D1.1. State-of-the-art of clinical and assistance management models and practices of older adults with cognitive impairment due to MCI or dementia

WP1 – Y1Q2

Lead participant: Hospital Universitario de Getafe
### INDEX

1. Introduction ......................................................................................................................................... 9

2. CI/MCI in literature and state-of-the-art of care pathways ................................................................. 9

  2.1 Cognitive Impairment in DECI ....................................................................................................... 11

  2.2 Care pathways for patients with cognitive impairment ...................................................................... 12

    2.2.1 Pharmacological treatment ....................................................................................................... 12

    2.2.2 Non-pharmacological treatment .................................................................................................. 15

    2.2.3 Integrated care pathways for treating patients with cognitive impairment ...................................... 28

3. Analysis of care models in the 4 pilot sites ......................................................................................... 36

  3.1 Italy ................................................................................................................................................. 36

    3.1.1 Background ............................................................................................................................... 36

    3.1.2 Care pathways for patients with CI in FDG ............................................................................... 49

    3.1.3 Conclusions ............................................................................................................................... 56

  3.2 Sweden ........................................................................................................................................... 58

    3.2.1 Background ............................................................................................................................... 58

    3.2.2 Care pathways for patients with CI in SHG .............................................................................. 60

    3.2.3 Conclusions ............................................................................................................................... 66

  3.3 Spain .............................................................................................................................................. 67

    3.3.1 Background ............................................................................................................................... 67

    3.3.2 Care pathways for patients with CI in HUG ............................................................................. 70

    3.3.3 Conclusions ............................................................................................................................... 78

  3.4 Israel .............................................................................................................................................. 80

    3.4.1 Background ............................................................................................................................... 80

    3.4.2 Care pathways for patients with CI in Maccabi ....................................................................... 85

    3.4.3 Conclusions ............................................................................................................................... 96

4. Cross-analysis of care models ........................................................................................................... 97

  4.1 Aspects among organisations .......................................................................................................... 97
4.2 Aspects within organizations ................................................................. 98
4.3 Professionals ...................................................................................... 99
4.4 Involvement of patients, caregivers and other users ......................... 100
4.5 Use of ICT ....................................................................................... 101
4.6 Compliance with quality standards .................................................... 102
5 Conclusions ......................................................................................... 109
6 References ......................................................................................... 112
List of Figures

Figure 1. Evolution from MCI to dementia................................................................. 11
Figure 2. The 8 pillars model of community support for dementia......................... 30
Figure 3. Service model in the Lombardy Region ..................................................... 44
Figure 4. 'Open Nursing Home' pathway................................................................. 48
Figure 5. Network of services provided by Instituto Palazzolo............................... 54
Figure 6. Interplay between internal and external networks of services................... 54
Figure 7. Stakeholder involvement in the current, validated care model .................. 61
Figure 8. An overview of the diagnostic processes at the primary care centres in Skaraborg ...................................................................................................................... 62
Figure 9. The networked care model for patients with CI and dementia in Skaraborg ................................................................................................................................. 64
Figure 10. A simplified overview of the Skaraborg Care Network (SCN) ............... 65
Figure 11. Care pathways for patients with CI at HUG ............................................. 72
Figure 12. Maccabi's telemedicine services.............................................................. 84
Figure 13. IT at the doctor’s office............................................................................. 94
Figure 14. Maccabi’s IT system Enterprise Service Bus .......................................... 95

List of Tables

Table 1. Summary of medications to treat Alzheimer’s Disease ............................... 13
Table 2. Pharmacological Treatment for different stages of the disease.................. 15
Table 3. Treating and counselling persons with MCI (Langa & Levine, 2014) .......... 15
Table 4. Options of non-pharmacological treatment................................................. 17
Table 5. Non-pharmacological treatments for different symptoms of cognitive impairment .................................................................................................................. 24
Table 6. Quality statement in the NICE pathway on dementia ............................... 31
Table 7. Number of services provided by the Palazzolo Institute in 2014 ............... 49
Table 8. Comparison of current care practice in 4 pilot sites vs. NICE Quality Guidelines .......................................................................................................................... 103
<table>
<thead>
<tr>
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<tr>
<td><strong>Authors:</strong></td>
<td>Ignacio Peinado, Myriel López (HUG); Valerio Gower, Fabrizio Giunco, Pietro David Trimarchi (FDG); Monika Jurkeviciute (CHI); Svante Lifvergren (VGR); Lewy Hadas, Einat Bergman-Bolchinski (Maccabi)</td>
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Executive Summary

All throughout the Western World, population is ageing. According to the 2015 Ageing Report issued by the European Commission, the overall size of the EU population projected to not only be larger by 2060, but also much older than it is now. This will imply a dramatic increase in the number of citizens suffering from comorbidities, including cognitive diseases such as Alzheimer’s disease. All National Health Services will be dramatically affected by this inversion of the age pyramid. Therefore, it is needed to adopt new approaches and strategies that foster healthy ageing and independent living for older adults in order to guarantee the sustainability of health and social systems.

Within this document, we present an analysis of the state-of-the-art in clinical practice for attending patients with different degrees of cognitive impairment, both in general and in the settings where the DECI solutions will be tested. First, we have conducted a thorough literature analysis aiming to identify the most widespread, evidence-based treatments for patients with MCI and dementia, and have explored different integrated care models that have been proposed and implemented in different settings worldwide. Then, we have analysed the provision of care for patients with cognitive impairment and dementia in four different settings: Italy, Sweden, Spain and Israel, all four DECI’s pilot sites. The approach adopted to carry out this analysis included a thorough literature review and interviews with relevant actors involved in the care of patients with CI and dementia. Moreover, we have organized Co-Creation Workshops in the four pilot settings in collaboration with Work Package 2 in order to get first-hand information about the needs and expectations of all different stakeholders involved in the care of patients with CI and dementia, from health managers to doctors, from social care providers to informal caregivers. The outcome of this research has been the analysis of all the needs, gaps and expectations of all of these stakeholders, as well as the barriers and facilitators that will affect the implementation of innovative solutions for the long-term management of older adults with CI and dementia.

After analysing the current state of affairs, we have conducted a cross-analysis of all four studies, aiming to identify the barriers and facilitators that could be addressed using DECI’s technology in the four pilot sites. To sum up, although the individual analyses show that there are wide differences between the care models in the four
pilot sites, we have been able to identify several common barriers and facilitators that can be addressed using the technologies proposed within the DECI project:

- As recommended by the NICE quality guidelines and stressed in the Co-Creation Workshops that took place in the four pilot sites, there is a need to count on a **named case manager** that will guide patients and informal caregivers throughout the overall disease process.

- Moreover, in many cases professionals in **Primary Care are not properly trained** to identify early symptoms of cognitive impairment, which might be disguised as age-related cognitive decline. Therefore, many cases of early dementia are underdiagnosed and are only detected when the disease has evolved and symptoms become obvious. Therefore, it has been stressed that professionals in Primary Care should be properly trained on the identification of early signs and about procedures for diagnosing.

- It is also needed to **raise awareness about the early signs of cognitive impairment among the general population**.

- All four pilot sites stressed the need to count on a **better coordination between the health and social care tiers**. Some of the organizations providing care for patients with MCI and mild dementia described in the present document – i.e. FDG or Maccabi – provide their patients with a number of social services, but they also need to count on third-party social services.

- All pilot sites have also reported the need to **provide patients and informal caregivers with more accurate, up-to-date information** about the disease and about practical aspects of the disease, such as legal aspects or the availability of social services to address the needs of the patients and their caregivers during the different stages of the disease.

- **ICT solutions** are a powerful tool to provide patients with **integrated care**, as they might foster a better coordination between Primary and Specialized care and between the health and social care tiers. ICT tools can also be used to perform remote monitoring of the patients, as well as to provide them with educational material and a communication tool with health and social professionals.
1 Introduction

This document is the outcome of Task 1.1: *Analysis of the state-of-the-art and best practices for the clinical management of elderly patients with cognitive impairment*. This document will lay the foundations for the whole project and will spread knowledge regarding mild to moderate Cognitive Impairment, the most widespread therapies available for its management and the state-of-the-art approaches adopted by caregivers, proximity networks and support networks while dealing with MCI-affected patients.

In order to achieve these results, Task 1.1 has performed a thorough literature analysis regarding improvement of clinical conditions, especially for what concerns the enhancement of quality of life, physical activity and independent living. First, we have conducted a research of the most widespread, evidence-based pharmacological and non-pharmacological treatments for patients with MCI and dementia. Then, we have analysed several cases of successful implementations of integrated care programs all around the world, and we have analysed quality guidelines for providing patients with MCI and dementia with holistic, integrated care. This general literature review adds to specific analysis related to the environments in the four pilot sites in Italy, Sweden, Israel and Spain. Finally, we have used the results of the Co-Creation Workshops that took place in the four pilot sites in collaboration with WP2 to elaborate our conclusions on the needs and gaps related to the care of patients with MCI and dementia, as well as the barriers and facilitators that might have an influence on the implementation of an ICT-based solution for providing patients and their caregivers with integrated care.

2 CI/MCI in literature and state-of-the-art of care pathways

Ageing population poses a challenge on the national health systems in the Western World. It is foreseen that in the following years the number of older adults suffering from chronic diseases will increase dramatically, hence increasing health and social care costs both for the public national systems and for patients and their families. According to the WHO, chronic diseases are responsible for 60% of deaths and account for 75% of public health expenditures [1].

Of all chronic diseases, dementia is the major contributor to disability-adjusted life years in people older than 60 years old [2]. The *World Alzheimer Report 2015* [3] estimates that the number of people living with dementia will reach 74.7 million in 2030 and 131.5 million in 2050, hence almost doubling every 20 years. The 2015
global societal cost of dementia will be an estimated $818bn, which represents 1.09% of global GDP. While dementia does shorten the lives of those affected, its greatest impact is upon quality of life, both for individuals living with dementia, and for their family and carers. Dementia does not only require comprehensive health care, but also social care with the aim to relieve the economic and emotional burden of patients and informal caregivers.

Currently, there are at least 19 countries that have planned or implemented a national dementia policy or plan, including Italy and Israel. According to the recommendations stated by the WHO, the priority areas of action that should be addressed within the national plans include raising awareness, timely diagnosis, commitment to good quality continuing care and services, caregiver support, workforce training, prevention and research. In 2010, The National Board of Health and Welfare of Sweden issued National Guidelines for the care of dementia. The guidelines emphasize evidence-based and evaluated treatments and methods in health care for people with dementia and support for their relatives. The purpose of the National guidelines is to support decision makers in municipalities, county councils and regions so that they can manage health care and social services through transparent and systematic prioritization. The guidelines cover the following areas:

- Values, rights, ethics and legal aspects.
- Person-centred care, multidisciplinary team work and education.
- Drug therapy against cognitive decline.
- Investigation of behavioural and psychological symptoms.
- Day activities, physical training and resources.
- Special accommodation.
- Support to relatives.
- Prevention of dementia.
- Indicators of good health care.
- Indicators for care of people with dementia.

1 [http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_executivesummary.pdf](http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_executivesummary.pdf)
This section will first describe the current recommendations for treating patients with MCI and dementia, and will explore integrated care solutions that have been proposed and implemented in different settings.

2.1 Cognitive Impairment in DECI

Dementia is not a specific disease, but a group of symptoms affecting cognitive and functional abilities that can be caused by several reasons, being Alzheimer’s disease the most prevalent. Mild Cognitive Impairment (MCI) refers to a clinical syndrome characterized by the presence of a subtle cognitive deficit, not related to physiological age associated cognitive modification, in a non-demented person. While not all persons with MCI will not develop Alzheimer’s disease or other forms of progressive dementia, almost all cases of Alzheimer’s start with MCI. Figure 1 presents an overview of the different stages of dementia.

As shown in Figure 1, the key criteria that distinguish MCI from dementia are preservation of independent and functional abilities and lack of significant impairment in social and occupational functioning [4]. The document Deliverable 1.2: Patient Clusters [5] presents all the clinical criteria and definitions that will be used throughout the DECI project to characterize patients throughout the overall cognitive impairment continuum, including the subtype of MCI, based on the presence of absence of memory difficulties (amnestic vs. nonamnestic).

DECI aims to design technological and organisational aspects of independent living in order to provide older adults with MCI and mild dementia with solutions to

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2 https://www.mccare.com/education/mcidementia.html
autonomously manage their wellbeing, hence focusing on the two first stages depicted in Figure 1. Technological solutions should address monitoring and identification of patient’s vital signs and environment information, as well as to enable caregivers to intervene promptly. At the same time, organizational settings should ensure resource efficiency, patient value, autonomy and comfort, and stakeholders’ convenience. The following sections represent the global practices related to the pharmacological and non-pharmacological treatments of elderly patients with cognitive impairment.

2.2 Care pathways for patients with cognitive impairment

2.2.1 Pharmacological treatment

Dementia describes a clinical syndrome that encompasses difficulties in memory, language, and behaviour that leads to impairments in activities of daily living. Alzheimer’s disease is the most common subtype of dementia, followed by vascular dementia, mixed dementia, and dementia with Lewy bodies. There is currently no cure for dementia, but some medications can stop it from progressing, helping to lessen symptoms, such as memory loss and confusion, for a limited time. Two classes of drugs are currently recommended for symptomatic (Alzheimer's disease and mixed) dementia: cholinesterase inhibitors and N-methyl-D-aspartic acid receptors.

Cholinesterase inhibitors like donepezil, galantamine and rivastigmine work by slowing down the process that breaks down a key neurotransmitter, and are recommended for patients with mild to moderate dementia. Memantine, a N-methyl-D-aspartic acid receptor, is recommended for patients in advanced stages of the disease. Memantine works by regulating the activity of glutamate, an important neurotransmitter in the brain involved in learning and memory. Attachment of glutamate to cell surface "docking sites" called NMDA receptors permits calcium to enter the cell. This process is important for cell signalling, as well as learning and memory. In Alzheimer's disease, however, damaged cells can release excess glutamate, leading to chronic overexposure to calcium, which can speed up cell damage. Memantine helps prevent this destructive chain of events by partially blocking the NMDA receptors. Except as part of properly constructed clinical studies, the NICE clinical guidelines do not recommend the use of cholinesterase inhibitors in mild cognitive impairment.

Table 1 presents an overview of the medications that are currently used to treat the symptoms of dementia, more specifically Alzheimer’s Disease.
<table>
<thead>
<tr>
<th>Generic and Drug type</th>
<th>How it works</th>
<th>Dosage</th>
<th>Stages</th>
<th>Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Donepezil</strong>&lt;br&gt;AChE</td>
<td>Prevents the breakdown of acetylcholine in the brain</td>
<td>Tablet or orally disintegrating tablet: initial dose of 5mg once a day. May increase dose to 10mg/day after 4-6 weeks if well tolerated.</td>
<td>All stages</td>
<td>Nausea, vomiting, loss of appetite and increased frequency of bowel movements.</td>
</tr>
<tr>
<td><strong>Galantamine</strong>&lt;br&gt;AchE</td>
<td>Prevents the breakdown of acetylcholine and stimulates nicotinic receptors to release more acetylcholine in the brain</td>
<td>Tablet or oral solution: Initial dose to 8mg/day (4mg twice a day). May increase dose to 16mg/day (8mg twice a day) and 4.0mg/day (12mg twice a day) at minimum 4-week interval if well tolerated. Extended-release capsule: same dosage as above but taken once a day.</td>
<td>Mild to moderate</td>
<td>Nausea, vomiting, loss of appetite and increased frequency of bowel movements.</td>
</tr>
<tr>
<td><strong>Rivastigmine</strong>&lt;br&gt;AchE</td>
<td>Prevents the breakdown of acetylcholine and butyrylcholine (a brain chemical similar to acetylcholine) in the brain</td>
<td>Capsule: initial dose of 3mg/day (1.5mg twice a day) May increase dose to 6mg/day (3mg twice a day), 9mg (4.5mg twice a day), and 12mg/day (6mg twice a day) at minimum 2-week intervals if well tolerated. Patch: Initial dose of 4.6mg once a day: may</td>
<td>Mild to moderate</td>
<td>Nausea, vomiting, loss of appetite and increased frequency of bowel movements.</td>
</tr>
</tbody>
</table>
### Generic and Drug type

<table>
<thead>
<tr>
<th>How it works</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memantine NMDA</td>
<td>Blocks the toxic effects associated with excess glutamate and regulates glutamate activation</td>
</tr>
<tr>
<td>Memantine NMDA</td>
<td>Tablet and oral solution: Initial dose of 5mg once a day. May increase dose to 10mg/day (5mg twice a day), 15mg/day (5mg and 10mg) 1wk interval 20mg/day (10mg twice a day).</td>
</tr>
<tr>
<td>Memantine NMDA</td>
<td>Extended-release tablet: initial dose of 7mg once a day: may increase dose to 14mg/day, 21mg/day and 28mg/day.</td>
</tr>
</tbody>
</table>

The pharmacological treatment of patients with dementia should also address conduct disorders. The most used drugs are antidepressants, antipsychotics and some anticonvulsants. Some antipsychotics can have severe side effects, so health professionals should assess the risk/benefit ratio of the use of each medicine.

Health professionals – either in Primary and Specialized care – should review periodically patients to check the effects of the pharmacological treatment, adjusting the drugs and doses based on the status of the patient. The pharmacological treatment should only be continued when it is considered to have a worthwhile on cognitive, global, functional and behavioural symptoms.

To sum up, Table 2 displays the pharmacological treatment recommended for the different stages of the disease.
Table 2. Pharmacological Treatment for different stages of the disease

<table>
<thead>
<tr>
<th>Pharmacological Treatment</th>
<th>MCI</th>
<th>Mild Dementia</th>
<th>Moderate Dementia</th>
<th>Severe Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pharmacological Treatment</td>
<td>No evidence</td>
<td>Donepezil</td>
<td>Donepezil</td>
<td>Donepezil</td>
</tr>
<tr>
<td></td>
<td>Rivastigmine</td>
<td>Rivastigmine</td>
<td>Rivastigmine</td>
<td>Memantine</td>
</tr>
<tr>
<td></td>
<td>Galantamine</td>
<td>Galantamine</td>
<td>Galantamine</td>
<td>Memantine</td>
</tr>
</tbody>
</table>

2.2.2 Non-pharmacological treatment

As MCI is an intermediate stage between normal brain functioning and dementia, it has less impairment symptoms and smaller cognitive decline compared to dementia. Therefore, while the individual is still highly functional, the non-pharmacological treatment therapies aim to target the disease progression and symptoms. The most widely recognised therapies include regular physical exercise and particular diet to control the overall health and to protect heart and blood vessels, especially those that support brain function, intellectual stimulation, social engagement and memory training to help sustain the brain function [4]. Table 3 presents some evidence-based strategies for treating and counselling patients with MCI, as described by Langa and Levine [4].

Table 3. Treating and counselling persons with MCI (Langa & Levine, 2014)

<table>
<thead>
<tr>
<th>Control of Vascular Risk Factors and prevention of stroke and subclinical brain injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension present</td>
</tr>
<tr>
<td>Diabetes present</td>
</tr>
<tr>
<td>Primary or secondary stroke prevention</td>
</tr>
<tr>
<td>Atrial fibrillation present</td>
</tr>
<tr>
<td>Beneficial behaviours</td>
</tr>
</tbody>
</table>
Engage in mental activity
Engage in physical activity
Stop smoking

**Social needs**
- Encourage and facilitate social interactions
- Discuss living will, durable power of attorney, financial and long-term care plans
- Provide community resources for patients and caregivers
- Discuss driving safety
- Discuss home safety, including kitchen safety, firearms, poisons and potential fall risk

**Prognosis and follow-up**
- Discuss current evidence and uncertainty regarding MCI prognosis with the patient and family
- Arrange a follow-up approximately every six months to assess changes in cognitive function and potential evolving needs for social support

Dementia is a complex disease resulting in memory disorders, personality changes, and impaired reasoning. Dementia disturbs the ability to carry out daily activities outside the home environment, and can eventually lead to personal care problems. The experienced disabilities might result in symptoms of depression, insecurity feeling and social self-isolation. Treatment of dementia starts with the treatment of the underlying disease, where possible. Problems related to the nutritional, hormonal, tumour-caused or drug-related dementia might be cured or managed to some extent. However, improvement of cognitive and behavioural symptoms can be achieved through a combination of appropriate medications and other non-pharmacological treatments, including psychotherapy. Considering the side effects of the pharmacological interventions, it is recommended to start a non-pharmacological treatment just after the diagnosis and before starting any pharmacological treatment. The prescription of medications without attempting other treatment options is of particular concern because of the substantial adverse effects associated with their use, especially in people with dementia.
An increasing number of non-pharmacologic therapies are now available for people with dementia. There are several areas of overlap between these therapies and each approach is rarely used in isolation. Table 4 presents an overview of the non-pharmacological treatment options presented by Douglas, James and Ballard [6], who also argued that these options, in best practice, should be applied prior to prescribing medication. For each of the non-pharmacological approaches, we have investigated the most recent studies with regards to their ability to improve the patient’s cognitive status, functional status and/or quality of life.

### Table 4. Options of non-pharmacological treatment

<table>
<thead>
<tr>
<th>Standard therapies</th>
<th>Behavioural therapy</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Behavioural therapy deals with such issues of dementia patients as wandering, sleeplessness and anxiety or aggression. The therapy is based on principles of conditioning and learning theory using strategies aimed at suppressing or eliminating challenging behaviour. The three key features are in focus when designing an intervention: taking account of the individual’s preferences, changing the context in which the behaviour takes place and using reinforcement strategies and schedules that reduce the behaviour.</td>
</tr>
<tr>
<td></td>
<td>For instance, patients with dementia may have a history of wandering because they feel restless. Therefore, encouraging them to take part in regular physical exercise may help to decrease their restlessness.</td>
</tr>
<tr>
<td></td>
<td>Interventions specifically targeted at behaviour performed by individual work with the family reduced behaviour disturbance in dementia patients displaying agitation [7] [8], aggressive behaviour [9] depression [8] or problematic behaviours [10].</td>
</tr>
<tr>
<td>Reality orientation</td>
<td>Reality orientation therapy mitigates sense of mental disorientation, memory loss and confusion by reminding individuals of facts about themselves and their environment,</td>
</tr>
</tbody>
</table>
with the objective of stimulating their temporal-spatial orientation.

The therapy is highly useful to increase self-esteem of the individual with dementia symptoms. The benefits are mostly apparent if the therapy is applied continuously. Nevertheless, there is a lack of high-quality studies and a low level of evidence regarding this intervention [11]

**Validation therapy**

**Validation therapy** deals with such symptoms as repetition and retreating into the past. The therapy is based on the general principle of validation, the acceptance of the reality and personal truth of another’s experience, and incorporates a range of specific techniques. It is focused on dementia from an emotional perspective, not giving too much importance to the actual facts. The method emphasizes listening and empathy. The caregiver’s role is to allow individuals express verbally and non-verbally, thus helping patients to feel unique and worthwhile.

Neal and Briggs [12] carried out an evaluation of the efficacy of validation therapy across a number of controlled trials, employing cognitive and behavioural measures. They concluded that despite some positive indicators, there is insufficient evidence from randomized trials to allow any conclusion about the efficacy of validation therapy for people with dementia or cognitive impairment.

**Reminiscence therapy**

This therapy involves helping a person with dementia to relive past experiences, especially those that might be positive and personally significant, for example family holidays and weddings. Reminiscence therapy is seen as a way to increase levels of wellbeing and provide pleasure and cognitive stimulation. In a Cochrane review, it demonstrated to improve
This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 643588

<table>
<thead>
<tr>
<th>Alternative therapies</th>
<th>Art therapy</th>
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<tbody>
<tr>
<td></td>
<td>Art therapy has the potential to provide meaningful stimulation, improve social interaction and improve levels of self-esteem. Activities such as drawing and painting are thought to provide individuals with the opportunity for self-expression and the chance to exercise some choice in terms of the colours and themes of their creations.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Music therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Music therapy is defined by the World Federation of Music Therapy as the use of music and/or its musical elements (sound, rhythm, melody and harmony) by a qualified music therapist, with a client or group, in a process designed to facilitate and promote communication, relationships, learning, mobilization, expression, organization and other relevant therapeutic objectives in order to meet physical, emotional, mental, social and cognitive needs.</td>
</tr>
<tr>
<td>A recent systematic review [14] concluded that music therapy is beneficial in improving the disturbances behavioral, anxiety and agitation in patients with dementia. A small clinical trial</td>
</tr>
</tbody>
</table>

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using singing training with Alzheimer Disease patients during 6 months showed that singing training may be useful for dementia patients by improving the neural efficacy of cognitive processing [15]

**Activity therapy**

Activity therapy involves recreations such as dance, sport and drama. It has been proven that physical exercise can have a number of health benefits for people with dementia, for example reducing the number of falls and improving mental health and sleep and improving their mood and confidence [16]. In addition, Alessi et al [17] found in a small-scale controlled study that daytime exercise helped to reduce daytime agitation and night-time restlessness. An interesting approach to dance therapy is described by Perrin [18], who employed a form of dance known as ‘jabadeo’, which involves no prescriptive steps or motions but allows the participants engage with each other in interactive movements. It is relevant to note that this may also fulfil a need for non-sexual physical contact that many people with dementia find soothing. Finally, Politis et al conducted a randomized, controlled, clinical trial of activity therapy for apathy in patients with dementia in long-term care [19]. This study demonstrated a substantial improvement in apathy scores, although there was no clear advantage over the reminiscence-based intervention over the time and attention, one-on-one control intervention.

**Complementary therapy**

This therapy complements other therapies and involves massage, reflexology, reiki, therapeutic healing, herbal medicine, aromatherapy and similar. In the study conducted by The Mental Health Foundation it was concluded that, in terms of effectiveness, careful consideration was needed to identify what was meant by ‘effective’ (e.g. were the therapies aiming to improve cognitive abilities or levels of well-being?).
Aromatherapy

Aromatherapy is one of the fastest growing of all the complementary therapies. It appears to have several advantages over the pharmacological treatments widely used for dementia. It has a positive image and its use aids interaction while providing a sensory experience. It also seems to be well tolerated in comparison with neuroleptic or sedative medication. The two main essential oils used in aromatherapy for dementia are extracted from lavender and melissa balm. They also have the advantage that there are several routes of administration such as inhalation, bathing, massage and topical application in a cream.

Fung et al [20] shows that aromatherapy has the potential to be applied as a therapeutic and safe complementary and alternative therapy for the management of BPSD on more evidence collected from better designed randomized control trial. Limitations on methodology are discussed and suggestions on directions of further studies.

Bright-light therapy

Bright-light therapy has been increasingly used in an attempt to improve fluctuations in diurnal rhythms that may account for nighttime disturbances and ‘sundown syndrome’ (recurring confusion or agitation in the late afternoon or early evening) in people with dementia. A single center randomized controlled trial [21]of bright light therapy versus standard light was carried out concluded that bright-light therapy is a potential alternative to drug treatment in people with dementia who are agitated.

Multisensory approaches (snoezelen)

This therapy involves using a room designed to provide several types of sensory stimulation such as light (often in the
This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 643588

<table>
<thead>
<tr>
<th>Brief psychotherapies</th>
<th>Cognitive-behavioural therapy</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>This therapy shows positive effects when applied to people in the early stages of Alzheimer’s disease.</td>
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</table>

<table>
<thead>
<tr>
<th>Interpersonal therapy</th>
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<tbody>
<tr>
<td></td>
<td>Interpersonal therapy examines the individual’s distress within an interpersonal context. It uses a specific framework in which the individual’s distress is conceptualized through one of four domains: interpersonal disputes; interpersonal/personality difficulties; bereavement; and transitions/life events. There have been good empirical evidence of the success of this form of treatment with older people [23]</td>
</tr>
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<table>
<thead>
<tr>
<th>Cognitive training</th>
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<tbody>
<tr>
<td></td>
<td>Cognitive interventions refer to stimulation, rehabilitation or training of higher cerebral functions. Many studies have shown a statistically significant improvement in objective and subjective measures of cognitive function in people at high risk of dementia [24] [25]</td>
</tr>
<tr>
<td></td>
<td>There is consistent evidence that cognitive stimulation interventions benefit cognitive function and aspects of well-being. Cognitive stimulation should be made more widely available in dementia care [26]</td>
</tr>
<tr>
<td></td>
<td>A scoping review of the current literature suggests that cognitive training interventions have been the most widely studied. In general, some evidence suggests that cognitive training focused on remediation has been associated with</td>
</tr>
</tbody>
</table>
significantly greater improvements in selected cognitive abilities, but the magnitude of improvements is small [24].

<table>
<thead>
<tr>
<th>Interventions with the caregiver</th>
<th>Strategies for the carers of people with dementia.</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Most studies focus on reducing perceived stress and depressive symptoms of caregivers, or increasing the quality of life [27] [28].</td>
</tr>
<tr>
<td></td>
<td>Approaches for caregivers include: individual psychotherapy support, intervention group, psycho educational groups, groups emotional support, self-help groups, etc..</td>
</tr>
</tbody>
</table>

Usually none of these therapies is used in isolated manner. Therefore, it is important for clinicians to be aware of these approaches in order to design the best treatment path for the individual needs of the patients. The selection of therapies depend on the symptoms of the patient. In early stages of the disease, patients might experience behaviours and personality changes such as irritability, anxiety and depression. In later stages, other symptoms may occur, including anger, agitation, aggression, general emotional distress, physical or verbal outbursts, restlessness, hallucinations, delusions or sleep disturbances. Table 5 presents the most appropriate therapy associated with specific symptoms of cognitive impairment:
Table 5. Non-pharmacological treatments for different symptoms of cognitive impairment

<table>
<thead>
<tr>
<th></th>
<th>Validation</th>
<th>Reminiscence</th>
<th>Behavioral Activity</th>
<th>Occupational Therapy</th>
<th>Caregivers</th>
<th>Aromatherapy</th>
<th>Snoezelen</th>
<th>Bright light</th>
<th>Complementary (massage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apathy</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Aggression</td>
<td></td>
<td>✓ ✓ ✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Depression</td>
<td>✓ ✓ ✓ ✓</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Wandering</td>
<td>✓ ✓ ✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Agitation</td>
<td></td>
<td></td>
<td>✓ ✓ ✓ ✓</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Verbal outburts</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td>✓ ✓</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Sleep disorders</td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
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</tbody>
</table>
Case examples of non-pharmacological intervention when the combination of methods are exploited, hence providing proven outcomes, are defined further.

A number of skill development programs have been implemented in different countries, addressing the problem not only from the patient’s angle thus improving independent living, but also from the organizational perspective, preventing hospitalization, emergency and homecare services. The re-ablement program launched by the United Kingdom [29] is a six-week program that includes teaching clients a set of daily living activities, motivation, personal care and hygiene, practical help (e.g., preparing meals), prompting medication, providing advice and information (e.g., preventing falls, local community services), helping establish social contacts and rebuilding confidence to get out (e.g., to go shopping). 60 per cent of persons who received re-ablement services no longer required home care services at the end of the program and 40 per cent of graduates continued to be independent with no further home care needs upwards of two years. As per investigation of long-term impacts of homecare re-ablement services [30], home care re-ablement appears to lead to better outcomes, taking no greater cost. Similarly, the Home Independence Program launched by Australia [31] was developed to cope person’s physical limits with an emphasis on early intervention. Along with exercises, disease self-management and fall prevention strategies the program promoted social interactions. As per evaluation, clients were 6.5 times less likely to require on-going care and 30 per cent less likely to use emergency or hospital services.

Self-management in MCI and dementia patients is an interesting area for research and application. Self-management includes self-monitoring, seeking assistance and maintaining a positive outlook [32]. Self-management interventions can be group-based, and/or individualised and may include computer-assisted, mail-delivered, telephone and face-to-face components [33]. While this approach looks promising as it involves the patient in proactive self-care, it can be challenging when it comes to dementia patients. Memory problems, low self-esteem, hopelessness and insecurities can become serious barriers for adoption of such practice, especially when the diagnosis is significantly progressed. However, self-management can be an effective strategy of care when an early diagnosis is made, before significant cognitive deficits develop.

According to Martin et al [33], healthcare professionals and systems can be barriers to self-management. Various authors recommend educating healthcare professionals to support maintenance of independence and self-management (since healthcare systems are recognised to often foster dependence). Moreover, self-management can
be effective for people with cognitive impairment, but require adaptations to reduce cognitive load, to be adjusted to individual’s strengths and emphasise meaningful and pleasurable activity. For people experiencing cognitive impairments, for example, multiple sclerosis and Parkinson's disease, group self-management can be feasible and beneficial. Support groups, with an emphasis on social activities, sharing experiences with peers and reciprocal support have been shown to be valued and beneficial. These findings are commonly reported in the self-management literature thus supporting the potential feasibility and usefulness of a group self-management intervention for dementia.

**Group support** is the main pillar at The Murray Alzheimer Research and Education Program (MAREP) in Canada⁴, which has adopted a partnership approach and integrates research and educational activities in an effort to improve dementia care. The program incorporates various channels of care: a Web tool called “Living with Dementia”⁵, Age-friendly Communities Initiative, Recreation Resource guide, By Us For Us Series of Guides and A Changing Melody Forum and Toolkit. The program’s approach is based on the idea that persons with dementia can continue to grow and learn but need adequate information, resources and support to do so. One of the strongest channels the program offers is the forum helping to connect with other patients. The community meetings are another empowering initiative helping patients cope with anxiety and encouraging co-learning.

**Telemedicine** holds a great promise as one of healthcare delivery models [34]. It helps solve a number of care-related issues, such as distance and physical access to healthcare services, and shortage of professionals to visit a large and growing amount of patients at their own homes. The American Telemedicine association defines telemedicine as the use of medical information exchanged from one site to another via electronic communications to monitor and improve patient’s clinical health status. Telemedicine includes a growing variety of applications and services using two-way video, email, smart phones, wireless tools and other forms of telecommunication technology. Hospitals and nursing institutions move towards application of

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⁴ [https://uwaterloo.ca/murray-alzheimer-research-and-education-program/](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/)

⁵ [https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/web-based-resources/living-dementia-resources-living-well](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/web-based-resources/living-dementia-resources-living-well)
telemedicine as a way to cut costs, at the same time providing patients the convenience.

One of the leading and most innovative healthcare organizations in the United States of America – Carolinas HealthCare System – runs a virtual visit program\(^6\), which allows their one million clients to access a health service provider for a small charge. The provider of the virtual consultation can access medical information about the patient. Notes made by the provider can be accessed by the primary care doctor and care team.

The Australian Virtual clinic model addresses problems of access to medical services for people living in remote and rural areas. The disadvantages are overcome through low-cost videophones, which operate through ordinary phone lines along with common home-used clinical tools operated by local trained volunteers. They assist in the data collection and virtual communication with the doctor. According to Meade and Dunbar \(^35\), along with regular home monitoring, the Virtual clinic model saves ambulance utilization, though provides a sense of medical security for patients living in disadvantaged areas.

The Basque region of Spain has applied the telemedicine program for the elderly patients and has helped gain healthcare access by phone, Internet and a patient monitoring system called TEKI \(^7\). The equipment of TEKI includes a heart rate monitor, a spirometer to check respiratory levels, and a motion sensor – originally designed for use in video games – which evaluates their mobility. Real-time data is sent to a patient’s doctor, who can then administer care and write out prescriptions remotely. The program savings encountered have been estimated to $55 million and have helped avoid 52,000 hospital visits in its first year.

It is worth to mention few powerful and growing start-ups - platforms such as Healthtap and Doctor-On-Demand that have made telemedicine available to patients globally and provides personalized advice. In the future, healthcare providers may partner with such platforms to connect their doctors with patients. Additionally, these apps could be offered through employers or insurance companies to help reduce costs or improve quality of care.

\(^6\) [http://www.carolinashealthcare.org/virtualvisit](http://www.carolinashealthcare.org/virtualvisit)

2.2.3 Integrated care pathways for treating patients with cognitive impairment

Value creation is a central activity of businesses in any field, also healthcare. Porter in 2010 suggested that value should be the preeminent goal in the healthcare system, because it is what ultimately matters to customers (patients) and unites the interests of all system actors [36]. However, numerous studies recognize that value creation in healthcare is burdened by conflicting goals of different stakeholders and organizational units thus limiting access to services, resulting in cost-inefficiency, lacking convenience and patient focus. Moreover, the current design of healthcare systems lacks the integration and coordination critical for establishing a coherent, sustainable care chain for multi-diseased, older adults [37]. In many places today healthcare systems are largely fragmented and resource-dependent (financial, skill, staff, hospital beds, facilities, etc.). Mate and Compton-Phillips argue that healthcare systems are focused on the historic way clinicians delivered care (by sites of care and by specialty) rather than by how people should receive care (centred on each person, individual conditions and relatives)8. Moreover, operations within the contemporary health care delivery models are not able to sustain availability of hospital beds and physicians while the population is growing and ageing.

As a solution to this problem integrated care models are widely discussed and slowly adopted by caregivers. Various healthcare providers explain the term as a co-ordinated work with the patient at the centre. To achieve integrated care, those involved with planning and providing services must impose the user’s perspective as the organising principle of service delivery [38] [39]. Its benefits are recognized as an improvement of patient’s experience of care, reduced utilization of hospital facilities, etc. Nevertheless, although there is evidence that service integration improves clinical outcomes, there is a particular scarcity of robust evidence on the economic impacts of integrated care approaches [40].

In the book The Innovator's Prescription [41], it was suggested that new ways of organizing healthcare are required, shifting the value configuration logic from traditional, vertical ways of operating towards horizontal customer-, process- and network-centred organization logics. Mixed goals, process management tactics and different business models within the same operating unit make it hard to provide a viable and customer-centred value. The book identifies three major categories

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8 https://hbr.org/2014/12/the-antidote-to-fragmented-health-care
towards which healthcare businesses should move: first, solution-shop model – intended to diagnose the problem and to recommend a solution (fee for service); second, value-adding process model, intended for doing medical procedures after diagnosis in a standardized way, such as surgery (fee for outcome); third, facilitated user network model intended for information exchange (membership fee), for instance, for treatment of chronic diseases.

Alzheimer Scotland, the leading dementia organisation in Scotland, has proposed a holistic, integrated, evidence-based care model for people with dementia, namely the 8 Pillars Model of Community Support [42]. This model follows a bio-psychosocial understanding of dementia, and sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia living at home during the moderate to severe stages of the illness. Figure 2 presents all the components that comprise the 8 pillars model.
The 8 pillars model introduces the figure of the Dementia Practice Coordinator (DPC), that will ensure access to all pillars of support on an on-going basis as appropriate to each individual, and will coordinate between all the practitioners delivering care, treatment and support. The DPC will come from among existing practitioners working within the field of dementia care. This model is currently being piloted in 5 regions in Scotland.

The National Institute for Health and Care Excellence (NICE)⁹ in the UK has used the model as a basis to create their Dementia Pathway, which include recommendations

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⁹ [https://www.nice.org.uk](https://www.nice.org.uk)
and quality metrics in order to provide people with dementia and their caregivers with integrated, holistic care [43]. Dementia pathways include recommendations for assessment, early identification and follow-up of mild cognitive impairment. Moreover, the NICE dementia pathway integrates the information from two quality standards in an integrated format: the NICE Dementia Quality Standard (QS1) 10 and the NICE supporting people to live well with dementia quality standards (QS30) 11. The QS1 covers care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. On the other hand, the QS30 applies to all social care settings and services working with and caring for people with dementia. Table 6 presents the links between the quality standard and the areas in the NICE Pathway 12.

<table>
<thead>
<tr>
<th>Areas in the NICE Pathway</th>
<th>Quality Statement in NICE QS1</th>
<th>Quality Statement in NICE QS30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff training</td>
<td>1 Appropriately trained staff</td>
<td></td>
</tr>
<tr>
<td>Promoting choice</td>
<td>5 Decision making</td>
<td>2 Choice and control in decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 Leisure activities of interest and choice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 Independent advocacy</td>
</tr>
<tr>
<td>Providing support</td>
<td>4 Assessment and personalised care plan</td>
<td>3 Renewing needs and preferences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 Physical and mental health and wellbeing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 Independent advocacy</td>
</tr>
</tbody>
</table>

10 [http://www.nice.org.uk/guidance/qs1](http://www.nice.org.uk/guidance/qs1)

11 [http://www.nice.org.uk/guidance/qs30](http://www.nice.org.uk/guidance/qs30)

<table>
<thead>
<tr>
<th>Areas in the NICE Pathway</th>
<th>Quality Statement in NICE QS1</th>
<th>Quality Statement in NICE QS30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrated and coordinated care and service provision</td>
<td>1 Appropriately trained staff 4 Assessment and personalised care plan</td>
<td>8 Planning and evaluating services</td>
</tr>
<tr>
<td>Promoting independence and maintaining function</td>
<td>4 Assessment and personalised care plan</td>
<td>5 Maintaining and developing relationships 10 Involvement and contribution to the community</td>
</tr>
<tr>
<td>Living arrangements and care home placements</td>
<td></td>
<td>7 Design and adaptation of housing</td>
</tr>
<tr>
<td>Inpatient care and care in an acute hospital</td>
<td>8 Liaison services</td>
<td></td>
</tr>
<tr>
<td>Support for carers</td>
<td>6 Emotional, psychological and social needs of carers 10 Respite services for carers</td>
<td></td>
</tr>
<tr>
<td>Palliative and end-of-life care</td>
<td>5 Decision making 9 Palliative care needs</td>
<td></td>
</tr>
<tr>
<td>Investigation of suspected dementia</td>
<td></td>
<td>1 Discussing concerns about possible dementia</td>
</tr>
<tr>
<td>Specialist assessment services</td>
<td>2 Memory assessment services</td>
<td></td>
</tr>
<tr>
<td>Needs arising from diagnosis</td>
<td>3 Written and verbal information</td>
<td></td>
</tr>
<tr>
<td>Interventions for non-cognitive symptoms and behaviour that challenges</td>
<td>7 Non-cognitive symptoms and behaviour that challenges</td>
<td></td>
</tr>
</tbody>
</table>
There are very few institutions that have gone through major change programs or have established this care model from the very beginning (such as Kaiser Permanente integrated managed care consortium in the United States). Most of healthcare providers adopt a soft integrated care approach by creating sub-units or so-called clinical microsystems aimed to provide better care outcomes.

In the case of nursing homes, dementia special care units are among the most popular innovations aimed to provide their patients with integrated home care. Dementia special care units are designed to maximize the quality of life through a reduction in functional deficits and environmental stressors. Although numerous studies suggest that existence of dementia special care has common outcomes of reduced feeding tube usage, less restrained environment and lower risk of hospitalization among cognitively impaired patients, the study of dementia special care units in the United States by Gruneir et al [44] reports that the biggest success factors are organizational philosophy or approach to care (for instance, in terms of investment).

Fraser Health, one of the largest healthcare providers in Canada, has established an integrated care model for older adults with complex and chronic medical conditions [45]. An integrated care model partners family physicians with community-based home health case managers to support frail elderly patients who live at home. Since the model resulted in faster response times to patient needs, more informed assessments of a patient’s state of health and pro-active identification of emerging patient issues, it is currently used in every day practice.

In 2006, the Regional Government of Extremadura (Spain) started developing an Integrated Plan for the Care of Cognitive Impairment Care, namely PIDEX. PIDEX defines the clinical and socio-sanitary pathways for treating patients with cognitive impairment at regional level and aims to ensure integrated care through the creation of specific cognitive impairment units that will manage cases individually. Hence, the diagnosis, follow-up and specialized treatment will be carried out by a Consultation for the Diagnosis, Treatment and Specialized follow-up of Cognitive Impairment (Consulta de Diagnóstico, Tratamiento y Seguimiento Especializados del Déficit Cognitivo, CEDEC). CEDECs are located within the Neurology Services of the main

<table>
<thead>
<tr>
<th>Areas in the NICE Pathway</th>
<th>Quality Statement in NICE QS1</th>
<th>Quality Statement in NICE QS30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-pharmacological interventions</td>
<td></td>
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</table>

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 643588
Hospitals and consist of a neurologist and a psychologist with specific training in Neuropsychology, with the support of other medical professionals. While CEDECs will focus on diagnosis and specialized treatment, the ultimate responsible for the continuous care of the patient is the Primary Care team, which comprises general practitioners and nurses. The Primary Care team collaborates with the CEDEC in the diagnosis, treatment and follow-up, and coordinates the actions of both social and healthcare sectors. On the other hand, welfare workers (social workers, psychologists, occupational therapists, etc.) will carry the weight of “continuous”, ambulatory care of patients and their caregivers. The Integrated Program for the Care of Patients with Cognitive Impairment has been working from 2011, and the number of patients attended in the program has risen from 700 people in 2012 to 850 circa February 2015\(^{13}\). Currently, there are 6 CEDECs operating in Extremadura, and 6 neuropsychologists were specially hired in order to ensure the implementation of the Integrated Plan. Moreover, PIDEX has facilitated the hiring of 20 occupational therapists for the realisation of cognitive stimulation therapies. The Spanish National Health System has recommended PIDEX as a reference plan in their National Strategy for the Integral Approach to Dementia [46].

As an example, the Spanish Society of Psychogeriatrics and the Spanish Society of Psychiatry published in 2015 the 2\(^{\text{nd}}\) version of their document ‘Consensus on Dementia’ that proposes a care pathway comprised by the following elements: patient/family, the Primary Care Team, the Mental Health Team, a Dementia and Cognitive Impairment Functional Unit and Hospitalization Units. The Mental Health Teams (MHTs) are the basis of the health care of patients with mental problems, and provide patients with mental health issues (including older adults with dementia) with continuous care, with a clear community-minded, comprehensive and multidisciplinary approach. The MHT comprises a Psychiatrist, a Nurse specialized in mental health and a social worker. They work very close with Primary Care, and sometimes in the same building or nearby. The MHT assesses suspected cases of cognitive impairment, especially when they are accompanied by psychological and behavioural (depressive symptoms, psychotic, pre morbid personality changes) or atypical (in the case of young people presenting with disorders psychological or behavioural prior the manifestation of cognitive impairment). The MHS also carries

out the assessment and differential diagnosis of different psychiatric illness. Nevertheless, the Strategy on Mental Health published in 2007 by the Spanish Ministry of Health and Consumer Affairs stressed the lack of specific multidisciplinary programs for the healthcare of older adults with mental problems. Dementia Units are located in specific hospitals, and are a key resource to Primary Care and Specialized Care, being able to carry out a global diagnostic as well as to offer an ambulatory service as an external consultation. Dementia Units are multidisciplinary teams that should include a health professional able to manage dementia (neurologist, geriatrician or psychiatrist), a psychologist / neuropsychologist, a specialized nurse, a social worker and clerical workers. According to the Spanish Consensus on Dementia, Dementia Units should also count with a psychogeriatrician in order to perform comprehensive cognitive assessments on patients diagnosed with Cognitive Impairment. Currently there are few Psychogeriatric Units in Spain, and not all psychiatrics are trained specifically in geriatrics.

The integrated care system built in the Basque Country deployed the Bidasoa Integrated Health Organisation during the period 2011-2014 [47]. Structural, functional and clinical integration policies have been employed to deliver integrated and person-centred care for patients, especially for those living with chronic conditions. The initiative was multi-dimensional and incorporated structural, functional and clinical perspectives. The vision behind the initiative was to achieve more efficiency and better quality of care. To implement more patient-centred approach and improve clinical practice, technical boards and mixed clinical committees were created so that issues like patient safety and palliative care would be managed in multidisciplinary teams. Among the improvement efforts, the Continuity of Care Unit was created to treat the chronic patients, with a goal to stabilize patients and facilitate continuity of care by the general practitioner. After organizational changes, improvements were found at collaboration between professionals of different care levels, patient's perceptions of care showed better experience, hospital utilization was reduced and cost decreased in terms of per capita expenditure.
3 Analysis of care models in the 4 pilot sites

This section presents a detailed description of the care pathways for patients with CI / MCI in the four pilot sites. First, we will present a brief overview of the health and social systems in the four countries where pilots will take place; then, we will describe the organizations that will run the pilots. Finally, we will present a detailed analysis of the care pathways adopted by these organizations for treating older patients with mild cognitive impairment and dementia.

3.1 Italy

3.1.1 Background

In Italy, as of 1st January 2014, the resident population exceeded 60 million (60.782.668 people); individuals over 65 years old represent 21.7% of the population and 14.7% claimed to be suffering from at least one chronic disease [48].

3.1.1.1 The Italian National Socio-Health care System

In Italy, socio-health care is provided by the National Socio-Health care System, which is composed by:

- The National Healthcare System provides citizens with health care services. The Italian NHS comprises all organizations, people and actions whose primary intent is to promote, restore or maintain the patient’s health. This Italian NHS is the appointed authority for the management of health care services, which include all performance services, generic or specialized care, of outpatient, curative or rehabilitative care. The National Socio-Healthcare System has a universal and solidarity nature (Beveridge model). In this model, health is considered a fundamental right of all citizens, who are entitled to make use of all the services established at national level. The healthcare system is funded from general taxation (plus a little part of amount determine by each personal gross personal income), and an important part of the care service providers are public companies, 46.1% of total companies [48].

- The Welfare System provides citizens with social care services and consists of all organizations, people and actions whose primary intent is to integrate all possible resources to prevent, eliminate, or reduce conditions of hardship, economic or social difficulties, not self-sufficiency and disability.
Within the Italian National Socio-Health care System, care services provided (health care, social care and socio-health care services) can be connected to three major phases of patient care:

- **Acute phase**, with a strong clinic intensity. This phase is characterized by the need to be solved in short time with professionalism and technologies. Health issues classified as critical, request the maximum amount of diagnostic and therapeutic options.

- **Post-acute or rehabilitation phase.** In this phase a series of treatments, subsequent to the acute phase, are delivered to the patient. These treatments have well defined characteristics based on temporal succession and on the objectives to be pursued. Within the post-acute phase can be made a division that identifies two main processes:
  
  o Long-term care, finalized to maintain the functional autonomy and to slow its deterioration, as well as to encourage the participation in social life;
  
  o Rehabilitation, divided into two phases:
    
    ▪ Intensive, characterized by a rehabilitative effort of high complexity and of short and defined duration.
    
    ▪ Extensive, characterized by a lower therapeutic intensity and a medium or long-term rehabilitation program.

- **Chronic phase.** This phase is characterized by a stabilization of the patient’s conditions, irrespective of the care’s intensity and action (health and social) dedicated. In this phase the patient can be defined as *frail*.

Connecting the phases of the care process with the types of services offered and the actors/structures involved, we can see that:

- **Acute care** is provided by Hospitals, Scientific Research and Treatment Institutions (IRCCS, particular organizations recognized by the Ministry of Health, which aim to improve patient’s treatment through a translational approach of the results of scientific research), the HealthCare Authority, and Clinic often placed in the same structure. This placement is due to the need to have access quickly to health professionals and diagnostic-therapeutic services.

- In the **post-acute rehabilitation** phase, there is a joint action of the health care component and the social care assistance. Due to this coexistence, the socio-health care services have a wider variety of delivery contexts. In fact, the post-acute phase has very different paths. The patient on the basis of a
multidimensional assessment on its clinical, social, family and care conditions can make use of services provided in a regime of:

- **Hospitalization/Day Hospital and Day Surgery.** In this case, the delivery will take place in a manner entirely similar to those defined for the acute phase.

- **Residential and semi-residential performance:** If the patient, after the acute phase, still has limitations that prevent the total healing and requires interventions that facilitate the recovery of full autonomy, it can turn to structures specialized in the rehabilitation and recovery of self-sufficiency. This performance shall be provided in structures such as Therapeutic Communities, Nursing Home, Day Care Centres and Housing Communities.

- **Domestic performance:** Domestic assistance consists of medical, nursing and rehabilitation treatments provided by qualified staff for the care and assistance of not self-sufficient and frail patients, with diseases treatable at home. The purpose is to stabilize the clinical picture, limit the functional decline and improve the quality of daily life without the transfer of the patient in other structures;

- **The chronic phase** also involves socio-health care services. In this phase, as an alternative to the domestic performance, the Italian National Socio-Healthcare System provides patients with dedicated facilities that take care of them depending on their condition, whether they are disabled (HRD - Healthcare Residences for Disabled), older (SHRE - Socio-Helpful Residences for Elderly, IDC - Integrated Day Care Centres) or belonging to other segments of the population.

Focusing on the chronicity phase, there is a huge amount of socio-health care services provided by different actors in different structures with different systems of delivery. We can link socio-health care services to three different phases of the chronic path (independent living, assisted living and dependence from formalized services):

1. Full autonomy in the initial phase of the disease (independent living), when the only support is provided by the healthcare services related to the diagnosis and cure, with the limitations mentioned beforehand.

2. Initial self-organization of the support network (assisted living), when other family members, neighbors or charities are engaged by the principal caregiver in the patient care. Formalized services are used but families keep autonomy
from them. Overall, the most used service is the request of a direct disability compensation for the patient, also because it includes the free supply of medical aids and devices and the dispensation from sanitary expenses. The engagement of a professional advisor to define the patient care path is rare at this stage. Usually a family member operates as case- and care-manager, recovering all the information he/she need from reliable and, sometimes, unreliable sources (e.g. the internet or through word of mouth).

3. Dependence from the network of formalized services: when the management ability of the family system is no more enough. This is a late stage resulting from physical decline of the patient, depletion of economic resources or caregiver burnout. At this stage, patient and family members adapt themselves to the formalized system of services and accepting all the system rules. A conflicting inclination toward the system persists. This complexity is further increased by the presence of different actors who interact in the care path of frail patients. Each actor plays a basic role in the patient care process, especially:

- **General Practitioner** (GP), who acts as the gatekeeper to the system. Indeed, the GP provides older patients with a binding agreement and an informative sheet regarding the provision of the performance. Moreover, in some cases, the GP participates in the drafting of the individual assistance plan for the patient.

- **Hospital**, that contacts the GP in case of protected resignation of the patient following the occurrence of an acute episode.

- **Local Healthcare Authority** (in Italy called ASL), that has the role of manager, and in some cases even of regulator, of health care and social care services (only for the hygiene performance of the patient).

- **Municipality** has the role of manager of social care services and in some cases of leader authority of the associated management between the municipalities in relation to social care services.

- **Care service provider**, is the actor that usually delivers the socio-health care services managed by the Local Health Authority and/or the social care services managed by the Municipality, when these actors cannot manage the delivery.

These actors, that compose this network, are connected to each other at various moments of care path of the patient. In particular:
In the need signalling phase, the GP contacts the Local Health Authority through the GP referral and in some case the Municipality informally. The Hospital, in the case of protect discharge, communicates the need of health care or social care services to the GP or to the Municipality.

In the needs evaluation phase, all stakeholders in the social-health care network should communicate with each other in order to make an integrated assessment of the patients, aiming to ensure that patients evaluated according to both social and health dimensions. However, these communications are often limited or not present.

In the care plan definition phase, both health and social actors should be present during the definition of the plan.

In the supply phase, the health care and social care operators have to coordinate themselves for the delivery of the activities to the patient. This activity is carried out by the operators by phone or by the patient’s caregiver that keeps track of the event planned during the week.

Due to the complexity of the network of actors that surround the patient, it is now explored the fundamental relationship between the Local Health Authority and the Municipality with the related care service providers. In the Italian National Socio-Healthcare System, there are substantially two types of models:

- **Tender**: the service is given in commitment exclusively, for a certain period of time, to a care service provider that has proven to have the relevant features to deliver it.
- **Accreditation**: the patient can choose the preferred structure from a list of accredited care service providers. The different providers are refunded at the end of the year for the provided services.

In Italy, in the Local Health Authority case, the first model was no longer used promoting a concept of competitive market (accreditation model). Municipalities still make extensive use of the Tender-based model.

The multiplicity of actors and services involved in the process of patient care and the increasing joint demand of health care and social care services, provided respectively by the Local Health Authorities and the Municipalities with the related care service providers, necessitate a continuous link between the different actors and services. However, in the Italian National Socio-Health Care System, patients and their caregivers often play the role of connector between the health care and social care realities. Therefore, the basic requirement in this context is to place the patient at the centre of this network of actors. The relationships among all actors involved in the care of older patients, then, have to be affected by an action of strengthening and
reviewing in order to ensure a better patient’s centrality. This result can be obtained only if the health care and social care processes are opportunely integrated offering a global service to the patient.

Considering the Italian context, the need for socio-health care integration is widely reflected not only at the operational level but also at the regulatory level. Since the 1990s, in fact, the Italian legislation has begun to address this issue. The first step towards integration was carried out through Section 14 of the “Law for the implementation of the integrated system of social interventions and services” (Law 328/2000) that highlighted the concept of “socio-health care integration”. The clause states that to achieve the full integration of frail people within the family and social life the Municipality, in agreement with the Local Health Authority, should prepare an individual project. The individual project includes, in addition to the diagnostic-functional evaluation and the care/rehabilitation performances, the services to the person provided by the Municipality, with particular reference to the social recovery and integration.

In the Italian National Socio-Health care System, the most important initiative in terms of impact on the integration of socio-health care services was represented by the institution of the Single Access Point (SAP) that ensures the integrated patient care. Moreover, the 2011-2013 National Health Plan refers to the concept of integration by defining a set of Guidelines that define a series of operational strategies aimed to promote different levels of socio-health care integration.

Therefore, at the regulatory national level, there is an increasing drive towards integration between Local Health Authority and Municipality, and consequently between health care and social care services. Although inside the Italian National Socio-Health care System there are many initiatives of integration, there is still not an effective and complete socio-health care integration.

The path to optimal management of these care processes is still long and the margins of improvement are numerous. Therefore, it is important to encourage continuously initiatives that promote the social-health care integration and:

- Extend integration initiatives at local level to regional or national level.
- Consider not only the process’s point of view but also the support of the technology as an essential lever of coordination and integration.
3.1.1.2 The Lombardy Socio-Healthcare System

The National Healthcare System and the Welfare System make use of three different fundamental tools for managing the care system:

- The *National Plan* of care services that the Governing Body prepares every three years and that identifies general addresses and criteria.
- The *Regional Plans* establish the integration between health and social care services in line with the Regional Health Plan goals.
- The *Local Plans* define, design and implement interventions that compose the overall offer of socio-health care services provided by public or private subjects.

Regions are autonomous in managing and defining their care services. The Lombardy Region represents an example of particularly virtuous region regarding provision of care services. There are approximately 3 million chronic patients in Lombardy, with an estimated amount of people in condition of frailty of approximately 600,000 people [49]. 35.1% of total companies are public, demonstrating a clear predominance of private structures [50].

In line with the national legislation, Lombardy has structured its intervention in the socio-health area through the regional law “Network government of interventions and services to people in social and socio-health area”. This law defines the functions and competence areas of Region, Provinces, Municipalities, Local Health Authorities and Providers describing thus the institutional and organizational layout:

- The *Region* must exercise the functions of policy, planning, coordination, monitoring and verification of the social and socio-health offering with the cooperation of local authorities, health agencies and third parties.
- *Provinces* contribute to the planning and implementation of the social and socio-health offering.
- The *individual or associated Municipalities*, according to the principles of subsidiarity, differentiation and adequacy, are holders of administrative functions concerning social interventions performed at local level. They also contribute to the realization of the objectives defined at regional level.
- The *Local Health Authority* programs, locally, the realization of the socio-health offering, in compliance with the regional planning and in harmony with the guidelines formulated by the Municipalities through the Conference of
Mayors of the territory covered by each Local Heath Authority. Moreover, they exercise supervision and control over the private and public supplying companies of socio-health services.

- Hospitals, as providers for acute care, and the Local Healthcare Authorities’ offices, as providers for socio-health care services.

As shown in Figure 3, in Lombardy, there is a huge amount of socio-health care services, provided by different actors and according to the management model previously described.

In particular, we have *services of social housing* (such as disability-adapted homes), *shared independent living* (such as co-housing) and *protected independent living* (such as community housing), which include homes within an apartment complex that offers transportation, security and recreational activities, but no health care services. These services apply to the independent living phase.

Then, we have *independent living supplementary services* (such as tele-assistance or hygiene) and *assisted living services* (such as assisted living centers), which are services providing support for daily activities including basic health care services, recreational and social activities. These services apply to both the independent living phase and the assisted living phase.

Finally, we have *primary and home care services* (such as GP, family counseling, SAD and ADI), *residential services* (such as nursing homes) and *integrated services* (such as Integrated Daycare Centers), which include the whole spectrum of services provided to the patient on an ongoing basis. These services apply to both the assisted living phase and dependence on the network of formalized services phase.
The multiplicity of actors and services involved in the process of patient care underlines the need for integration interventions, according to the innovative integration model proposed by national legislation. The Lombardy region is therefore activating different initiatives in order to achieve alignment with national legislation. A significant example of this intent is the introduction of Centres of Home Care (in Italy called CeAD) as Single Access Points (SAP) to the home care service. Therefore, each Local Health Authority has activated at least one CeAD with the aim to coordinate the use of all resources and all health care and social care services provided in the home environment. In particular, the CeAD enables certain functions, specifically:

- It collects the demands of both patients and alerts from services in the area (GP, specialist, social workers, call centres, etc.).
- It organizes, coordinates and confirms the activation of a range of social and health care services, creating integrated and customized packages of performance.
- It compiles and updates the individual care plan relative to the home performance.
• It orients the possible choice of the type of care facility and coordinates the intermediate structure for the management of complex cases that have no immediate solution (dismissal, home aggravations, etc.).

• It interfaces with health facilities to simplify the diagnosis and treatment paths.

Therefore, through the birth of CeAD, even Lombardy has taken a step forward in terms of socio-health integration. In fact, while initially the process of patient’s taking charge was done through multiple access points and various possible paths, a different login for each service or performance, now the final goal is to carry out a patient’s taking charge of care through a single access point and a multidimensional integrated evaluation to ensure care continuity and fairness of services provided.

In conclusion, the described governance structure is characterized by a strong level of autonomy. Therefore, the various local districts apply the regional guidelines in a territorial declination. Coherently with the regulatory limits, in the most of territories have been activated local initiatives of process and organization integration. On the other hand, only a few isolated cases of technological integration have been identified.

A recent reform in the Lombardy Region (Law of the Region Government of Lombardy L.R. n.23/11 August 2015) is involving the reorganization of public health structures. The reform merges acute care providers (formerly: Hospitals / Public Providers of care) with social-care functions previously provided by the Local Healthcare Authorities, in one unique organization (in Italy called ASST). The Local HealthCare Authority will loose local socio-healthcare services provisioning and will perform only management, control and planning functions. They have the task to supervise the care continuity provided to patients, including fragile ones. The implementation of this reform will begin at the end of 2015, so there will be a subsequent update in the next project phases. Private entities, such as “Fondazione Don Carlo Gnocchi Onlus”, will undergo an impact related to a change of external referees, rather than internal operations.

3.1.1.3 The Palazzolo Institute of Fondazione Don Carlo Gnocchi Onlus

The Palazzolo Institute, located in Milan (Italy), is the largest of the FDG centres offering care and assistance services to older adults. The Institute offers both health and social services for residential as well as community-based patients (home care services). All the services are integrated to offer a care program that is shared with patients and caregivers. The Institute has implemented specific discharge pathways that integrate the health care units with other services, including community-based
services. Discharges are programmed to follow the patient and progressively facilitate their return home.

The Palazzolo Institute offers the following services:

**Acute and sub-acute care units**

The **Acute Care Unit** (20 beds), offers internal medicine services and support to the patients at the nursing home of the Institute as well as to patients at the home community services.

The **Sub-acute Care Unit** (20 beds), takes care of patients needing health support after an acute event or suffering from chronic diseases without preeminent clinical instability.

**Rehabilitation units**

Rehabilitation units include the **Neurological and Orthopaedic Rehabilitation** (25 beds) and the **Pulmonary rehabilitation** (15 beds). The objective of those units is to achieve a rapid and adequate social re-inclusion of frail older adults.

The Palazzolo Institute also includes an **Intermediate care unit** (75 beds). This unit takes care of patients in the intermediate phase between the discharge from the acute or sub-acute unit and their return home.

**Residential long-term care units**

A large **Nursing Home** (NH), counting 517 beds, offers hospitality to frail older adults with severe functional limitations. All patients periodically undergo a multidimensional assessment aimed at defining the Individual Assistance Program.

Within the Nursing home there is a special **Alzheimer Unit** counting 30 beds. Patient in this unit are affected by dementia and behavioural symptoms, but are still able to walk. Permanence of patients in this unit is not intended to be indefinite, as it is finalized at managing, and possibly improving, the behavioural symptoms for a return at home or in another unit of the nursing home.

This unit has adopted an approach that avoids the use of restrictive physical interventions (in Italian "approccio protesico non contenitivo"). Operators of this unit are specifically trained to support patients with dementia and their emotional, physical and functional needs. Two special units are available for patient with **Chronic Consciousness Disorders** (29 beds) and patient with **neurodegenerative diseases**, such as Multiple Sclerosis and amyotrophic lateral sclerosis (18 beds).
Finally there is an **Hospice** for terminally ill patients counting 10 beds.

**Residential and semi-residential social units**

A **day centre for elderly** is integrated in the Palazzolo Institute. It can offer daytime hospitality to 30 frail older adults. The day centre is addressed to frail older adults with functional limitation in the motor area and/or in the cognitive area. The Palazzolo institute manages a **sheltered house** for frail older adults (named **Casa Aurora**). The house, that can host up to 11 people, includes a large living room a library, a kitchen and a laundry. Casa Aurora is an "Assisted Living Facility" that hosts people with functional limitation in the Instrumental Activities of Daily Living (IADL) and some minor limitation in the Basic Activities of Daily Living (BADL). The main activities of the operators of Casa Aurora are focused on monitoring the guests and supporting them in structuring the activities. Some assistance is also given in the activities of daily living.

**Community and home-care services**

The **integrated home care assistance** (in italian Assistenza Domiciliare Integrata - ADI) are a set of health and specialized home care services offered to those people unable to benefit from the standard outpatient services offered by the Institute. The Local Health Authority (LHA) evaluates the request, defines an individual project and gives the patient a voucher for a set of services (the number and kind of services depends on the patient's profile). The patient selects a health care provider, among the ones acknowledged by the LHA, and the provider defines the individual assistance plan. Regarding medical needs, patients remain in charge of their general practitioner. The ADI service can provide specialist medical services, infirmary services, rehabilitation services and assistance for basic daily life activities.

A specific service is available for **home care assistance of people with dementia** (named **ADI demenza**). It is an experimental service, started in 2015, that involves three institutions in the city of Milan (Palazzolo institute, Pio Albergo Trivulzio, and Istituto Golgi Redaelli) all having an Alzheimer Assessment Unit (UVA). Besides the standard home care assistance described above, this service can provide support to caregivers and family members in managing behavioural issues and assistance (to avoid burn out of the principal caregiver). The team is specifically trained in managing dementia and behavioural issues and a direct phone line with specialists is active for caregivers and family members.

Since 2014, the Lombardy region has activated an experimental service named "**Open Nursing Home**" (RSA Aperta in Italian). The idea is to bring the services of the
Nursing Home to the patient’s home. The process is similar to the integrated home care assistance but with a tighter integration of social and medical interventions. Figure 4 presents an overview of the pathway since the patient initiates a service request until the service provider takes charge of the patient.

The Institute provides older adults with **Social Home care Services** in synergy and close cooperation with social services of the municipality of the city of Milan, and non-profit and voluntary organizations. Services are address to frail elderly people living alone, at risk of social exclusion and/or with economic difficulties with the aim of allowing them to live at their homes as long as possible and supporting the person in difficult moments their lives (due for example to death of a family member, solitude, ageing, etc.)

The interventions include for example housekeeping, small home maintenance activities, help with bureaucratic and administrative procedures, help for medical exams, help on daily living tasks, etc. Some other activities include the support in toileting, in meal preparation, in acquiring drugs or foods.

Within frame of social home care services, a specific service has been activated in collaboration with the municipality of Milan, named "Custodi Sociali". The service employs a number of community operators in the areas of Milan with the higher concentration of frail people (mostly elderly people living alone). The main activities of this service are related to monitoring the territory (in cooperation with the operators of social housing) to detect expressed and unexpressed needs of the population; exploiting of the resources on the local community; supporting the people in the use of services and resources in the local community; activating formal and
informal networks; facilitating the active participation in social activities and organizing social and entertainment events in the available facilities and spaces.

**Outpatient services**

The Institute offers **specialists outpatient services** in the following areas: geriatrics, angiology, cardiology, general surgery, endocrinology, internal medicine, neurology, ophthalmology, orthopaedics, otolaryngology, psychiatry, urology, dermatology, psychiatry, gastroenterology, oncology, pneumology, radiology, laboratory analysis, dentistry and special needs dentistry. Pain treatment and acupuncture are also available. An **outpatient rehabilitation service** is also available both **at the Institute** and **at home** providing rehabilitation in the neurology, orthopaedics and pneumology areas.

Table 7 summarize the activities and the number of services provided in the year 2014.

<table>
<thead>
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<th>Service Type</th>
<th>Beds</th>
<th>Persons/year</th>
<th>Day of stay/year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute and sub-acute care units</td>
<td>73</td>
<td>753</td>
<td>17.881</td>
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<tr>
<td>Rehabilitation units</td>
<td>115</td>
<td>1.445</td>
<td>54.573</td>
</tr>
<tr>
<td>Residential long-term care units</td>
<td>605</td>
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<td>208.933</td>
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<td>Residential and day care social units</td>
<td>41</td>
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<table>
<thead>
<tr>
<th>Service Type</th>
<th>Person/day</th>
<th>Contacts/year</th>
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<tbody>
<tr>
<td>Community and home-care services</td>
<td>1.236</td>
<td>106.802</td>
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<tr>
<td>Specialist outpatient services</td>
<td>68,4*</td>
<td>18.481</td>
</tr>
</tbody>
</table>

* mean value year 2014

**3.1.2 Care pathways for patients with CI in FDG**

**3.1.2.1 Organizational model and processes**

In the Palazzolo Institute the provision services is organized in five different settings: Home-based services, Facility-based services (e.g. Adult day care or senior centres), Residential care facilities, Health care centres and Medical Nursing Homes.

The Palazzolo Institute provides different type of services: health care services, social care services and socio-health care services. Different but functionally related administrative offices are responsible for managing the influx of patients: the...
Registration Desk (UAR), the Social-care Services Helpdesk (PASS) and the Territorial Services (ST).

Registration Desk (UAR – "Ufficio Accettazione Ricoveri")
The UAR manages all the processes related to the admission and discharge of patients from the hospital services. A section of it manages the Outpatient Access Services devoted to the ambulatory care clinic. The UAR has one coordinator and eight full-time employees, and is functionally connected to the General Administrative Office and to the Clinical Management Staff. The procedures of the UAR are managed by two Web-based ERPs (AmbWEB and AcceWEB) that were adopted in 2013. Patients can request appointments or services by phone, email or direct access to the offices.

Social-care services Helpdesk (PASS – "Punto di Accesso Socio-Sanitario")
The PASS manages all the processes related to social-care services (Nursing Home, Alzheimer nursing home, Severe Brain injury and neuromuscular disorders unit, Intermediate care, Hospice unit). The PASS is managed by a welfare worker who acts as a case manager for the received persons. The PASS, functionally connected to the General Administrative Office and to the Clinical Management Staff, manages all the requests relating to social-care services and social services. Moreover, it manages waiting lists, interacts with the other authorities (Hospitals, Local Health Authorities, Municipality), assists patients and caregivers during the interactions with the Institute services, assists patients and caregivers in the definition of the course of treatment and with bureaucratic procedures (e.g. legal disability procedure, sanitary devices obtaining, designation of a legal representative). The PASS works in synergy with the UAR, for the projects regarding the protected discharge of persons hospitalized in the hospital services or to manage internal or external transfer of patients to or from hospital services from or to Social-care services, and the Territorial services (“Servizi Territoriali”), to manage the course of treatment to or from facilities external to the Institute (Home-based services, Senior centres).

The procedures of the PASS are managed by a web-based ERP (RSA Web), available from 2013.

Territorial Services (ST – "Servizi territoriali")
The ST manages all the processes related to the external services of the Palazzolo Institute (senior centres, home health care, home social care and the Open nursing home) and the connection with the district's social agencies. The operations manager is a welfare worker who shares with the PASS manager the role of system case
manager. The operation manager is responsible for managing the path of patients through the system of services and help them in their interactions with the social services managed by the Municipality, non-profit-making organizations, voluntary organizations, federations of families and the Palazzolo Institute internal health services. The ST works in synergy with PASS, and the relations between ST and UAR, if needed, are managed by the PASS intervention. The ST has not a Web ERP to manage his activity.

As a whole, the PASS and the ST form a single functional unit that ensures the regular exchange of information between the Institute and the users, manages the processes related to the patients and caregivers interaction with the Institute services and with other authorities responsible for social services, and supports the processes of admission to and discharge from the Institute.

In the Palazzolo Institute, services for people with cognitive impairment are organized along an ideal temporal line which follow the different stages of the illness (from the onset of the first symptoms to the terminal stage of the disease):

- **Diagnostic suspect.** MCI and dementia are characterized by an insidious onset of cognitive symptoms. Usually both the patient and the family members perceive a behavioural change in the everyday life but they have trouble to link that to a cognitive impairment at the beginning. At this stage, often the patient is not referred to a specialized service for the diagnosis of MCI or dementia, and when the patient interact with his General Practitioner or with a specialist, often there is a misdiagnosis (e.g. mood disorders) or a vague diagnosis (cognitive decline) that delay a correct diagnosis and care process of several years.

- **Diagnosis.** Usually a specialized geriatrics service (e.g. Unità Valutazione Alzheimer - UVA) is responsible for diagnosing patients with MCI or dementia. At the Palazzolo Institute, patients can be referred to the UVA by their GP, by another specialist or by a geriatrician in the Institute who saw the patient for another issue. At this point, the UVA starts the assessment protocol for MCI and Dementia, a standardized protocol aimed to reach a diagnosis as accurate as possible. After the diagnosis, MCI patients are regularly followed up to monitoring cognitive functions and reversible clinical conditions potentially associated with cognitive impairment are managed with pharmacological and non-pharmacological treatments (e.g. depression), for patients diagnosed with Dementia a pharmacological treatment with AChEI could be started, if possible, and a follow-up is scheduled. At this stage, for both patients suffering
from MCI or Dementia, the specialist of the UVA can interact with PASS and ST services to start a home-care service, a case-management or a psychological counselling to caregivers, if needed.

• **Clinical path.** Once a diagnosis has been made, patients diagnosed with MCI or Dementia are followed-up at regular intervals and, if needed, on demand. The variables that influence the quality and quantity of clinical care in this phase are related to the adjustment of the drug therapy, the presence of unexpected clinical events or the presence of behavioural disturbances related to dementia. The network of services available in the Institute can manage the majority of patient’s clinical issues.

• **Care path.** The care path develops in parallel to the Clinical path. It will have a different composition depending on the presence of cognitive disability only or both cognitive impairment and behavioural disturbances. At present, it is common that family members or caregivers assume the responsibility of organizing the care path of their dear ones, depending on the progressive reduction of their autonomy. If patients are cared for by the UVA of the Institute, the care path can be managed by PASS/ST services, with several home-based and facility-based services. From 2015 two new home-care services devoted to patients with dementia are available: ADI Demenza and RSA Aperta.

• **Domestic care system breakdown.** The breakdown of the domestic care system can be caused by several reasons (e.g. clinical or functional deterioration, evolution of behavioural and psychological symptoms of dementia, falls, malnutrition, dysphagia, etc.). Usually, this is the phase at which caregivers look for the assistance of formalized social and health services. Other reasons of breakdown are related to caregiver issues and stress (e.g. caregiver burnout, temporary unavailability of principal caregiver, caregiver holidays, or sudden unexpected deterioration of patient autonomy after an acute clinical event). In these last cases, the use of facility-based care services can solve the breakdown.

• **Complete disability/end-of-life:** the last stages of life of dementia patients (patient with severe dementia, CDR score 4 and 5) are usually managed in nursing homes or, seldom, in end-of-life care services. It is also possible to manage patients at this stage at home by services like ADI and ADI palliative care.
3.1.2.2 Care network

Figure 5 and Figure 6 show, respectively, the network of services provided by the Palazzolo Institute and a concise picture of the interplay between internal and external networks of services.

The network of services for elderly people in Lombardy is oriented to complex clinical situations. Nursing homes and senior centres (day centres for older adults) are usually devoted to totally dependent older adults with high level of comorbidity and short estimated life expectancy. Often, the same is for home-care services. Therefore, the use of structured services by patients and their families starts when a patient has lost the autonomy in daily life almost totally. FDG is developing best practices to help families and caregivers in the management of patients suffering from MCI or Dementia, spending a lot of time to understand the complexity of services and actors in FDG and in the city of Milan. Case-managers and physicians from FDG services operate in an integrated way, according to the NICE Dementia Pathway model. MCI patients are actively looked for and promptly recognized, in order to receive the same quality of care of people with more advanced disease. Relatives and caregivers receive information and support to project care plans and advanced care plans. During the entire history of the disease, case managers help families to identify and activate the right services, either from FDG or from any other actors of the network. Case management is the focal point of the continuity of care and all services are family-oriented, according to the latest regional guidelines.
This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 643588
3.1.2.3 Integration of ICT

All the community and home care services provided by the Palazzolo Institute (both in the medical and social areas) operate mainly without the support of ICT devices or platforms (if we exclude medical devices such as oximeters, infusion pumps, glucometers, etc.). All the clinical and assistive documents and records are (and must be, due to specific normative rules) paper-based. Activities and services provided are then entered, on a daily basis, in the platforms provided by the LHA (“ADI web” and “DB Flux”) for administrative and economic reporting purposes. Those platforms do not allow service providers to extract data or generate reports. Data entering can only be done manually and not importing procedure from other databases or files is available.

Community services use some rudimental “databases” to keep track of the patient data and the services provided. Those are mainly Excel files, self-managed by the coordinators of the services, that do not include clinical information but only the number and kind of services provided (e.g. medical, infirmary, physiotherapy, etc.). All the medical and socio-assistance information are paper based and this makes it difficult to extract data useful for improving the processes.

Communication between the patients/family members and operators are mainly done by telephone, and only seldom by email. Most of the patients do not have any kind of technologies in their home. Only few have Social Alarm systems, consisting of a pendant with an emergency button that allows users to call a contact centre. The operators of the contact centres, usually people without specific professional competences in the field of care of older adults, can call the user back to verify false alarms, and, if needed, call a caregiver or emergency services. Unfortunately, this kind of phone services are not suitable for patients suffering from dementia, because often these patients have no sufficient communication and procedural skills to effectively interact by phone with an operator.

Very few older adults currently use a computer, a tablet or a smartphone, and in any case people with MCI or dementia only use smartphone for voice calls. The same situation holds for home automation systems, which are very rarely present at patients’ homes.

More sophisticated ICT tools are available to the PASS service and to the residential and outpatient services of the Institute. In particular:

- Web-Hospital, an integrated system for managing the patients admission/discharge, including the following modules:
- AcceWeb: for hospital (acute, sub-acute care units and rehabilitation) and hospice.
- AmbWeb: for specialists outpatient services.
- RSA Web: for the Nursing home, the Alzheimer unit, and the special units for neurodegenerative disease and Chronic Consciousness Disorders.

Web-Hospital is used to manage all the admission/discharge processes: allows to collect patient personal data, as well as basic medical and assistance data, and to enter the services provided to the patient. The web-hospital platform is connected to laboratory and diagnostic facilities and allows to receive tests results "in real time". Web-hospital is not intended to work as an electronic patient record (EPR), it does not include detailed day-by-day medical and assistance data.

- A Business Intelligence (BI) system allows to extract data from the Web-Hospital database, and to integrate them with economic data to generate detailed reports.

Both Web-hospital and BI are not connected to the community and home care services and therefore cannot be used to keep track of the activities provided by those services. As described above, data of those services are collected on self-managed Excel files not completely harmonized across different services. This makes it difficult to extract and analyse data.

Finally, it should be mentioned that all the Italian citizens have a personal electronic card (called "Tessera Sanitaria – Carta Nazionale dei Servizi") that stores personal identification data on a chip and can be used to access the personal Electronic Health Record (EHR) online. The implementation of the EHR in the different Italian regions is still in progress, and only some of the citizens have started to use it. The regional EHR in Lombardy Region is active and it has a good level of use.

### 3.1.3 Conclusions

The integration process of the network management services is under development. In the following strengths and weaknesses of the model are reported.

#### 3.1.3.1 Strengths

1. Italian legislation is focusing on integration of different care services (health care, social care and socio-health care services) provided by different actors.
2. The interaction among the supervisors of different services and their workers has introduced a “care culture” in the management of older adults which is less "cure oriented". Moreover, a main task of the system is to define, as early as possible, a diagnosis and a therapy.

3. The integration among the different services is enhancing the offering of complex services which integrate, if needed, the several programs offered by the Institute.

4. The case managers of the different services can design a long-term patient care path in a simpler way than before, because there is more integration among the different services and this makes more flexible and adaptable the system.

5. The Palazzolo Institute was born to offer hospital and nursing home services, and the system was more cure-oriented than care-oriented. This tendency is inverting today.

6. Today, the activities of the Institute are gradually moving toward the community and the network of external services that overcame, in terms of number, the hospitalizations.

7. An improved geriatric and gerontological culture has been promoted, more related to functional assessment of patients and analysis of variables associated to a better outcome in terms of quality of the patient care path and quality of life for patients.

3.1.3.2 Weaknesses

1. The Italian socio-health care system is caregiver driven, because they have the role of coordinators and integrators of different services, provided by a multiplicity of actors.

2. Family sustains the majority of the burden related to the costs of care and the organization of the support network.

3. The integration between health and social services is still incomplete. While PASS and ST operate in close interaction with each other, UAR in not so integrated yet. This can depend on several factors: the UAR workers have an administrative-oriented view more related to planner management and admission/discharge procedures; no welfare workers are in UAR service; clinical supervision is directly managed by head physicians.

4. Maybe also for the above-mentioned factors, the admission from home-care services to hospital services are greater than the discharge of patients towards
home-care services. The discharge of older patients from hospital services is usually more related to cure factors than care factors and often physicians and healthcare assistants have no complete information about home-care services and rarely discuss with family members about support possibilities planning a structured home-care project during the hospital stay.

5. The physicians in the memory clinic also are more oriented towards the diagnosis and therapy process than the care process. Seldom they suggest solutions about how to manage the patient in their daily life. At the same time, it is rare that physicians discuss issues regarding on how to change the domestic life of the family to adapt it to the new patient needs. Moreover, it is not widespread the assessment of patient frailty and the systematic evaluation of risks that may affect a patient suffering from dementia. For these reasons, the integration of UAR and PASS/ST services have to be improved and this will be a target of further organizational interventions.

3.2 Sweden

3.2.1 Background

3.2.1.1 The Swedish National Health System

In Sweden, as in many other countries in the European Union, the health care needs of all legally registered citizens are covered by the state. The Government and the Parliament have the overall political responsibility for healthcare, while 20 counties/regions and 290 municipalities bear the operational responsibility for citizens’ care. The regions and municipalities have a mandate to tax the population through employee and employer salary-based taxes. Primary- and hospital healthcare are managed at regional level and after-care services at municipal level. The regions and counties are responsible for the overall Primary and Specialized care delivered to all their citizens within their geographical area. On the other hand, the municipalities are responsible for providing citizens with after-care services, including home care and care of older adults in nursing homes. In total, healthcare amounts for around 9.5% of the gross domestic product in Sweden [51].

Sweden's healthcare system is recognized as one of the better systems in the world, attaining good medical outcomes at a reasonable cost [52] [53] [54]. Several studies during the 2000s indicate that Swedish healthcare is also efficient compared to other European countries and to the United States [53] [55]. For instance, in a comprehensive report published by SALAR, the Swedish Association of Local
Authorities and Regions, in 2008, indicators, indices and results from 3 international healthcare comparisons for the period 2005 to 2007 were assessed and compiled against national data. The overall assessment showed that medical outcomes are among the best in Europe at a relatively moderate cost using a reasonable level of resources [56]. These results seem rather stable: in 2011 Sweden had the 8th longest life expectancy and the second lowest infant mortality rate in Europe at 9.5% of GDP [51]. The most recent Euro Health Consumer Index [57] put Sweden at the 6th best position in Europe using a composite index compiled from measures of patient rights and information, accessibility, medical outcomes, prevention, range of services and pharmaceuticals. The same report ranks Sweden, together with Norway, as number one in Europe in terms of medical outcomes.

However, many shortcomings remain, not least in the delivery of integrated care to the elderly with chronic illnesses including patients with dementia. Sweden has one of the oldest populations in Europe with more than 5% of its citizens being 80 years or older whereas birth rates are relatively low [58] [53]. Sweden is also at the forefront of medico-technical developments, making it possible to deliver more treatments to the growing population of patients with multiple and chronic illnesses. Still, numerous reports testify to the lack of integration and coordination of care for elderly patients with chronic multiple illnesses. From the patients’ perspectives, it is difficult to know what care provider to address regarding different care problems. Furthermore, the different care providers do not sufficiently connect and integrate various care activities regarding the same patient. The individual patient thus perceives the care as being fragmented and disorganized). Already in 2002, a survey of all regions in Sweden showed that the development of integrated care for the elderly was highly prioritized by two thirds of the respondents [59]. Still, 70% of the regions did confess that the development or establishment of coordinated care pathways from a patient perspective was very limited [60] [59]. Some years later, two comprehensive reports from ‘The Integrated Care Project’, described lessons learned from experiences of the improvement of integrated care for the elderly in 14 out of 20 regions [55] [61]. According to the reports, it was unclear whether any outcomes from a patient perspective had been reached at all.

3.2.1.2 VästraGötalandsregionen Healthcare System

The Skaraborg County was independent until 1999 when the counties of Skaraborg, Bohus, Älvsborg and Gothenburg were united to form the VästraGötaland Region (the Western Region). The Western Region is one of the largest counties in Sweden, with an area of 24,000 kms². The 1.5 million people who live in the region’s 49
municipalities make up 17% of the Swedish population. The region has an overall responsibility for healthcare and dental care within the area. It operates 17 hospitals, 121 healthcare centres and 170 public dental care centres. The highest decision-making body in the VästraGötaland Region is the Regional Council. The region’s inhabitants directly elect its 149 members every four years and the Council convenes eight times a year. The Regional Executive Board consists of 15 members, who lead and coordinate the Region’s political activities. There are also committees and boards, for example healthcare committees, hospital and primary healthcare boards, a regional development committee, and environmental and cultural affairs committees. Healthcare makes up 90% of the Region’s budget.

3.2.1.3 The Skaraborg Hospital Group

The Skaraborg Hospital Group (SHG) is located in the Eastern part of the Western Region. SHG is a specialist hospital group that serves a population of 260,000 inhabitants in the former county of Skaraborg. The hospital group consists of four hospitals in the towns of Lidköping, Skövde, Mariestad, and Falköping and offers services including acute and planned care in 30 different medical specialities. The hospital group has over 700 beds and employs approximately 4,300 people. Each year the hospitals handle around 41,000 inpatient episodes, 204,000 outpatient visits, 19,300 surgical procedures, and 2300 births.

The hospital of Lidköping, a part of SHG, serves a population of about 85,000 people that inhabits the six surrounding municipalities in West Skaraborg – Lidköping, Vara, Skara, Essunga, Grästorp and Götene. It is an acute carehospital with complete departments and staff on call, more than 160 beds and about 700 employees. The West Skaraborg area was the pilot site for the design and implementation of the networked care model for elderly patients.

3.2.2 Care pathways for patients with CI in SHG

3.2.2.1 Organizational model and processes

The prevalence of dementia in Sweden among people older than 65 years is 7%, which corresponds to more than 15000 inhabitants in Skaraborg with varying degrees of cognitive impairment.

There are three main care-providing stakeholders involved in the long-term care of patients with CI / dementia in Skaraborg: the Hospitals, the Primary Care Centres and the Municipalities. Organizationally, the Hospital and the Primary Care Centres are under the jurisdiction of the Western Region, whereas the municipalities (15 in
Skaraborg) have their own, individual organization (based on the community self-management principle in Sweden). All the three care providers play a more or less pronounced role in all of the five steps of the care pathway portrayed in Figure 7.

The Primary Care Centres are responsible for the initial examination of patients with suspected CI or dementia. The basic examination rests on the ambition to involve multiple perspectives on the patients’ current condition including his or her social situation:

- A structured anamnesis including interviews with nearest and dearest.
- An assessment of the physiological and psychological condition of the patient.
- Cognitive tests including MMT and the Clock test.
- A structured assessment of patient activities of daily life and level of activity.

In addition, tests to include other conditions include:

- A CT scan.
- Relevant Neuropsychological tests.
- Blood tests to exclude hyperkalaemia, high levels of homocystein as well as of thyroid hormones.
• In case of clinical suspicion, the basal investigation also includes liquor tests for Borrelia and Syphilis.

Figure 8 outlines the diagnostic processes at the Primary Care Centres in Skaraborg.

The physician and the specialized nurse at the primary care unit continuously monitor patients with MCI. This monitoring includes at least yearly visits to the physician, including a pre-visit to the ND, according to the Swedish National Guidelines for the care of dementia. Moreover, patients can contact the specialized nurse at request at any time between visits to the physician. Nevertheless, the National Guidelines do not include a clinical pathway for patients with MCI, and interventions are decided on an individual basis.

If patients with MCI or mild dementia deteriorate and develop moderate/severe dementia, the aid assistance coordinator, who belongs organizationally to the community, designs an individual care plan for those patients together with representatives from the hospital and the Primary Care Centre. Based on this care plan, community care resources are made available for the patient, including basic home care.
Basic, long-term care of patients with dementia is provided by cross-professional teams under the management of the Municipality. These teams are led by a specialized nurse – namely the community dementia nurse -, with the support of the general practitioner and the specialized nurse at the Primary Care Centre. Nevertheless, the primary care physician has always the overall medical responsibility for the patient. This process complies with the Swedish national guidelines for patients with dementia described in the introduction to section 2.

There are no physicians employed in the communities in Sweden. The special investigation unit at the Falköping Hospital - namely the Centre for Elderly Patients in need of Psychiatric Care, CEPP - might be also involved in the long-term care of the patient, giving advanced medical advice to the primary care unit and to the community. The CEPP is the main centre for dementia at SHG, serves the entire Skaraborg County and supports the municipalities and the primary care units in various ways. The CEPP has an inpatient clinic that has the capacity to care for 12 patients simultaneously, as well as an outpatient clinic consisting of a senior physician, specialized nurses, psychologists, welfare officers and occupational therapists. The outpatient clinic is responsible for the care of around 450 patients at any time and there is a continuous flow of 15 referrals/week. The clinic carries out 200 investigations each year out of which 100 patients/year are diagnosed with dementia. Currently, CEPP is also the home base for the mobile team that specializes in patients with cognitive impairment. This team consists of a senior physician and a specialized nurse and serves the entire county. In addition, there are three other mobile teams in Skaraborg (that belong organizationally to SHG) that care for instable older patients with multiple diseases. These latter teams will constitute the core of the future networked mobile care model for patients with CI and dementia in Skaraborg.

There are several local care centres for patients with moderate and severe dementia in the municipalities. However, patients with severe or complex symptoms and concurrent diseases are referred to SHG for further examination. The hospitals in Skövde, Falköping and Lidköping have the capacity to take care of patients with complex care needs. In particular, they provide care for multi-diseased patients with dementia.

### 3.2.2.2 Care network

The Skaraborg Care Network (SCN) leads the development and design of coordinated care efforts for patients with CI/dementia and the executive operational committees
in North, South and West Skaraborg. Furthermore, co-workers from the three care-providing organizations (Hospital, Primary Care Centres and Communities) collaborate in real-time to improve care for this patient group. The composition of the networked care model for patients with CI and dementia is outlined in Figure 9.

Figure 9. The networked care model for patients with CI and dementia in Skaraborg

<table>
<thead>
<tr>
<th>Network management team with representatives from the three care providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile team</td>
</tr>
<tr>
<td>Coordinating nurses and teams at the municipalities</td>
</tr>
<tr>
<td>General practitioners at the primary care units</td>
</tr>
<tr>
<td>SkaS Hospitals</td>
</tr>
</tbody>
</table>

In West Skaraborg, a Development Coalition (DC) was formed already in the early 2000s to meet the increasing demands on the healthcare system due to a growing proportion of older patients with complex care needs. A Development Coalition Steering Group (DCSG), consisting of senior managers from the hospital, the six communities and the primary centres was established to lead the West Skaraborg DC, connected to the Lidköping hospital. As of today, the DC has developed into a formal organizational network, The Skaraborg Care Network (SCN), entailing the entire Skaraborg County including all primary care centres and 17 communities and the 4 hospitals at SHG (see Figure 10 for an overview of the network). A common political collaboration group together with representatives from the top management teams of the three care providers jointly lead the SCN.
As far as networked care models for chronic diseases are concerned, the Skaraborg County is divided into three areas – the North, South and West parts of Skaraborg. Each area has its own operative executive committee consisting of local representatives from the three care providing organizations – SHG, the Primary Care centres and the municipalities. These committees are responsible for pursuing and managing agreed upon strategies for the SCN. In each area, development networks with cross-professional improvement groups have been initiated. Thus, front-line co-workers in close collaboration with patients carry out prioritized development initiatives, supported by local managers in the executive committees. In addition, five improvement facilitators support and coordinate the improvement initiatives.

The goal of SCN is to design and sustain an integrated safe care of high quality for all patients with chronic diseases. Furthermore, the care model is genuinely cross organizational, cross professional and based on the individual needs of each patient. The care is to be perceived as integrated and coordinated without boundaries. The design is of a networked, person-centred care model including features such as:

- Good quality of life at home.
- Upstream perspective – before anything happens.
- Patient empowerment.
- Patient self-monitoring.
- Centralized coordination.

Figure 10. A simplified overview of the Skaraborg Care Network (SCN)
• Contact nurses.
• Mobile teams.
• Emergency beds at the hospitals.
• Big data to identify risk patients.
• Close collaboration with the surrounding care system – e.g. ”safe discharges” - to mention a few features.

Early experiences from West Skaraborg have shown that the model is successful, improving quality of life and relieving symptoms while simultaneously and dramatically reducing care consumption among elderly with multiple illnesses (see e.g. Lifvergren et al, 2015; 2012).

Currently, the care model is implemented in the Northern and Southern parts of Skaraborg. In addition, the care model is also expanded to include other groups of patients with chronic diseases, including patients with cognitive impairment and dementia.

3.2.2.3 Integration of ICT

Unfortunately, the various ICT systems in the three care providing organizations are poorly integrated and coordinated. Currently, the three care providers along the patient process cannot share the patients’ electronic medical record. Further, there are few, if any, innovative ICT solutions for patient empowerment or patient monitoring in place. In addition, there are no systems to continuously monitor patient flows. However, the three Regions in Sweden (Stockholm, Gothenburg and Malmö) – providing 50% of healthcare services in Sweden – have jointly initiated the Future ICT System Development Healthcare Project (FICT), the ambition of which is to design and develop coordinated ICT systems drawing from 13 different generic patient scenarios, including patients with various chronic diseases. A member of the main project group at FICT has been associated to the DECI project at SHG.

3.2.3 Conclusions

3.2.3.1 Strengths

The various parts of an integrated care model for patients with CI and dementia are in place in Skaraborg. Organizationally as well as from an improvement perspective, there is also a long tradition of working cross-professionally and across organizations.
to improve care for patients with chronic diseases in Skaraborg. In particular, action-reflection platforms for managers, project managers, co-workers and stakeholders from the three care providers are established throughout the care system [62].

3.2.3.2 Weaknesses

More work is needed to integrate and coordinate the various parts of the CI care model from a patient’s perspective. As reported in the CCW that took place in Sweden, patients refer to not knowing which help is available for them at an early stage of the disease.

Furthermore, management systems for monitoring patient flows including production and capacity planning across all the care providing organizations is also a featured development issue. In addition, agreed upon long term and short term goals have to be developed and followed up in SCN for this particular patient group.

Finally, severely immature ICTs with poor integration between the care providing organizations offer a major challenge in the future developing activities.

3.3 Spain

3.3.1 Background

Spain is one of the world’s countries with a higher life expectancy, especially in women. According to the WHO’s World Health Statistics 2014\(^{14}\), in 2012 female life expectancy in Spain was 85.1, the 2\(^{nd}\) highest in the world. According to data from the Spanish National Institute of Statistics, by the end of 2011 up to 17.3\% of the overall population was over 65 years old. On the other hand, according to data from the World Bank\(^{15}\), the birth rate in Spain in 2012 was of 10 new-borns for each 1,000 inhabitants, one of the lowest in the world. Hence, the population is rapidly growing older and it is estimated that by 2050 the population over 65 years old will account for 36.5\% of the overall population.

The progressive ageing of the population implies a subsequent increase of dementia. In Spain, in 2004 the number of people affected by dementia was 431000; if growth


\(^{15}\) [http://data.worldbank.org/indicator/SP.DYN.CBRT.IN](http://data.worldbank.org/indicator/SP.DYN.CBRT.IN)
forecasts are correct, it is estimated that by 2030 the figure will reach almost 600,000 older adults with dementia, peaking to nearly a million in 2050. However, these figures probably underestimate the extended problem, since a non-negligible percentage of cases go undiagnosed or do not appear in official statistics.

In Spain, the prevalence rate for people over 65 years are estimated to be between 5.2 and 16.3% [63], reaching 22% in men over 85 and 30% in women in the same age group [64].

3.3.1.1 The Spanish National Health System

The Spanish National Health System (SNHS) provides Spanish citizens with universal coverage. The SNHS is a clear example of a Beveridge model: the Government acts as the main responsible for providing citizens with healthcare and the system is funded through taxes. Healthcare provision is free of charge at the point of delivery, with the exception of some pharmaceuticals, which are charged with a percentage co-payment, adjusted on age and dependency. Private Voluntary Insurance (PVI) plays a minor function in the Spanish healthcare system, and it is mostly used for specific specialties such as Dental Surgery, to speed up waiting lists or for complementary care (5.9 % of total healthcare expenditure). The Spanish can freely purchase health care services from private health insurers that contract private health providers (e.g. Quirón, Ruber, etc.) or independent specialists. Approximately 13% of the total population in Spain is covered by private health plans [65].

The National Ministry of Health, Social Services and Equality (MSSSI) is the Government body responsible for the planning and execution of the national health policy, for planning and providing healthcare and for ensuring the right of citizens to health services. The MSSSI is responsible for actuations such as the legislation on pharmaceuticals or the definition of the portfolio of healthcare services that Regional Health Systems are obliged to provide. Spain comprises 17 highly decentralized regions (Autonomous Communities, ACs), which have the faculty in fields such as finances and healthcare. The Spanish National Government provides each AC with general resources\textsuperscript{16} according to their population, area and special conditions such as

\textsuperscript{16} Basque Country and Navarra have special conditions due to historical issues. They self-finance and support their own regional services (health, regional police bodies, etc). Contrarily, they must reimburse an annual invoice for the services provided by the Central Government (National police, Justice, etc).
insularity. ACs can freely allocate those funds among their Ministries. This freedom brings out heterogeneity in health expenditure per capita and access to different baskets of services, as each AC can give more or less importance and support to health issues.

3.3.1.2 SERMAS, Madrid Regional Health System

The Community of Madrid is a region in the centre of Spain. The Community of Madrid is the third most populous (6,495,551 inhabitants) and the most densely populated (809.11 inhabitants/km2) region in Spain.

The Ministry of Health of the Region of Madrid is the regional body liable for the provision of healthcare services in the Region of Madrid. The services are provided through the Health Service of the Region of Madrid (SERMAS, Servicio Madrileño de Salud), which integrates all the public healthcare organisations of the Region of Madrid. The SERMAS is under the authority of the Regional Vice-Ministry of Health. It was created in 2001, along with the Health Institute of Madrid, as part of the devolution of health competences from the National state to the different regions in Spain. Later, in 2005, the Health Service of Madrid was integrated with the Health Institute of Madrid, and its name changed to SERMAS, in order to avoid duplication and foster rationalisation, efficacy, simplification and efficiency in healthcare provision.

Law 6/2009 reorganised the healthcare services in the Region of Madrid, merging the 11 Healthcare Areas in the Region into a Single Healthcare Area. One of the main objectives of the integration of all health areas into a single health area was to ensure the free choice of physician within the whole region. Order 52/2010 defined the basic structures of the Single Healthcare Area including the Basic Healthcare Area, which is the territorial framework where health centres carry out their activities.

The organization chart of the SERMAS comprises 33 Hospitals and 3 non-Hospital medical centres, Primary Care (organized into seven Healthcare Directorates) and the Emergency Service, namely SUMMA 112.

3.3.1.3 The University Hospital of Getafe

The University Hospital of Getafe (HUG) is one of the 33 general hospitals under SERMAS. The HUG started its operations in 1991, and provides service to over 200,000 inhabitants. The HUG covers 13 municipalities including urban centres such as Getafe (over 170,000 inhabitants) and Pinto (over 47,000 inhabitants in 2014). The HUG is a Level 2 hospital with a staff of around 2,300 people. It offers up to 39
specialties, including key specialties such as General Surgery, Cardiology, Paediatrics, Genetics or an Intensive Care Unit (ICU). Despite its youth, the HUG is recognised as a reference hospital in specialties such as the Burn Unit, the Geriatrics Service, the Transplants Unit or the Tissue Bank. Moreover, as a University Hospital, the HUG also has a teaching facility, and is accredited to teach the Degree of Medicine in collaboration with the Universidad Europea de Madrid.

Amongst all the services provided, the HUG has a Geriatrics Service that attends more than 5,000 older patients/year (in 2013 2,874 patients were assessed at outpatient visits, 276 at the Day Hospital, 214 by Liaison Team and 1,714 were hospitalised). It is worth noticing that not all hospitals in the Region of Madrid have a Geriatrics Service: indeed, from all 33 hospitals in Madrid, only 7 have a Geriatrics Services. Moreover, among the latter, only 3 (including the University Hospital of Getafe) have a Community Care Unit.

The Geriatrics Service of the University Hospital of Getafe comprises 10 physicians plus support staff. The 10 geriatricians are divided into different units as follows: (1) the Community Care Unit has 2 professionals; (2) the Outpatient Office and Day Hospital, 1 professional; (3) the Falls and Fractures Unit, 1 professional; (4) the Acute Care Unit, 4 professionals, (5) the Liaison Team, 1 professional and, finally, (6) a Head of the Geriatrics Service. Support staffs include 1 secretary, 1 assistant nurse and 2 dedicated nurses (1 in the Acute Care Unit and 1 in the Geriatrics Service), 1 occupational therapist and 1 social worker, shared with other services in the Hospital.

**3.3.2 Care pathways for patients with CI in HUG**

**3.3.2.1 Organizational model and processes**

Within the region of Madrid, there is not a regional strategy for the care of patients with cognitive impairment or dementia. Consequently, there is not a specific care pathway at the HUG for patients with mild cognitive impairment or dementia. The usual care and resources are the same for all the elderly, regardless their diagnosis or condition. Broadly, there are four main health care areas dealing separately with different aspects of dementia care: acute hospital care, primary and community care, specialized care and long-term institutional care.

Due to their proximity and close contact with patients and their families, General Practitioners (GPs) in Primary Care are responsible for the early diagnosis and long-term monitoring of the health condition of patients with cognitive impairment or dementia. This close contact provides GPs with the opportunity for an early detection
of MCI. In case there are symptoms of non-age-related cognitive impairment, the GP takes the anamnesis and performs a basic screening test a (i.e., Pfeiffer or MMSE). It is worth noticing that the region of Madrid is the only region in Spain that counts on a screening for Alzheimer for people older than 65, assessed using the MiniMental and conducted by a Primary Care nurse. In case the results of the basic screening test are not conclusive enough, the GP can change the patient’s medication in order to check whether some medication is suspected to trigger the symptoms or not, and can provide patients and their relatives with advice to adopt a healthy lifestyle in order to reduce risk factors (e.g. cardiovascular hazard falls...). The GP can also recommend the patient with leisure activities in the community. Then, GPs will repeat the test in the subsequent visit. Nevertheless, dementia – and especially MCI - is still underdiagnosed, due to the lack of specific training and the limited time to perform a complete mental assessment during a regular medical visit.

In case the basic screening test performed by the GP yields positive results, the GP will refer the patient to Specialized Care, depending on their condition and morbidities. If the patient is younger than 65 years old, they are usually referred to the Neurology Service; if the patient is older than 65 years old, they are usually referred to the Geriatrics Service; and finally, if the patient has a history of psychiatric problems, they are referred to the Psychiatric Service. Figure 11 presents an overview of the care pathways for patients with CI at HUG.
Both the Geriatrics and the Neurology Service have specific consultations for dementia. These consultations comprise one hour for a new patient and half an hour for subsequent revisions. In the case of the dementia consultation in the Geriatrics Service, during the visit the geriatrician performs a Geriatric Multidimensional Assessment, comprising the following elements:

- Clinical anamnesis (medical and family history).
- Physical and neurological exam.
- MMSE (MiniMentalFolstein Spanish adaptation) and MoCA (Montreal Cognitive Assessment).
- GDS (Geriatric Deterioration Scale for Dementia) or FAST (Functional Assessment Staging).
- ADL (Activities of Daily Living).
- IADL (Instrumental Activities of Daily Living).
- Blood tests, in order to screen common metabolic disorders, Vitamin B12 deficiency, Vitamin D, hypothyroidism, syphilis, etc.

Further examinations include a Brain CT Scan or a Brain MRI. Furthermore, it is recommended to perform a neuropsychological assessment (with a cognitive and behavioural anamnesis, involving a caregiver of the patient) and a formal neuropsychological. Less commonly, and only for specific etiological differential diagnosis in selected cases, the following tests are prescribed: Brain PET, DaTSCAN, EEG and lumbar puncture.

On the other hand, the Neurology Service in the HUG has a neuropsychologist that comes once a week in order to assess the most extreme cases. The HUG does not count on a specific Psychogeriatric unit; indeed, commonly if an older adult diagnosed with dementia presents a disruptive behaviour, they are admitted in the acute care unit of the Geriatrics Service. On the other hand, there is a Psychogeriatric Unit in a Hospital 70km away from Getafe called Virgen de la Poveda Hospital. It is a service with limited duration, with the objective of treating major behaviour problems that are difficult to control in an ambulatory setting or in other Hospital facilities. Patients are referred to this Unit from the HUG or from other hospitals of the community, mainly in extreme cases. Moreover, the Psychogeriatric Unit of the Virgen de la Poveda Hospital has established a telemedicine service with the HUG, where both services can share imaging results and radiology reports.

In case the patient is diagnosed with MCI or dementia, the specialist starts the treatment. The treatment covers two different approaches: the pharmacological and the non-pharmacological.

In case the patient is diagnosed with MCI, no specific actions are started. Recommendations and guidance are provided depending on the results of the Comprehensive Geriatrics Assessment, aiming to reduce risk factors (unhealthy lifestyle, depression, etc.) and to improve the functional status of the patient. Patients are referred for follow-up in the Memory Clinic in a period of 6 months.

On the other hand, patients diagnosed with Alzheimer will start the pharmacological treatment. Before the patient starts with the medication they have to show the prescription to the GP and to an independent inspector (MD and/or clinical pharmaceutical), who will approve or reject it. From then on, the GP will perform a close follow-up of the status of the patient and the possible adverse effects of the medication, increasing the dose if no adverse effects are detected until the maximum recommended dose is reached. Once the patient is stable, the GP establishes routine
visits (6 months or 1 year, depending on the condition of the patient) with a couple of screening tests to evaluate the performance in the daily basis, progression and the effectiveness of the medication.

Regarding the non-pharmacological treatment, there is not an established protocol or program for the long-term support of patients with MCI or dementia at the HUG. Sometimes, the Specialized Services can refer patients to other specialists in case the patient has specific problems: these specialists include physiotherapists, speech therapists, nutritionists, etc. The Geriatrics Service in the University Hospital of Getafe has a Day Hospital with an occupational therapist, where patients with problems to perform their daily activities are enrolled in a personalized exercise program that aims to promote their independent living. Patients with mild cognitive impairment can be included in the exercise program.

Once the patient has been diagnosed, the specialist (geriatrician, neurologist or psychiatrist) will attend the patient at regular intervals: 3 months at the beginning of the disease and every 6 – 12 months as the disease progresses. Primary care will also schedule regular visits, but the patient can attend on demand at any time.

3.3.2.2 Care network

Due to the cultural idiosyncrasy and strong family values in Spain, patients with CI in Spain are not usually institutionalized until advance stages of the disease, when the complexity and burden of care of the family becomes unbearable. Hence, people with dementia live at home while their families can afford to take care of them and still maintain a relative degree of independence. Indeed, institutionalization is considered as a last resource, and many families consider long-term institutionalization as abandonment [66]. Regarding reasons for institutionalization, it is worth mentioning that according to [67], 50% of informal caregivers often gave a reason related to themselves as reason for institutionalization. According to a study conducted by Rivera et al. in 2009 in the Region of Madrid [68], 62% of the older adults with dementia included in the study lived in a steady home with their families, 15.3% lived in several homes ‘rotating’ among several relatives and roughly 20% lived in long-term care institutions. Besides, it is very possible that the economic crisis that Spain endures since 2008 has reduced the figures of older adults institutionalized in long-term care facilities.

Despite the near-universal coverage provided by the Spanish health care system, there is still insufficient provision of social services to support individuals and their families compared with other more comprehensive social care systems such as those
found in other European countries [69]. In 2006, the Spanish Parliament approved the Law “Promotion of Personal Autonomy and Care for People in Situation of Dependency”, popularly known as the “Dependency Law”. The “Dependency Law” established the System for the Autonomy and Attention to Dependency (SAAD), that establishes the set of services and benefits oriented to the promotion of personal independence, as well as the protection and attention to people in situation of dependence, though public and authorised private services. The Law aimed to universalize social care, offering the following services: telecare, home care, Day Centres or Night Centres and Services for Residential Attention. Other services contemplated in the Law include home visits or delivery of daily cook food. In 2013, the “Dependency Law” received a total public funding of around 7,000 M€ 17. Nevertheless, many potential beneficiaries have complained about the lack of funding and the delays in patient's assessment. As an example, the waiting lists for public home care institutions in Spain is around 2 years, and many patients die before receiving the results of their assessment.

Since the “Dependency Law” came into effect, all benefits have to be channelled through the mechanisms established in the Law. In order to get information about the available social services, the patient or the family can request an appointment with the social worker in the Primary Care Centre. The social worker in the Primary Care Centre has a direct communication with the social worker at HUG, and collaborate in providing patients and their relatives with the adequate recommendations. Available services include public and private nursing homes, day services, patient associations and research foundations, among others.

Traditionally, social services such as home attention services, day attention services or Residential Centres offered the same services portfolio to all older adults, regardless their condition. With an estimated 30 – 40% residents in Residential Centres suffering from Cognitive Impairment or dementia, many of them have become specialized centres, providing patients with healthcare services that sometimes act as a substitution of the medical coverage provided by the Regional Healthcare System, hence tackling the integration between the two environments. As an example of the transformation of the residential centres from accommodation centres to care providers, currently 60 – 70% of the staff of many Residential Centres are health professionals (geriatricians, occupational therapists, etc.).

17http://www.tcu.es/tribunal-de-cuentas/es/search/alfresco/index.html?docTitle=dependencia
dichotomous model that arises from this specialization (social – sanitary) has led to a wide heterogeneity among centres that hinders the development of effective collaboration programs between the social and healthcare environments. All residents in Residential Centres are beneficiaries of the NHS, which means that they are assigned a doctor from the nearest Health Centre, plus a Specialties Centre and a reference hospital for acute episodes, consultations with specialists and the realisation of complementary tests. When residents are assigned a doctor in the corresponding Health Centre, the Residential Centre issues a medical history report that includes information about the treatment. Nevertheless, these reports are not integrated with the HIS in Primary Care, and have to be handed out by patients when visiting the doctor. Moreover, the communication with the reference Hospital is not always adequate, especially in Specialties that the older adult does not use frequently, hence compromising the continuity of care between different healthcare tiers.

Relatives associations pay a pivotal role in helping patients in early phases of the diseases, families and informal caregivers. Relatives associations perform actions such as: (1) to inform, to advice and to provide patients and their relatives with psychological support; (2) cognitive stimulation of the patient; (3) providing the relatives with “breaks”. Currently, there are 15 Associations of Relatives of Patients with Alzheimer in the Region of Madrid, plus the Spanish Alzheimer Foundation, AFAL Contigo and the Madrid Federation of Families of Patients with Alzheimer. These 14 associations are managed by the Regional Ministry of Social Affairs. The Reina Sofia Alzheimer Foundation Centre, managed by the Regional Ministry of Social Affairs, provides relatives, informal caregivers and health professionals with a training plan that comprises monthly courses and workshops on the disease and its care. The Alzheimer National Association, AFALcontigo, was founded in 1989. Currently, it has more than 4,000 members nationwide, has been declared of public interest, and provides the ones affected with information, training, support and representation. In 2014, it was estimated that 1.050 patients with Alzheimer and 4.383 patients were attended in the Patient Associations. Generally, it is considered that it takes too long for families to attend the Family Associations. They attend when they feel too overwhelmed, when they require any specific services, when symptoms start to be disabling of after several visits with the neurologist. Indeed, in the initial phases of the disease most families do not contact their local patient associations. Home help is available through the Municipal Social Services, after the assessment of the dependency level.
3.3.2.3 Integration of ICT

The HUG has developed a proprietary medical information visualisation tool, called Clinical Documentation (CD). CD aggregates data from different Health Information Systems available in the hospital. These HIS include medical imaging in PACS format, lab imaging, bronchoscopy reports, endoscopy reports, etc. CD is an Intranet application that can be accessed only from a local VPN.

The x-GPC (extensible Clinical Requests Manager, Gestor Extensible de Peticiones Clínicas) acts as a transaction manager, allowing the communication between the different Health Information Systems that are involved in the workflow of a clinical request. x-GPC is capable of integration with all Health Information Systems available on the market. Within HUG, this communication is standardised in the Consultation Request (Petición de Interconsulta, PIC). This document enables professionals from different units to share information about those patients who either require parallel care from different units or are being referred from one to the other.

The HUG is working on implementing a new Health Information System, named “HP HCIS”, an integrated Healthcare Information System developed by Hewlett Packard. HP-HCIS will be deployed in 2015 in 7 hospitals in the Region of Madrid, while another 3 hospitals will integrate HP HCIS with their own Health Information Systems. Moreover, the General Directorate of Health Information Systems of the Region of Madrid, which is responsible for the strategic orientations of the Regional Health Ministry, is working on the implementation of a visualisation system named HORUS. HORUS aggregates data from different Health Information Systems: administrative data from the platform that manages all horizontal aspects of health information such as the unique identification of the patient or the administrative data of the patients (named CIBELES); primary care information, stored in the OMI-AP and AP-Madrid services; and secondary care information, including secondary care reports extracted from the HIS of the hospitals (SELENE, HP-HCIS, DC, etc.) that store clinical reports and patient cases, digitalised reports or digital imaging (PACS, RIS) amongst others.

Different Health and Social bodies are working jointly aiming to achieve the integration and interoperability between their Health Information Systems. In 2013, health professionals from social centres from the Regional Service of Social Welfare (RSSW) (nursing homes, occupational centres and centres for the care of people with mental disabilities, 466 health professionals) were provided with access to the Centralized Unified Electronic Health Record (CUEMR) available in AP-Madrid. These professionals can also use the x-GPC system in order to refer patients to Specialized
Care. In 2014, HORUS was integrated with RSSW’s Health Record system (HIRE), allowing for a bidirectional communication. Therefore, professionals from the social services can access the information in HORUS from the HIRE system, and health professionals in the Regional Health Service can visualize a summary of HIRE’s medical data in HORUS. Accredited private nursing homes will be included in the near future.

General Directorate of Health Information Systems of the Region of Madrid is working in developing a web-based Portal for the Socio-Sanitary Coordination that will be available for professionals both from the SERMAS and the social entities, and that will comprise information about regulations, processes, access to information systems, etc. This initiative also involves a Corporate Viewer of Social Information, that will allow professionals to access the patient’s social record regardless its origin.

3.3.3 Conclusions

3.3.3.1 Strengths

The Geriatrics Service in the HUG has implemented a comprehensive, integrated care model that has been continuously updated in order to take into consideration new available technologies. The Geriatrics Service has implemented a set of good practices than include the Falls and Fracture Unit and the integrated care program for in- and out-patients, and has been selected as a Reference Site within the European Innovation Partnership on Active and Healthy Ageing, that has awarded it with 3 stars, the highest qualification awarded. The Community Care Unit (CCU) is the body within the Geriatric Service responsible for implementing the integrated care program for in- and out-patients. The CCU provides older adults with comprehensive and continuous care, based on careful coordination between the different stakeholders involved in their care (geriatrics facilities, other specialties, Primary Care and other resources). The CCU, comprised by two geriatricians, visit patients at home on a regular basis. The professionals carry a ‘medical toolkit’ comprising a laptop, a small printer, a 3G USB drive that allows them to remotely connect to the Hospital’s Virtual Private Network and some measuring devices, such as a blood pressure cuff or an oxygen saturation meter. Integration with other stakeholders, such as nursing homes and social services, is carried out in an informal way (via telephone or email). Therefore, the practices and care model adopted by the Geriatrics Service are a good basis for building an integrated care model for patients with CI or dementia.
Moreover, the HUG has consultations on dementia twice a week, both in the Geriatrics and the Neurology services. During these consultations, patients get a comprehensive evaluation, access to imaging services and counselling for them and their families.

The Region on Madrid has developed a strategy for implementing tools aimed to improve the coordination between healthcare and social services. Some health professionals in nursing homes have been granted with permissions to read and write information in the Electronic Health Record of the patient. Although this solution has been implemented in a small number of public funded nursing homes – providing service to roughly 8,000 patients in the whole community -, the willingness of the local authorities to work on tools for improving the coordination among social and healthcare services open a good framework for future steps in achieving coordinated care for patients with CI and dementia.

Patients and relatives associations and Foundations play a pivotal role in reducing the burden of patients and informal caregivers, and are acting as a lobby for recommending Regional Governments to adopt a Regional-level strategy for the care of patients with Alzheimer and other dementias. Moreover, the foundations collaborate in different research projects and are more willing and flexible to look for real solutions for improving the lives of their members.

3.3.3.2 Weakness

The main problem identified in the literature is the lack of coordination between the different stakeholders that participate in the care of patients with CI or dementia and their relatives. These stakeholders include Primary Care, Specialized care and social services. As an example, there are no well-established care plans linking primary care teams with acute hospitals.

There is not a national plan or strategy for managing patients with CI or dementia. This strategy should take into account socio-sanitary policies, should ensure the continuity of care between the different healthcare tiers and should promote the development of psychosocial studies.

As mentioned before, Primary Care professionals will be the responsible for the long-term management of patients with CI, with GPs acting as case managers. Nevertheless, the consultation time is usually very short (5 – 10 minutes), and in many cases GPs are not trained to deal with all aspects – both social and sanitary – of CI. Therefore, it is needed to provide Primary Care professionals with tools and training aimed to improve their capacity for early diagnosis, management and long-term monitoring. Moreover, the symptoms and consequences of cognitive
improvement and other dementias change dramatically over time, which is really difficult for informal caregivers. Health care providers should promote a culture of actively supporting self-management as a normal, expected, monitored and rewarded aspect of care.

Regarding the access to social services, many times after the diagnosis the patients and their families do not have clear where to attend. Social workers act as the liaison between the clinical and social sectors, but in many occasions the patients do not visit them until it is too late to mitigate the symptoms.

Patient associations and foundations play a pivotal role in helping patients and their families coping with the disease. Despite their fundamental role, they do not take part of the official care pathway and they are not involved in the definition of policies. Any solution or decision on a National or Regional strategy should count on patient associations, as they can offer a unique perspective on the day-to-day problems faced by patients and their caregivers.

3.4 Israel

3.4.1 Background

In 2009 the number of residents aged 65 and over in Israel was 742,000, representing 10% of the population. The rate of increase of the elderly population is twice that of the general population, thus the predicted number of elderly for 2020 is around 1,025,000, representing a 60% increase. While this process is determined by a decline in both fertility and mortality, in Israel immigration has also been a central factor in the process of aging. For 13 years (since 1994), the elderly population has constituted 10% of the general population and is expected to reach 14% by 2030. Concomitantly with the aging of the general population, the elderly population itself is aging. While in 1980, 14% of the 65+ group were aged 80+, the percentage had risen to 28% in 2009, namely 207,760 elderly aged 80+. Together with Japan, Australia, and Sweden, Israel has the highest life expectancy for males at birth in the world (79 years). Life expectancy for females at birth in Israel is 4 years less than that of Japan, which has the highest rate in the world – 82 and 86 years respectively (2006). At age 65, life expectancy is 20 years for women and 18 years for men; at age 80, it is about 9 years for women and men. The major factor influencing the increase in life expectancy during the past two decades has been the prevention of death among older people. Population ageing, or “the demographic transition,” also represents an “epidemiological transition” from high rates of infectious and communicable diseases to high rates of chronic diseases among older people.
3.4.1.1 The Israeli National Health System

Israel is a small country (i.e. 22,145 km² territory) founded in 1948 and located in the Middle East, at the junction of three continents (Africa, Asia, and Europe). Lying on the Mediterranean Sea shore, it is surrounded by Syria, Lebanon, Egypt, Jordan and the Palestinian Authority (Gaza and the West Bank). Israel has the highest GDP per capita of its region and can be considered the main economic engine in the Middle East. The population at the end of 2012 was 8 million, with a remarkably young society (28% under 15, 10% over 65)\textsuperscript{18}. Israel’s population is growing remarkably (200% since 1990). This phenomenon can be explained by the high total fertility rate (highest in OECD, 2.88 per woman) and the increasing migration, mainly from Former Soviet Union countries during the 90s and in more recent years from North America and Europe.

Israel has a tax-funded national health insurance (NHI) system that provides its population with universal coverage of healthcare. There is free choice among four competing, non-profit-making health funds (Health Maintenance Organisations (HMOs), which receive NHI funds from the Government according to a capitation formula. The four HMOs are Clalit, Maccabi Healthcare Services, Kupat Holim Meuhedet and Leumit.

The HMOs are health insurance funds recognized by the Israeli National Health Insurance Law, and are obligated to a uniform basic basket of health services. They are allowed to offer supplemental health and care services beyond the basket, for an additional premium. Approximately 75% of the population purchases complementary health insurance from one of the four health insurance funds that covers services outside the basic package, such as dental care, ancillary services, and provides choice of private provider and a third of the Israeli population buys commercial health insurance that offers additional benefits such as lump sum payments for certain diseases additional benefits for treatment abroad and cover for lifesaving medication not included in the public basket of services. A further two-thirds of the population also purchases commercial insurance for long-term care the vast majority through group policies purchased by their HMO.

The system is financed primarily from public sources via payroll and general tax revenues. Healthcare accounts for 7.9% of gross domestic product (GDP) in 2009 – the eighth lowest among OECD. Hospitals and public clinics each account for

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approximately 40% of national health expenditure, and dental care accounts for 10%. In recent years, the share of public financing has declined to 64% of total health system financing, while the share of private financing, especially voluntary health insurance and co-payments, has increased to 36%. Healthcare providers are paid by a variety of payment methods including salary, capitation and fee for service.

Israel has a centralised governance model, which also applies to healthcare. However, there are Public Health Divisions that operate through regional and local offices. Their aim is to ensure the implementation of those policies and strategies developed at national level. Every HMO is also governed in a similar way. Although national headquarters are responsible for the management and planning, the operation of services is decentralised, to the Regional level and below that to the branch level, which eases access to care in the community.

The National Insurance Law aimed to reduce the role of government in service provision in three key areas of activity: personal preventive care, long-term care and mental health care. These competences should have been transferred to HMOs shortly after the passage of the Law, but has been seriously delayed. Mental health care is in the process of being transferred to the HMOs beginning in 2015. Since the 1990s policy makers have tried to transform state hospitals into independent, as non-profit trusts. This has failed because of the opposition of health care unions. As a result, these hospitals have gradually become more autonomous.

### 3.4.1.2 Maccabi Healthcare Services

Maccabi Healthcare Services is the second largest Health Maintenance Organization (HMO) in Israel. It was founded as an independent, mutual, non-profit health insurance fund in 1941. Following the enactment of the Israeli National Health Insurance Law in 1995, Maccabi Healthcare Services was recognized as one of the four health funds charged with providing healthcare services under the Law. Maccabi now provides services more than 2 million people, i.e. 25% of Israel’s total population.

Maccabi is organized into five districts, encompassing 150 branches, which provide both administrative and healthcare services throughout the country. Most of the services are provided by contracted independent providers, the bulk of which are 4,000 independent physicians including primary care physicians and specialists. There are another 300 senior consultants (who are hospital department heads), 250

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19 [http://www.maccabi4u.co.il/1781-he/Maccabi.aspx](http://www.maccabi4u.co.il/1781-he/Maccabi.aspx)
diagnostic institutes, 700 private pharmacies and public as well as private hospitals. In addition, Maccabi employs over 600 salaried physicians and owns a centralized laboratory system, a teleradiology system, telemedicine services (both diagnostic and home monitoring or telecare), specialty clinics, and a chain of 53 pharmacies and a private network of hospitals, named Assuta Medical Centres.

Maccabi Healthcare Services have created a Training and Human Resources Development Department, which aims to enhance employee professional standards and keep up to date with new and advanced medical procedures. In 1983, Maccabi recognized that the healthcare system of the future would require sophisticated information and communication technologies for efficient management, as well as effective and innovative health care services delivery. Maccabi Healthcare Services considers the ‘Maccabi Coordinated Care’ system a ‘way of living’, more than a mere ICT project. The ‘Maccabi Coordinated Care’ system aimed to use Information and Communication Technologies (ICT) to create a comprehensive, progressive and fully computerized system. The idea was to develop a networked infrastructure at all levels (administrative, diagnostic, therapeutic, and preventive) to connect physicians, nurses, therapists, primary caregivers and patients. Therefore, all the people involved in the system are provided with the information and tools to ensure a faster, more accurate, safer and easier model of care provision. Since 1996, all doctors associated with Maccabi Healthcare Services are using a unique Electronic Medical Record (EMR) database and since 2002, Maccabi has implemented a Central medical record on which all care providers are updated online. Today, Maccabi is fully computerized and services are continuously added to the system including mobile phone applications, telemedicine and tools for doctors, healthcare professionals and patients. Figure 12 displays the telemedicine services available in Maccabi:
In July 2012, Maccabi Healthcare Services established a multidisciplinary centre for the treatment of patients with chronic conditions and co-morbidities, in coordination with the patient’s primary physician and other community-based care providers. The program treats 10,000 patients with chronic conditions; CHF, COPD, diabetes, stoma, cancer, home care and psychiatric patients. Maccabi Healthcare Services developed a new platform/tool for Integrated Care Management that system that connects care providers to deliver care to patients with complex needs. The solution enables the physician to maintain "ownership" of the patient throughout the patient’s journey, starting from a patient identification according to clinical criteria and inclusion in the care program, through treatment plan definition, consultation by multidisciplinary teams and nurses follow-up. The Centre is managed by members of a multi-disciplinary staff that includes nurses, specialized physicians (Geriatrician/Psychogeriatrician), social workers, nutritionists, and clinical pharmacists, who use diverse technologies, including telephone calls and video calls, to monitor patients. Simple, easy-to-use, high-quality video communications help solve many client concerns involving accessibility and availability. The nurses operate as a supporting envelope to the GP, and maintain constant touch with the patients according to the treatment plan, protocols and alerts received from the system. The integrated care model offers better accessibility to medical advice for a broad range of population and empowers the patient in decision making for improved health outcomes. It is a framework in which medical treatment and health services are coordinated. This approach has been developed and used by Maccabi internally for the last few years with considerable

| Tele-Diagnosis                  | • Teleradiology   
|                                   | • Tele- ECG/Holter 
|                                   | • Tele-mammography: mobile truck 
|                                   | • Tele-Ophthalmology 
|                                   | • Tele-dermatology - Skin ulcers 
| Tele Treatment/ Consultation      | • Video Conference - care giver - patient 
|                                   | • Video Conference- home care 
|                                   | • Video Conference- Service Station 
| Center                           | • Multidisciplinary Telecenter for Chronically Ill Patients 
|                                   | • Maccabi Pharm 
|                                   | • Nurses Call Center - Triage 
|                                   | • Smoking Cessation 
|                                   | • Interpreter Services 
| Information Access               | • Web Site 
|                                   | • PHR 
|                                   | • Cellular
success. The application includes built-in alerts, clinical protocols and treatment plans and interfaces with remote monitoring devices and can integrate with EMR and other organizational systems or function as a standalone solution. It is based on open architecture and enables the care provider to effectively manage the delivery of integrated care to patients. The Information and communication-sharing platform aggregates relevant treatment information for each patient and provides that information to all caregivers who provide services to that patient at the point of care, regardless of communication channel used. The system can interface with a wide variety of devices. The system can be integrated to rehabilitation solutions and system for CI evaluation at home that will enable the assessment, early detection and evaluation of functional condition in older adults.

3.4.2 Care pathways for patients with CI in Maccabi

3.4.2.1 Organizational model and processes

Maccabi uses several pathways for identifying and diagnosing patients with CI:

- By visiting a specialist: obtaining a diagnosis of dementia and consulting with a specialist, including a comprehensive geriatric evaluation.

- Gathering valuable data from various relevant data sources (e.g., EHR, the patient’s close surroundings). Maccabi queries the EHR looking for risk conditions, according to 7 criteria:
  - Age above 75 years old.
  - Co-morbidity - 2 or more chronic diseases.
  - More than 2 hospitalizations/emergency room visits in the last year.
  - More than 2 physician home visits (emergency).
  - Malnutrition.
  - Polipharmacy- above 8 medications.
  - Permanent use of one of the following drugs: insulin, NSAID, diuretics, digoxin, anti-platelet, coumadin, sulphonilureas or heparin antithrombotic agent.

Using these data, the system is able to identify patients at risk of frailty or cognitive impairment, given that they meet at least 4 out of the 7 criteria. Patients who meet the criteria are proactively invited for assessment in the clinic by a geriatrician or occupational therapist.
• Monitoring of early signs of cognitive decline will consist of a "gentle/by the way" 75th-birthday screening. Maccabi recently launched this initiative as a proactive program for screening the large older population, following the literature recommendation for wide range screening of clinical and age-related condition. Maccabi employs 30 geriatricians and 1400 GPs. Furthermore, most elderly people go to the GP and not to the geriatrician unless they have a specific problem. Therefore, as a strategic decision, Maccabi decided to use the large community of GPs for screening older population. During these screening visits, older adults undergo a short assessment consisting of a physical examination and a battery of questionnaires. The screening comprises the following tests:
  o GDS-Test for assessing depression.
  o DSM- definition of depression.
  o DSM- definition of dementia.
  o MMSE cognitive test.
  o SWEET 16 cognitive test.
  o BARTHEL estimate functional evaluation.
  o Up and go.
  o Definitions functional status of elderly geriatric clinic referral labels.

The diagnosis is of great importance and requires the GP to be trained in the assessment of frailty and other complications, such as cognitive impairment. One main barrier for a comprehensive assessment is that the GP usually has 5-10 minutes per visit and the screening takes 45 minutes. Maccabi decided to pay a special fee for this screening. Another advantage of this approach is that it raises awareness that will be used in their daily practice even with patients that are not directly in the target group (older than 75 years old). Moreover, it is possible that younger populations will be screened for cognitive, frailty and depression prevention.

If the screening turns positive for cognitive impairment or dementia, the general practitioner may refer patients to a specialist in one of the following fields: geriatrics, neurology and psychiatry. Patients are referred to the specialist given the following criteria:

• Uncertainty in the diagnosis, even after initial assessment or continued monitoring.
• The onset of dementia at a relatively young age, or dementia at a young age in a family member.

• Problems with treatment or failure of drug treatment specific for Alzheimer’s disease.

• Depression or behavioural disturbances, especially in cases of a lack of response to treatment.

• The need for additional assistance in treating the patient (e.g. behavioural problems) or support for a family member caring for the dementia patient.

Geriatricians lead the teamwork in the treatment of cognitive conditions. General practitioners collaborate with nurses, social workers and nutritionists to manage elderly patients with comorbidities and disabilities. Frail patients, including patients with mental weakening, are referred to the comprehensive geriatric assessment (CGA) units. CGA units are responsible for conducting a multidisciplinary assessment of the patient. A multidisciplinary team, led by a geriatrician and comprising other professionals such as nurses and social workers, carry out this comprehensive geriatric assessment. Other professionals can also be included in the multidisciplinary team, such as an occupational therapist, dietician, physiotherapists, psychiatrists and others.

In many cases, if patients are diagnosed with cognitive impairment and dementia, and the disease cannot be cured, drug treatment is recommenced to slow down the symptoms of dementia and to control behavioural problems. The symptoms can also be attenuated by activities such as sensory stimulation (e.g., listening to music), cognitive stimulation (handiwork, writing, memory games) and physical exercise.

Homebound older adults, as well as other patients, are treated by multidisciplinary homecare teams. Although efforts are made to train dedicated professionals with different expertise that will address the needs of the growing population, future shortage is expected. New approaches are being implemented, such as telemedicine solutions and techniques to achieve the empowerment of patients and caregivers. Maccabi has recently launched a new program that aims to improve screening, early detection and intervention. This program involves the GP as first screening for the elderly.

The following paragraphs present the treatment approaches adopted in different stages of the disease.

**Treatment of Mild Cognitive Impairment (MCI)**
Mild cognitive impairment (MCI) is an intermediate condition with complaints of cognitive difficulties, but no signs of clinical dementia. Only 10%-15% of persons with this condition deteriorate within one year to clinical dementia. Early diagnosis might permit a rapid and effective intervention, considering that there is evidence that “using brain helps in preserving it instead that losing it”. Longitudinally, an early treatment might have some benefit on the progression of dementia in patients’ immediate future. In Maccabi, the treatment provided is only preventative, and includes control of risk factors for cardiovascular diseases (e.g., hypertension, high blood lipid levels), physical exercise and cognitive exercise.

MCI is a multi-domain syndrome that involves different cognitive and emotional components, although still permits a certain level of autonomy. These neuropsychological characteristics imposes a training aimed to take care of these multifaceted alterations.

The aim of cognitive training is to improve core abilities required to manage everyday life activities. Functions such as memory and attention are diffusely employed in basic tasks requiring monitoring and control such as compliance with drug treatments, cooking, reading, and watching television with competence. These functions start to be impaired in MCI patients in different ways and are frequently fragile areas even in graceful ageing. Accordingly, the training focuses on these general abilities. The final aim is to preserve and prolong daily life competences by enhancing the cognitive reserve in individuals in order to improve the more dynamic and adaptive strategies in daily life. When successful, the training will induce a double measurable effect: on the cognitive functions and on the QoL assessed both on the patient and on the caregiver. The maintenance of QoL is the principal outcome of this project and that is the reason why it privileges a global rehabilitative approach involving physical, mental, behavioural and cognitive components.

The intervention program focuses on equipping the elderly with physical and cognitive training (with an emphasis on executive functions and strategies for memory storing and extracting). The cognitive training module will address the major obstacles relating to age-related cognitive impairment:

a. Executive functions.

b. Motor planning.

c. Decision making.

d. Multimodular memory.
Transversal cognitive functions such as attention, self-monitoring and multisensory integration.

This is done by **private individual training or group training**. Cognitive training aims to improve the patient’s cognitive functions, mainly executive and strategic, and reaction times through games and tasks directly derived from the most ecological activities. A good example could be a task like prioritizing items in his grocery list based on his/her home inventory or scheduling his/her regular medications along the week in a shape of a colourful puzzle or crossword. Individual training teaches older adults to cope with distractors, whether visual or vocal, occurring while the subject is performing single or parallel tasks, that although simulated on the mobile tab, will be strongly connected to their real lives (e.g., arranging a family tree of faces while the faces change position on the screen or while they are coloured/uncoloured interchangeably). Moreover, older adults are proactively **exercised to extend their attention** spans by performing tasks that demand an increasing time of sustained attention.

This cognitive training is backed up by **support workshops** that will further equip older adults with evidence-based strategies for fostering executive functions, enhancing memory and conceptualizing by means of changing the order of execution of a set of tasks, self-operating of several sensory channels while performing tasks, dividing tasks to mini-tasks to fit the attention span, avoiding automatic activities as much as possible and so on. These **workshops also serve as a means for reducing social isolation of older population**, increasing their social interaction and involvement in society by encouraging them to participate in various activities (cognitive and physical tournaments, social activities like lecturers given by healthcare professional regarding health ageing, charity events etc.), thus contributing directly to his mental wellbeing.

**Treatment of Early to Moderate Stages of Clinical Dementia**

Treatment of a person diagnosed with dementia depends on the type of dementia and the stage of the disease. To this end, it is possible to consult with a physician specializing in geriatrics, neurology or psychiatry - in cooperation with the patient’s primary care physician. It is important to understand that dementia cannot be cured, and the deterioration cannot be stopped in the long term.

It is recommended to treat patients that have mild to moderate Alzheimer’s disease with **medications** from the “acetylcholinesterase inhibitor” group, which may stabilize or slow down the patient’s deterioration with regard to cognitive
functioning, day-to-day functioning and/or behavioural functioning for a limited amount of time; an effect has also been found on the patient's and caregiver’s quality of life and on delaying the need for long term hospitalization. A number of medications of this type have similar actions. Treatment with these medications is prescribed for a limited time, usually up to two years, under appropriate professional monitoring. The treatment can be changed in cases of side effects or clinical deterioration despite the treatment. As the patient’s cognitive and functional condition declines, a stage will be reached when the patient’s physician assesses that no further benefit may be gained by continuing the drug treatment, and the medication will be stopped accordingly. For further information, patients are recommended to consult the treating physician. Medical treatment for dementia, including medication for Alzheimer's disease, is included in the basic health basket provided by the under the provisions of the National Health Insurance Law.

**Treatment for the Psychological Manifestations of Dementia**

A significant percentage of dementia patients may suffer psychological problems during the course of their disease, manifesting as behavioural disturbances such as delusions, agitation, aggressiveness, severe disturbances in the sleep-wake cycle, impaired judgment, depression, anxiety and more. These disturbances cause great anguish for the patient, impose suffering and a burden on the caregiver, and constitute one of the main factors leading to hospitalization of the patient in a long-term care facility.

Treatment for the psychological manifestations of dementia is usually carried out outside Maccabi. In cases the patient remains at home, Maccabi offers a home care program to support the care at home and support the family.

- Treatment of these disturbances must be undertaken by a physician who is knowledgeable, skilled and experienced in the treatment of dementia patients, in cooperation with the primary care physician, taking into account medical and environmental factors and the quality of life of the patient and caregivers.

- It is important to rule out coexisting illness (such as infection or side effects of drug treatment), which could cause conditions of acute confusion and behavioural disturbance. Timely identification and treatment of a coexisting illness can improve these behavioural effects.

- Behavioural disturbances do not necessarily require drug treatment, which would involve side effects for the patient.

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 643588
When behavioural disturbances involve suffering for the patient, or endanger the patient or those around him, then treating them with drugs is considered.

Drug treatment of behavioural disturbances is monitored by the physician, with periodic reassessment as to whether changes should be made or the drug treatment is no longer needed and may be discontinued.

- Sleep disturbances are one of the most common disturbances in dementia, and are also professionally assessed.
  - Treatment of sleep disturbances must be multidisciplinary and should initially include non-drug intervention, such as exposure to light, physical exercise and activities directed at sleep hygiene.
  - If necessary, drug treatment is available.

**Behavioural interventions for patients with dementia**

- **Cognitive Interventions** - Interventions such as practicing cognitive skills and strengthening the sense of reality may have a positive, though mild and transient, effect during the early stages of dementia. It is important that activities of this type be performed in a manner that is dignified and pleasant for the patient.

- **Environmental Intervention** - Dementia patients suffer from an inability to adapt to new environments or changes in their surroundings. It is therefore important to adapt the environment to the patients’ abilities and limitations, and to create a secure and safe environment for them. For example, for persons with dementia who “wander” - walk around with no clear aim and a tendency to get lost - walking activity should be adapted in a way that does not endanger them.

- **Interventions that provide pleasure** - It is important to identify which interventions are enjoyable and pleasant for dementia patients, in accordance with their character, past habits and the progressive state of their disease; e.g., music therapy or touch therapy.

**3.4.2.2 Care network**

The majority of elderly people in Israel live or are cared for at home; only 4.1% reside in long-term care institutions. Even among the disabled elderly, 78% live at home. It is clear that such a situation would be impossible without a great degree of family
involvement. 46% of older adults who reside in the community (96% of the elderly in Israel) live in households consisting of couples without children. 25% of older adults live alone, 10% live in a household comprising a couple with children, 5% live in a household comprising a single parent and his or her children, and 14% live in other types of arrangement. Older adults who do not live in the community (approx. 4% of the elderly population) reside in long-term care institutions (homes for the aged, hospitals for the chronically ill, or various forms of nursing care).

In Israel, community care is provided by HMO’s. Maccabi healthcare services is a community-based healthcare provider that provides most of the care in the community. Therefore, most of the community services are provided by Maccabi, working according to organizational guidelines and according to the national law. Nevertheless, although Maccabi offers and maintains its own social care services, it also contracts some services with outside providers. Although outside companies are responsible for providing these services, they are coordinated and assisted by Maccabi’s team. For instance, social workers in Maccabi assist the family to have the knowledge about their rights and communicate with the outside service providers. In cases of hospitalization, it is in the responsibility of the hospital however if the patient is released from hospital Maccabi takes responsibility for the care.

All professionals involved in the social and health care of older adults with MCI can access information about the patients in a fully computerized system that comprises a coordinated EHR. The access grants and information available depend on the profile and privileges of the professional. All community and health care providers, including GPs, geriatricians, nurses, homecare units, social workers and occupational therapists are working on the same system and therefore the communication and level of collaboration is high.

The communication between Maccabi’s social service and the state’s social care professionals that are not connected to Maccabi’s platform is made through face-to-face meeting, mails etc. There are several national programs at the stages of planning and pilots that aim to integrate and combine resources in order to address the complex medical and social needs of the relevant population.

In addition to the universal services for which all citizens are eligible (e.g., community health services and hospitalization), there is a unique system of special services for older adults. This system is divided into community services, which are provided in the home of the older adult or at various day-care facilities, and institutional long-term care services, which are provided in residential facilities where older adults go to live. Since the 1980s, there has been a significant development of services provided
within the community, and new services designed to preserve the quality of life of older adults have been added to longstanding services.

During the past decade, a number of formal services – some of them quite innovative - were established to help families cope with the burden of care. Nevertheless, these solutions are far from comprehensive and raise questions about the direction that service development should take.

3.4.2.3 Integration of ICT

Israel has been a pioneer in the implementation of Health Information Systems. In 1983, the leaders of Maccabi decided to move towards a fully computerised organization and started working on the computerization of their main organisational processes. In 1989 Maccabi completed the computerization of claims management and of the prescriptions and pharmacies. In 1996, a Electronic Health Record (EHR) system was already working.

Currently, Maccabi boast a comprehensive health ICT system that comprises a full Electronic Health Record / Electronic Medical Record (EHR / EMR), a Central Medical Record, Decision Support Systems, E-Laboratory, E-Prescription, E-Consultation, Telemedicine, Tele-Radiology, Alerts and Reminders and a patient’s website. Figure 13 presents an overview of all the services available for physicians in Maccabi’s Health Information System.
The Maccabi IT system allows all providers and health services to be electronically interconnected and to share clinical data in real time. The major strength of the Maccabi IT system is the level of connectivity between all the different technology systems. The system has been designed to be modular and flexible, building on industry standards in order to ensure the interoperability between the different modules of the system. The system architecture has been designed as a Service Oriented Architecture (SOA) infrastructure, a web and cloud-based infrastructure that facilitates the bidirectional communication with any data sources and users. The core technological component is the enterprise service bus that aggregates all data acquired by different sources, regardless of their format. The Enterprise Bus Server takes the data from different sources (labs, Imaging, the EMR, claims, etc.) and delivers them to the patients and physician portals in a format they can understand, hence enhancing the user experience for all stakeholders. Figure 14 shows an overview of the system architecture, with the Enterprise Service Bus as the core element that communicates raw data with the visualization applications.
This modular approach ensures the scalability and interoperability with other proprietary of third-party systems. Moreover, the Maccabi IT system has achieved a high level of data security between its central system and the outside world at its gateways through a number of firewalls, including an intrusion prevention system, an application firewall, anti-virus and anti-spam.

The Maccabi IT system comprises technology solutions not only for doctors, but also for patients. Patients can access a web portal where they can access their medical information from the EMR as well as perform administrative procedures. In the patient portal, users can access their schedule of medical visits, their laboratory tests and the results of radiology tests; get educational content on prevention of risks and personalised recommendations for health promotion, etc. From an administrative standpoint, patients can use the portal for scheduling appointment, requesting prescriptions and referrals from their doctor, ordering drugs from the pharmacy, etc.

Additional tools are continuously added to the system to support care of all care providers, provide standardised guidelines online, mobile applications, educational tools and analytical tools to support care.

Since all data is registered and analysed we have large sets of longitudinal data on patients and their families that helps supporting risk factors identification, personalized timely intervention and follow-up.
3.4.3 Conclusions

3.4.3.1 Strengths

The strength of Maccabi’s system is in the ICT infrastructure that enables all care providers to have the relevant information about the patient. There are multidisciplinary teams treating the patients addressing his needs and technological support for the treatment using patient portal and telemedicine tools.

There are many treatment programs in Maccabi operated by nurses, occupational therapists, and doctors that address different aspects of the patient needs as well as programs to support the family. Maccabi’s ability to develop and implement programs in the organization became a strength in addressing needs of large-scale populations in an efficient way with high quality of clinical care.

The availability of information enables data analysis and screening for better understanding and monitoring of the patients. For example, the use of EHR data for identification of risk factors serves as a tool for screening and early detection and intervention. Data from EHR serve also for follow-up and research of intervention outcomes.

3.4.3.2 Weaknesses

The weakness of the system is the ability to have continuity of care from different stakeholders since Maccabi is limited in data sharing and integrated care outside the organization.

In addition, programs such as individual training and group therapies are limited because of shortage of carers that are limited in the number of patients they can treat. Another weakness is the number of geriatrics that can do geriatric assessment.

There are many tools and programs however still there is a need for comprehensive understanding of patients’ condition and follow-up. There are several programs under development, aimed to address these weaknesses and follow-up and closure is defined as one of the organization strategies.
4 Cross-analysis of care models

4.1 Aspects among organisations

There are many different professionals and organizations involved in the care of patients with cognitive impairment and dementia. From the healthcare side, both primary care and specialized care need to collaborate in the diagnosis and long-term care of these patients. Social care provision is much more distributed, and usually involve organizations such as private service providers – i.e. nursing homes, etc. -, Non-Profit Research Foundations and Research Centres and/or Municipalities, among others. The lack of coordination between healthcare and social care organizations is one of the main problems identified both in the literature and during the co-creation workshops that took place in the four pilot sites.

Some Health Management Organizations, such as FDG or Maccabi, offer some social services in-house. Nevertheless, these HMOs have a limited number of vacancies or do not cover the patient’s needs during the whole evolution of the disease, which makes it necessary to involve some third-party social care providers. FDG’s Palazzolo Institute counts on one unit (Punto di Accesso Socio-Sanitario, PASS) dedicated to coordinate health services and in-house social services, and another unit (Servizi Territoriali, ST) dedicated to manage all processes related to social services outside the Institute. Both units ensure a level of coordination in terms of the follow-up of the social care pathway of patients attended in the Palazzolo Institute. Nevertheless, there is still a lack of coordination in terms of information sharing. For instance, while PASS and ST operate closely, the UAR is not integrated with both services. Moreover, many social care providers do not count on an ICT system to record information about the status of the patient, and use spreadsheets or other “rudimentary” methods to keep track of the status of their clients. In Israel, Maccabi also provides patients with social care services, such as community care. Nevertheless, some social care services are contracted with other social care providers. Although these social services are provided by third-party organizations, the overall care of the patient is coordinated by Maccabi’s team. The social care providers do not have access to Maccabi’s centralized EHR, and communication is carried out informally, via face-to-face meetings, mails and/or telephone calls.

In Sweden, the Skaraborg Hospital Group (SHG) has set up a networked care model that aims to provide patients with CI and dementia with integrated care. Basic care is provided by a multidisciplinary team lead by a specialized nurse that collaborates with the general practitioner and the nurses at Primary Care. Nevertheless, during
the CCW held in Sweden it was noted that there is still a need for closer connection between the community dementia nurse in the Municipality and Primary Care.

In Madrid, there is no connection at all between the health care system and the social care providers. The social worker at the Hospital provide patients and their families with recommendations and advice on where to attend, but there is no communication between both tiers of care whatsoever. Regarding future actions, the General Directorate of Health Information Systems of the Region of Madrid is working in developing a web-based Portal for the Socio-Sanitary Coordination that will be available for professionals both from the SERMAS and the social entities, and that will comprise information about regulations, processes, access to information systems, etc. This initiative also involves a Corporate Viewer of Social Information, which will allow professionals to access the patient’s social record regardless its origin.

4.2 Aspects within organizations

As reported in the Israeli, Italian and Spanish cases, General Practitioners act as the gatekeeper to the rest of the healthcare system. Primary Care is responsible for the preliminary diagnosis and long-term management of patients with CI and dementia. On the other hand, professionals in Specialized Care are responsible for performing a detailed diagnosis, based on a more profound knowledge of the specific conditions and on the access medical technologies, and to start and manage the pharmacological treatment.

One main problem identified in settings like Getafe is the time that goes from the initial visit to the general practitioner to the visit with the specialist. It can take up to six months to get an appointment with the specialist, and during that time, the condition of the patient can deteriorate, losing the opportunity to adopt pharmacological and non-pharmacological strategies that might delay the course of the disease. As an example, in Italy, participants in the Co-Creation Workshops stated that the clinician’s decision process is currently too slow. Therefore, it is important to provide Primary Care with better training and resources for the diagnosis of CI and dementia.

Three different specialties are usually involved in the diagnosis and treatment of Cognitive Impairment: Neurology, Geriatrics and Psychiatry. Patients are referred to the specialist from different points of entry that include the Emergency Room in the Hospital or the General Practitioner. In many cases, patients are referred to a given specialist depending on other conditions or co-morbidities. For instance, in Getafe patients older than 65 years old with symptoms of cognitive impairment are referred
to the Geriatrics Service, while patients with a history of psychiatric disorders are referred to the Psychiatry Service, regardless their age. Moreover, as presented in the current document, cognitive impairment and dementia mostly affect older adults, that usually suffer from several comorbidities, are attended by different specialists and usually have complex medication regimes. Hence, each professionals work on treating the symptoms related to their specialty. There is a need to create a common goal between the different services that attend the patient, putting the focus on the patient as the centre of the whole care process. As an example of a good practice, FDG counts on a specialized geriatrics service – namely the Alzheimer Assessment Unit, Unità Valutazione Alzheimer, UVA – that counts on a standardized protocol for assessing older adults with dementia. Moreover, the interaction among the supervisors of the PASS, the ST, the UAR and their workers has introduced a “care culture” in the management of older adults within FDG which is less “cure-oriented”. Something similar happens in Getafe. The Geriatrics Service in the HUG has adopted an integrated care approach through the development of the Community Care Unit. The Geriatrics Service in the HUG has the capacity to perform a Comprehensive Geriatrics Assessment that covers aspects such as the cognitive and functional statuses of the patient, and to provide patients with integrated care aimed at improving their quality of life and independent living, while optimizing the pharmacological treatment.

4.3 Professionals

In the four pilot sites analysed in the present document, Primary Care is responsible for the initial diagnosis and long-term management of patients with CI and dementia. According to the information provided by the different pilot sites, it is common that professionals in Primary Care – i.e. General Practitioners and nurses – are not properly trained to diagnose cases of mild cognitive impairment. Moreover, the consultation time is very limited – Israel and Spain have reported consultation times of around 5 minutes -, which prevents general practitioners to perform a complete assessment of the cognitive status of the patient.

In most of the pilot settings, it has been identified the need to count on the figure of a case manager, that will follow the patient throughout the disease process and will act as the main contact point with the overall healthcare services and social services. In Sweden, long-term care is provided by multidisciplinary teams in the Municipality, led by a community dementia nurse. Nevertheless, dementia nurses have not the authorization to manage the path of the patient throughout the care system, and they need to need better coordinated with the physicians in the Health Centres.
Participants in the CCWs in Spain and Italy also stressed the need of the presence of a case manager able to carry out the follow-up of patient with MCI or dementia.

Most health services and organizations do not count on a **protocol for diagnosing and managing patients with CI and dementia**. It is very common that physicians and healthcare assistants have no complete information about home-care services and rarely discuss with family members about support possibilities planning a structured home-care project during the hospital stay. In Italy, the UVA in the Palazzolo Institute has set up a protocol for assessing patients with suspected CI and dementia. Nevertheless, there is not a predefined protocol for the long-term management of these patients. It has been stated the need to provide health professionals with a coherent view of the available health and social services. Participants in the Spanish CCW reported the effectiveness of a protocol used for assessing psychiatric patients in local health centres, while in Italy participants stated the need to define a set of regulations and training requirements both for formal and informal caregivers.

### 4.4 Involvement of patients, caregivers and other users

**Social awareness** about the disease is a fundamental point for enhancing prevention and early detection of cognitive impairment and dementia. In many cases, general population are not able to distinguish cognitive impairment prodromal symptoms from normal ageing (i.e. “grandpa is old and losing his head”). As an example, during the CCW in Sweden it was stressed that there is not a standardized process or routine that encourages patients/relatives to contact healthcare services in case of early suspicion of MCI. Hence, many patients do not attend a healthcare professional until the symptoms are too obvious and the disease is in an advance phase, losing the opportunity of adopting pharmacological and non-pharmacological strategies that might have delayed the onset of the symptoms. In Israel, Maccabi has implemented a strategy of geriatric assessment for all patients in their 75th birthday. This will help detect unnoticed cases, as well as to improve awareness between the general population and the health professionals. Other awareness strategies, such as the dissemination of educational and informative leaflets in public spaces, TV ads or even short movies were discussed in different pilot settings during the CCWs.

Plus, informal caregivers play a pivotal role in the long-term management of patients with CI and dementia. In most pilot settings, statistics show that patients live with their families until they are too deteriorated and require 24-hour attention. At latter phases of the disease the improper use of emergency or hospital services is frequent,
which increases the hospitalization costs. Long-term care imposes a great burden, both financial and psychological, on the informal caregivers. Moreover, all pilot settings have reported that caregivers do not receive enough information about the evolution of the disease of their dear ones, and/or about the availability of social resources that might help lower the burden. It is needed, thus, to provide informal caregivers with educational content about the disease and with information about pharmacological and non-pharmacological treatment and available social services.

During the CCWs, it was also stressed the need to count with a caregiver ‘spokesman’ that will be the main contact point with the patient, the healthcare organizations and the social care organizations.

### 4.5 Use of ICT

Information and Communication Technologies are expected to play a pivotal role in facilitating the integrated care of patients with CI or dementia. The use of ICT tools was stressed in all CCWs, as they might facilitate the communication between all health and social care providers that participate in the diagnosis and long-term treatment of this type of patients.

Most HMOs in the pilot settings count on Health Information Systems that facilitate information sharing among health professionals. The use of ICT is specially remarkable in the case of Maccabi: they started implementing a common Electronic Health Record (EHR) in the mid-eighties, and currently all healthcare tiers have access to a common pool of information about the health status of the patient. Moreover, social care providers within Maccabi have also access to the information in the EHR. Nevertheless, third-party social care providers do not have access to the EHR, and communication is carried out in an informal way, i.e. via telephone calls or emails. Something similar happens in FDG: the PASS and the ST provides communication among the health and social tiers via different web platforms. Nevertheless, the UAR is not connected to this system and communication among the three departments has to be carried out informally. In Sweden, the various ICT systems in the three care providing organizations are poorly integrated and coordinated, and currently the three care providers along the patient path cannot share the patient’s EHR. Finally, in Spain there is no connection whatsoever between the health and social tiers. The Community of Madrid is currently working in developing a web platform where professionals in both sectors can share information about the patient. This platform has been tested in a small number of social care providers, but there is not a date for a wide scale implementation.
4.6   **Compliance with quality standards**

Finally, Table 8 compares the current status of the care models adopted in the four pilot sites to the quality standards developed by the UK’s National Institute for Health Care and Excellence (NICE Quality Standards). The NICE quality standards are not mandatory, but aim at providing practical support tools to help organizations providing care for patients with dementia with tools to help drive up quality. Hence, this section aims at finding the correspondence between these standards and the gaps in care analysed in the literature analysis and co-creation workshops that took place in the four DECI pilot settings.
**Table 8. Comparison of current care practice in 4 pilot sites vs. NICE Quality Guidelines**

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<th>NICE Quality Guidelines</th>
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<tr>
<td>QS1: People with dementia receive care from staff appropriately trained in dementia care</td>
<td>No. Long-term care is usually carried out by caregivers. Just a small part of patients, usually with BPSD, are in charge of services devoted to dementia patients where trained staff operate.</td>
<td>Yes. GPs and nurses in Primary Care, who are usually specifically trained in dementia care, carry out long-term assessment of patients with dementia. Further, there are also specially trained dementia nurses in the communities.</td>
<td>No. Long-term assessment of patients with dementia is carried out by GPs and nurses in Primary Care, who are not usually specifically trained in dementia care. Nevertheless, although the day-by-day follow-up is carried out in Primary Care, the Geriatrics Service in the HUG counts on a Memory Assessment Unit that monitors patients in regular intervals, usually every 6 months or 1 year, or after a referral from the ER or Primary Care.</td>
<td>Yes. Every district manages small therapy groups for MCI patients guided by occupational therapists and social workers, which includes games and exercise for memory maintenance.</td>
<td>In most pilot settings, Primary Care is the ultimate responsible of the day-by-day care of patients with MCI or dementia. In some cases (Italy, Spain), professionals in Primary Care are not properly trained to properly diagnose patients with MCI or dementia. Moreover, they cannot act on relevant Two out of four pilot sites count on trained staff for early identifying MCI or dementia. In Italy and Spain, staff in Primary Care should be trained within the field of cognitive impairment.</td>
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<td>QS2: People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial assessment of dementia</td>
<td>Yes. People with suspected dementia are referred to dedicated memory clinics (Unità di Valutazione Alzheimer). Unfortunately, high variability is present about the quality of assessment protocols (many clinics have no neuropsychologist or have</td>
<td>Yes and no. The general practitioner makes the initial assessment based on national guidelines. If needed, the patient is then referred to a dedicated memory clinic for further evaluation.</td>
<td>Yes and no. Diagnosis and initial assessment is carried out by the geriatrician or the neurologist. The Geriatrics Service in the HUG counts on a Memory Assessment Service that carries out a standard follow-up of patients with MCI and</td>
<td>Yes. Individual diagnosis is performed by an occupational therapist and/or professionals in the geriatric service, nurses or home care units. Related depression may</td>
<td>All pilot sites count on dedicated staff able to diagnose patients with MCI or dementia. Nevertheless, in some settings the time between the initial suspicion and the diagnosis is too long, preventing patients to start cognitive training programs</td>
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<td>QS3: People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area</td>
<td>no access to advanced diagnostic instruments as functional brain imaging or biomarker analyses so that diagnosis is often made just when a mild to moderate dementia has already developed.</td>
<td>no access to advanced diagnostic instruments as functional brain imaging or biomarker analyses so that diagnosis is often made just when a mild to moderate dementia has already developed.</td>
<td>dementia, but do not provide patients with an integrated approach. Both the geriatrics and neurology services in the HUG count on a neuropsychologist that screens patients with suspected dementia once a week.</td>
<td>also be diagnosed by a social worker. Early screening is also performed by the GP under the 75th birthday visit program. In addition, the information systems include referrals to free and accessible to all, online websites offering self-diagnosis and self-exercise.</td>
<td>that might delay the onset of more severe symptoms.</td>
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<td>QS4.a: People with dementia have an assessment and an ongoing personalised care</td>
<td>There is no a standard protocol. The amount and the quality of information given to patients and caregivers depend on the initiative of the single clinical providers.</td>
<td>There is no standard protocol. The quality of the information given to patients and caregivers depends on the single clinical provider.</td>
<td>No. Information comes from different sources. Support options are provided by the social worker. Specialized care provides patients with verbal information and a medical report. There is not standardized information.</td>
<td>Leaflets in preparation include explanations of the essence of Dementia and MCI to patients and family members and provide recommendations for coping with behavioral disorders.</td>
<td>This is a relevant point, as patients and caregivers in most pilot settings state to feel lost and overwhelmed after the diagnosis. Adapted material should be developed in order to support patients and caregivers, staff in Primary Care, social workers, etc.</td>
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<td>plan that addresses their individual needs</td>
<td>No. Communication is performed in an informal way</td>
<td>Yes and no. Co-workers from the various care providers are coordinated to some extent. Social care to a lesser extent.</td>
<td>No. Communication is performed in an informal way</td>
<td>In Maccabi there is a social worker that works with the clinical team. There is very little integrated care with external organizations that provide social care</td>
<td>This was one of the main problems stated in the four co-creation workshops. In order to make a difference, the DECI system should facilitate the communication between health and social services.</td>
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<td>QS4: Health and social care are coordinated in order to create a personalised care plan and assess the patient</td>
<td>No. Usually the caregiver or the GP acts as case manager.</td>
<td>Yes and no, Some patients have a named care coordinator, but the variation between communities is large.</td>
<td>No. The GP acts as a case manager, but usually has no access to full information about the condition of the patient.</td>
<td>Yes. The Case Manager is either the GP or the home care team.</td>
<td>Trained nurses in Primary Care could play this role (their salary is lower than the salary of a specialist). The DECI platform could be used as the communication method.</td>
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<td>QS4b: Patients with dementia have a named care coordinator</td>
<td>No, there are no standard protocols about these issues and patients, older adults in particular, are usually excluded from the decision making process.</td>
<td>Yes and no. There is now a law in Sweden addressing these issues. However, the implementation of the law varies among care providers.</td>
<td>No. Especially in the case of older adults, carers do not provide patients with enough information..</td>
<td>In accordance with the terminally ill patient law, the GP can help fill out a &quot;living will&quot;. Patients who have capacity may also provide power of attorney. These declarations are stored in the ministry of health database.</td>
<td>The named care coordinator should be able to provide patients and their caregivers (preferably a spokesperson) with information on medical, legal and practical aspects. This information should be available in the DECI platform.</td>
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<td>QS5: People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of: (1) advance statements, (2) advance decisions to refuse treatment, (3)</td>
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<td>lasting power of attorney, (4) preferred priorities of care</td>
<td>No. There is no a widespread protocol about this issue. Usually this is a missed point in memory clinics, which is, by tacit agreement, delegate to family caregivers associations.</td>
<td>No. There is no widespread protocol about this issue.</td>
<td>There is not an established protocol in the National Health System. Most of these actions are performed by patient associations of Alzheimer Foundations.</td>
<td>A program intended for carers is comprised of (1) specialized support groups (2) a proactive web center which initiates contact with the primary carer providing information on preventative medicine</td>
<td>Support to caregivers is one of the most urgent needs in all health care systems, and one of the greatest possibilities to make a difference using the DECI system.</td>
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<td>QS6: Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.</td>
<td>No. Behavioral and Psychological Symptoms of Dementia (BPSD) are addressed in acute care. The only opportunity for caregivers are relief recovery of patient in devoted units to improve caregiver distress.</td>
<td>Yes and no. These types of problems are addressed in acute care. However, patients with dementia are registered in a national quality register in which key care quality indicators are documented. Currently, there are plans to link the national register to the EMR and the care plan.</td>
<td>No. These types of problems are addressed in acute care.</td>
<td>Every district employs a psychogeriatrician (MD). In addition, there exists a diversified geriatric array which includes: multidisciplinary geriatric clinics, advisory geriatric clinics, portable geriatric clinics and virtual geriatric consultation services. Any healthcare professional may confer with the above units.</td>
<td>Assessment instructions could be provided via the DECI platform. Any interventions could be recorded in the patient's care plan available in the platform.</td>
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<td>QS7: People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress</td>
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<th>Israel</th>
<th>Conclusions and actions</th>
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<td>should be recorded in their care plan.</td>
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<td>QS8: People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specializes in the diagnosis and management of dementia and older people’s mental health.</td>
<td>In the emergency departments there are no services devoted to patients with dementia. In general hospital inpatient services just in geriatric units there is this kind of service.</td>
<td>Yes. There are specialized care homes in some of the communities that specializes in the management of moderate to severe dementia. In addition, there is a specialized clinic at the hospital that diagnoses and stabilizes complicated cases of dementia.</td>
<td>Yes, if they are hospitalized in the geriatrics or psychiatric units.</td>
<td>Yes. The care is community based. All diagnosis and management is done in community. Only patients at advanced stages are treated in acute care. Even at advanced stages, they are treated at home by special care teams.</td>
<td>This action could be performed by the named care coordinator in coordination with the staff in acute care or emergency departments. However, this might fall outside the scope of this project.</td>
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<td>QS9: People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.</td>
<td>n/a</td>
<td>n/a</td>
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<td>QS10: Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the</td>
<td>Yes.</td>
<td>Yes.</td>
<td>Yes.</td>
<td>Yes.</td>
<td>Although this quality standard is fulfilled by all pilot settings, the DECI platform should provide guidance to caregivers about the available services.</td>
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5 Conclusions

Within the present document, we have analysed the care pathways and care networks of patients with cognitive impairment and dementia in four Health Management Organizations (HMOs) with different structures and environments. These HMOs differ in the number and variety of services provided. For instance, HUG only provides patients with health care services, while FDG and Maccabi provide patients with both health and social services in-house. On the other hand, VGR collaborates closely with the municipalities in order to promote continuity of care. Nevertheless, in all settings it has been reported a certain degree of disconnection between the health and social care tiers.

Each of the pilot settings have their own barriers and facilitators for implementing an integrated strategy for managing patients with CI and mild dementia. FDG and HUG have implemented a “care culture” with respect to older adults that goes beyond the usual “cure culture”. VGR and Maccabi have set up all the pieces to provide patients with integrated care. Despite the differences, some common barriers and facilitators have been identified in the four pilot settings.

- As recommended by the NICE quality guidelines and discussed in the Co-Creation Workshops that took place in the four pilot sites, there is a need to count on a **named case manager** that will guide patients and informal caregivers throughout the overall disease process. There is no consensus on who should adopt this role – i.e. general practitioners, trained nurses in Primary or Specialized care, etc. - , but it has been identified that Primary Care plays a pivotal role in the early detection of the disease.

- On the other hand, in many cases professionals in **Primary Care are not properly trained** to identify early symptoms of cognitive impairment, which might be disguised as “normal ageing”. Many cases or early dementia are underdiagnosed and are only detected when the disease has evolved and symptoms become obvious, disabling any prevention options. Hence, there is an agreement that professionals in Primary Care should be properly trained on the identification of early signs and about procedures for diagnosing. Programs such as the 75th-Birthday Screening implemented in Maccabi pose a good way to implement prevention strategies.

- Not only health professionals should be alerted about the prodromal symptoms of cognitive impairment. During the Co-Creation Workshops,
professionals and informal caregivers stressed the need to **raise awareness about cognitive impairment among the general population.** In many cases, early symptoms of cognitive impairment are attributed to normal ageing – i.e. “grandma is losing her head, she’s getting old” - , which might prevent older adults to visit any health professionals. Moreover, usually patients and their families do not look after social or care support until the disease starts affecting activities of daily living or even disabling the patient. Patients and caregivers should be informed about preventive actions and programs that might help delay the onset of more severe symptoms.

- **In most pilot settings, there are no defined clinical pathways for patients with MCI.** In many cases, they are cited for regular appointments in order to check their evolution, but no intervention is adopted. It has been demonstrated that cognitive training could alleviate some of the symptoms and could delay the onset of more severe symptoms. The DECI platform poses a good opportunity for providing professionals with recommendations and guidelines on actions to take, such as recommendation of non-pharmacological treatments.

- **Non-pharmacological treatments** are highly recommended in order to foster independent living and to delay the onset of more severe symptoms. HMOs like Maccabi offer these services, but the number of vacancies is quite limited. On the other hand, in Madrid these services are provided by social care institutions or non-profit research foundations, and are not monitored or overseen at all by health professionals.

- All four pilot sites stressed the need to count on a **better coordination between the health and social care tiers.** Some of the organizations providing care for patients with MCI and mild dementia described in the present document – i.e. FDG or Maccabi – provide their patients with a number of social services, but they also need to count on third-party social services.

- All pilot sites have also reported the need to **provide patients and informal caregivers with more accurate, up-to-date information** about the disease and about practical aspects of the disease, such as legal aspects or the availability of social services.

- **ICT solutions** are a powerful tool to provide patients with integrated care, as they might foster a better coordination between Primary and Specialized care and between the health and social care tiers. ICT tools can also be used
to perform remote monitoring of the patients, as well as to provide them with educational material and a communication tool with health and social professionals.
6 References


