)
Personal income below € 12.000	93.048 (31%)

5.2 Health and Social Care: Legislation and Organisation

In Italy, health and social services still represent two different and only partially integrated sectors. The Italian National Health Service (NHS) ensures the provision of public health care services while public social services are “governed” by Regional Government and municipalities. The integration between the two sectors, although promoted first by the Act 328/2000 (*Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali*) which concerned the social care sector) and then by the so called “Legge Balduzzi” (Act 189/2012) – promoting a reorganization of the primary care and territorial assistance in order to foster integration with the social care system and hospital services for the improvement of the efficiency level of the services – has never been concretely applied, except in some regional contexts leading to good practices³⁸.

³⁷ Data taken from the frailty database of AUSL di Bologna and presented by G. Cavazza in 2013: <http://www.ausl.bologna.it/news/archivio-2013/auslnews.2013-05-29.6580923145>

³⁸ A. Curto, L. Garattini, La riforma delle cure primarie nel Servizio Sanitario Nazionale: fra teoria e pratica, Quaderni di Farmacoeconomia, May 2014

The Italian NHS is organised at three levels: national, regional and local (Figure 5.4). At national level, the Italian parliament sets the objectives for **public health** and approves framework legislation, the central government (Ministry of Health) defines the targets of the NHS through the National Health Plan (NHP), which outlines programmes and defines general guidelines. Regional governments are legally responsible for planning, administration and practical delivery of services through the Local Health Trusts (LHTs), these are public bodies with a reasonably high level of independence, which in turn are organised in districts. The central state and regional governments set the total budget for public health expenditure, and local taxes are a major contribution mechanism in this respect.

Organisational model of the Italian National Public Health Care System

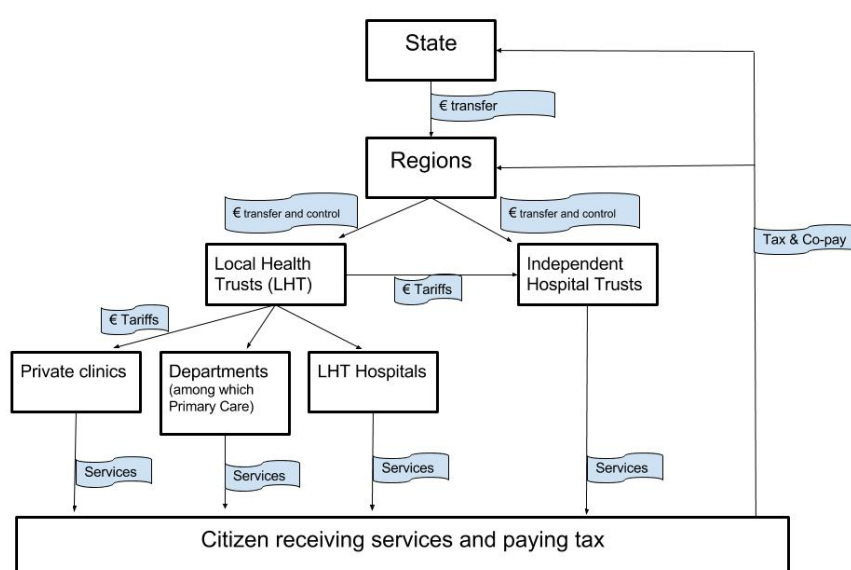


Figure 5.4: Organisational model of the Italian National Public Health Care System

The whole population is covered for health care costs, including inpatient and primary care which are free at the point of use, with the exception of some services that see financial co-participation of the service user in relation to his/her income. Benefits are comprehensive, though the financial crisis and the necessity to cut down health care expenditures (the so-called “Spending Review” carried out in 2013) has had crucial consequences in terms of reduced access for patients to services. Patient cost sharing is generally applied to outpatient prescription drugs, specialist visits and diagnostic procedures, with exclusion of particular categories of people (e.g. 65+, with low income, with specific chronic diseases).

In 2011, 77.8% of the total health expenditures was paid from public sources of funding, leaving 22.2% to be paid privately by service users or from external sources and spent in private clinics or specialist visits. Very recent data however show a large increase in of out-of-pocket expenses, with 12.2 million Italians reporting this in the last years³⁹.

³⁹ ICARE4EU: Caring for people with multiple chronic conditions in Italy: policy and practices, http://www.icare4eu.org/pdf/Country_Factsheet_Italy_ICARE4EU.pdf

The Italian **social care** system is characterized by high fragmentation in terms of sources of funding, governance, and management responsibilities. The actors involved are the central state (for national legislation) and the municipalities (delivering services) under the control of Regions.

Social Care is indeed delivered at local level and every municipality can opt for direct provision or can outsource services to an external market provider, including the Local Health Trust. Following European trends, social services are increasingly outsourced to private accredited care providers (profit or non-profit) with service delivery contracts or to independent or “institutional” public services. Under Act n. 328/2000 and decree-law n. 8207/2001 a new institutional setting for social care organisations was defined and the reforms also created a new institutional actor, the ASP (Azienda Pubblica Servizi alla Persona – Public Company for Services to the person), with the intent to improve the way social services are provided. The ASP is intended to be a more professional, efficient and flexible type of organisation, compared to the municipalities. Most of the social care in several Italian regions is now provided through ASPs as autonomous entities usually owned by the municipalities themselves. The ProACT partner ASP Città di Bologna, is one of them.

Social care services are funded mostly by the State, the Regions and the Municipalities through general taxation, by the National Institute of Social Security (INPS) and by the service users. INPS provides 75% of the national welfare resources through direct cash transfers to families while regions and municipalities in charge of providing the welfare in-kind services, manage the rest of the funds (25% of the total)⁴⁰.

The public expenditures on social care in 2010 in Italy equals 1.91% of the GDP: 0.49 % for care delivered at home, 0.55 % for care in institutions, 0.86 % as cash benefits. From 2002-2010, the growth of the expenditure dedicated to so called “companion”-grants (i.e. cash-for-care allowances available to severely disabled people) has been the most important change in social care provision (from 6.0% in 2002 to 12.5% in 2010 of older citizens in the same age group in the period 2002-2010), this however is not due to a change in the policy itself, but rather to a less strict application of the requirement criteria over time.

Conversely, in 2010 5.5% of older citizens made use of public home care services, and 2% used residential care. The Italian social care system is relying highly on a cash-for-care scheme, with direct monetary transfers prevailing over in-kind services, but it is also characterized by diversity among regions both in funding levels and in integration/direct supply of health and social services (more public/integrated support in North-Centre Italy compared to the South of Italy).

In order to cover the needs of resources of the social care regional system, Emilia Romagna established the *Regional Fund for non-self-sufficient people* (DGR n.509/2007) aimed at the funding of services for the disabled and other non-self-sufficient people (the total regional spending in 2014 was €470.3 million).

Furthermore, the main characteristic of the Italian social care system is the importance of informal/family care for the elderly and non-self-sufficient persons and the use of companion

⁴⁰ CERGAS- Bocconi, Francesco Longo, a cura di, Welfare futuro: scenari e strategie, 2016, EGEA Edizioni, p.122



grants to privately employ (often) migrant care workers (so called “badanti”) as private home assistants. In the Emilia Romagna, estimations says there are about 100.000 “badanti”, with a total expenditure of €1.2 billion; in the sole municipality of Bologna, where non-sufficient elderly are almost 43,000, there are 23,100 “badanti”, one for every two elderly⁴¹.

With regards policies, it is the Ministry of Health, together with the Italian National Institute of Health, that define the general guidelines. A decree-law of the Ministry of Health on June 30th, 2004 resulted in the set-up of a ‘Guidelines National System’, in which the contribution of the national institutions, regions and scientific community are collected with priorities identified and shared. Outcomes indicated a favouring of areas related to current clinic needs and targets of the National Health Plan⁴².

Over the last decade **the integration of the care system** has become a central issue of the National Government, prompted by policies at European level. The evidence of the increasing number of chronically ill citizens and the weakening of the social and parental network, together with the lack of economic resources resulted in a redefinition of the priorities and a reorganisation of the system. In 2001 with the Governmental Decree of the 29th November, the importance of the integration between health care and social care was affirmed, in particular regarding the provision of services to people with social frailty. In 2012, with the Balduzzi Act n. 189, this concept was enhanced and a reorganization of the primary care and territorial assistance sectors was conducted in order to foster integration with the social care system and the hospital services. The aim was to improve the efficiency level of the services assigned at regional level.

Moreover, in order to respond to needs of people with multimorbidity and chronic illness, some new policies and regional projects were initiated to adapt the health care system and care practises to better respond to patient needs. In 2005, the IGEA project was developed by the National Institute of Health and the Italian Centre for Disease Prevention and Control of the Ministry of Health, with the aim of improving the quality of diabetes management by implementing integrated care. The Expanded Chronic Care Model⁴³ was experimented in the Lombardy Region through the project “Chronic Related Group” (CreG)⁴⁴: the main innovative aspect of this model is the presence of a referral guarantor (manager of the CreG), that could be a GP, an accredited association or private organisation, who – against payment of a predefined amount of resources – must ensure continuity in all extra-hospital services needed for the successful management of chronic diseases. To date, the main outcomes from this experimentation is the gradual increase in availability of the GP to take the role of guarantor, with a consequent redefinition of the role of general medicine in the primary care system⁴⁵.

⁴¹ CERGAS- Bocconi, op.cit., 2016, p.64

³⁰ National Health system website, retrieved from <http://www.salute.gov.it/>

⁴³ T. Bodenheimer, E.H. Wagner, K. Grumbach, Improving primary care for patients with chronic illness, JAMA 2002; 288:1775-79

⁴⁴ A. Curto, L. Garattini, La nuova continuità assistenziale: tre esperienze a confronto, Quaderni di Farmacoeconomia, May 2013

⁴⁵ Regione Lombardia, Policy paper “Indicazioni di policy per l'integrazione sanitaria, sociosanitaria ed assistenziale”, June 2014 (Cod. Éupolis Lombardia REI 13013).



5.3 Health and Social Care in Emilia-Romagna: Organisation and Data⁴⁶

5.3.1 Regional Health Service

The public **Regional Health Service** of Emilia-Romagna comprises:

- **8 Local Health Trusts** (AUSL – Azienda Unità Sanitaria Locale): Piacenza, Parma, Reggio Emilia, Modena, Bologna, Imola, Ferrara and Romagna⁴⁷. They usually cover the entire provincial area, with the exception of Bologna where there are two AUSL's: AUSL di Bologna and AUSL di Imola. The Trusts deploy a wide range of services and service locations (facilities), along with hospitals and community based outpatient clinics;
- **4 University Hospitals**: Parma (Maggiore Hospital), Modena (Policlinico Hospital), Bologna (S. Orsola-Malpighi Policlinico Hospital) and Ferrara (S. Anna di Cona Hospital);
- Other specialised institutes and hospitals.

There are 14,224 public hospital beds in Emilia Romagna with 61,220 employees in the Regional Health Service (which include 3,070 GPs and 628 primary care paediatricians). To rationalise expenditure and to optimise quality and efficiency of technical/logistic services or integrated care functions, three 'Vast Care Areas' were created: Emilia Nord, Emilia Centrale and Romagna. 'Vast Care Areas' do not possess a legal status and consist in a functional grouping of the Health Trusts.

The **Health District** is the territorial organization of the Local Health Trust guarantor for the delivery of what is considered the basic level of care in the geographical area of reference. The Health District is the framework within which requirements are gathered, services are planned, healthcare and social-health care is provided, and results are assessed. Health Districts commission the delivery of services to the different Departments (Primary Care Department, Public Health Department, the Mental Health and Pathological Addiction Department) including the hospital departments. As of the 31st December 2014 there are 38 Health Districts and 204 Primary Healthcare Units in the 8 Local Health Trusts of Emilia Romagna.

The **Proximity Outpatient Clinics** (Case della Salute) Envisaged by the resolution of the Regional Council 291/2010, the Proximity outpatient clinics are designed to represent a point of reference for citizens to access primary care, as places that receive patients and direct them toward services, but also for providing ongoing care in relation to the management of chronic diseases and the completion of the main diagnostic pathways that do not require hospitalization. The philosophy that underlies the Proximity outpatient clinics is the concentration of efficient services with proximity care.

The Proximity outpatient clinics fall under the supervision of the District and is managed by the Department of Primary Care of the Local Health Trusts. They can differ in terms of

⁴⁶ Data in this section are taken from: Regional Health Service Office, The Emilia-Romagna Regional Health Service: Facilities, expenditure, activities as of 31st December 2014

⁴⁷ On January 1st, 2014 the Local Health Trust of Romagna (regional law no. 22/2013) was established. It gathers the facilities and services of the Local Health Trusts of Cesena, Forlì, Ravenna and Rimini which starting from that date ceased to be

complexity (and offer different services) in relation to the population density of the area in question and their geographical location. The Proximity outpatient clinics provide care through the joint action of general practitioners, paediatricians, territorial specialists, nurses, midwives, social care workers and front office staff.

According to a recent regional survey carried out in August of 2014, in Emilia-Romagna there are 61 functioning Proximity outpatient clinics, including 26 “small” ones, 21 “medium”, and 14 “large”. At present, 120 projects for Proximity outpatient clinics are planned for the local Health Trusts (59 Proximity outpatient clinics in the Health Trust’s planning). There are three types of Proximity outpatient clinic:

1. The ‘small’ Proximity outpatient clinic: it guarantees general medical assistance 12 hours a day (8 a.m. till 8 p.m.), nursing care, 1st level family advisory health centre with obstetrician, in-home care co-ordination department, and unified booking centre (CUP). A social worker is also available.
2. The ‘medium-sized’ Proximity outpatient clinic: it guarantees outpatient specialist services, out-of-hours service (24 hour assistance), paediatric clinic, public health clinics for vaccinations and screening activities. Possible presence of a gym for physical exercise.
3. The ‘large’ Proximity outpatient clinic: It guarantees all healthcare activities relating to primary care, public health and mental health. It ensures a response to health and social-health needs that do not require hospitalisation.

In some Health Districts the development of the ‘Case della Salute’ model is still underway.

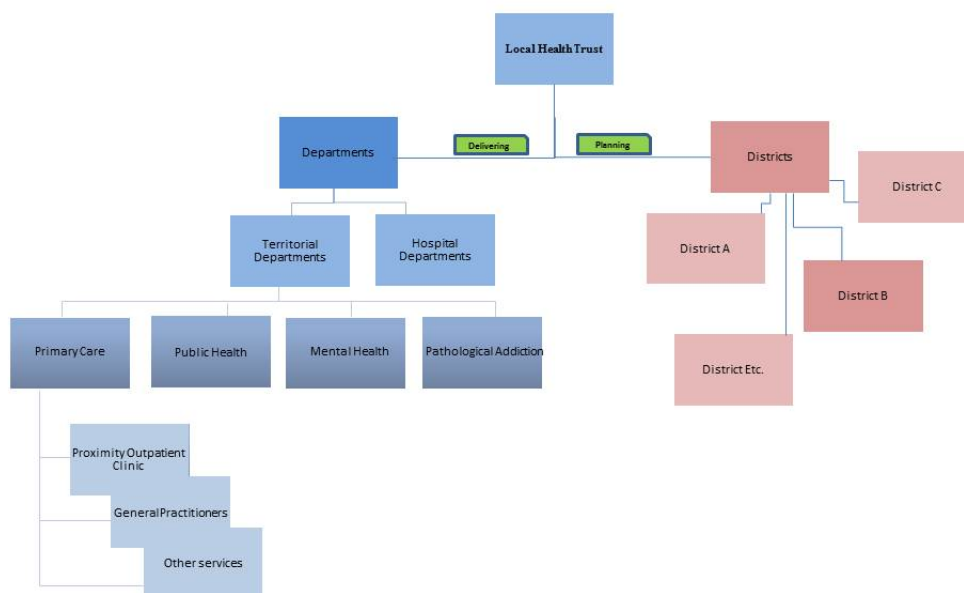


Figure 5.5: Framework of the Regional Health System as implemented by the Local Health Trusts of Emilia-Romagna

5.3.2 Regional Social System and Long Term Care

This paragraph provides a brief overview of the main services provided today by the Welfare system of the Emilia-Romagna Region, especially considering the area of elderly and “non self-sufficient”⁴⁸ people. Despite this sector of services traditionally being the most resourced of the regional welfare (along with those for the disabled and for children aged 0-3), it only covers between 25% and 35% of epidemiologically identified needs.

Long-Term Care support can come under two forms: cash benefits and/or in-kind services. With regard to the first, in addition to the “companion-grants” that, as mentioned above, are provided nationally by INPS, there are others cash benefits that are provided by municipalities, e.g. the “care-voucher” that supports home care. In-kind services can come under different forms, among which the most important are: 1) home care; 2) semi-residential or daily care and 3) residential services. Home care is managed by the Local Health Trusts and/or the Municipalities. There are two different types of home assistance, described more in detail in the next paragraph: ADI (Assistenza Domiciliare Integrata), that includes health and social services, and SAD (Servizio di Assistenza Domiciliare) that focuses on personal assistance only. When the sole home assistance is not the appropriate solution semi-residential and residential services might be provided whose characteristics, ways of access and costs depend on regional rules and municipalities’ regulations. Residential services provide temporary or permanent accommodation and housing to non-self-sufficient elderly, while semi-residential services are provided to partially self-sufficient people. These services are the base for an innovative network of community care (Figure 5.6).

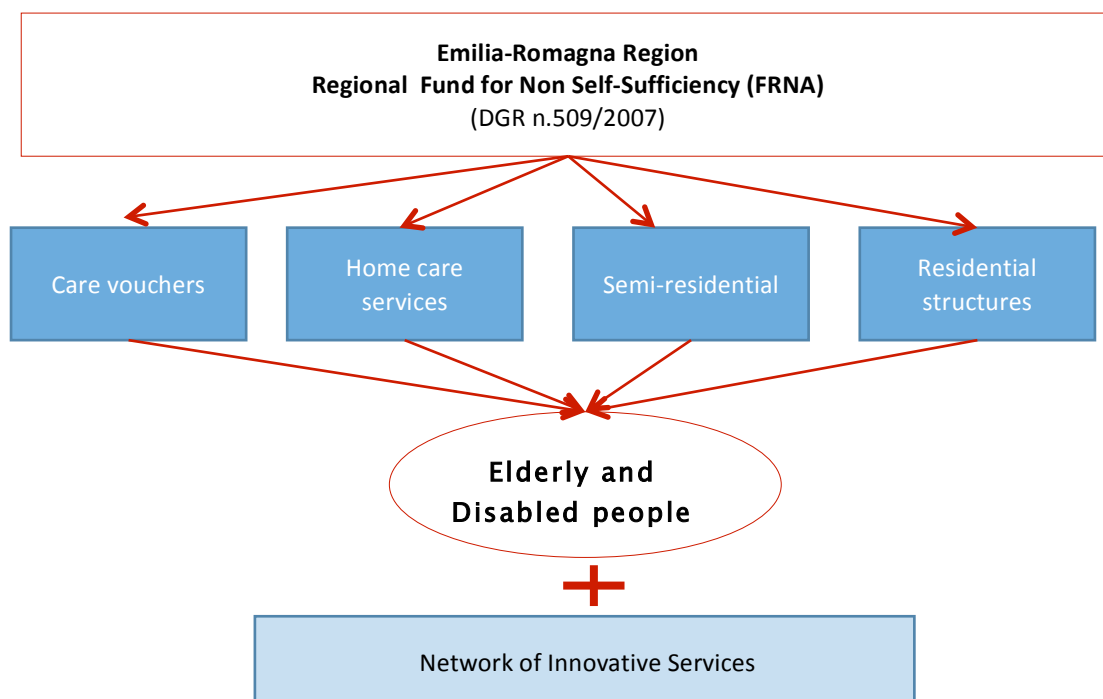


Figure 5.6: Framework of the Long Term Care public social system as implemented by the Emilia-Romagna Region and Local Authorities

⁴⁸ “Not self-sufficiency” is the literal translation of the Italian term *non auto-sufficiente* used to refer to individuals with certified functional limitations that impact on their independence in daily life.

5.3.3 In-Home Care System

The in-home care system takes care of non-self-sufficient persons or people at risk of non-self-sufficiency, who have clinical conditions that can be treated at home, live in suitable accommodation and can be supported by family or neighbours. This form of care aims at avoiding improper hospitalizations, while guaranteeing care continuity, enhancing autonomy and relational abilities, supporting families, simplifying access to medical aids. Support for home care is one of the priorities of the Regional Fund for non-self-sufficient people.

In-home care could be divided in two different sectors: ADI (Assistenza Domiciliare Integrata) and SAD (Servizio di Assistenza Domiciliare). The so called ADI is the branch of in-home care that includes health and social services. Most of these services are indeed related to General Medicine and Nursing Care (respectively 50.2% and 46.6% in 2014), a small part is dedicated to Social Health care (1%) and care provided by accredited not for profit organisations.

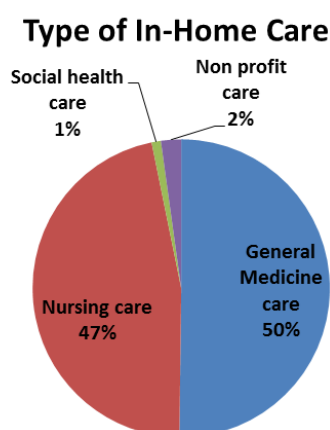


Figure 5.7: Type of in-home care provided to ADI service users in Emilia-Romagna in 2014

In 2014 the number of in-home care (ADI) patients in Emilia Romagna amounted to 102,947, with a small increase in comparison to the previous year (102,531). The number of patients handled (i.e. the in-home care paths planned for a person or for a family of cohabitants, according to the level of care needed) showed an increase of 7% in 2014 or 135,310 compared to 125,725 in 2013, with a total amount of more than 2.5 million service calls provided by assistants for in-home care. In 2014 more than 60% of the total expenditure is for low intensity care (2.4% decrease compared to 2013), 25.7% is for medium intensity and 10.6% for high intensity care (respectively 24.5% and 10.2% in 2013). The data show thus a slight increase in the intensity of in-home care. The levels of intensity of care are determined in the personal care plan on the basis of criteria defined by the Regional Government. They basically refer to the clinical needs of the patient and the frequency of the intervention of medical professionals, but take social and environmental factors in account as well.

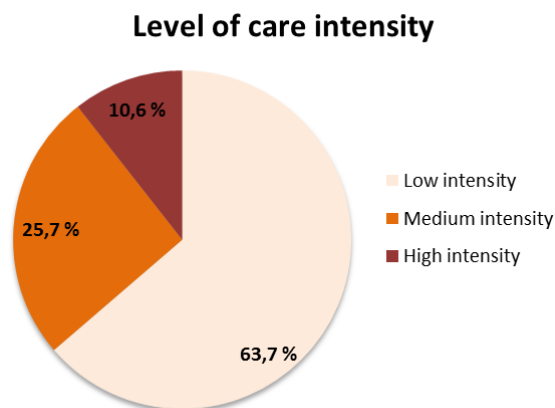


Figure 5.8: Level of care intensity of ADI service users in Emilia-Romagna in 2014

Considering the specific rates by age group, people aged over 80 use ADI services the most: 163 for every 1,000 inhabitants in the 80-84 age group (158 in 2013), 308 in the 85-89 age group (292 in 2013), 495 in the 90-94 age group (462 in 2012).

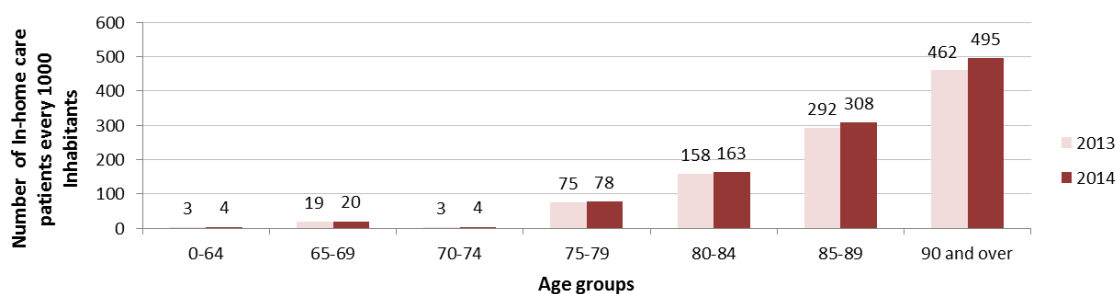
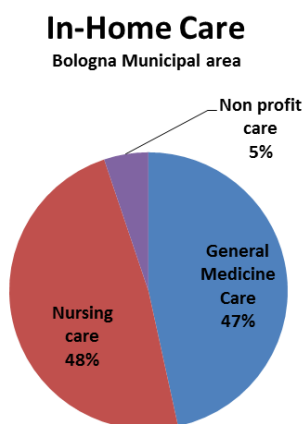


Figure 5.9: Use of ADI services by age groups in Emilia Romagna



Focusing on the municipality of Bologna, the number of in-home care (ADI) patients in 2014 was 10,250, almost 10% of the total service users in Emilia Romagna. Figure 5.10 shows that, in line with the regional data, most of the care is related to general medicine and nursing care. However, in Bologna the care provided by accredited non-profit organisations has a wider slice of in-home care services compared to the regional data.

Figure 5.10: Type of in-home ADI care in the Bologna area in 2014

Considering the number of in-home care patients (ADI) by age group, people over 85 are the main users of the services (5,368 out of 10,250), 2,114 are the patients between 80 and 84, 1,119 between 75 and 79 and 941 are included in the group 65-74.

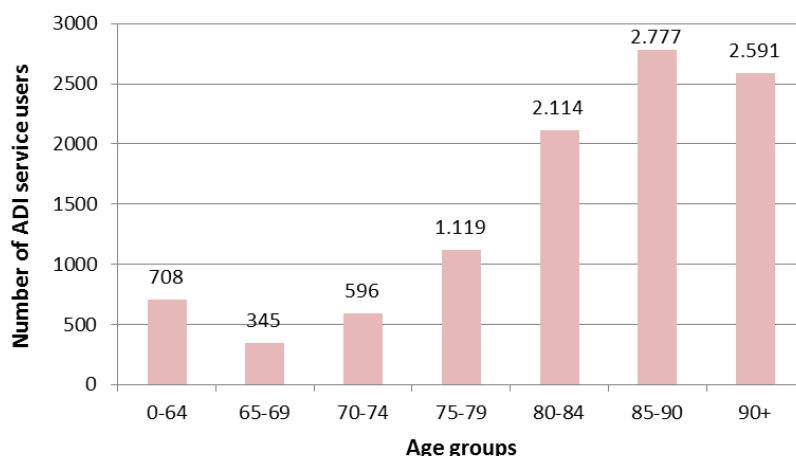


Figure 5.11: Breakdown of ADI service users by age group in Bologna in 2014

As regard the SAD Service (Servizio Assistenza Domiciliare), related to the provision of social care support according to the self-sufficient degree of the patients and older adults, numbers are smaller: in 2015, 848 persons used the SAD service provided by ASP, the organisation in charge of this service in Bologna (562 women and 292 men).

0-65		65-75		75-80		80-85		85-100		>100	
a.v.	%	a.v.	%	a.v.	%	a.v.	%	a.v.	%	a.v.	%
45	5,3	133	15,7	125	14,7	174	20,5	364	42,9	7	0,8

Figure 5.12: Use of ASP SAD services by age groups (Bologna area) in 2015

Figure 5.13 classifies the people that benefit from SAD services on the basis of the “Care Profile”, an index that evaluates two core aspects for guaranteeing older people to stay in their homes: the person care needs and the capacity of his/her social network of delivering care.

Among the sample of 848 recipients of SAD services in Bologna, almost 50% of them are reliant older adults with significant and severe impairment of functional autonomy and/or cognitive impairment; 10% are fully dependent, such as persons confined to bed, while 40% are slightly reliant older adults that require supervision and help for daily activities.

Figure 5.13 also shows the social capital of the groups, i.e. their possibility to rely on someone helping to respond to their fundamental needs. It is important to highlight that more than one third of the group has no informal support.

This data reveals the extent to which family and social networks can be frail, particularly those of older people that need long-term care. However, more than 50% of older adults fall under the frequently occurring condition where only the integration between the informal network and formal services can guarantee the sustainability of in-home care.

Care Profiles	1		2		3		Total	
	Absence of family / social network / support		Presence of family / social network partially fair		Presence of family / social network fair			
	a.v.	%	a.v.	%	a.v.	%	a.v.	%
A Elder fully dependent	15	1,7	59	7,0	12	1,4	86	10,1
B Elder reliant	115	13,6	239	28,2	45	5,3	399	47,1
C Elder slightly reliant	159	18,7	170	20,0	34	4,1	363	42,8
Total	289	34,0	468	55,2	91	10,8	848	100,0

Figure 5.13: In-Home Social Care Recipients by Care Profile, ASP Città di Bologna, 2014

5.3.4 Semi-residential and residential service

There are many semi-residential (day care) and residential services in Emilia-Romagna that provide temporary or permanent relief to informal carers. Access to the services is most of the time managed by the geriatric multidimensional assessment teams on the basis of health, social and economic criteria.

6 Stakeholder Mapping

Prior research has examined relevant stakeholders for integrated care. The iCARE4EU project reviewed 101 integrated care programmes across Europe and identified key stakeholders involved in integrated care of older adults with multimorbidity (van der Heide et al., 2015). In terms of care providers, the most frequently involved are GPs (81%), followed by medical specialists (66%), district/community nurses (53%), hospital/specialized nurses (53%), physiotherapists (33%), social workers (40%), home helps (37%), psychologists (33%), informal carers (32%), pharmacists (32%), dieticians (32%) and others (17%). This provides an indication of what general stakeholders should be involved in integrated care for this cohort.

Stakeholder mapping is an important task to understand who the primary stakeholders of ProACT are, what priorities they have and how they might benefit from the system. There are different approaches to mapping stakeholders. Our approach is person-centric and adopts features of the WHO's conceptual framework for people-centred and integrated health services. We further aim at implementing a user centred design process, which means that the expectations and user experience of end users and informal carers will be considered extremely relevant for the project.

Table 6.1 provides an overview of the primary stakeholders involved in multimorbidity care drawn from existing literature, healthcare policy and initial interviews in all three partner countries. For this deliverable, we have focused on mapping primary stakeholders – those end users who we expect will benefit from directly interacting with ProACT technologies and interfaces. We have outlined the potential roles for these stakeholders within the ProACT ecosystem but this will be refined and developed with data from user requirements as part of T1.2. Further indirect beneficiaries, or secondary stakeholders, including government agencies, hospital organisations etc. are also currently being mapped. Table 6.3 presents a brief summary of these to provide context. However, these stakeholders and the relevance of ProACT to them, will be more fully explored as part of WP6.

Each pilot partner mapped the key stakeholders in their region, following a specific template to ensure consistency. This process was informed by desk research and meetings with stakeholders, as well as the input of ProACT's multidisciplinary team of researchers. The three individual tables were then compared and summarised to highlight similarities and differences, resulting in Table 6.1. The full stakeholder tables are available on request. The scope of the summary table outlined below is to map all relevant stakeholders across the pilot sites, to identify their possible role in the deployment of ProACT as a project and as a future product/service, to turn their challenges into resources for the project and to identify possible pitfalls for the smooth implementation of the project. These are they key stakeholders who we will engage with as part of our requirements gathering process to help us build and evaluate ProACT.

Immediately following the table some key stakeholders are described in more detail.

6.1 Summary of Primary Stakeholders

Table 6.1: Summary of stakeholders across ProACT pilot sites

	Ireland	Belgium	Italy (Transferability Pilot)	Stakeholder Role in ProACT
People over the age of 65 with at least 2 of the primary selected conditions (COPD, dementia, diabetes and CHD and/or CHF)				
Patients with multimorbidity	62% of the Irish population report having one chronic disease (HSE). Prevalence of multimorbidity in over 65s for whole population in Ireland is less well studied. Glynn et al. (2011) suggest prevalence in over 50's is 66.2%. Savva et al. (2011) found multimorbidity is twice as common in over 75's as those aged 50-64. Diabetes: In 2010 10% of Irish adults aged 55+ years were estimated to have diabetes (IPH, 2012a) Chronic Airflow Obstruction (including COPD). In 2010 6% of adults aged 55 years or over were estimated to have clinically diagnosed CAO. (IPH, 2012b) The prevalence of COPD in Ireland is currently unknown but it is estimated that there are 400,000 people with the disease in Ireland (O'Farrell, 2011). CHF: Current data suggest a 2% prevalence of symptomatic heart failure in the general population rising to 10% for those over 75	Belgium 39% of people 75 and older have at least two chronic conditions (WIV-ISP, 2013) Diabetes prevalence (65+): men 14.6%, women 12.4% COPD prevalence (65+): men 7.7%, women 2.8% CHD (65+) men, 6%, women 4.3% (Van der Heyden & Charafeddine, 2013) Dementia prevalence : citizens (65+) 8.3%, female and male (Berr et al., 2005)	In Italy 52% of the persons over 65 have at least two chronic diseases⁴⁹ Diabetes prevalence (65 - 74): 15.1% (75+): 20.4 % COPD prevalence (65 - 74): 10.8% (75+) 19.5% Heart diseases (65 – 74) 9% (75+) 16.6 (ISTAT, 2013) Dementia: Official prevalence rates reported by the National institute of Statistics are 0.6 % for 65-69 but rise to 11% for over 80 (ISTAT, 2013)	• A beneficiary of health and social care • The manager of own daily life activities and behaviours • A partner in care relationships • A learner of health conditions and of devices and assistive technologies • A communication partner with other stakeholders within ProACT system • An individual with the right to have a good quality of life

⁴⁹ http://ec.europa.eu/eurostat/statistics-explained/index.php/Causes_of_death_statistics_-_people_over_65

	(Department of Health, 2010) Dementia Prevalence rates for dementia in Ireland are estimated to be 1.6% for 65-69 rising to 22.9% for people over 85 (Pierce, Cahill and O'Shea, 2014)			
Informal Carers				
Family	The majority (80%) of Irish informal carers for older people are related to the care recipients. 68% of carers are female (Kamiya, 2012)	In Belgium 79% of carers are informal caregivers (Vandenboer, 2006). 65% of informal carers are female (CBS, 2012; Oudijk, 2010)	In Italy 93,9% of informal carers are related to the care recipient and 75% of such carers are women (Censis, 2010).	• A main caregiver; • A teacher of how to manage the wellbeing of the care receiver; • A learner of health conditions and of devices and assistive technologies;
Friends, Neighbours, Peers	Friends peers and neighbours make up a smaller but significant group of informal carers. Friends and neighbours were reported as representing 18% of care in a study of informal carers in 16 OECD countries including Ireland, Italy and Belgium (OECD, 2011) This group may also give secondary levels of care in addition to a primary family carer.			• A champion for behaviour change • An individual with the right to have a good quality of life; • A person (likely older) with their own health to manage; • A communication partner
Formal Carers				
Organised Formal Care sector	Public (HSE) or Private organisations i.e. Home Instead. Provide assistance with activities of daily living (ADL) and with instrumental activities of daily living (IADL)	Ambulatory home care nursing (independent nursing, or grouped within organisations) for medical assistance, auxiliary care workers for non-medical related services.	Formal public care services that intervene at home are either employed by the local health trust (GP and nurse) or by the municipalities and their social care agencies or by cooperatives and other service providers (Social worker - Assistente Sociale and OSS - social sanitary care worker).	• A user and learner of ProACT system • A manager of patient data (With permission from person with multimorbidity) • A teacher/helper with the use of devices for health/wellbeing monitoring;
"Grey" Paid Care sector	Paid carers not affiliated with any organisation.	Not common in Belgium and underexplored in literature	Family support worker (Assistente familiare) In many case family support workers are migrant women that have replaced the role covered before by the female	• A teacher of medication management; • A champion for behaviour change

			members of the family.	• A communication partner with all stakeholders • Can provide feedback to family members or to formal care company/organisation
Voluntary organisations	The voluntary sector is active in providing home care to older people (sometimes funded through HSE) and there are also a number of voluntary organisations providing support and training to informal carers (Kamiya, 2012)	Voluntary organisations are focusing on supporting informal caregivers and provide education and training. These organisations try to defend and unite interests of volunteers and informal carers	Volunteer association address different health and social issues offering different competencies. Some of them are relevant for home care assistance (medical assistance for terminally ill patients)	
Primary / Community Care Healthcare Professionals				
GP	GP is typically first point of (healthcare) contact for patients and acts as the first 'care trustee' of the patient.	Physicians (GPs and specialists) operate in solo or group practices	MMG (GP) or family doctor has a primary role in providing access to specialised health care services	• A user and learner of ProACT system • An expert in healthcare • A champion for behaviour change • Gatekeeper of (digital) care plan • Source of information, advice, referral • A manager of ProACT patient data, medication and treatment plans • Can monitor baseline information of person in their home environment, exacerbations of conditions, fluctuations over time
Integrated community care teams.	Community Primary care team (a typical primary care team consists of GPs, nurses, speech and language therapists, physiotherapists and occupational therapists, dieticians)	Community health centre operate as a multidisciplinary team including several GPs, administrative and reception staff, nurses, a physiotherapist and a psychotherapist.	UVM (Unit for multidisciplinary/comprehensive assessment). This team consists of a nurse, a doctor and a social worker and in more complex cases a geriatrician. PCAP (Community based Sanitary Primary Care Team).	
Other key community based clinicians	Public Health Nurse Provides care on discharge from hospital	Ambulatory Home Care nursing	Ambulatory Home Care nursing	
Acute / Hospital Based Clinicians				
Clinicians specifically for older people (over 65)	Geriatrician Psychiatrist of Old Age provides specialist mental health services for older people with decreased cognitive capacity/dementia.	Geriatrician	Geriatrician and geriatric units in hospitals.	• A user and learner of ProACT system • Gatekeeper of (digital) care plan • An expert on single state conditions and/or multimorbidity
Specialist	Older patients with multimorbidity	Most Specialists (over 90%) that	Medical specialists in the public health	

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Clinicians	may be referred to different specialist consultants and medical physicians for each condition	operate in Belgian hospitals, do so as self-employed doctors	care system work either in hospitals as part of larger teams of doctors or in community services (poliambulatorio).	• A manager of ProACT patient data, medication and treatment plans • A communication partner with other clinicians, community healthcare workers, carers and patients • Manager of post-discharge care plan, treatment and medications
Integrated or multidisciplinary team	Multidisciplinary Team (nurses, physiotherapists, occupational therapists, speech and language therapists, dieticians and social workers)	Multidisciplinary Team	UVM (as above) is activated also in the hospital in case there are social indicators creating alarm.	
Other Key Hospital Staff	Discharge Co-ordinator, Home Care package Manager	Discharge coordinator	Discharge team, social worker	
Pharmacist				
	Pharmacists dispense medicine, offer information about treatments, explanations on medication interactions and refer to other health professionals or community services, if required. A pharmacist may also offer blood pressure measurement, cholesterol testing, smoking cessation service and seasonal flu vaccination (PSI, 2011)	Pharmaceuticals are exclusively distributed through community pharmacies and hospital pharmacies. In Belgium, the pharmacist does not have any role in care or referral. However, they provide information and education on the prescription. The GP remains the single/central point of contact for care and refers patients to other healthcare professionals.	• In Italy pharmacists are: Providers of prescribed drugs (and providers of other health products, e.g. vitamins) • Providers of basic health related information • Providers of basic health assessment operations (blood pressure, heart beat, weight) • Booking service for medical specialist services	• A user and learner of ProACT system • A communication partner with patients, carers and clinicians • A source of information, advice and referral (in Italy and Ireland) • Manager of prescriptions and daily medications

6.1.1 Older People with Multimorbidities

Detailed empirical research focusing specifically on the profile of people living with multiple chronic conditions is limited across partner countries. However the profile of patient users of the ProACT system in each site will be people over the age of 65 with at least 2 of the primary selected conditions (COPD, dementia, diabetes and CHD and/or CHF). Multiple chronic conditions are important determinants of frailty, functional decline and disability (Ryan et al., 2015). In addition to potential disability due to chronic conditions, we must also acknowledge that sensory, physical and cognitive impairments associated with the ageing process can hinder older users' perceptions and experiences when interacting with technology (Fisk, 2009). Creating inclusive and accessible interfaces is an important design challenge for ProACT patient interfaces.

6.1.2 Informal Carers

The informal care sector represents the main source of care for people over the age of 65 in all three ProACT partner trial sites. Informal care can be defined as care that relates to personal relationships and affective ties with the recipient (Bulmer, 1992). In Ireland, data from the first wave of the Irish Longitudinal Study on Ageing (TILDA) shows that the majority of caregivers for community-dwelling older people are unpaid (89.5%) informal caregivers (Kamiya et al, 2012). Similarly in Italy, where the model of the welfare state has been historically defined as "traditional", the main care responsibility is for the family while governments provide very meagre support (Ferrera 1996). In Belgium 79% of carers are informal caregivers (Vanden Boer, 2006).

Family carers are the backbone of any long-term care system in Ireland, Italy and Belgium. Across the OECD, more than one in ten adults aged over 50 years provides (usually unpaid) help with personal care to people with functional limitations. Close to two-thirds of such carers are women (OECD, 2011). While the most significant care relationship is with relatives, the informal sector includes others with personal ties to the recipient, such as friends, peers or neighbours. They may also give secondary levels of care in addition to a primary family carer.

Informal carers will be central users of the ProACT system and will play a crucial role in many aspects of user interactions some of which will be designed for them (for example training on use of technology, disease management and how to react to data) but they will also have a key role in maintaining interest and use of the technology for the person that they are caring for. Informal carers are often older adults themselves (Wren, 2009; Kamiya et al, 2012) and as users of the ProACT system may have age related sensory, physical and cognitive impairments similar to the care recipients.

6.1.3 Formal Carers

The precise definition of a formal carer may vary across each partner country but for the ProACT ecosystem we will define formal caregivers as those that are organised for their work (by state or private organisations). Their motivations for caring are based on carrying out a professional role for economic remuneration or the desire to feel useful (as in the case of voluntary work) as opposed to having personal ties or relationships with the care recipient. The organised care sector in Ireland, Italy and Belgium is made up of a mixture of public,



private and non-profit organisations. In Ireland and Italy there is also an emerging “grey” market of paid caregivers operating outside of the organised public and private care sector.

Table 6.2: Types of care and motivations (developed from Bulmer, 1992)

Care	Formal Care	Informal Care
Paid	Professional Care	
Unpaid	Volunteer Care	Family care, neighbours, Friends
Motivation/Relationship	Organised Activities	Personal Ties

Note: This conceptual map defines the main analytical distinctions between informal and formal care. In “real life” there are many grey zones where fields overlap. For example, professional caregivers have to demonstrate relational abilities and unusual affective involvement to provide quality care; on the other hand, the relatives tend to ‘professionalize’ their care learning from health and social care workers. Another important distinction is between paid and unpaid work. In Italy, the emergence of an informal market of migrant familiar assistants highlights this grey zone of informal paid care.

In Ireland, data from the first wave of the Irish Longitudinal Study on Ageing (TILDA) shows that one third of paid carers were identified as originating outside the organised home care sector (Kamiya et al., 2012). This profile of “grey” market workers in older person’s home care is currently underexplored in empirical research in Ireland. However, in Italy where there are many migrant workers in this “grey” formal care sector, many studies on this topic have been carried out and published in the last decade. “Grey” workers live in the home of the family and they are often involved in 24-hour care assistance, although without a formal contract (Bettio and Simonazzi, 2006; Del Boca and Venturini, 2014). They are paid for their work, but their work is not socially organised. In Belgium the “grey” market of formal care is not common and is underexplored in the literature.

In Ireland the prevalence of migrant care workers in the formal care of older people is not limited to the “grey” sector. In a survey completed by 50% of long-stay residential care and home care organisations in Ireland, just under a third of all care workers in the organisations surveyed were foreign nationals (Walsh and O’Shea, 2009). Understanding the cultural context of care workers is important for the design of the ProACT ecosystem to ensure that the system is relevant and accessible to carers.

6.1.4 Community Care

In all three sites the GP plays a central role to patients with multimorbidities. In Ireland the GP is recommended by the Irish Medical Council to act as ‘gatekeeper’ of patients with multimorbidity, referring patients to specialists and other services (medical and social) as needed. Similarly in Italy and Belgium the GP (MMG or family doctor) has a primary role in providing access to specialised health care services and has therapeutic responsibilities as part of long-term chronic disease management programmes.

The presence of integrated care or multidisciplinary community care teams exist in some form in each country and are comprised of a variety of health professionals such as GPs, nurses, speech and language therapists, physiotherapists, occupational therapists and dieticians. The extent to which these multidisciplinary teams are integrated within the wider health sector varies considerably within each country and within local regions. It will be very important for the ProACT ecosystem to engage with health professionals working in community settings to understand the reality of integrated care pathways, current technologies and methods of communication that could be enhanced and supported by a new system.

6.1.5 Hospital clinicians

The geriatrician or geriatric specialist is the key stakeholder playing a lead role in multimorbid care for all three partner countries. In Ireland, the geriatrician leads the multidisciplinary team in the hospital for patients over the age of 65 and is described as a “GP in the hospital”. All countries have a form of specialist geriatric multidisciplinary team (MDT in Ireland and Belgium, VDM assessment team in Italy) in the hospital setting. The prevalence and formation of these teams varies greatly among different acute care settings and regions. It is important to identify and engage with as many health professionals involved in multidisciplinary teams in all sites as their role in assessment, treatment and discharge planning for people with multimorbidities will be crucial for the ProACT ecosystem.

Additionally in all sites there are designated roles to co-ordinate discharge for patients with multiple conditions. These discharge co-ordinators play a key role for older people in creating their care plans for returning to the community and will be key stakeholders in the design of requirements for the ProACT system.

6.1.6 Pharmacists

Pharmacists play a key role in community care in Ireland. In addition to providing prescribed drugs they also provide health information and can refer people to other health professionals. Additionally pharmacists can conduct some basic health services such as blood pressure measurement (in Italy as well), cholesterol testing, smoking cessation service and seasonal flu vaccination. However, this is not the case in Belgium and Italy. In those countries pharmacists distribute medicine and information on its use, while the GP remains is the single/central point of contact for care and refers patients to other healthcare professionals. In Emilia Romagna many pharmacies can access the central booking service for specialist visits and examinations.

Polypharmacy is an important issue in the care of people with multiple chronic conditions and we need to engage with pharmacists to improve medication management as part of the ProACT system. Pharmacists will be an important communication partner within the ProACT ecosystem allowing patients to better track and manage their prescriptions and daily medications and share this information with carers and GPs.

6.2 Summary of Secondary Stakeholders

The stakeholders outlined in Table 6.3 and the potential relevance of ProACT to them, will be explored further as part of WP6.

Table 6.3: Summary of secondary stakeholders across 3 sites

	Ireland	Belgium	Italy	Relevance of ProACT
Health and Social Service providers - Organisations providing health and social care services				
Public health and social care sector	HSE (Health Service Executive) Health and personal social services are delivered by HSE, through medical professionals and hospitals and through a network of Local Health Offices, health centres and clinics at community level (Citizens Information, 2015). The HSE is responsible for Homecare packages, support for long-term nursing home care“(Fair Deal”) and medical cards for older people. HSE or Public Hospitals – funded by HSE or from state funds (sometimes owned by private bodies, for example, religious orders)	Health and personal social services are delivered through medical professionals and hospitals (public & university). Nursing professionals & home care services are in mostly grouped in not for profit institutions and/or public insurers (ie. CM, MLOZ etc.) that ensure no additional fees are being attributed to the patient. For all medical goods and services, reimbursement applies. The full list, together with its reimbursement rates can be found in the Belgian ‘nomenclatuur’. This list is created and updated by the National Institute for Health and Disability Insurance (Government).	Public Health Care Providers: <i>Local Health Trusts</i> (f.i.: AUSL di Bologna) • Departments of Hospital Care • Department of Primary Care among which, the network of general practitioners, the proximity outpatient clinics, home care medical services, UVM multidimensional assessment teams. Public health care services might also be delivered by <i>private providers</i> in the framework of long term service delivery contracts. Public Social Care providers: <i>Municipalities</i> with their social services operated by social workers and UVM multidimensional assessment teams (f.i. Municipality of Bologna) <i>Azienda Pubblica Servizi alla Persona</i> (f.i. ASP Città di Bologna) with its	ProACT can benefit health and social care services by: • Providing potential for better communication and insights around the patients • Decreasing administrative time and thus increasing cost-effectiveness of healthcare delivery • Increasing the quality of healthcare delivery • Serving the needs of individuals that currently are not met by the public system or that rely for their care entirely on own resources. • Exploring the e-Health sector as a potential profitable sector. • Providing added value to costly private health and social care services.

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			home care (delivered through cooperatives), day care and residential services. http://www.maretermalebolognese.it/terme-felsinee-bologna-casalecchio-corsi-piscina-cure-convenzione	
Private <i>health and social</i> care sector	Private Hospitals - receive no State funding. Private home care organisations such ProACT partner Home Instead	Private hospitals and medical professionals Private home care and services organisations	Permanent profit driven organisations planning, delivering and monitoring the provision of health care services directly paid from private resources: hospitals, clinics, rehabilitation centres, individual medical specialists. Companies, cooperatives and associations delivering social care services against direct payment from the client, or that act as intermediates between care workers and employing families.	Through engagement with ProACT private care and health organisations could see their services more integrated and embedded in wider care ecosystems.
Voluntary organisations	Older person NGO service organisations and advocacy groups (e.g. Age Action, Alone, Alzheimer's Society)	Advocacy groups, on individual basis or as part of a micro care eco-system: • Steunpunt Mantelzorg • Liever Thuis LM • Ziekenzorg van de Christelijke Mutualiteiten • Ons Zorgnetwerk • OKRA-ZORGRECHT • S-Plus Mantelzorg • etc.	Organisations providing specific services without payment: f.i. ambulance services, accompanying services, social and leisure activities, e-shopping delivery, etc. (f.i. AUSER)	ProACT could benefit relevant voluntary organisations and advocacy groups by: • Integrating and embedding them in wider care ecosystems • Contributing to the professionalisation of voluntary sector. • Promoting cross sector collaboration
Health and Social Care sector: governance, financing and resources				
Health Policy and Governance	The Irish Government, the Minister for Health and the Department of Health	Ministry of Social Affairs and Public Health, Federal Public Service Social	National Ministry of Health Regional Government	ProACT can is relevant to health policy and governance by:

	are at the head of the health service. The Department of Health supports the Minister and Minister of State in the development and implementation of policy for the health services. It also monitors the performance of health services (Citizen's Information, 2015).	Security, National Social Security Office, National Institute for Health and Disability Insurance	Local Health Trusts (f.i. AUSL di Bologna) and its Districts	- Demonstrating an opportunity to deliver integrated health care where it is needed. - Creating tools to effectively support the continuity of care. - Promoting the cost-effective use of resources to improve outcomes.
Social Care Policy and Governance	Department of Health Department of Social Protection	Ministries of Health of Regions and communities	Regional Government and Municipalities Local Health Trust (if delegated by the Municipality) <i>In the Territorial conference for social and social-sanitary policies the municipalities and the Local Health Trust collaborate with the scope to respond to changing needs.</i>	For social care policy and governance ProACT has the potential to: - Address unmet needs in social care for older people - Link social care to wider health services by providing integrated solutions..
Healthcare Regulation	The Medical Council regulates medical doctors in the Republic of Ireland. CORU - regulator for health and social care professionals HIQA - Health Information and Quality Authority are responsible for Health Technology Assessments (HTA) on the clinical and cost-effectiveness of health technologies in Ireland. Health Products Regulatory Authority The Office of the Data Protection Commissioner is responsible for upholding the privacy rights of	Federal Parliament (legislative), Federal Minister of Public Health and Social Security (executive). A typical characteristic of the Belgian health system is the participation of several stakeholders in the management of the system. Besides extensive regulation by the federal and federated governments, an important part of the health system is regulated by national collective agreements made between representatives of health care providers and sickness funds	National Ministry of Health	ProACT's value network analysis and policy and regulatory guidance and recommendations will be of interest to both Health regulators and data protection officers.

	individuals in relation to the processing of their personal data.			
Public Finance	Department of Social Protection – Allocates Carer's allowance/benefit, Carer's Support Grant Department of Revenue - Income tax relief is available on fees paid for nursing homes and for carers and people with disabilities. Local Authorities - Housing Aid for Older People Scheme, Mobility Aids Grant or Housing Adaptation Grant for People with a Disability	National Institute for Health and Disability Insurance (NIHDI) This institute is responsible for the general organization and financial management of the compulsory health care and benefits insurance. National Social Security Office. The NSSO is the central institution in the social security system for private sector employees and most civil servants. Public Sickness Funds	National Government for universal healthcare coverage. Regional Government for health care (integration of national funds) and social-sanitary care for non-self-sufficient persons (<i>Fondo Regionale per la non-Autosufficienza</i>). INPS (Italian Social Security Agency) for pensions and integrative grants (indennità di accompagnamento) in case of ascertained invalidity.	ProACT has been developed not only to improve clinical advantages but also practical issues such as cost, income flows, new workflows, organisational change and multi-organisational co-operation to ensure success and catalyse at all levels from policy to front line workers out dated models of practice and service delivery. This care model will be relevant to both public and private financial sectors in health.
Private Finance (Health Insurance)	The Voluntary Health Insurance Board (VHI) is the largest provider of voluntary private health insurance. It is a statutory body whose board is appointed by the Minister for Health. Other private companies include Laya Healthcare, Aviva, GloHealth and HSF Health Plan (Citizen's Information, 2015) The Health Insurance Authority (HIA)	Private Insurance Funds	Private Insurance Funds (limited use in Italy)	

	is the independent statutory regulator for the private health insurance market in Ireland.			
Other sectors: Education, Research, Innovation				
Education and Training	Irish Universities (Schools of Nursing, Medicine, social work) Professional training providers in healthcare (i.e. CMG Healthcare) Colleges of Further Education institutions (FETAC level training for carers)	Universities, University colleges	Universities (f.i. University of Bologna) for initial education (doctors, nurses, social workers, educators, managers). The Training centre of the Local Health Trusts for lifelong learning (nurses, doctors, other staff) (f.i. The training centre of the AUSL of Bologna) Private training centres for training the care workforce.	Training applications and toolkits developed within ProACT will be relevant to all healthcare training and education institutions.
National Research policy and practice	Health Research Board Institute of Public health Age Friendly Ireland	KCE - Belgian Health Care Knowledge Centre is the official advisory and research organisation to the federal government on healthcare related topics	National Institute for Health (<i>Istituto Superiore di Sanità</i>) Regional level (Emilia Romagna): <i>Agenzia sanitaria e sociale dell'Emilia Romagna</i>	The design and implementation of ProACT will be important for national evidence based policy and practice and research in the field of digital health and ageing research. The EU-wide feasibility study to assess the transferability of the ProACT system across member states will assess opportunities and barriers from social, cultural, legal and policy perspectives which will be very relevant to national health policy and governance.
Academic Research Centres	CASALA (DKIT) Irish Centre for Social Gerontology (NUI Galway) TCPHI (TCD) Connected Health (UCD)	Strategic Research Centers (SRC's). VIB, iMinds, VITO, IMEC, Flanders Make	Research centres in the area of health care: INSB IRCSS AUSL di Bologna (Institute for Neuro Science)	
Innovation	National Health Innovation Hub (NHIH) NDRC	Strategic Research Centers (SRC's). VIB, iMinds, VITO, IMEC, Flanders Make	Partnerships and consortiums for innovation: <u>Aster</u> .	
Other sectors: Examples of providers of relevant technical products and services				
Data network providers and	Virgin Media, Eir, Sky	Previous national research projects (O'CareCloudS, Care4Balance etc.)	Cup2000 and its participating entities (Regional Government, AUSL di	Providers of data networks and innovative technologies for health

installers		on integrated care prove that data network providers are gaining importance on coordinating and integrating IT services. Examples in Belgium: Proximus, Telenet, Televic, Cegeka, Corilus, CareSolutions etc.	Bologna, other AUSL's in the Region) Providers of SOLE/FSE. SORTECH (Providers of Garsia integrated care management software).	and integrated care are important stakeholders for the exploitation and commercialisation activities which will be mapped in more detail as part of Wp6.
Medical technology Industry	McKesson ProACT industry Partners (Philips IBM) BioConnect Ireland (networking organisation for biotechnology)	Medical Technology providers are increasingly trying to find solutions contributing to integrated care. Philips	<u>Distretto Biomedicale di Mirandola</u> One of the most important biomedical districts is located in Emilia Romagna close to Modena (50 km. from Bologna).	
Industry/Startups in integrated care/digital health	Healthxl Nutritics	Belgian startups are increasingly trying to find solutions contributing to integrated care. Cubigo, Pridiktiv.Care, LindaCare	iCubo, Lorenzo Tesauri	

6.3 Stakeholders in the Irish Context

An overview of stakeholders in the Irish context is presented here, alongside details of organisations/stakeholders who will participate in the Irish pilot of ProACT.

The HSE's National Clinical Programme for Older People⁵⁰ states that the majority of care for older people is provided in the community, through GP, public health nurse and home care support services. According to the Irish Medical Council (2009), the GP is the main point of care for older adults with multimorbidity. However, older people who have complex multimorbidity, are referred to specialist geriatric services (SGS), consisting of a consultant geriatrician supported by a multidisciplinary team (MDT, which can include nurses, physiotherapists, occupational therapists, speech and language therapists, dieticians and social workers). According to HSE, the geriatrician "specialises in diagnosis, treatment, and prevention of disease and disability in older adults". They deal with falls, pain, memory loss and evaluate the person's ability to self-care. The geriatrician and the MDT work across a number of settings including, acute, community and nursing homes. They work closely with GPs and public health nurses, as well as pharmacists.

6.3.1 Care of the Older Person Assessment Unit

One of the Irish pilot sites is the 'Care of the Older Person Assessment Unit' – a geriatrician-lead SGS, supported by an MDT (including a physiotherapist, occupational therapist, speech and language therapist, dietician and general nurse). As part of this research, and to understand how the unit operates, a meeting was held with the geriatrician, as well as a focus group with the MDT. Patients with multimorbidity are typically referred to the unit from a GP, though they can also be referred after a hospital stay or acute care visit. On referral to this unit, older adults with multimorbidity undergo a Comprehensive Geriatric Assessment (CGA) which involves the patient meeting with and being assessed by the geriatrician and all members of the MDT. The CGA is described as "a multi-dimensional diagnostic process focused on determining a frail older person's medical, psychological and functional capability" (HSE & RCPI, 2012) and is outlined in Table 6.. The results of this are documented in the person's permanent health record and should be accessible to both primary and acute care teams.

A detailed care plan is then created for, and with, the patient. This unit is located within a day hospital setting. It has only recently (summer 2015) been established. Further details on the CGA, the feedback from the geriatrician and the MDT and the pathways of care within SGS as well as communication with other stakeholders are outlined in section 7.1. During the pilot, older adults with multimorbidity will be recruited from this unit, their care network (e.g. informal and formal carers, GPs and primary care team) will be identified and invited to partake in the pilot. Older adults attending this unit are a mix of those living in both urban and rural areas.

⁵⁰ <http://www.hse.ie/eng/about/Who/clinical/natclinprog/olderpeopleprogramme/about/>



Table 6.4: Basic Components of the CGA (Source HSE)

Assessment	Components of the CGA
Medical Assessment	Problem list Co-morbid conditions and disease severity Medication Review Nutritional Status
Functional Assessment	Basic activities of daily living Instrumental activities of daily living Activity exercise status Gait and balance
Psychological Assessment	Mental status (cognitive testing) Mood / depression testing
Social Assessment	Informal support needs and assets Care resource eligibility / financial assessments
Environmental Assessment	Home safety Transportation and telehealth

6.3.2 Home Instead Senior Carers

A second Irish pilot site will occur with ProACT partners Home Instead Senior Care (HISC). HISC are a global formal care company. In Ireland, HISC employ over 4,500 formal carers and have more than 4,000 older adult 'clients' throughout the country. HISC also employ a number of Quality Assistants (QAs), whose role is to meet with the client and/or their family, and to do an initial assessment to develop a care plan. Older adults with multimorbidity will be recruited from HISC offices in the Dublin region, alongside HISC formal carers and QAs. Similarly, the person's care network will be invited to take part. Together, both trial sites will cover different geographic areas, including urban and rural, and will provide the opportunity to examine any regional differences in care.

A focus group was held with 5 QAs from HISC to better understand both their role and the role of the formal carer in caring for those with multimorbidity, including the level of communication amongst HISC and other healthcare professionals around the person. The overall goal is to provide quality of care, and to ensure that the "client is at the centre and everything around them is working for them". Following the initial assessment, the QA develops a care plan, focused primarily on ADLs, manual handling, home safety etc. which the formal carer works with. The QAs in most cases will also have access to a care plan developed by a healthcare professional. These plans remain separate, but both are used in providing care. While the formal carer is the key stakeholder interacting with the client, the QAs perform regular assessments, the frequency of which depends on the needs of the individual clients, and update the care plan as needed. Apart from re-assessing ADLs and wellbeing, these assessments are also used to ensure the client is happy and satisfied with the care being received.

The HISC QAs reported having very good communication links with other stakeholders. They have established good relationships with hospital clinicians, as many of their referrals are as a result of acute admissions. They reported particularly good links with the public health nurse (PHNs) and the primary care team (PCT). Given the lack of capacity of PHNs in many areas, the HISC formal carers are their “eyes and ears on the ground”. While the role of the formal carer is not to diagnose issues or be responsible for responding to changes in physiological symptoms (e.g. BP, blood sugar levels), they are interested in data regarding ADLs (such as activity levels, time outside, sleep patterns etc.).

Of note for ProACT is potential privacy issues around formal carers having access to patient/client data. While HISC strive to assign one carer to the client, in reality there can be a lot of change in provision of care, as there is a high turnover in carers and those on leave or ill need to be replaced. Thus, it will not be a simple case of a client providing consent for their data to be viewed by one named carer. Furthermore, as formal carers should not be responsible for having to act on data, it is likely that they should only be able to view data on ADLs and not physiological data. These issues, including others such as whether they will assist with usage of devices, will be further explored as part of T1.2 requirements gathering, and a more detailed analysis of the focus group will be provided in D1.2. Privacy issues will be addressed in WP3.

6.3.3 Other Key Support Stakeholders

Given the close relationships noted between the MDT and HISC staff with PHNs and PCTs, some of these stakeholders will also be invited to take part in the ProACT trial. Other potentially relevant (non-medical) stakeholders and services in the Louth area include:

- **Cúltaca** – The Cúltaca is a service developed within ProACT partner NetwellCASALA at DkIT. They act as a service broker for older adults, helping to support them in their home and ensuring they are aware of services which could be of benefit to them. The Cúltaca develop a personal plan for the older person, focused on their goals as well as their needs, which is not necessarily health-based. A team of over 50 volunteers work with Cúltaca clients to ensure their goals and needs are being met, as well as acting as a befriending service. The potential of the Cúltaca to act as a lay care coordinator for older adults using ProACT will be explored as the project progresses. Cúltaca receives referrals from the HSE, including from the MDT at the Louth trial site.
- **Good Morning Louth (GML)** – GML is another service developed within NetwellCASALA which provides a friendly phone call to a number of older adults. A team of 50 volunteers is involved in making calls to GML clients, acting as a ‘checking-in’ service as well as a social connection. As GML clients’ needs change, meaning they may need a higher level of support, they are transferred to the Cúltaca service whose clients tend to be more frail.
- **Memory Café** – A third relevant service developed at NetwellCASALA is a Memory Café which is held once a month in a café in the Dundalk area of Louth. The café provides a relaxed and informal setting for those with dementia, their families and anyone interested in dementia, to come and learn more about memory loss. Each month, an invited speaker (such as a psychologist, geriatrician, or dementia

researcher) discusses a certain issue around memory loss, followed by a discussion/Q&A session with those attending.

Given that the MDT in the Louth trial site are currently referring their patients to these services, they are likely to be involved in the ProACT trial in some capacity.

6.3.4 Discussion

This section outlined some of the key stakeholders (additional to the person with multimorbidity and their informal carer) who will be involved in the ProACT trial in Ireland. While both the MDT and HISC provide a comprehensive, beneficial service for older adults with multimorbidity, there are a number of wider challenges which can impact on the patient. For example, there is only 1 geriatrician in the Louth region, which has a total population of 122,897 as of 2011. Thus gaining access to the MDT can be difficult for the majority of older adults. There are 12 primary care teams to address this population, with typically 3 PHNs per team, and these services are geographically clustered. Therefore there are often long waiting lists for primary care services and PHNs have little additional capacity. HISC QAs also referred to this as being an issue in Dublin and noted that two people can be living on opposite sides of a primary care geographic boundary, and experience vast differences in the services they receive.

Older adults receiving services from these stakeholders typically require complex care necessitating high levels of coordination and communication. Further details on such communication between stakeholders in the Irish context, as well as additional detail from the focus groups with the MDT and HISC, is presented in Section 7.1.

Issues around privacy of data transfer and display to different stakeholder interfaces (as well as individual access within stakeholder groups) will be important, and ProACT will need to develop detailed protocols around this.

6.4 Stakeholders in the Belgian Context

The Belgian elderly care infrastructure includes hospital care, home care and community services, short-term and long-term residential care. Long-term residential care includes service-flats, homes for the elderly⁵¹ and nursing homes. In Belgium, elderly individuals preferred to be cared for at home with the help of family and friends, as well as with the help of health care professionals. This has led to the development of a wide range of home assistance and personal care services as well as short-term or temporary care facilities (Gerkens & Merkur, 2010).

In most cases, entry into a residential institution is closely related to a serious health issue or to the inability of informal caregivers to continue to provide home care. In these cases, the combination of formal and informal help at home is not enough to cover the elderly person's needs. As a consequence, residential care facilities are reserved for more severely

⁵¹ Mostly referred to 'Woonzorgcentra (WZC)' in Dutch or 'Maison de repos pour personnes âgées' (MRPA) in French

dependent individuals. Currently, in terms of public policy, integration and coordination between the different types of care (home care, hospital care, residential care, etc.) needs to be considered. As a consequence, concrete measures, such as the reclassification of beds according to patients' health status, have been put into place (Gerken & Merkur, 2010).

6.4.1 Home Care

Service tasks include cleaning and laundry services, help with shopping, post office and bank services, and preparation of meals. Personal care can include assistance with meals, getting dressed, personal hygiene and mobility. For those in need, subsidized security alarms are available. These are linked to family members, GPs, or to the nearest special housing or call centre, where a nurse responds and attends to alarms (Gerken & Merkur, 2010).

Until 2002, coordination of home care services was done at the level of federated authorities. However, in 2002, the federal government introduced the Integrated Services for Homecare (ISHC) at the local level. The ISHCs have to coordinate all disciplines involved in home care in a defined geographical area (maximum 1 per 70,000 inhabitants per community). Each ISHC is composed of representatives of several health professions, with at least one representative of GPs and nurses involved in home care. The main task of each ISHC is to oversee the practical organization and to support care providers and their activities within the framework of home care. In particular, this includes the evaluation of the patient's ability to perform instrumental activities of daily living, the development and monitoring of a health and welfare plan, the assignment of tasks between care providers and multidisciplinary consultation to achieve objectives (Gerken & Merkur, 2010).

In Flanders, the coordination of home services is in transition. To simplify the organization the 'Cooperation Initiatives in front-line health care' (SELS⁵²) were founded. These SELs coincide with the ISHCs. The cooperation initiatives between the different representatives of health care in a specific region are aimed to optimize front-line health care by organizing care. A SEL covers the area of a regional city. SELs are active at the micro level (the organization of care around a dependent person) and the meso level (cooperation between different health care providers, ensuring continuity of care, for example transmural reach agreements, etc.) (Gerken & Merkur, 2010).

In Wallonia, home care is coordinated by 49 centres (Centres de Coordination de Soins et de Services à Domicile, (CSSDs)) distributed in 13 ISHC zones⁵³. Their main task is to guarantee the quality of care and cooperation between workers involved in home care, including GPs, home nurses, accredited services for family aid, aid for the elderly and social work, and so on. The support and coordination of care are (in the first instance) aimed at people who are in serious need of care in order to enable them to remain at home as long as possible (Gerken & Merkur, 2010).

Home coordination in the care in Brussels region is very complex since both federal and community rules are applicable. Dutch-speaking coordination centres are assembled in

⁵² Samenwerkingsinitiatieven Eerstelijnsgezondheidszorg

⁵³ <https://ec.europa.eu/growth/tools-databases/regional-innovation-monitor/base-profile/wallonia>



BOTs (Brussels Thuis Overleg). For the French speaking, since 2007, five CSSDs have been part of a single federation (Fédération bruxelloise des centres de coordination de soins et de services à domicile). These five centres are financed by the COCOF and share the same objectives. Their aims are to evaluate patients' and their families' needs and resources and put into place the services needed, as well as to follow up on the individuals' situation (Gerken & Merkur, 2010).

6.4.2 Residential Care

Long-term residential care comprises "service-flats", homes for the elderly and nursing homes. In these types of residential care, the usual household care is given partly or completely. Residential care is available to elderly people, who are defined by the legislator as individuals aged 60 years and older (Gerken & Merkur, 2010).

The preference of the elderly to live in housing where they can continue to live independently is supported by service-flats and service-housing complexes. In "service-flats", elderly individuals without major health conditions live in independent units but are offered a broad range of services (meals, house-cleaning, primary care at home, etc.). Use of services is not required but is available on demand. Currently, service-flats are increasing in the Belgian landscape. Moreover in Flanders, with increasing dependency of individuals, service-flats become "care-flats", combining the housing qualities of a service-flat with the care qualities of residential care. The individual house units are adapted to the needs of the elderly and a house assistant is present to stimulate the social network and aid in emergency situations (Gerken & Merkur, 2010).

Homes for the elderly and nursing homes are defined as one or more buildings that functionally generate a collective residence in which elderly people live on a long-term basis. Services such as meals are also collectively provided. Both alternatives offer a home replacement environment when possibilities for long-term care at home or short-term residential care are no longer sufficient for individuals having different levels of disabilities (Vander Stichele et al. 2007). Indeed, nursing homes (or nursing beds) are designed for people with long-term care needs, who have serious disabilities in ADL. Eligibility for admission to a bed in nursing home or in a home for the elderly rests on the following criteria (Gerken & Merkur, 2010).

Each home for the elderly and nursing home must have a coordinating and advisory physician who is always a GP. This advisory physician is responsible for the coordination of pharmaceutical care, wound care and physiotherapy. Each home for the elderly and nursing home must always have a functional link with a hospital. They must cooperate with the geriatric service of the hospital and a specialized service for palliative care. The degree of a resident's dependency is assessed by the formal caregiver using a standardized instrument (Katz scale). The flat-rate allowance for each group is paid directly to the institutional managers. The amounts received are used to pay the formal skilled caregivers (Gerken & Merkur, 2010).

6.4.3 Hospital Care

In acute hospitals, the geriatric ward was distinguished as a separate entity in 1984, and in 1986 geriatric medicine was recognized as a new medical specialty. These steps recognized the need for comprehensive geriatric assessment, evaluation and management of frail older patients to reduce morbidity and mortality, prevent hospital admission, and delay or postpone institutionalization (Gerken & Merkur, 2010).

In acute hospitals, a specific care programme for geriatric patients was developed (Royal Decree of 29 January 2007). The aims were to optimize functional performance and to increase the independence and quality of life of elderly patients by providing a specialized, multidisciplinary and intensive care. The multidisciplinary approach, involving both physical and psychosocial aspects, is aimed at shortening hospital stays. In 2008, the Flemish community had 4,093 geriatric beds, while the French community had 2,753 beds in 46 facilities (63.42% in the Walloon provinces and 36.58% in Brussels in 23 facilities) (Gerken & Merkur, 2010).

Elderly patients with cognitive impairments can be treated in psychogeriatric departments (dienst SP-psychogeriatric). In 2008, there were 192 psycho-geriatric beds in the Flemish community and 196 in the French community.

As a component of the geriatric care programme, geriatric day hospitals were founded. In this setting, an efficient and multidisciplinary screening and evaluation of elderly individuals can be performed on an ambulatory basis. Besides the diagnostic evaluation, therapy and rehabilitation are also provided. In 2008, there were 76 geriatric day hospitals in Belgium. In this year, the Ministry of Public Health financed 84 projects concerning geriatric day hospitals, of which 52 were in the Flemish community, 24 in the French community and 8 in Brussels (Gerken & Merkur, 2010).

Finally, specialized centres for dementia were founded to provide information and care services to patients (and their families) and caregivers involved with dementia. In 2008 in the Flemish community, there were 10 regional centres with specific expertise in dementia, supervised by one coordinating centre (Expertisecentrum Dementie Vlaanderen). These centres cooperate with the Flemish Alzheimer's League (Vlaamse Alzheimer Liga) (Gerken & Merkur, 2010).

6.5 Stakeholders in the Italian Context

Some of the key stakeholder in the Italian context where ProACT intends to pilot are described in more detail below.

6.5.1 ASP City of Bologna

The ASP City of Bologna, a public company for personal care and welfare services, inspires and directs its activities to comply with the purposes and principles set out in the Regional Law n. 2, 2003 "*Norme per la promozione della cittadinanza sociale e per la realizzazione del sistema integrato di interventi e servizi sociali*", and has as main scope the organization and provision of social and health services. In particular to provide:

- assistance to the elderly and especially to those who are disabled or physically and/or psychologically not self-sufficiency;
- assistance to adults who have social and/or health needs, including people with disabilities, to ensure them a better quality of life;
- social services in the area of parenthood, childhood, and adolescence;
- international protection services for asylum seekers and refugees.

Regarding assistance to the ageing population, ASP provides residential and semi-residential services to frail elderly. It further commissions, through its social service unit, measures to support home care including: home based assistance, protected discharge pathways, so called 'relief recoveries' to provide temporary relief to informal carers (families), and a helpline. ASP manages these services in partnership with private actors such as social cooperatives, voluntary associations and employment agencies.

The most innovative services managed by ASP are set up in order to head off the arising social needs of older adults which are not covered by current assistive measures. These community services are low-threshold and provide new forms of care. One example is the **Meeting Center** – a specialized daily centre targeting older people with cognitive-behavioural disorders, to reduce the social impact of these impairments and to support families, reducing the burden of care. The purposes of the Meeting Centre include information and awareness around dementia. The meeting centre offers hospitality and opportunity for socializing, as well as offering early diagnosis, psychological support and training for formal and informal care givers.

In 2015 another new measure that involves the network of semi-residential services has been set up with the aim of extending the supply of services to the older adults and families, diminishing the waiting list. The daily centres are also open on Sunday. This community service has been widened to support families not only for work time, but also free time. With regards to residential services, ASP is investing in a new line of services which will provide low-intensity assistive care and high solution to safety needs spread among self-sufficient older adults.

The **protected apartments** provide housing for able old people and offer them a safe, sociable and enabling environment. The apartments offer the following services:

- **An emergency call system**, linked 24/24 hours to the care staff;
- A **daytime supervision** with two daily visits by the operators of the care team and the possibility of calling the day care centers by phone or by intercom from the apartment at any time. If further assistance is needed, home care or any other kind of assistance can be provided.
- The elderly and their **families are periodically involved** in plenary meetings to assess the performance of the service; periodical individual interviews are used to evaluate the evolution of the inhabitant's needs;
- **Mobilizing and recreational activities**, based on an integrated personalized care.

ASP manages 140 places in the protected flats in the face of growing demand (380 individuals on the waiting list) which is destined to remain unfulfilled partly because of a low turnover of the guests who live there.

The ASP perspective on residential services is based on the idea of care flexibility to fill the changing needs of the person over time. That prospect foreshadows the ASP's commitment to the creation of centers expanded services, which are reconfigurable and dynamic in terms of the size and types of services offered. Such multi-functional centres (Centri Servizi) are shaped to propose a variety of solutions. In this sense, the CS are able to maintain the senior members in the same environment of life as those with aggravated health conditions. The CS are configured to be open places for the communities where they are located, offering a significant resource for the surrounding area (Figure 6.1: ASP's model of multi-functional centres of services, 2015).

ASP City of Bologna

Multifunctional Centers for the Elderly

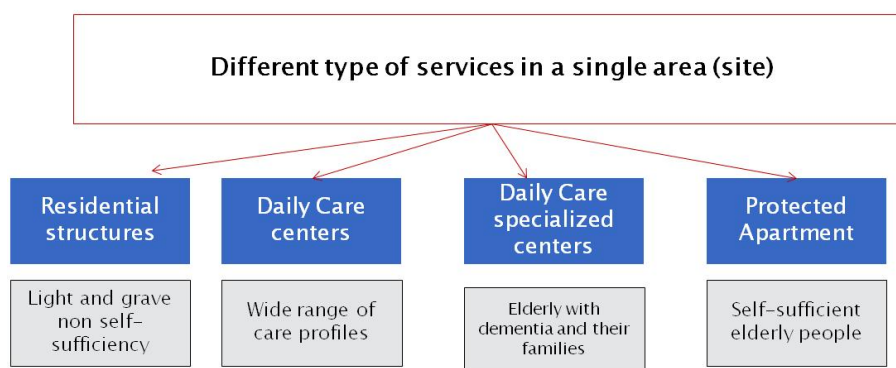


Figure 6.1: ASP's model of multi-functional centres of services, 2015

6.5.2 AUSL di Bologna: The Public Local Health Trust of Bologna

The public local health trust of Bologna is the largest health care provider in Bologna with over 8,000 employees in 2014⁵⁴. Its services are basically free of charge for the citizen, although for specific specialist interventions co-participation in the costs (entity depends on income) is requested from the service user. The AUSL di Bologna provides a wide range of emergency, diagnostic and therapeutic services through a wide network of professionals and in different facilities and locations, such as hospitals, community centres, general practitioner studio's and at home.

The AUSL di Bologna is not unique in its kind. The entire public health care system in Italy is delivered by similar Local Health Trusts. Being such important and dominant players, successful outcomes for ProACT are strictly related to its success to involve and positively in engage with the AUSL di Bologna, both for the requirements study and the pilots.

⁵⁴ AUSL di Bologna. *Piano della Performance Azienda AUSL di Bologna Anni 2015 – 2017*, Retrieved from <https://www.ausl.bologna.it/asl-bologna/staff/sviluppo-capitale-umano-e-relazioni-sindacali/trasparenza/piano-della-performance/piano-della-performance/files/Piano-della-Performance-Ausl-Bologna-2015-2017.pdf>

Districts

Covering a large territory, the AUSL di Bologna has articulated its governance structure in six so called Districts: City of Bologna, Casalecchio di Reno, Pianura Est, Pianura Ovest, Porretta Terme and San Lazzaro di Savena. The Districts, each with a Director, are responsible for interinstitutional relationships, guaranteeing citizens access to a network of appropriate services, reporting results back to citizens. It is among the tasks of the District to monitor the development of needs and to respond to those needs by activating and integrating the various resources available (individual, family, community, public health care) in a holistic welfare system. This includes actively stimulating the integration of social and sanitary care, both at governance and at organizational level, and functionally monitoring the quantity and quality of care provided. The “planning” of services by the District might involve the Municipalities, service user organisations and other stakeholders. For ProACT the Districts are important as they are speech partners in the design of innovative solutions to respond to the increasing need for sustainable integrated and continuous care delivered as close as possible to the citizen, especially to those whose needs are currently not or not sufficiently met by the existing resources.

Departments

The “production” of services is the task of the Departments, among which the Hospital Departments. The Hospital departments provide emergency aid, diagnostic and therapeutic care. The Territorial Departments, among which the *Department for Primary Care* is the most relevant for ProACT, deliver services in many different locations in the Province of Bologna. The policy orientation is to increase the level of integration and coordination between the sanitary and social services, thus creating better and less fragmented care pathways to citizens. This includes the link between hospitals and services delivered at territorial or community level. The departments further have a role guaranteeing homogeneity in the provision of services and the professional development of the staff.

The Directorate Socio-Sanitary Activities

The Directorate Socio-Sanitary Activities supports the General Director of AUSL di Bologna in collaborating and responding to the local governments, in relation to concerns regarding the development of the social and social sanitary policies. It promotes an integrated approach to care at organizational and professional level in particular in responding to the needs of vulnerable groups, such as the elderly and the disabled. The Directorate coordinates the work of the Social-Sanitary Units at District level (UASS), among which the Integrated Social-Sanitary Units (USSI) for minors, elderly and adults with disabilities. This coordinative role aims at guaranteeing homogeneous service pathways at AUSL level and the development of integrated and multidisciplinary care plans for single citizens.

The directorate:

- collaborates in realizing the integration of continuity in care pathways;
- collaborates in pathways aiming at improving the quality of home care services;
- promotes the development and use of the information system of the social and sanitary services GARSIA (www.garsia.org).

Operational Unit “Geriatrics”

The scope of the Operational Unit “Geriatrics” of the AUSL of Bologna is to ensure appropriate care of the older person at different stages of the diagnostic and therapeutic

pathway: from the acute phase to the post-acute phase including follow-up monitoring and control of the disease. It also ensures an educational activity to service users and their families providing information, prevention and early detection of diseases specific to the elderly. The Unit is basically structured as a network of services and facilities sharing common clinical and evaluative procedures: this guarantees fair treatment to patients, regardless of the Hospital of reference.

The core hubs of the network are located in three hospitals in the Metropolitan Area: Bentivoglio, Budrio and Bologna (Ospedale Maggiore). Intervention in the acute phase is assured by Bentivoglio and Bologna. Long term hospital recovery is provided by Budrio. Therapeutic continuity of discharged patients is guaranteed by protected discharge pathways, outpatient checks scheduled at discharge and ambulatory monitoring of cognitive disorders and memory. The network works in close relationship with the “Districts” of AUSL (geriatricians are also active at the outpatient clinics and take part in the UVM assessment teams), and with the University Hospital S. Orsola-Malpighi in relation to the multidimensional geriatric evaluation and activities for cognitive disorders and memory.

Proximity outpatient clinics (“Case della Salute”)

The AUSL di Bologna has 9 *Case della Salute*, among which the one of Borgo Reno Quarter seems to be the most advanced in realising integrated care pathways.

Frailty Database

The construction of a Frailty Database, was one of the activities of the project “Support to Frailty and Non Self-sufficiency Prevention”, started in 2012 in Bologna. The aim of the project was to identify persons in conditions of frailness and to monitor the individual risk of their health and dependency conditions.

The Frailty Database is now an updated, complete and structured database, collecting information related to the socio-demographic context (economic, social, housing and family context) and health and social conditions (use of health services or medicines, First Aid Emergency accesses, social support demand, taking charge by the services, etc.), of citizens aged over 65.

All this information obtained from this and other databases used by health and social services in Bologna are cross-referenced and subjected to a statistical modelling (derived from experience of the NHS, the British Health Service) in order to assign a level of fragility across a range of 0 to 100, representing the probability of incurring a negative event of health in the course of a year for a particular individual.

6.5.3 CUP 2000 S.p.A

CUP 2000 is a leading company in Italy in e-health and Internet networks for care management and delivery. It is the in-house company of the Emilia-Romagna Region, local authorities and all the local health trusts. It operates in the areas of planning, research, development, testing and management of services and products for e-Health and e-Care solutions.

With the realization of SOLE (the largest e-Health data network in Europe) and other regional projects CUP 2000 has contributed to the construction of a regional health data

network architecture which qualifies Emilia-Romagna as a front runner in Europe. The objective of building this network is to allow the systematic sharing of real-time data and information between healthcare professionals (primarily among family doctors and medical specialists and hospitals), and between the health system and citizen.

The individual Electronic Health Record (ESF) is an integrated part of SOLE. Through the ESF the citizen gains control over personal health data and decides about the sharing of these with doctors in respect of the privacy policy and to complete them through personal contributions, thus obtaining important advantages in terms of continuity of care and in emergency situations.

6.5.4 The Regional Healthcare and Social Agency

The Regional Healthcare & Social Agency (hereafter, Agency) operates as a technical and regulatory support agency for the entire Regional Health Service System. Its main function is to integrate healthcare interventions and social services, and works as an autonomous agency on behalf of the Regional Board. In particular, the functions of the Agency include:

- the promotion of the quality assurance of the services provided by the Local Health Trusts and other facilities that provide services to Regional Health Care System;
- the promotion of transparency towards the citizens, users and their organized representatives and their participation in the evaluation of services;
- Planning and regulating the supply of public and private services;
- The participation of the Health Trusts preparation by local authorities, the health plans provided by the Regional Health Plan;
- Clinical governance of the Health Trusts and organizational participation of the operators;
- The integration between the different forms of health care and between health and social care;
- The integration of care, research and training.

The Region makes use of the Agency for conducting the following activities:

- Research and development in relation to health services, their impact on health, their forms of organization, methods of operation and the criteria and funding mechanisms, with particular reference to the introduction, spread and clinical and economic impact assessment of clinical and organizational innovations;
- Support for the accreditation of health and socio-sanitary facilities;
- Monitoring and control of biological and infectious risks, with particular reference to the emerging and re-emerging infections;
- Integration and coordination of the regional system documentation;
- General training of the socio-health professionals;
- Technical and scientific support to the planning, evaluation and reporting of services in the social area, health and social services.

The Agency also acts as a connection point and facilitator for the competition, the purpose of the quality objectives of the Regional Health Service, the integrated system of interventions

and social services, the system of the universities of the region, and the level of the research system nationally and internationally⁵⁵.

6.5.5 Discussion

In this section we will discuss the main opportunities and challenges for ProACT in Italy related to the stakeholders identified in the previous section. The section is informed by our own findings analysing the available literature and websites and on the outcomes of meetings with decision makers in the Local Health Trust (AUSL di Bologna), in particular Dr. Carlo Descovich, Responsible for Clinical Governance and Quality (PDTA's), Dr. Monica Minelli, Responsible for Social-Sanitary Integration, Dr. Gabriele Cavazza, Director of the District City of Bologna, Dr. Fabia Franchi, Director of the District Casalecchio di Reno, and with Mrs. Cristina Malvi and Mrs. Cristina Bertagni (District of Bologna). Other meetings have been held with the Director of the Regional HealthCare and Social Agency, Dr. Maria Luisa Moro and with Dr. Teresa Gallelli, Head of Research and EU projects of CUP2000. These meetings had a formal character, but were rather unstructured in nature and saw the participants brainstorming together. At this stage the ProACT team in Italy has prioritised presenting the project and its objectives, as well as capturing feedback on how the project could contribute to increase the quality of the care provision in the public health and social care sector.

The Italian context seems receptive for further innovative experiences in eHealth care and for integrated care. The same is true for the Region Emilia-Romagna and the AUSL of Bologna.

This conclusion is based on the positive dialogue that has been installed with high level managers of the AUSL and on the following considerations:

Governments at all levels in Italy, national, regional and local, acknowledge ageing as a major challenge for the future welfare. There is widespread concern that the current public health and social care system in place will not be sufficient to cater for the increasing demand for services from citizens and families. The sector needs further reform and technology can play an important role in keeping care sustainable. Further efficiency needs to be brought in the system, basically by avoiding hospitalisation and unnecessary clinical examinations and by keeping citizens as long as possible independent and active in their own homes and social life environment. This means strengthening community based primary care and home care services, especially in the case of person with chronic diseases. This awareness has led the Regional Government and the Local Health Trusts to favour the development of outpatients proximity clinics and care pathways for specific health conditions, among which the chronic diseases. Pathways that integrate formal and informal resources are less developed.

The public welfare system in Bologna (AUSL and Local Authorities) is well structured on paper and trying to express an increasingly integrated approach, stimulated by interinstitutional bodies and national and regional policy. There is no reason to assume that

⁵⁵ Source: <http://assr.regione.emilia-romagna.it/it/agenzia/chi-siamo/lagenzia>

the situation in other areas of the Region is very much different. Nevertheless various stakeholders reported the lack of integration between the health care professionals, although particularly important in case of multi-morbidities, and between health care and social care professionals. Geriatricians are therefore mentioned by some of the stakeholders as the most appropriate “case-managers”.

The public health care system is providing clinical services to the large majority of the population on the basis of universal access principles. Budget restrictions and cuts obligate administrators to make choices, but there is awareness that increasing the quality of care without spending more is possible through reform, aggregating the supply of services and better integration between professionals and services.

Social services on the contrary, mainly due to budget restrictions, respond to a much small proportion of the population (approximately 30%) and is very far from a universalistic system. Among policymakers and managers there is awareness that large part of the needs of the population are not met by the public social services, resulting in citizens either solving their care needs within the family or with individual care workers, either directly contracted or through specialised private agencies. Access to services is determined on the basis of different health and social indicators, leading to a concentration of the resources to those with high levels of dependency.

Both the Health and the Social Care system are therefore allies in seeking solutions in prevention, proactive medicine and associated integrated care pathways. The “frailty”-database that was designed and implemented in 2012 as common effort by the AUSL and the local authorities is seen as an important tool for implementing preventive programmes, based on early identification of the population at risk of developing high levels of care needs. Being able to proactively serve the needs of the frail population is seen as an important strategy to delay hospitalisation and to reduce stress on specialist services. A lot is expected from the Casa della Salute model, bringing different services closer to the population and reducing the communication barriers between professionals. The District is activating community resources, such as associations of elderly and volunteers to integrate their contribution in comprehensive programmes aiming at increasing the quality of life of frail citizens mainly through socialisation and lifestyle education. More than one manager suggested that ProACT should be a flexible platform targeting in particular the group of citizens with a relatively low or moderate level of frailty but with one or more chronic diseases in order to empower their coping skills and self confidence in managing their conditions while fully exploiting the social connectedness functions (serene lifestyle!). In case of persons with more severe levels of frailty the informal care network will become crucial to be involved as cognitive levels, concentration abilities and digital skills are expected to be quite poor.

There is further awareness that implementing technology in care is a challenging process that requires careful planning and that is full of pitfalls. Not only the end user, especially those without digital skills, but also the relatively old workforce is seen as a potential obstacle. As a matter of fact there are examples in the Region of eHealth projects that have not managed to go beyond the pilot stage because they were too challenging for the established “ways of working”. On the contrary Emilia-Romagna offers also a highly developed infrastructure for patient health data management systems, among which SOLE



is the best developed and used in the entire Region. Other systems such as GARSIA are widely used to plan and manage social sanitary home care interventions. Any development of ProACT in Emilia-Romagna should take these existing data networks and their interoperability standards into account.

As part of T1.2, interviews, focus groups and design workshops will be held with all key stakeholders across pilot sites to gain further insight into the design implications and challenges for ProACT. Several interviews have already helped inform the content of this document. Based on final analysis and reports of user driven needs and requirements as part T1.2 and the associated deliverable D1.2 due in October 2016, this document may be revised if new additional material is provided, that enhances our knowledge of the stakeholders, care pathways and challenges faced by patients managing with multimorbidity.



7 Mapping Care Pathways

Having identified the key stakeholders for ProACT in Section 6, it was then necessary to understand how they fit into the patient's journey through the healthcare system, how care is coordinated and how these stakeholders communicate. We started with the understanding, well-documented in the literature, that the majority of healthcare systems are fragmented, have poorly-organised service integration, compounded by underdeveloped home and community supports and poor information access and exchange. To support the main ProACT pilots in Ireland and Belgium, and to understand issues around transference of the system to other EU countries (in the first instance, Italy), a review of current pathways for older adults with multimorbidity was conducted by each pilot partner. This task identified that while there are general pathways in place for older people, there is a lack of focus on multimorbidity, and in some cases no defined pathways for chronic disease management. Further detail is provided in the sub-sections below, while a summary of findings is included at the end of this section.

7.1 Care Pathways in Ireland

Understanding care pathways in Ireland involved desk-based research, interviews and focus groups with healthcare professionals, including the consultant geriatrician and members of the MDT (including a nurse, OT, dietician and speech and language therapist) from the Care of the Older Person Assessment Unit at Louth Hospital (see Section 6.3.1), 5 formal carer providers (HISC) Quality Assurance staff and two pharmacists.

7.1.1 Specialist Geriatric Services Pathway

To map the care pathways of older adults we started with the premise outlined in the Specialist Geriatric Services Model of Care (HSE, RCPI, 2012), which indicates that a frail older person (identified as someone with a history of falls, delirium, dementia, polypharmacy and immobility) should be referred to Specialist Geriatric Services (SGS). A referral process is outlined in Figure 7.1. and further described in the National Clinical Programme for Older People (HSE, RCPI, 2012). Information in this section comes primarily from this report.

It is recognised that the majority of older people are living within the community, and this is where the majority of care occurs. To improve health and wellbeing within the community, new health promotion strategies are needed, and the role of the voluntary sector and media is deemed important in this. The GP is considered central to this care, and particularly to the coordination of care, referring to other specialists as required.

A patient is referred to SGS through primary care, on acute admission or an Emergency Department (ED) visit. However, there is no particular process for identifying someone as frail - it is described as a "random process". The report recommends that the SGS team educate other healthcare professionals in the identification of frailty. To support this, a geriatrician-led SGS team needs to be available, but this is not currently the case in all hospital settings. SGS typically sits within either an acute care setting (i.e. in an ED or acute hospital) or a Day Hospital / outpatient clinic. On referral, patients should undergo the

Comprehensive Geriatric Assessment (CGA) that was outlined in Table 6.. A critical part of the CGA process is the development of an integrated care plan for treatment and long term follow up. The CGA has been associated with better health outcomes for frail older people including health improvement, reduction in disability, reduced institutionalisation and greater chance of living independently at home (Ellis et al. 2011). However, the 2012 report recognises that there is “no IT structure for capturing SGS pathway, process or outcome data” and that the current system “does not accurately capture discharge plan or destination of patients to rehab etc.” It is recommended that best practice would involve a paperless system for referral, dissemination of results, CGA and performance measurement.

Patients can be referred from SGS to an outpatient department or a day hospital, or back to other community services. This pathway can include a combination of outreach visit and phone call or home visit.

Another important aspect of the SGS Pathway is discharge planning for frail older adults who have been hospitalised (in both acute and rehabilitation settings), which should include consultation with the patient and family / carers as well as close communication with healthcare professionals in other settings. It is the responsibility of the SGS team to send referrals electronically, by phone or by fax. GPs and the primary care team should have direct access to a doctor within the SGS to discuss patients. Once the GP / primary care team has seen the patient, they must communicate the outcome back to the referring source on the same day the patient is seen.

Fifteen pathway enablers are described, including involving older people and carers in planning, a good partnership between healthcare professionals in different settings, training of all staff caring for older people in geriatric medicine, offering choice in treatment to older people, use of a single assessment tool and older person case management to monitor and ease their journey through the healthcare system.

Multimorbidity is not explicitly outlined in the SGS Model of Care document. To better understand how this pathway applies to those with multimorbidity, a meeting was held with an SGS consultant geriatrician followed by a focus group with the MDT working with the geriatrician. The geriatrician explained that if a person has multimorbidity (two or more of the ProACT conditions) they are referred to SGS, led by a consultant geriatrician and supported by the MDT. Often, the patient may never have seen a specialist for their condition. However, if a patient experiences an exacerbation in any one particular condition, the geriatrician refers them to the relevant specialist for that condition, within an outpatient clinic. Further feedback from the geriatrician and MDT is outlined in Section 7.1.4.

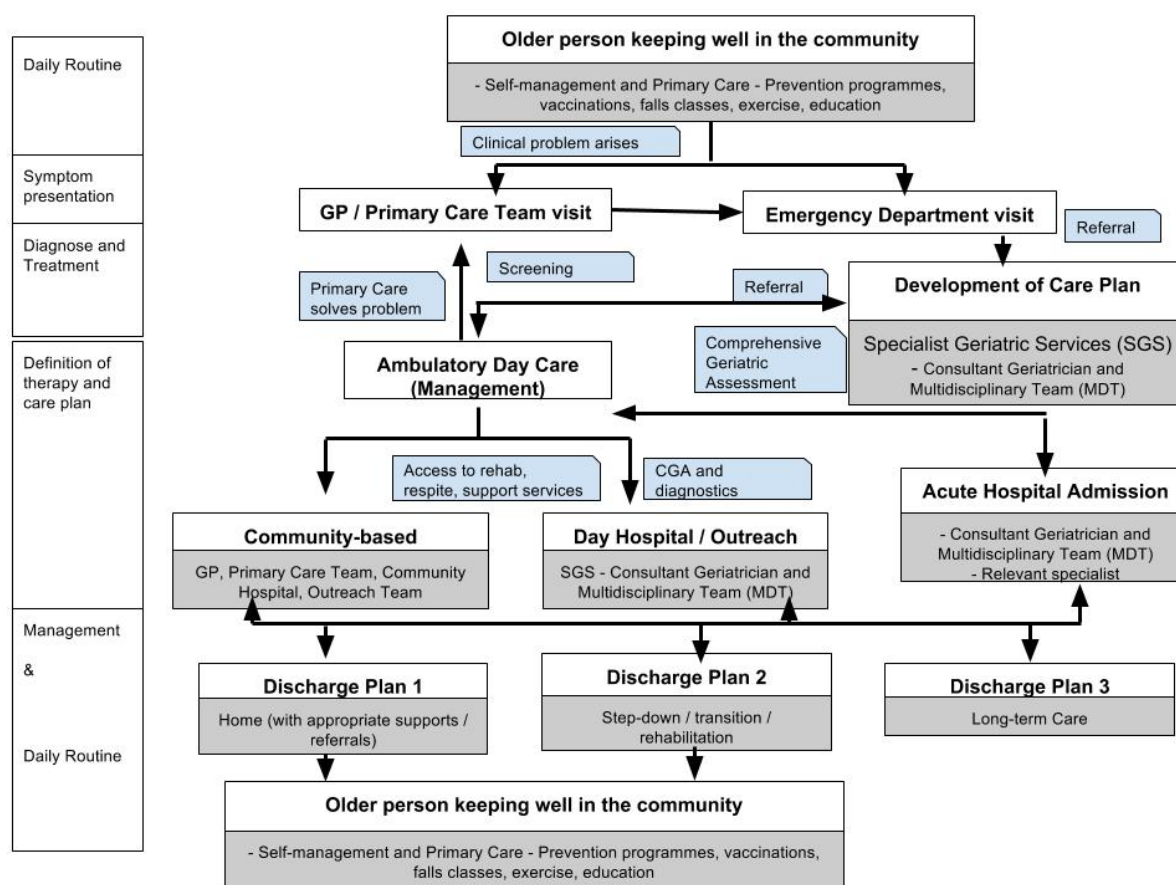


Figure 7.1: Specialist Geriatric Services Pathway (Adapted from the HSE)

7.1.2 National Clinical Programmes for Chronic Disease

In Ireland, in addition to the National Clinical Programme for Older People, there are National Clinical Programmes for COPD, diabetes and heart failure. Some are more detailed than others. For example there is very little information on how the aims of the COPD programme will be implemented, or to what extent they have⁵⁶. More detail is available for diabetes. For example, detailed documents are available outlining models of care for the diabetic foot related problems, diabetes in pregnancy and diabetes in children. Table 7.1 shows the risk categories of development of diabetes-related foot problems and which healthcare professionals should be involved. This table has been developed by the National Diabetes Programme within the HSE and is based on NHS NICE guidelines. A model of care for Acute Coronary Syndromes (ACS)⁵⁷ was developed in 2012 to develop protocols for best-practice patient care. While a detailed care pathway is not included, the document refers to standardised responses across hospitals, the establishment of cardiac rehabilitation programmes in acute care settings, the establishment of secondary prevention programmes in primary care and patient information and awareness campaigns to recognise symptoms. It should be noted that of the disease groups of relevance to ProACT, only diabetes qualifies

⁵⁶ <http://www.hse.ie/eng/about/Who/clinical/natclinprog/copdprogramme/>

⁵⁷ <http://healthaffairs.ucd.ie/wp-content/uploads/2015/09/Model-of-Care-ACS.pdf>

as a long-term illness, meaning the person with diabetes is entitled to free drugs and monitoring equipment for that illness. This contrasts greatly with COPD, CHF and dementia.

Table 7.1: Overview of risk categories for diabetic foot care and healthcare professionals involved (Source: National Diabetes Programme)

Risk Group	Risk Category	Foot Examination Frequency	Examiner
Green	Low Risk	Annual	Primary care nurse
Amber	At Risk (Moderate Risk Category)	Annual or more frequently as required	GP/primary care nurse. Annual review by podiatrist either in community or hospital.
Pink	At Risk (High Risk Category)	Annual or more frequently as required	GP/primary care nurse or hospital diabetes clinic, Plus scheduled annual review or more frequent review as required by member of foot protection team.
Red	Active Foot Disease	At least once weekly or as required	Diabetes multidisciplinary foot care service

7.1.3 Care Pathways for People with Dementia

Currently, there are no defined pathways or care models in place for those with dementia. The initial pathway in many areas is referral by a GP to a memory clinic for diagnosis. However, there are inconsistencies in the availability of memory clinics throughout the country. Care is largely delivered through existing community services, with signposting to additional and ad hoc voluntary services, such as the Alzheimer's Association, carers association, day care services and meals on wheels. There are some examples of pathways in development in the country, but they are influenced by availability of staff, and resources at a local level. The coordination of care in the community is largely coordinated through the PHN.

The Irish National Dementia Strategy⁵⁸ is a government commitment to develop a "national Alzheimer's and other dementias strategy to increase awareness, ensure early diagnosis and intervention and develop enhanced community-based services. The strategy identifies a number of key principles necessary to deliver these commitments, including

- Timely diagnosis and intervention.
- Assigning HSE management and front-line staff clear responsibility for dementia to manage patients across healthcare pathways, including a named key worker within primary care who is the first point of call for the person with dementia, and who has responsibility for coordinating care. There is no clear pathway described for a person with multimorbidity and dementia.

⁵⁸ <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

- The development of clear care pathway descriptions, with information and assistance being made available to GPs, patients with dementia and their families in identifying and accessing appropriate supports.
- The development of a specific work stream on dementia care with the Integrated Care Programme for Older Persons.

The strategy notes that “a person with dementia and their carer(s) need a clearly signposted pathway that directs them to the direct care and support, in the right place and at the right time”.

7.1.4 Input from Healthcare Professionals – Pathways, Care Plans, Integration and Communication

While policy documents and programmes such as those outlined above and in Section 3 are very beneficial in understanding best practice guidelines and plans for reform within the health service in Ireland, it is important to have insight from healthcare professionals on the ground, treating older adults with multimorbidity. The interviews and focus group with the consultant geriatrician, MDT and pharmacists helped to understand how they perceive the patient’s pathway, how the care plan is developed and who is involved in this, as well as how integration and communication happens in practice. Key findings that will help inform the development of ProACT are outlined below.

7.1.4.1 Care Pathways

In terms of pathways, the MDT team described how the patient’s journey is dependent on where they are first diagnosed. If diagnosed by a GP, they tend to be managed by the GP and community services, whereas if diagnosed within an acute setting, they will be managed by the appropriate service there before being referred back to the community. This process is evident in Figure 7.1. However, the MDT spoke about how every patient’s journey can be different and that the pathway is also dependent on the particular condition, as well as geography and what services are available in the person’s location. It was noted that when a patient has multimorbidity and co-morbidities, it can often be difficult to determine what the cause of an admission or a GP visit is – although understanding this is critical in determining the treatment/rehabilitation pathway. The MDT members felt that within the community, day centres and groups are particularly important for social (non-medical) support. The team typically refers patients to day centres and makes them aware of any groups in the area that may be of benefit (for example an Alzheimer’s Café, or a COPD support group). The team feel a responsibility to be aware of what services are out there, as this forms part of the patient’s information and education to help them self-manage.

7.1.4.2 Care Plans

The geriatrician and MDT spoke about the profile of their typical patient – the average age is 80; all have co-morbidities; high levels of cognitive impairment; 20% are at high falls risk; a further 20% are at moderate falls risk; 10% are severely frail; and 28% are moderately frail. On referral, each patient meets with all members of the MDT on the same day, to undertake the CGA outlined in Table 6.. If deemed necessary, an occupational therapist will do a home visit to conduct further assessments. However, there is considerable rationing of service and

there is the requirement and scope for carers to engage in self-management at the earlier stage of illness to preserve function and safety.

All of this information is used in the development of the care plan. Each MDT discipline also sets individual goals for the patient (with their input), and does so with a full picture of the person and their home environment. Together, the MDT decide on appropriate referrals to the community and follow-up. The MDT only follow up with a patient if there is a concern that the patient might not adhere to the self-management care plan (for example if there is cognitive impairment). This follow-up happens after 6 months. The MDT spoke about the importance of the patient being central to the care plan development. They felt that ***“every patient can direct their care and should be encouraged to, once they have capacity”***. A large part of their role is empowering the individual patient, involving family members only if the patient consents. The main goal of treatment and care plans is to improve quality of life for the patient, understanding that ‘quality’ means different things to different people. Education was deemed critical to support self-management. What remained unclear however is how the care plan is linked with services outside the MDT (such as the GP, primary care teams). Furthermore, whether and how other services can input to the care plan is unknown. While summary reports on the patient are sent to the appropriate services, the extent to which these are used in further treatment planning is unknown.

7.1.4.3 Integration and Communication

The MDT spoke of how there is definitely integration between healthcare professionals across different services and settings, though they described that it often involves *“piecing together bits of information”*. This doesn’t only relate to medical care, but also the person’s situation (e.g. are they isolated, are their family living abroad, do they have issues with medication management). It was noted that there are no guidelines on how information should be communicated. When a patient is discharged from a service back to their GP, or is referred to another service, a letter and summary report is typically sent. If a new patient presents, the team spoke about how communication with other professionals tends to be over the phone, and involves reviewing patient notes and charts. The team provided an example of a patient presenting to a clinical nurse specialist (CNS) in an acute or outpatient setting. The CNS might ask the patient about their history, learn they have been to the assessment unit run by the geriatrician and MDT, and they will call the relevant staff member there depending on what they need to know. The MDT staff member might also have to phone a particular community service that they know the patient is attending for a further update. The CNS would also typically call the patient’s pharmacist, if the patient provides this information, to understand their current prescriptions.

The MDT spoke of the challenges with this type of communication, likening it to *“playing detective sometimes”*. Specific challenges mentioned included

- Getting conflicting information from different people (e.g. community, family, other MDTs) making it difficult to know which information is most accurate.
- The ease or difficulty in getting information can be dependent on what services the patient has been linked to.
- The quality of information depends on the person writing the notes and how detailed a history they took.
- People can forget to write a note.
- Handwriting can be difficult to interpret.

- Information can be missing.

With regard to the last point, the MDT said that information can often be missing which can have a serious negative impact on care.

Strategies undertaken by the MDT to improve integration and communication include:

- Putting as much information into reports to help other healthcare professionals fully understand the patient and their circumstances.
- Relying heavily on community support to understand where there are shorter waiting times for services.
- Empowering the patient (and/or family) to be in control of their health so they can provide as much information to healthcare professionals as possible.

Effective communication between the healthcare professional and the patient was also considered very important. The MDT spoke about the importance of building up a rapport, of ensuring the patient felt like an 'equal' and felt comfortable asking questions. Communication is considered key to ensuring the patient understands how to self-manage and also that they have good insight into their condition, including what they are and aren't capable of. Similarly, communication with informal carers can help to manage expectations, provide education and also help the carer understand the 'state' of the patient they are caring for – as it may be difficult to notice gradual changes or decline due to their close relationship with the patient.

Two pharmacists interviewed also spoke of the challenges and potential implications with poor integration and communication. They have experienced conflicting medications being prescribed to a patient by different healthcare professionals, providing an example of an out-of-hours GP prescribing an antibiotic and not being aware that the patient is on another medication that can cause an interaction. The pharmacists also spoke of how communication with other healthcare professionals tends to be over the phone, but said one of the major challenges is that patients can go to multiple pharmacists and there is no national database recording a patient's current prescriptions – each pharmacy retains their own. This issue was also highlighted in previous research (Smith, O'Kelly & O'Dowd, 2010). Thus healthcare professionals calling a pharmacist to understand a patient's current medication regime may not get an accurate or full picture.

A more detailed analysis of all interviews and focus groups conducted as part of T1.2 Requirements Gathering will be presented in D1.2.

7.1.5 Summary and Key Challenges

The HSE National Service Plan (HSE, 2015) recognises that to deliver better quality care, and ensure patients are supported throughout their care journey, it must implement effective, integrated pathways across acute, primary care and home settings, delivering care that is appropriate to the person's needs. New plans include the establishment of nine Community Healthcare Organisations, delivering integrated care through 90 primary care networks and the development of specific Integrated Care programmes for older persons and (single) chronic disease management.

In addition, the Future Health strategy (Department of Health, 2012) states that patients will be managed within the primary care system and will only be referred elsewhere when their needs are sufficiently complex. Plans for reform include compulsory registration with a primary care team. Similarly, the Department of Health (2013) suggests that chronic disease patients should be cared for in primary care.

The Irish Medical Council (2009) have identified GPs as the main gatekeeper for those with multimorbidity: *“It is in the best interest of the patient that a general practitioner supervises and guides the overall management of their health. Normally, consultants will see patients following referral from their family doctor or other treating doctor”*. GPs are typically the first point of contact for patients and are in a unique position to ensure continuity of care. However, research acknowledges the potential challenges with this. Wallace et al. (2015) ask ‘what can be achieved in a 10 minute consultation?’, noting that GPs internationally have cited a lack of time as one of the key barriers for providing care for patients with multimorbidity. This issue was also raised in focus group research with Irish GPs, with GPs noting that they typically do have to spend more than 10 minutes with multimorbidity patients, which results in an increased workload and longer days (Smith, O’Kelly & O’Dowd, 2010). Wallace et al. (2015) state that this is compounded by lack of clinical guidelines on caring for people with multimorbidity, which means that GPs need to use their clinical judgement in making decisions regarding care. The authors suggest flagging certain patients with complex multimorbidity needs who should be provided with longer consultation times, including time for review of disease and medication management, as well as a ‘triage’ type service with the GP nurse prior to the GP appointment.

As indicated in Section 7.1.3, a key element of the National Dementia Strategy (2014) is to identify a named person within primary care who will be the main point of contact for those with dementia seeking assistance. The aim of policy in this area is to maintain persons with dementia (PwD) in their own homes as long as possible and to avoid hospital admission or premature transfer to long term residential care. Although there are plans to create dementia case managers roles to assist families in navigating care, the main point of contact for access to community care services at this time in Ireland is the Public Health Nursing services. They will interact with GPs, home care allocation services and other allied health professionals at Primary Care team meetings, which are usually held every 1-2 months in most community care areas. Interaction with GPs for PwD is mainly around key milestones in the disease trajectory such as diagnosis/referral to specialist services, establishing cognitive capacity and during periods of acute illness. Day to day care in the community will be coordinated through the public health nursing service if the patient has significant care needs or lives alone. If the care needs are not significant most of the care will be overseen by family carers. In the absence of families with adequate commitment and resources, there is a fairly low threshold to transfer to long term residential care.

There are a small number of dementia specialist nursing staff located in specific areas of the country that will provide specialist advice but this is the exception rather than the norm. It is planned that care of persons with dementia should be delivered at the lowest point of acuity where possible so that the care will be mainly delivered in the community through the primary MDT. There are a number of pilot initiatives underway throughout the country with plans to enable outreach and inreach to specialist services as and when required. However providing such flexible options (e.g. telecare, specialist dementia medical and nursing staff



with roles between hospital and community, dementia education to all health care staff, standardised cognitive assessment) are some of the strategies that are being advanced but are still at pilot stage and are not uniformly available. It is anticipated that enabling access to specialist support and knowledge will contribute to, for example, overcoming polypharmacy, and ensuring early treatment of sepsis. This will be examined further as part of our ongoing requirements gathering.

7.2 Care Pathways in Belgium

In Belgium, the terms clinical pathways and care pathways are interchangeably used, with a preference for clinical pathway. However, in line with the European Pathway Association we will refer systematically to care pathways (Sermeus et al., 2009).

Care pathways are often used in Flanders, but are scattered and unstandardized. There is a lack of general care pathways: most care pathways are developed within hospitals and only internally used. The care pathways are developed as local protocols of care, and are therefore less transported between different care settings. This also causes a lack of information on the content of these mostly internally developed and implemented care pathways. A study by the Federaal Kenniscentrum voor Gezondheid (KCE) shows that in 2005 an estimate of 73% of the Belgian acute hospitals used clinical pathways. A total of 310 care pathways were identified within the 66 hospitals that were part of this study: 10 concerning the respiratory system (3.2%), 31 concerning the circulatory system (10%) and 17% had a diabetes care pathway. The care pathways were often found to not be trans mural (involving different levels of care, in this case more than just the hospital care): the multidisciplinary team often only included hospital care (in 74% of the cases) (Devriese et al., 2005).

However, there are some overarching organizations that develop care pathways. A key player in this is the Vlaams-Nederlands Netwerk Klinische Paden (NKP) which was founded in 2000 to support organizations in the development, implementation and evaluation of care pathways. This initiative consists of over 100 participating organizations: mostly hospitals but also homecare organizations and rehabilitation centres. The NKP states that there are more than 1,100 care pathways in use or in development. Data from the NKP and the government identified that these overarching organizations developed and implemented 138 trans mural care pathways initiatives in Flanders (Sermeus et al., 2009).

Also, a division is made between care pathway, 'zorgprogramma' [care programme] and 'zorgtraject' [care trajectory]. However, semantically and conceptually differentiating and internationally comparing these concepts is not simple. A care programme is concerned with 'clearly defining the target group, the nature and content of the care, the minimal level of activity, the required structure, the required medical and non-medical staffing and expertise, quality and monitoring standards, business economic criteria and geographic accessibility criteria.' There are, among others, care programmes defined for cardiac pathology and geriatric patients. Care trajectories are defined as a structural approach in organizing and coordinating the care and follow-up of this care for patients with a chronic illness who need a complex treatment. The care trajectory is a contract between the patient, his GP and his medical specialist to ensure quality, coordinated and personalized care. Within the care

trajectory the dialogue and cooperation between patient and the healthcare professionals is stimulated, education of the patient on the illness and managing it is provided and a personalized care plan is set up (Sermeus et al., 2009)⁵⁹. Currently there are only care trajectories for chronic renal insufficiency and diabetes type 2, but the plan is to develop more for other chronic illnesses in the future. Care pathways are seen as a method to translate the nationally defined care programmes and care trajectories into the organization or region specific daily healthcare practice (Sermeus et al., 2009).

7.2.1 Overview of Care Pathways, Trajectories and Programmes in Belgium

Care pathways in Belgium are not standardized nor easily accessible due to their scatteredness and mainly internal use. Because of the limited amount of information on the content of Belgian care pathways and since they provide us with relevant information, the care programme for geriatric patients and diabetes care trajectory will be discussed. The care programme for cardiac pathology is excluded due to its very clinical and organizational nature and lack of description of care pathways or multidisciplinary.

7.2.1.1 Care programme geriatric patient

This care programme aims to identify geriatric patients, together with the GP and other care professionals. The programme strives to standardize and optimize the care for these geriatric patients. It focuses on the multidisciplinary diagnostic and therapeutic process as well as the rehabilitation and follow-up of the geriatric patient. The main goal is to achieve optimal reinstatement of the functional capabilities and the greatest independence and quality of life as possible. To achieve this, maximum use of geriatric day centres is advised which can be reached through the GP or a specialist. Next to this, every hospitalized person over 75 years old needs to be evaluated to see if there is a need for geriatric help. Following this there is a liaison with internal and external MDT teams. The internal hospital liaison focuses on sharing geriatric expertise with specialists and teams treating geriatric patients that are not based within the geriatric department. The external liaison aims to share expertise with GP's and other care professionals and institutions that are involved, outside of hospital care. The multidisciplinary teams that are responsible for the internal and external liaison consist at least of a full time geriatric specialist, two nurses, a social worker, a physical therapist, an ergotherapist, a speech therapist, a dietician, a psychologist and an auxiliary nurse^{60,61}.

7.2.1.2 Care trajectory diabetes type 2

As earlier mentioned, there is a care trajectory defined for patients with diabetes type 2. This care trajectory is based on the Chronic Care Model and aims for multidisciplinary cooperation between first and second line health care (directly accessible care and care which is preferably and mostly reached through a GP) with a bottom-up approach to deliver

⁵⁹ <http://zorgtraject.be>

⁶⁰ Koninklijk Besluit Houdende Vaststelling Eensdeels, van de Normen Waaraan Het Zorgprogramma Voor de Geriatrische Patiënt Moet Voldoen Om Te Worden Erkend En, Anderdeels, van Bijzondere Aanvullende Normen Voor de Erkenning van Ziekenhuizen En Ziekenhuisdiensten.

⁶¹ <http://www.azmol.be/files/BROCHURES/Zorgprogramma%20geriatrie.pdf>

effective and personalised care for diabetes patients. After signing a care trajectory contract the patient is reimbursed in full for GP and specialist consultations. The diabetes educator is a nurse, dietician, podiatrist or physiotherapist e.g. that had special training on diabetes. A specification of the care that is offered within the diabetes type 2 care trajectory can be found in Table 7.2 (Leys & de Roeck, 2013; Zorgtrajecten Diabetes Type 2).

Table 7.2: Care Trajectory for Diabetes type II in Belgium

	Role in Care Trajectory
GP	Key role: create care plan, work together with specialist
Specialist	Supporting role as illness-expert: work together with and support of GP and other caregivers
Diabetes educator	Providing yearly educational sessions: start, follow-up and solve problems during education
Dietician	Provision of two sessions a year
Podiatrist	Provision of two sessions a year
Pharmacist	Delivery of self-care material to support medication manage to patients and inform on the use of these materials.
Patient	Self-management and empowerment; define preferences to illness management (lifestyle, medication, medical control). These preferences can be used to guide the MDT.

7.2.1.3 Care pathway COPD

The five circles of GP's and the pneumologists of the six hospitals of the region Central West-Flanders created a care pathway COPD (Zorgpad COPD, n.d.). In this transmural care pathway GP's, pharmacists, physiotherapists and pneumologists work together to improve the quality of care for people with COPD. The care pathway focuses on optimization of detection in the first line of care (mainly by the GP) and correct referral to and communication with the second line of care and vice versa. The long term goal is to have less patients in the emergency room with exacerbation. Pharmacists, physical therapists and nurses educate the patient and inform the GP if problems arise. Additional care is advised based on patient specific symptoms and includes EKG, bone densitometry, dietetics and physical therapy⁶².

7.2.2 Summary and Key Challenges

When trying to give an overview of care pathways above, it became clear that there is no standardized process of care pathways. They are very often developed in an individual setting, without being integrated with different stakeholders. Unlike care pathways used in

⁶² “http://www.lmn-cwv.be/sites/default/files/uploads/lmn/Zorgpad%20COPD_stappenplan_def.pdf

the UK (developed by NICE), Belgium has no institute developing standards for care pathways. In 2009, the Catholic University of Leuven (Sermeus et al., 2009) studied the use of integrated care pathways and gathered key insights into the challenges and threats of care pathways in Flanders. The study puts the following 6 challenges/weaknesses/threats of care pathways in Flanders forward: lack of standardisation, lack of a coherent regulatory framework, priority to intramural care, fragmented care sector, absence of care coordinators and absence of evidence based sources for integrated care pathways. Below, these challenges will be discussed in more detail.

Currently, there is no standardisation in terminology or content. Concerning terminology, different terms are being used (zorgpaden, klinische zorgpaden, zorgtrajecten, zorgprogramma etc.), without a common and clear understanding of their definitions and relation to each other. Also, there is no clear streamlined standardisation of the content of these care pathways; for instance, hospitals are often individually using different pathways and these pathways again differ from the ones that ambulatory caregivers use etc. This makes it difficult to attain a vision on integrated care and the existing practices and knowledge.

The transmural care pathways and integrated care in Belgium lacks a coherent regulatory framework. Care pathways are optional and noncommittal, and are not underpinned by policy or a financial incentive. There is no 'quality label' or clear guideline concerning the minimum requirements of a care pathway (Sermeus et al., 2009). There is a strong need for a governmental institution to develop standardized pathways (such as presented by NICE⁶³) or a 'quality label'. These could for instance lay down the key interventions and evidence-based insights that must be part of specific pathways. The current lack of standardisation and accreditation leads to an underuse, misunderstanding and lack of consistent and controllable quality for care pathways.

At the moment, the priority seems to go to intramural care pathways, Flanders will look to integrated pathways in a later phase. There is a recognition with the Belgian government of the need to develop personalised care pathways in the healthcare sector and for such pathways to be utilised by persons needing care (Sermeus et al., 2009). However, due to the lack of standardisation that leads to every hospital using its own care pathways, the development of cross institutional integrated care pathways runs slowly.

Healthcare and health insurance is provided by a diverse range of entities in Belgium, which makes collaboration and integrated work processes between different providers difficult. This fragmented landscape makes it very hard to develop, implement and evaluate unified care pathways (Gerken & Merker, 2010).

Successful development and implementation of care pathways should be supported and coordinated by a care coordinator. Today, within the fragmented care landscape there are some care coordinators, but these are mainly active within their own care groups based on ideological, geographical or philosophical background (Sermeus et al., 2009). This lack of a neutral, subordinate coordinator prohibits a full care integration between all care actors and

⁶³ <https://pathways.nice.org.uk/>

stakeholders. It also stands in the way of a transparent registration and evaluation of outcome measures.

Finally, the study of the Catholic University of Leuven (Sermeus et al., 2009) states that the differences in information between the healthcare sector and care sector are too big concerning scientific information. This is seen as a threat to the development and implementation of integrated care pathways. There are less evidence based scientific resources for the care sector, and the information used in the healthcare sector needs to be translated to fit the practice of the care sector.

7.3 Care Pathways in Bologna

7.3.1 Disease specific care pathways

In recent years the healthcare system in Emilia Romagna, in line with similar changes in most of the Italian regions and other European countries, has started to move from specialized (and fragmented) care, dedicated to treating specific pathologies (separate health departments), to a more integrated and harmonised model of assistance. Central to this new care model are the pathways named Percorsi Diagnostici Terapeutici Assistenziali (Diagnostic Therapeutic Assistive Pathways; PDTA). The definition of PDTA picks up on that of 'clinical pathway' (also termed integrated care pathways), which is a structured multi-disciplinary care plan that details essential steps in the care of patients with a specific clinical problems. The innovative aspect of the PDTA approach is that it promotes a comprehensive approach to health care. PDTAs are developed by multi-professional teams, composed of all types of physicians, nurses and social workers, who manage the disease processes and are responsible for the care of the person. In this view, caring for a person with a specific pathology means taking into account all the factors that may impact on the individual's health, from the body structures and functions to the context in which the individual lives. The development of specific PDTAs means that, for each specific disease, practitioners from different specializations and services are required to collaborate in order to develop a single care process where any single operator is aware of the progress of the intervention plan, from diagnosis through to follow-up, and shares the various information on the specific user utilizing common instruments and organizational procedures. In doing so, the objective is to deal with the increasing proportion of individuals requiring treatment for more than one disease, for which it is necessary to integrate several interventions at different levels (medical, psychological, social and technological).

The care pathway illustrated in Figure 7.2 reflects a pathology-oriented care pathway developed by the Bologna Local Health Trust. It targets Cardiac decompensation patients, which may benefit from the ProACT system as well.

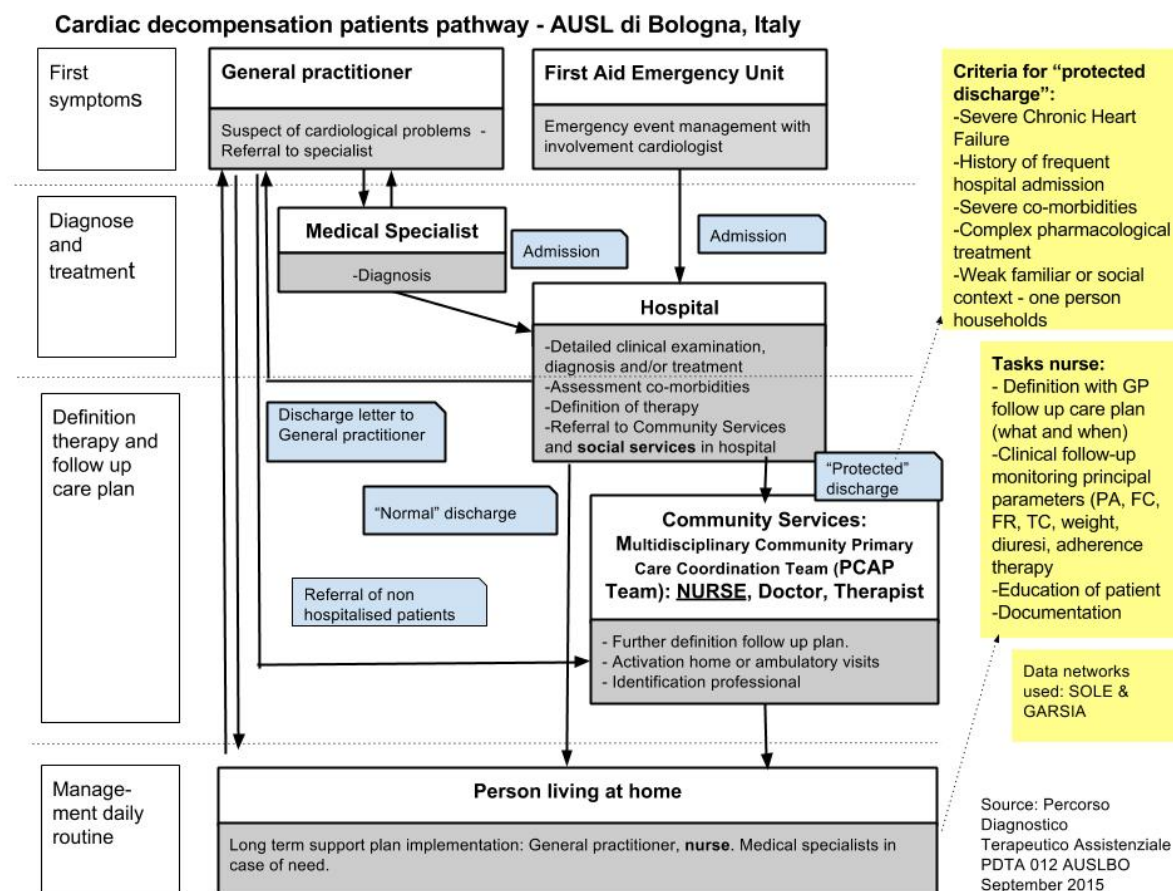


Figure 7.2: Cardiac decompensation patients care pathway

The PDTA for COPD is close to release, with the draft based on a very similar structure to the Cardiac PDTA. On the basis of the level of the severity the case manager is either the general practitioner or the pulmonologist. Again on the level of severity a follow up pathway is defined attributing a key role to the community nurse.

Regarding diabetes the Region Emilia-Romagna has developed guidelines that are followed by all Local Health Trusts covering the provision of hospital, ambulatory and home care.

7.3.2 Integrated Health and Social Care Pathways

Access to home based social services can typically happen through two strategic points: the Desk of Social Community Services (Municipality) or the Social Service of the Hospital (Local Company for Health, the latter occurs only if the user was hospitalized and is ready to be discharged). In both cases, the evaluation of the user's needs and the family network's sustainability is carried out by the Multidimensional Assessment Unit (UVM) with the attribution of a Care Profile and the definition of a Personalized Care Programme (PAI). At the end of this process, the ASP home-based care teams, composed of social workers, have the task of drawing up a Care Intervention Plan that may include home care, family support, relief hospitalization, and remote assistance.

Main pathways for older people accessing health and social care services in Bologna (AUSL & City of Bologna)

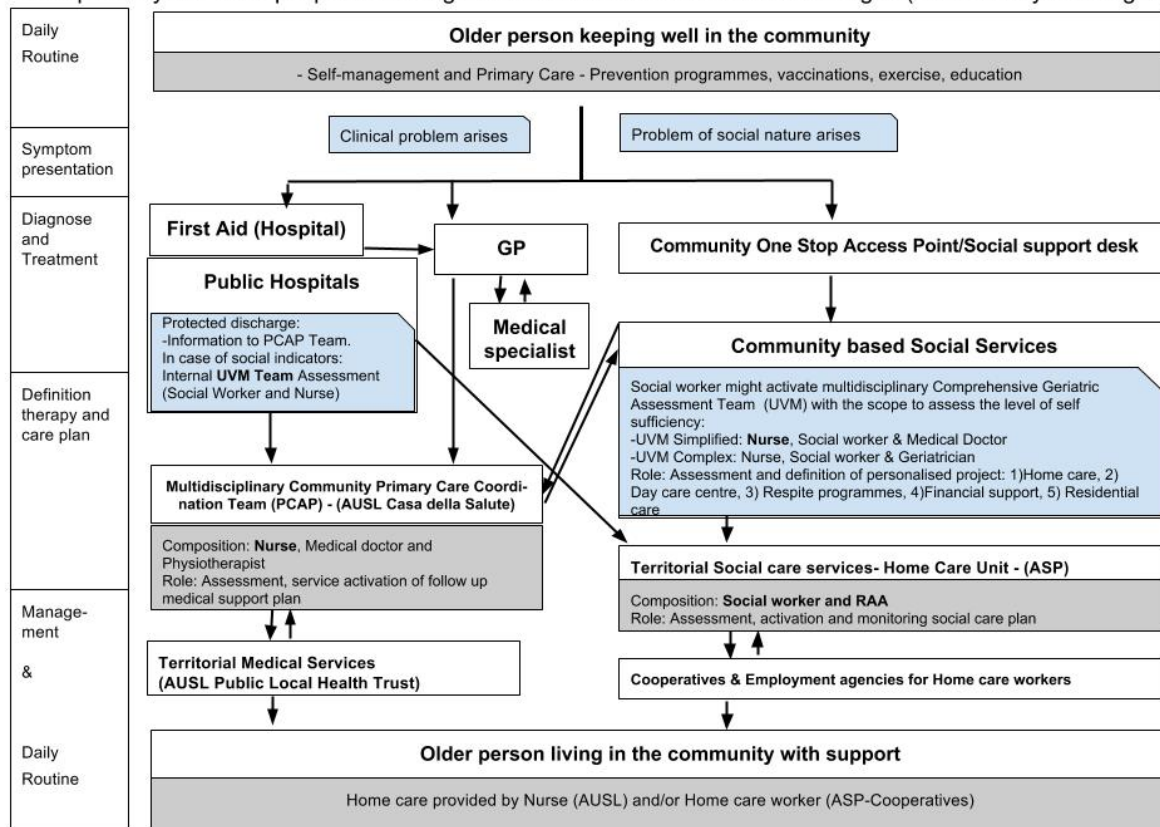


Figure 7.3: Main pathway for older people assessing health and social care services in Bologna

UVM, based on the collaboration of the Municipality of Bologna, ASP Città di Bologna and the AUSL di Bologna is the crucial element for the social-health integration. Its output, the assessment of the case with the attribution of Care Profile, comes out from the knowledge accrued by different services.

The main actors of this shared assessment and planning are:

- the social worker responsible for the case;
- the nurse in charge of the case.

These professionals are the core of the UVM and they may involve other professional figures as doctors, geriatricians and operators for additional information on the case. The assessment aims to give to the user one of the predefined care profiles and the definition of an individualized plan (PAI) containing details about objectives and timing. The prevailing instrument of the UVM functioning is the BINA Protocol, which highlights the elderly situation in terms of the level of dependency, of the social capital and the consequent effects in terms of service needs (FRNA - The Regional Fund for non-self-sufficient people). The team is activated either by the GP, the social services, or in the hospital during a "protected" discharge. The team provides an assessment on the basis of a standardised tool and defines a care plan that might comprise home support (nurse, social care worker, familiar

assistant) or other forms of support (day care center, Alzheimer's cafe, etc.). Unfortunately the delivery of the services is not yet fully integrated, for example the nurse activated by public health trust does not necessarily communicate with social care worker activated by the municipality services.

The Community One Stop Access Point is a Social Service Desk aimed at citizens and families that find themselves temporarily or permanently in difficult situations. It is the main gateway for information and advice on social and welfare services of the Municipality and of the non-profit organizations. This service has call-in desks located in every neighbourhood of the city.

The Desk is the natural access point to a wide range of specific opportunities, such as:

- financial support through grants or other incentives for individuals or families in temporary or continuous need;
- home assistance carried out by qualified operators to support non self-sufficient individuals and families;
- social integration interventions targeting children, lonely elderly and adults with socialisation and relational needs;
- residential and semi-residential facilities such as nursing homes and protected apartments for the elderly, housing communities and 'family' groups for adults and minors, day centres for the elderly, emergency shelters for persons without fixed accommodation.

7.3.3 Mapping the Local Health ICT Infrastructure for supporting Healthcare Pathways Data Management

Currently, in the Bologna area the contribution of ICT solutions to the integration of social and health processes takes place mainly through the use of specific management software suites and databases. The main solutions used are three:

- **Garsia:** a system dedicated to the management of integrated care pathways with health and social professionals as users
- **Mysanità:** dedicated to the management of the hospital pathway
- **Sole:** an integrated management system for health pathways throughout the Emilia-Romagna Region

GARSIA

The system was initially developed within Action 2.2 of the Regional Innovative Actions Program on behalf of the public bodies involved. It targets people of all ages and in all health conditions, including chronic diseases.

The objective of the Garsia system are to:

- Create a unique access to social and healthcare databases;
- Improve communication and to standardize the assessment tools among the different actors involved within the service delivery process;
- Eliminate delays due to the exchange of data between services and different subjects;
- Bring the network of services closer to the user through a widespread distribution of access points spread over the territory;

- Simplify the "de-hospitalization" process of the patient by directly activating the local services and ensuring the continuity of care between the various health and social networks nodes;
- Support the reference figures (Case Manager and General Practitioner)
- Make available new tools of government for the network and support future planning;
- Increase the use of mobile ICT systems among medical and social workers
- Ensure greater transparency and equality

The main technical developer of the system is Softech. (<http://www.softech-engineering.it/>)

MySanità

My sanità is a system developed to operate on different functional areas, mainly focused on managing hospital patients' pathways. The main functional areas of the system are:

- *Health Area*: First Aid, Management Departments, Medical Record Management, Specialist Outpatient, Physical Medicine and Rehabilitation, counselling, sports medicine.
- *Integration Area*: the system is able to integrate with other ICT system used by the public health system as: Corporate Registry, Diagnostic Imaging, Laboratory Analysis, booking system, regional database system Sole (see below).
- *Administrative Area*: allows the user to manage activities related to General Accounting, Cost Accounting, Management Reporting, Health Production, Health Mobility, Accredited Specialist Centres, Protocols, Resolutions.

Sole/FSE

SOLE ("Sanità On Line" – "Health Care On Line") is the integrated network of local health units, hospitals, general practitioners and paediatricians of the Emilia-Romagna region in Italy. The project started in 2002 and the service begun in 2010. Together, these entities constitute the physical and virtual infrastructure of all patient-centred Integrated Care services organized by the health actors of the Emilia-Romagna region. The FSE ("Fascicolo Sanitario Elettronico" –Electronic Personal Health Record) is a software application which helps to organize, retrieve and manage the clinical history of any citizen of the region. The SOLE/FSE case addresses the population of the Emilia-Romagna in its entirety and is used by all GPs/paediatricians of the public health system. Some specific initiatives activated within the SOLE/FSE framework include:

- *Integrated Home Care Assistance (IHCA) project*: SOLE/FSE acts as enabler of independent living solutions in the region.
- *The PROFITER project*: for developing a frailty index and related frailty prevention and care protocols, based on the retrospective analysis of the information continuously collected through the SOLE network and stored in the FSEs of the citizens. The operational model is supported by a technological infrastructure integrated within the SOLE network and based on a mix of portable devices and home sensors to allow for the monitoring of elderly persons at their home and outside, in order to prevent them from falling and give them faster access to assistance and care.
- Home care management of diabetic patients. It comprises the development of a personalized integrated care pathway for patients with diabetes,

- Integration of drug addiction treatment services to the SOLE/FSE. It consists in the development of an information-sharing protocol between the organization in charge of the drug addiction treatment and the GPs.
- Cardiovascular disease prevention. This project promotes the integrated use of a cardiovascular risk card. The SOLE/FSE allows managing all the phases of the cardiovascular disease diagnosis process. Collected data on cardiovascular risk of a given patient are made available by the GPs in the SOLE/FSE to patients, so they can access their records online, as well as to other health care professionals, to whom the patient has given written consent.
- Haemophiliac regional portal: The regional health record for haemophilia is made available by the SOLE/FSE for the citizens and for health care professionals, to whom the patient has given a written consent.

7.3.4 Summary and Key Challenges

In this section we will discuss the main opportunities and challenges for ProACT related to the existing care pathways in Emilia-Romagna.

A lot of work has been done by the Regional Government, Local Health Trusts and the Local Authorities to standardise pathways of citizens with health and social care needs. Proactive medicine and integrated care pathways have been identified as determinants of better and more efficient care systems. The design and implementation of care pathways for specific diseases (PDTA's) is widely practiced and are often developed with the involvement of different Local Health Trusts. Most care pathways include a follow up phase and the involvement of social services and a multidimensional assessment team during the "protected" discharge process.

Access to supportive home care is therefore possible either through a medical pathway or a social care pathway that have their meeting point at the moment of the Multidimensional Assessment, either in the hospital or in the community services. Nevertheless in the implementation of the services there is a lack of coordination, also due to the fact that it involves different actors that not necessarily communicate. Their bringing together in the *Casa della Salute* might be a step forward.

It is important for ProACT to build on this existing infrastructure of services that due to reforms underway are increasingly focussed on collaboration and integration.

7.4 Summary

A review of care pathways across all three pilot countries was performed to determine similarities and differences. These are highlighted in **Error! Reference source not found.** Across all 3 countries, there is a lack of focus on multimorbidity, though there are specific programmes and care pathways outlined for older adult care. The Bologna health region has developed care pathways for specific diseases, however such information is not currently available within the Irish and Belgian healthcare contexts. Therefore we decided to review

the NHS NICE pathways⁶⁴. The NHS NICE pathways and guidelines do not specifically address multimorbidity. Hughes, McMurdo & Guthrie (2013) reviewed the guidelines for a number of chronic conditions, including type-2 diabetes, COPD, heart conditions and depression and identified that comorbidity was not consistently addressed in the guidelines, and in some cases wasn't discussed at all. However, NICE are currently preparing specific guidance on multimorbidity. Scoping workshops have been carried out and the guidelines are anticipated in September 2016. On release of these guidelines, ProACT pathways will be reviewed and refined as necessary.

Table 7.3: Comparison of care pathway findings across trial countries

Care Pathway Finding	IRE	BE	ER ⁶⁵
A care pathway for geriatric patients exists that is multidisciplinary	Y	Y	Y
GP is the key person within the community who should coordinate care for older person with multimorbidity	Y	Y	Y
Older person with multimorbidity is referred to geriatrician	Y	Y	Not automatically
Older person with multimorbidity receives comprehensive geriatric assessment	Y	Y	Not automatically
Specific care pathway for multimorbidity	N	N	N
Specific care pathway for COPD	N	N ⁶⁶	Y
Specific care pathway for Diabetes	N	N	Y
Specific care pathway for CHD	N	N	Y
Specific care pathway for Dementia	N	N	N
Standardisation of care pathways in region / country?	N	N	Y
Good integration between health services in different settings?	N	N	Y
Good integration between health and social care?	N	N	Not necessarily
Integration of health and social care on government agendas	Y	Y	Y
Use of IT to support pathways?	N	N	Y
Recognised need to improve chronic disease management and health promotion?	Y	Y	Y
Recognised need for health system reform to support integrated care?	Y	Y	Y

Specific challenges arising from our research into stakeholders and care pathways identified a number of challenges for ProACT, as well as opportunities the ProACT ecosystem can address. These are detailed in Sections 8 and 9 respectively.

⁶⁴ <http://pathways.nice.org.uk/>

⁶⁵ Emilia-Romagna region of Italy

⁶⁶ Specific care pathways for COPD, Diabetes, CGD and dementia do exist within hospitals. When getting released from the hospital, there isn't a follow-up on the care pathway.

8 Challenges for ProACT

Each pilot partner also mapped the key challenges identified in their country or region. These were grouped and compared, and are outlined in Table 8.1. This table will be updated as requirements gathering continues with key stakeholders, and we learn about specific challenges they face in caring for people with multimorbidity.

Table 8.1: Summary of main care pathways challenges identified across pilot countries

Main Challenge Identified	Level of importance to tackle		
	* = not so important, ** = important, *** = very important		
	IRE	BE	ER[1]
Pathways and Pathway Descriptors			
Lack of pathways that address multimorbidity	**	***	**
Lack of pathways that integrate medical and social resources	**	***	**
Lack of regulatory framework	*	***	*
Existing care pathways tend to be used within organisations (e.g. within individual hospitals)	*	***	*
Absence of evidence to develop effective pathways for multimorbidity	***	***	**
Fragmented care sector	**	***	**
Integration between health and social care sector institutions is poor	***	**	*
Patient transfer between services (in acute and primary care)			
Current systems don't adequately capture discharge plans or referrals to rehab (or other services) – referral points are critical in the patient's pathway	**	**	*
Patient Care and the Care Plan			
Lack of care coordinator	***	*	*

Potentially inaccurate and inaccessible (patient) data	***	***	*
Access to services can be dependent on geography and local services available	**	*	**
Care plans reside with particular healthcare professionals - There isn't a single care plan document that all key stakeholders contribute to.	***	**	*
Lack of coordinated medication management approach	***	*	*
Communication			
Lack of follow up during referral process - potential for patient to fall into 'gaps' between referral points	**	*	*
Poor communication amongst stakeholder across the pathway - Relying on paper, phone calls, 'digging for information'	***	***	*
Few guidelines exist on how to communicate with other healthcare professionals	*	***	***
Patient Information			
Incompatible ways of collecting /organising / storing data across different services - Poor data capture along patient journey due to lack of interoperable systems	***	**	**
Time Constraints and Workload			
Long list of comorbidities requires significant time to review – not possible within short consultation times	***	***	*
Patient history often not detailed enough due to limited time during consultations	***	***	**
Lack of resources (staff and structural)	**	*	*

[1] Emilia-Romagna region, Italy

8.1 Addressing Challenges around Care Pathways for ProACT

Some of the major challenges identified in this research involve the lack of standardised, integrated pathways for multimorbidity across the three regions. To better understand patient pathways for chronic disease management, we reviewed and compared the British NHS NICE pathways for single disease management of the ProACT conditions COPD, CHD, Diabetes and Dementia. NICE provides an interactive tool, primarily for health and social

care professionals, providing access to a range of guidelines and quality standards. The various pathways, while implemented from a healthcare professional point of view, provide good insight into how the NHS recommend care pathways should be implemented for patients. The Public Health Care System in Emilia-Romagna has developed and implemented similar pathways, while others are still under development.

The existing pathways available are very specific, very detailed and are developed for use in particular countries or regions. Similar challenges were also identified by the SmartCare project⁶⁷. We therefore adapted the NICE pathways for each of the four ProACT conditions, focusing on those areas of relevance to the patient⁶⁸. The adapted pathways for all four conditions can be found in Appendix A. We then compared these with existing pathways identified in each region (outlined in Section 7 above). From this process, we identified 4 important steps within each individual disease pathway, as well as general older adult care pathways. These are outlined in Figure 8.1 and are:

- Diagnosis
- Development of the care plan from a holistic perspective
- Management of the medical and social conditions (remaining stable or improving)
- Managing exacerbations

Within this diagram, we have indicated the key stakeholders involved at each step as well as key functions. These aspects of care will form the basis of ProACT. They will be further examined during the requirements gathering phase and regional differences emerging from the requirements will be mapped for individual pilot sites. More detail on each of these 4 elements of the pathway, outlining the stakeholders involved, potential challenges and opportunities for ProACT, is presented in Section 9.

⁶⁷ SmartCare white paper number 1 “The SmartCare Pathways”

⁶⁸ http://pilotsmartcare.eu/fileadmin/smartcare/documents/whitepaper_smartcare_no1.pdf

⁶⁸ As the pathways were developed for health and social care professionals, they are at times quite complex and detailed, for example regarding particular drugs that should be prescribed

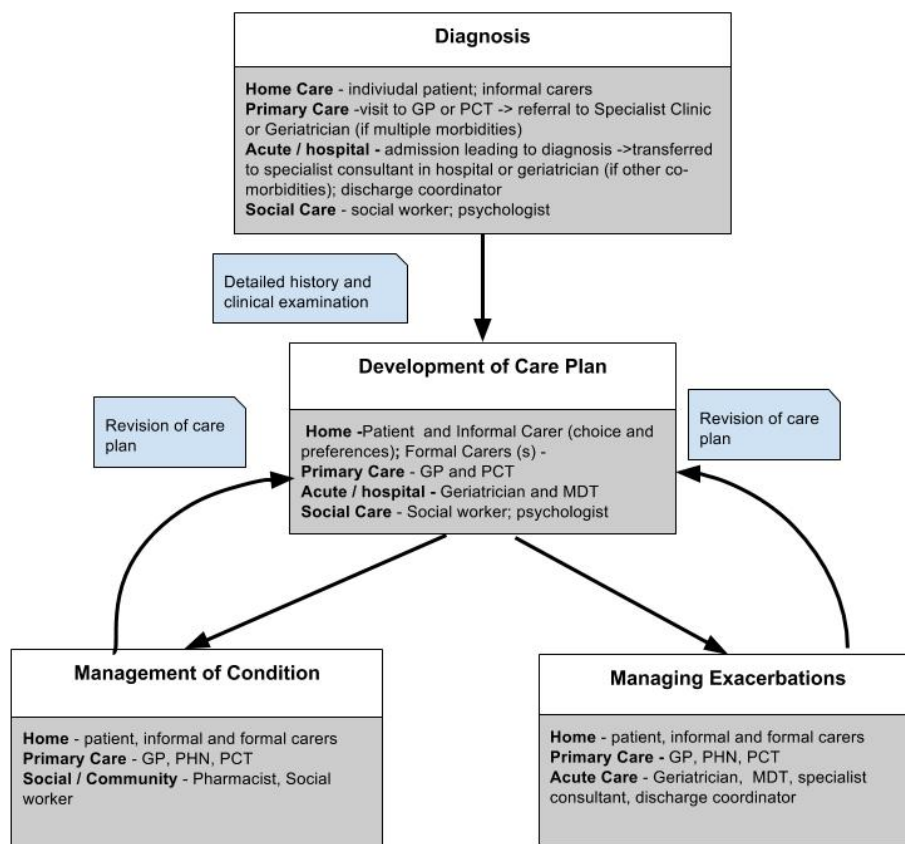


Figure 8.1: Overview Pathway of Condition Diagnosis and Management

Nevertheless the ambition of ProACT is to go beyond the management of chronic conditions from a strictly medical point of view by also considering other factors that impact on the quality of life of persons with chronic diseases, such as social connectedness, coping with functional limitations, security, as well as on the prevention of the deterioration of their condition as frail elderly through education and the promotion of healthy life styles.

9 Final Summary – Key Factors to Integrating Care in ProACT

The conceptual framework underlying the design of the ProACT Ecosystem is based on the integration of health and social determinants of the quality of life of the prime beneficiary. In other words, chronic diseases and their management are important, but equally important is the interaction of these determinants with other determinants, such as functional limitations, social connectedness, self-confidence, etc. These determinants are often interrelated and together form a holistic picture of the person and his/her level of frailty.

It is necessary that the ProACT Ecosystem takes into account as many determinants as possible, and their relationships (Figure 9.1). Furthermore, regarding quality of life, a personalised approach needs to be taken to understand what ‘quality’ means, as this will be different for different people. By perceiving these as interrelated it will be possible to empower the person and the care context and thus to build a truly integrated tool for person-centred care.

The findings outlined in this document and those that will be identified in further interaction with the stakeholders need thus to be interpreted within this wider framework of factors.

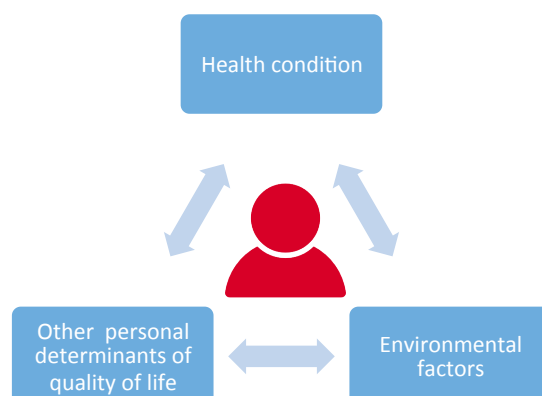


Figure 9.1: Holistic view of the person

In summary, the outputs from the process described in this report are:

- Identification of the primary stakeholders for ProACT
- Identification of current pathways for older person services and condition-specific services (where they exist)
- Confirmation of the lack of care pathways for older adults with multimorbidity
- Extraction of 4 key steps identified across current existing care pathways that are important for managing multimorbidity
- Awareness that social factors and stakeholders in the social context also have to be considered and involved
- Identification of critical moments in the information management process
- Identification of key challenges in care pathways for those with multimorbidity
- Identification of regional similarities and differences across ProACT pilot countries

Key Findings have been identified as follows:

1. Current level of integration of healthcare services (both horizontal and vertical) and of healthcare and social care is limited, though it is a priority for health care systems and governments across all 3 countries.
2. The GP is apparently the most obvious and accessible primary source of care coordination for people with multimorbidity living in the community. However, short consultation times, the complexity of multimorbidity management and limited guidelines on treating people with multimorbidity can prevent effective case management and a thorough review of treatment plans, medications etc.
3. Geriatricians and/or multidisciplinary specialist teams, where they exist, are thus a key referral for those older adults with complex needs (including multimorbidity) across all 3 countries.
4. Development (and updating) of a personalised care plan is also a critical component of the pathway for a person with multimorbidity. It should take into account the person's full medical history (including co-morbidities), their social / environmental situation, patient choices and preferences for treatment and patient goals. However, there is often no single care plan developed for and with patients that is accessible by all relevant stakeholders.
5. The development of a digital platform for integrated care has the potential not only to support existing practice, but also to improve the management of a complex and integrated care plan, introducing new ways of collaboration between key actors.

Overall, ProACT must integrate disparate stakeholder clusters into an ecosystem, streamlining healthcare delivery with management processes. Where possible social care needs and providers should be included in the ecosystem. We have identified key data entry and exits points between acute (hospital) to primary care (community & home). A key intersection where information exchange and service capacity is poorly coordinated and organized is highlighted and will be filled by the ProACT system. Thus ProACT will collect and analyze data from patients and actors in these models via ICT-AT to improve the connections and flow between care delivery locations and improve intelligent decision making support from data collected in the models. The outcome will be to increase patient and informal carers capacity to inform home based self-care by directing relevant support services and stakeholders; improve the ability of services to understand from feedback data the best delivery of care (e.g. mobilization and allocation of community resources); provide 24/7 real time feedback to key support stakeholders and services; provide information on the patient at home and in the community. The approach will improve visibility of the patient's activity to support service delivery.

ProACT will address 4 key steps in the pathway described in Figure 8.1. Table 9.1 to Table 9.4 provide more detail on each of these 4 elements of the pathway, outlining the stakeholders involved, potential challenges and opportunities for ProACT.

Table 9.1: Summary of diagnosis pathway, including stakeholders, challenges and opportunities for ProACT

Diagnosis (acute/outpatient care)		
Stakeholders involved	Challenges	ProACT Opportunity
• A&E staff • Specialist consultant (refer to geriatrician) • Geriatrician and MDT if available (determine care plan incl self-management and referrals) • Discharge coordinator (organise discharge; contact primary care team for referrals; (letters to GP, PHN, other disciplines as needed) • Pharmacist (manages new prescription) • Acute (outpatient): - Specialist consultant • Clinical nurse specialist	• Difficulty getting information on the person • Might not get referrals depending on availability, location • Updating of care plan should take into account all conditions and potential interactions • New medication, potential for interactions, adding to cognitive complexity of medication management	• Acute care team has access to patient data from those who have already been monitoring and self-managing • Early identification and risk stratification for multimorbidity • Care coordinator role to follow up on referrals • Education on new condition • Digital communication and referrals • Digital medication prescription can be viewed prior to new drug being prescribed and is updated with new prescription
Diagnosis (primary care)		
• GP • GP nurse • Primary Care Team • Pharmacist (manages new prescription)	• As above, plus: • Limited time with GP for care planning and education	• As above, plus: • Access to patient data to help nurse perform triage during visit
Diagnosis (social care)		
• Social workers services • Psychologists • GP (in certain cases) • Individual patient • Informal carers	• Identification of real needs • Limited time of social care worker • Identify impact of medical diagnosis on social life and environment	• Allow for holistic assessment • Broad interpretation of “health” condition (not only absence of illness but well being)

Table 9.2: Summary care plan development, including stakeholders, challenges and opportunities for ProACT

Development of Care Plan		
Stakeholders involved	Challenges	ProACT Opportunity
• Patient • Informal caregiver • Geriatrician and MDT • Other healthcare professionals (primary and acute) • Formal carers may develop care plans to address ADLs • Social worker services • Psychologists	• Developing careplans that are efficient to deliver (common features) and effective for the person (personalisation) • Integration of different existing careplans in a co-ordinated care plan • Care plan should be based on the assessment of all factors relevant for the independence and quality of life of the person.	• Support the development of careplans that facilitate the collaboration between stakeholders. • Digitised care plan resides with patient • Digitised care plan is accessible by all relevant stakeholders • Digitised care plan can be updated by certain stakeholders (e.g. GP, hospital staff, public health nurse) • Care plan also accessible by formal carers • ProACT data can show if goals are being met

Table 9.3: Summary of condition management in the home, including stakeholders, challenges and opportunities for ProACT

Management of Condition (Home)		
Stakeholders involved	Challenges	ProACT Opportunity
• Patient • Informal carer • Formal carer	• Raising interest to use ProACT; • Maintaining motivation over time; • Managing expectations; • Training and support in use of technology (devices and interfaces); • Training and support in how to act on data; Intuitive interfaces and navigation suitable for all; • Personalised care apps- Accessibility issues due to chronic illnesses or other age related impairments • Informal caregiver appropriation of technology – desire to also self-manage • Formal carer may view learning new technology as increasing their burden of work	• Improving the self management of care (quality of daily life) • Empowering the patient to be “in control” • Increased self-efficacy • Increased knowledge of condition and how to self-manage • Patient and informal carer feeling connected – improved communication with other stakeholders, including peers • Informal carer can feel part of a larger ‘caring system’ • Digital literacy for patient, informal and formal carer

Management of Condition (Primary Care)		
- GP - Primary Care MDT - Public health nurse	- Fear of 'data dumps' (data overload) - Fear of increased administrative work - Different GP practices (size of practice, way of working etc.) which results in a very diversified view on what provides added value and what does not - Resistance to implementing new IT-systems	- Increased knowledge sources for patients' condition, which simplifies applying the correct treatment - Lower administration times - Providing a view of the patient as a 'whole' - Daily access to a wide range of information about the patients without the need to meet them - The ability to provide better care towards the patient
Management of Condition (Social Care / Community)		
- Pharmacist - Social worker	Fear of increased administrative work	- The potential of offering new services - More information about the patient's treatment and other administered medication - The opportunity to supply the complete medication for a single patient - Reduce workload for GP regarding minor illnesses
Social / volunteer groups	Potentially low levels of involvement / less motivation to use	If appropriate, support the user in simple day to day activities including managing the platform.

Table 9.4: Summary of managing exacerbations, including stakeholders, challenges and opportunities for ProACT

Management of Exacerbation (Home)		
Stakeholders involved	Challenges	ProACT Opportunity
- Patients - Informal carers - Formal carers	- Accessing MDT services can be challenging, making admission avoidance more difficult – escalation to acute care often necessary to get necessary support or prioritisation of care supports in community - Managing expectations - Training and support in use of technology (devices and interfaces) to manage symptoms - Training and support in how to act on data;	- Support recognition of symptoms and symptom exacerbation – through education and data readings - Clearer understanding of care pathways and where to go - Guidance for patients and carers on ways to risk-assess and self-manage

Management of Exacerbation (Primary Care)		
• GP / PHN • PCT	• Managing expectations • Training and support in use of technology (devices and interfaces) to manage symptoms • Training and support in how to act on data	• Protocols for providers across care pathways • Recent history of patient • Update of digital care plan
Management of Exacerbation (Acute Care)		
• ED staff • Specialist consultant • Geriatrician • Hospital MDT • Discharge coordinator	• Existing patient admission procedures and patient data handling procedures are difficult to change due to lock-in effects • Discharge policies for follow up in community are quite cumbersome without clear pathways of community follow up and loss of data between services • Seamless discharge and patient flow through the systems is influenced by shortfall in community infrastructure and financial incentives across and between services • Resistance to implementing new IT-systems (due to bad experiences of previous implementation) • Compliance issues will play a big role in integrating care-pathways and will provide resistance to change • Hospitals are not operating homogenously, different hospitals, even single departments inside hospitals will sometimes demand customized solutions	• Protocols for providers across care pathways • Recent history of patient • New drug prescribed - added to patient profile and communicated to GP and others • Update of digital care plan • Proactive discharge planning supported by ProACT primary care health analytics • Transitioning back to home – monitoring within the home can support early discharge; mitigate risk of discharge and increase confidence

9.1 Key Factors

We have identified 3 key factors for achieving integrated care:

Key Integrating Factor 1: Existing organisational structures looking to improve their outcomes by integrating resources.

Key Integrating Factor 2: Clear digital information flows and performance measurements along the care pathway and good digital communication between actors in the ProACT system.

Key Integrating Factor 3: Incentivisation / supportive systems / protocols for stakeholders using ProACT.

Effective analytics, systems and interfaces for all stakeholders will need to be designed and developed to support this. Work performed in Tasks 1.2 and 2.1, including requirements gathering and design workshops with stakeholders, is already underway and will help to inform this process. It is important to not only understand the specific needs for each disease pathway and combinations of these, but also how this changes when other morbidities and co-morbidities are considered. Thus patients with different levels of complexity need to be addressed. It is further important to assess how the chronic conditions impact on the quality of life of people and their independence and how assistive technology can improve lives.

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11. Appendix A – Care Pathways for Single Disease Management

The following pathways are adapted from the NHS NICE pathways. The adaptations made are based on a review of any existing pathways that exist across the three pilot countries, as well as the stakeholder-mapping task to understand what stakeholders are involved along different parts of the pathways.

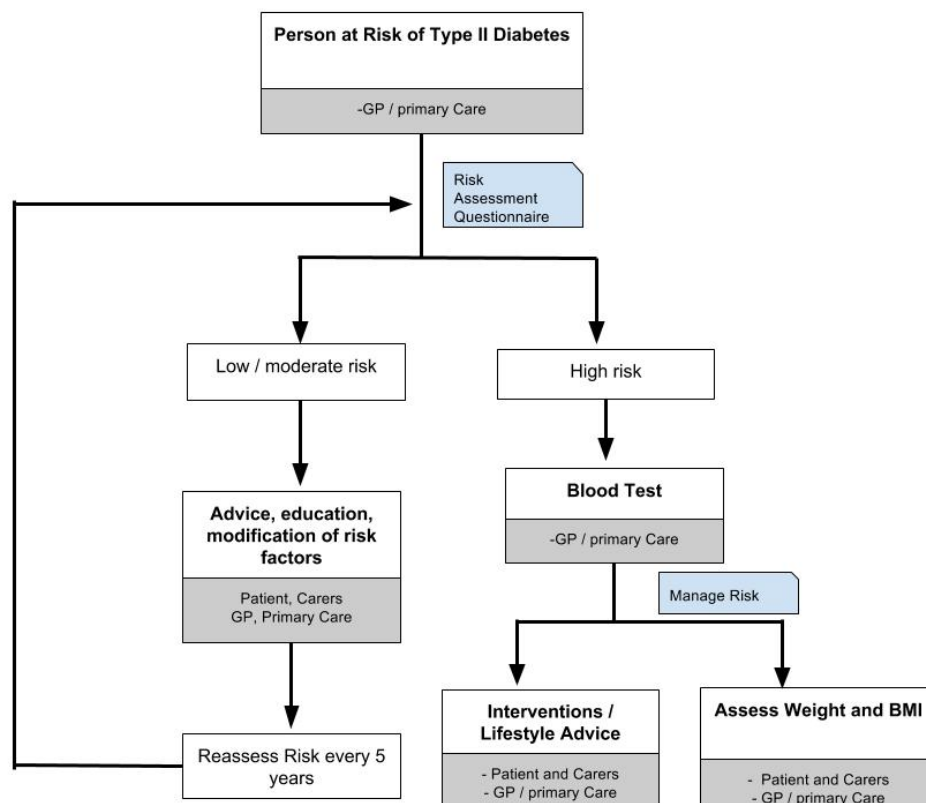


Figure A.0.1 Pathway for diagnosis and assessment of diabetes

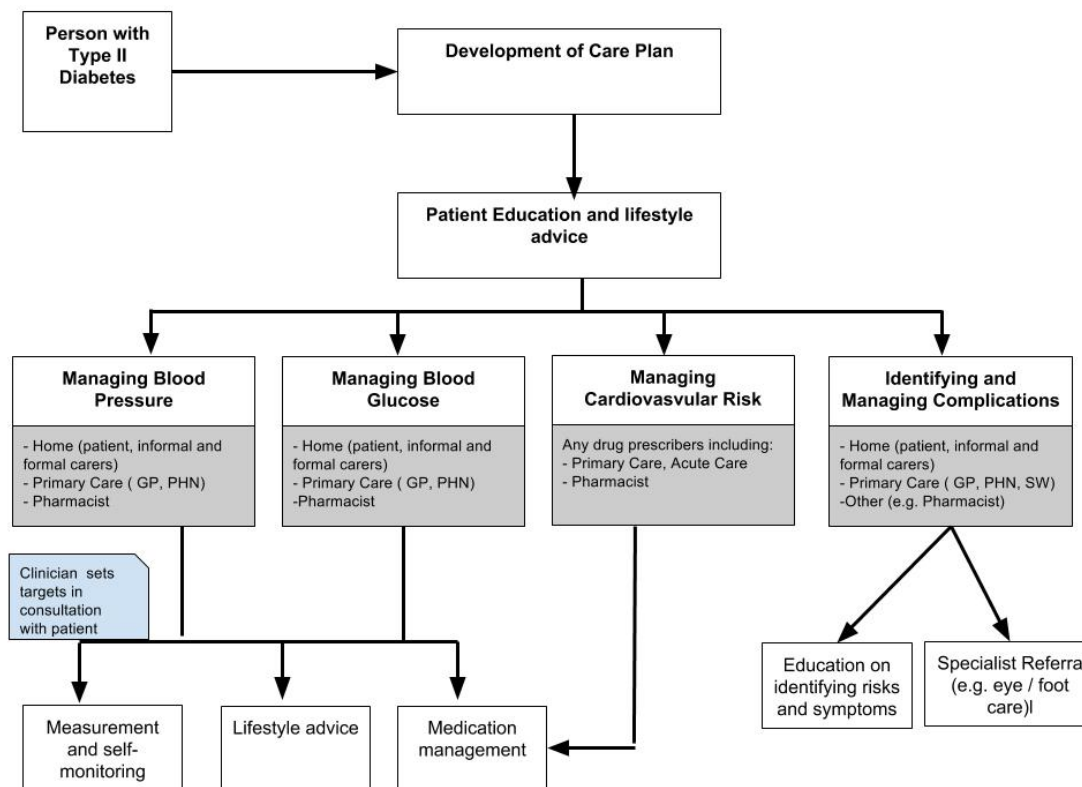


Figure A.0.2: Pathway on management of care for person with diabetes

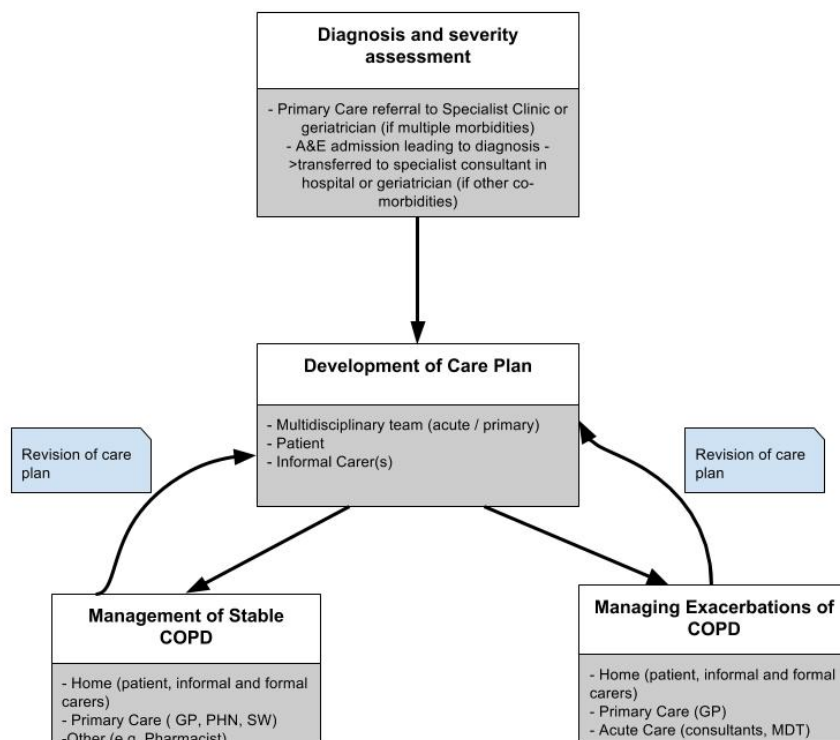


Figure A.0.3: Overview pathway of COPD

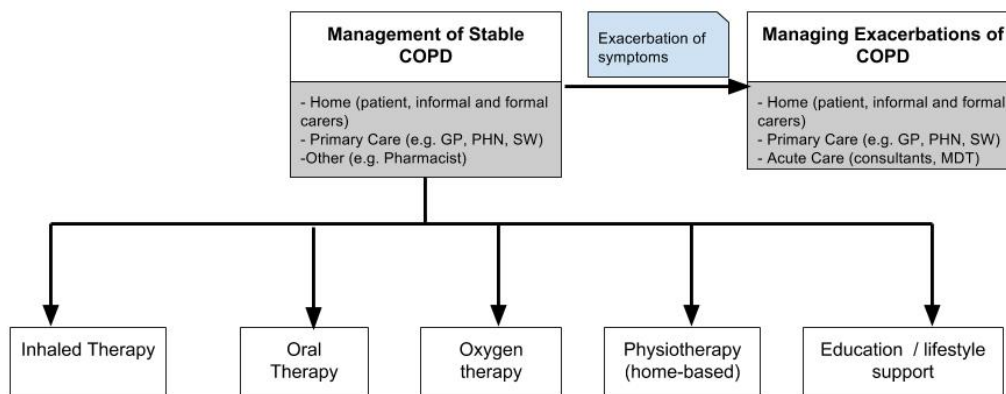


Figure A.0.4: Pathway for managing stable COPD

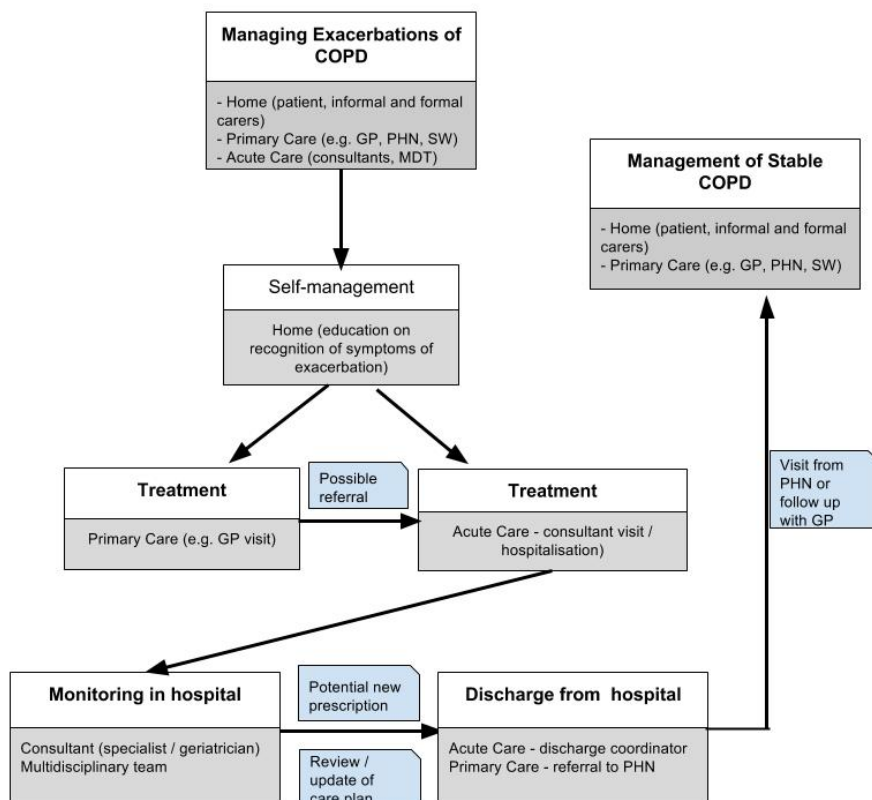


Figure A.0.5: Pathway for managing exacerbations of COPD

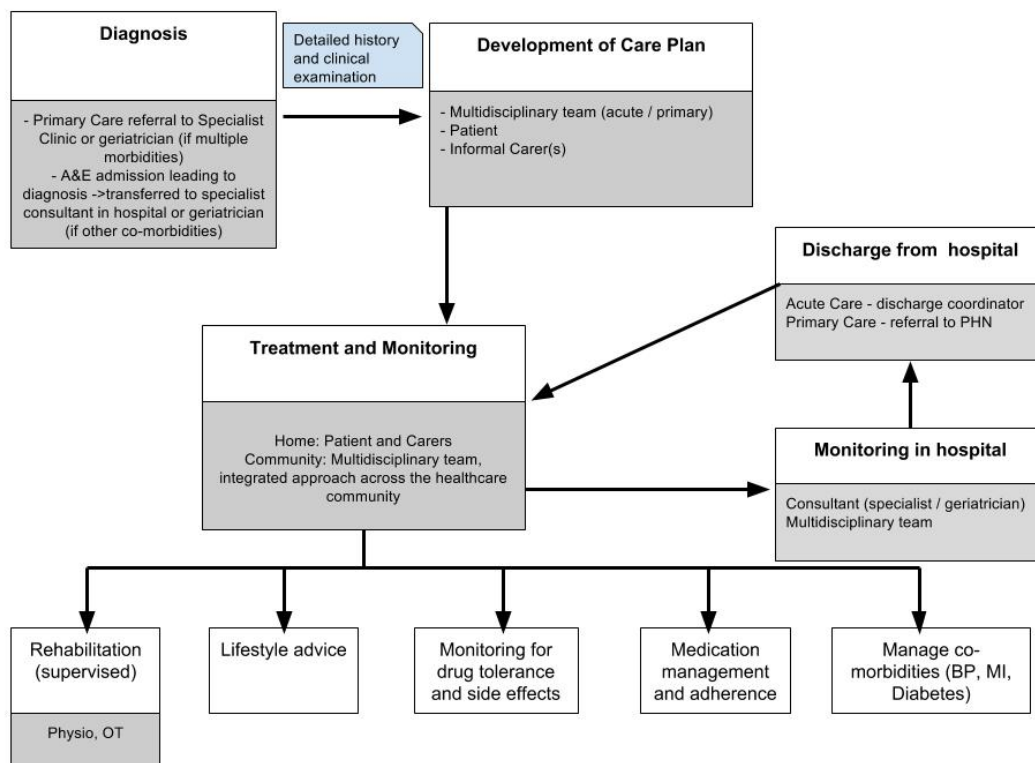


Figure A.0.6: Pathway for managing CHF

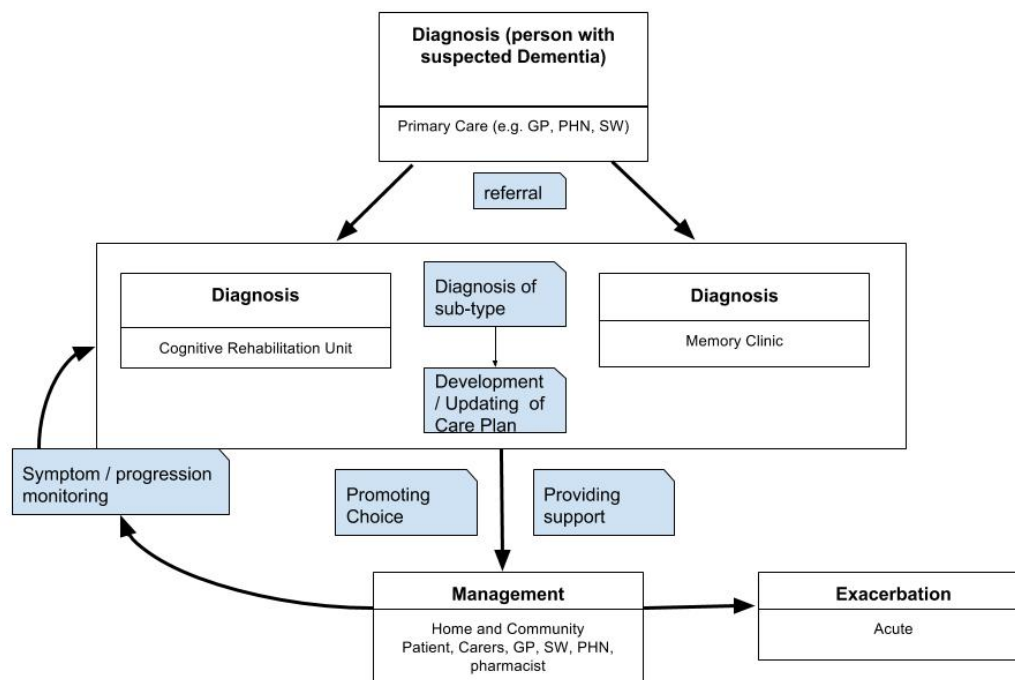


Figure A.0.7: Pathway for diagnosis of dementia

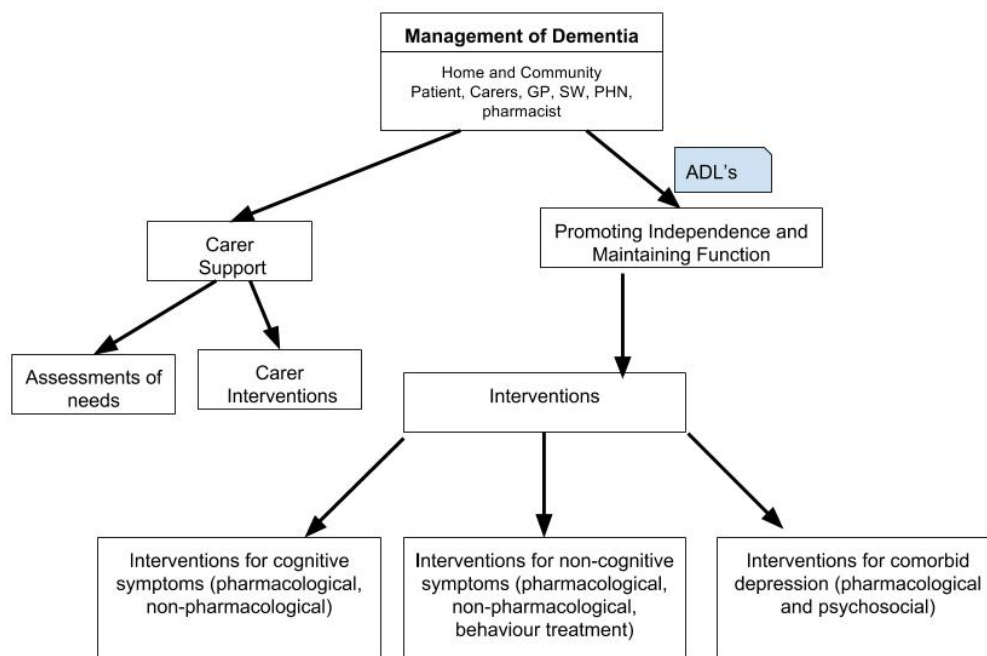


Figure A.8: Pathway for managing dementia



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