Output: Model care for the elderly

Deliverable: FCN Model validation

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Authors:	**Social Protection Institute of the Republic of Slovenia and ASL Città di Torino**
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List of acronyms

ADI	Integrated Social-Health Home Care
ADL	Activities of Daily Living
ASL	Local Health Authority
BMI	Body Mass Index
CONSENSO	Community Nurse Supporting the Elderly in a Changing Society
COPD	Chronic Obstructive Pulmonary Disease
FCN	Family Community Nurse
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
ISTAT	Italian National Institute of Statistics
LEA	Essential Levels of Health Assistance
NGO	Non-governmental organization
OECD	Organization for Economic Co-operation and Development
SHARE	Survey of Health, Aging and Retirement in Europe
SID	Home Nursing Service
SURS	Statistical Office of the Republic of Slovenia
TIA	Transient Ischemic Attack
UNECE	United Nations Economic Commission for Europe
WHO	World Health Organization
ZDUS	Slovene Association of Pensioners

1. Objective of the report

This report fuses together the project output 2.1 "Model of care for elderly" and the project deliverable 3.2.1 "FCN Model validation", and represents the overall evaluation report of the project.

Output and deliverable were fused together, because the description of the model validation, i. e the different ways of implementing the same model adopted by partners, logically follows the results of the model care. The first chapters of this report correspond to the output 2.1, and the qualitative descriptions in the end of the report refer much more to the deliverable 3.2.1.

The project CoNSENSo (COmmunity Nurse Supporting the Elderly iN a changing Society) objective was to develop a care model that puts the older adults[1] at the centre of health and social services building on the crucial role of the family and community nurses. The project focused on improving and promoting human relations to allow the elderly to remain living at home as long as possible.

The overarching goal of the CONSENSO project was to improve the life quality of older adults and thus enable them to live at home independently as long as possible. More specifically, the project tested a model of a community and family nurse (FCN) who, through periodical visits to the elderly evaluated risk factors, managed minor health and social needs, promoted healthier lifestyles to clients and coordinated the network of stakeholders (governmental/regional, communal, nongovernmental, informal) and their programmes, services and activities. The model was tested in four countries (Austria, Italy, France, and Slovenia) or five CONSENSO regions (Carinthia, Liguria, Piedmont, Slovenia and Var). This holistically designed intervention approach tailored to individuals' needs should lead to the improvement of the life quality and consequently enable senior citizens more independent life at home. The FCN and project partners mobilised all the necessary resources, knowledge, skills, and competences to adequately address the needs of each individual senior included in the project.

The project put forward the policy measures based on the concepts that have been uniformly promoted by the OECD countries in the past ten to twenty years, having somewhat normative connotations: deinstitutionalisation, community-based care, user-centred care, care coordination, prevention and case management. Extended life at home (and not in institutional setting) was prioritized. In 1994, the World Health Organisation defined home care as "an array of health and social support services provided to clients in their own residence" (Thomé, Dykes and Hallberg, 2003). Newer definitions define it as "a phenomenon in which care is provided by professionals to people in their own homes with the ultimate goal of not only contributing to their life quality and functional status, but also to replace hospital care with care in the home for societal reasons." This definition consists of everything from preventive visits to palliative care (Rechel, Doyle, Grundy and McKee, 2009). Two core arguments are underpinning the effort to deinstitutionalise care: prioritising user's quality of life and increasing the sustainability of care systems (Ilinca, Leichsenring, and Rodrigues, 2015) by preventing hospital care and institutionalisation. Services offered at home can consist of preventive measures and assessments, providing care based on individuals' needs (physical, psychosocial, social, cognitive), health promotion, activities and assessments after discharge (assessments, planning, implementations, follow-ups) (Rahm and Kristensson, 2004). Elderly population is a very heterogeneous group, not just in a manner of diversity, but also in a manner of health and needs: therefore, the interventions need to be suitably adapted to particular situations of each individual. It is argued (Ilinca et al, 2015) that low institutional rates can be reached only by a well-balanced mix of formal care community services, targeted support of informal care and by improved coordination between different care settings. The focus should also be on preventing the need for institutional care by developing alternative solutions and opportunities for early interventions which can

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[1] The target group of the CONSENSO project were older adults (those aged 65 years or more). Due to identified needs in pilot areas, in a few rare cases clients were younger (60 – 64). The representatives of our target group in this report are called "clients", "elderly", "older adults" or "senior citizens".

delay or help avoid the development of intense care needs (Ilinca et al, 2015). Over past decades, countries across Europe have developed strategies to support community-based services: however, there are differences in needs, approaches and commitment levels, which result in diverse results and different pace of progress (Ilinca et al, 2015).

The CONSENSO project tackles two of the above-mentioned categories that lower the rate of institutionalized care: improved care coordination and new preventive services at home. In general, health promotion strategies for the elderly have three basic aims: "maintaining and increasing functional capacity, maintaining or improving self-care, and stimulating one's social network" (Golinowska, Groot, Baji, and Pavlova, 2016) and these strategies should contribute to a higher quality of life, social participation, integration, social bonds, which are all essential for healthy aging (Golinowska et al, 2016). Measures that strengthen social networks are not always formal and do not always need direct external financing but they frequently require appropriate social and transport infrastructure (Golinowska et al, 2016). The CONSENSO model is inspired by all concepts mentioned above. It brings them together in practical approach to case management. The case management can be understood as a goal-oriented and structured method. Its aim is to support people in challenging life situations. At its core there are both − the individual-oriented work with the client (case management) as well as the efficient use and coordination of service and performance processes in the care system (system management).

The structure of the report is the following: the introductory chapter, followed by the description of the participating CONSENSO countries at the macro level where the basic socio-economic information as well as basic policy overview in the fields related to CONSENSO are given. The methodology of the evaluation of the CONSENSO intervention is described in the next chapter. The report continues with a detailed description of the CONSENSO model, the analysis of the results of the pilot interventions and their adaptations to the national context. The report ends with the discussion and the conclusion highlighting the most important results of the project and lessons learned.

2. Description of CONSENSO participating countries at the macro level

This chapter is structured as follows: for each CONSENSO participating country, a short description of social and health care system is provided, followed by the presentation of general socio-economic data, the description of home care policies, practices and measures related to the coordination and integration of health and social services in each country, a brief introduction to the situation of informal carers and the presentation of issues identified for each country. The aim of this part of the report is to give the reader a brief and general overlook of the needs of the elderly in each participating region and current policy responses in place.

2.1. Austria (Carinthia)

The foundation of the health care system in Austria is a social insurance model that covers the majority of the population (99%). Services are accessed according to regulations among which General Social Insurance Act is the most important. At the federal level, the main stakeholders of health care system are the Austrian Parliament, the Federal Ministry of Health, the Federal Ministry of Labour, Social Affairs and Consumer Protection, social security institutions and advocacy groups. The central role is played by Federal Government with its power of legislation enforcement and the Federal Ministry of Health which prepares laws, coordinates different players, supervises and makes decisions. While the Federal Government is responsible for out-patient care, in-patient is dealt with between the federal and the provincial level. The Federal Government makes a legislative framework while the provinces (known as Länder) attempt to define legislation on enforcement and carry out the implementation (The Austrian Federal Ministry of Health, 2010). Länder and local authorities take care of public health services and administration. Ensuring hospitals, health promotion and prevention services are done by the provinces while local governments take care of social welfare benefits and services (The Austrian Federal Ministry of Health, 2010).

General statistics

In 2014, Austria spent 30% of its GDP on social protection (Eurostat, 2014). Health expenditure as a share of GDP accounted to 10.4% (out of which 2.5 percentage points is voluntary/out-of-pocket payment) in 2016 (OECD, 2017a). The population in Austria is growing steadily, and is projected to increase to 1.1 million by 2050, almost exclusively in Vienna, whereas the population in other federal states will stagnate or even decrease. The birth rate in Austria is generally low and the population is progressively aging. Austrians live longer but spend fewer of these extra years in good health compared to many of their EU peers. Healthy life expectancy at birth for females in Austria was 57.1 years in 2016, and 57 years for males (Eurostat, 2017).

The need for care will increase in the following years, however not as significantly as e.g. in Italy and Slovenia. Between 2015 and 2050 the old age ratio is expected to increase from 27.5 to 45.3 (Eurostat, 2018).

Behavioural risk factors are a major public health issue in Austria. Alcohol consumption and smoking rates have not declined and are among the highest across the EU. Austria is however more successful regarding the prescribed antibiotics (14 daily per 1000 inhabitants, in comparison to 20.6 in OECD) (OECD, 2017a).

On average, Austria has 5.1 physicians and 8.1 nurses per 1000 persons. The number of physicians is high (3.4 in OECD countries), and the number of nurses around average (9 in OECD countries) (OECD, 2017a).

Most OECD countries conduct regular health surveys which allow respondents to report on different aspects of their health. A commonly asked question is: "How is your health in general?" Despite the subjective nature of this question, the indicators of perceived general health are a good predictor of future health care use and mortality (Palladino et al., 2016 and OECD, 2017a). In Austria, 69.8% of population perceive they are in good or very good health (OECD, 2017a).

According to Eurostat, there were 22.4% of population at risk of poverty or social exclusion in EU-28. The percentage is below average in Austria (18.1%), and even lower in Carinthia (16% in 2016, data for 2017 not yet available)[2] (Eurostat, 2018).

The employment rate of women is above average in comparison to EU-28 (71.4% in 2017 compared to 66.5% in EU-28) (Eurostat, 2018a). The unemployment rate in 2017 (November) for EU-28 was 7.3%, in Austria 5.5%, in Carinthia 4.8%.

Home care

The description of health and social services in Austria is complicated due to its federal system. Organization, infrastructure, provision and even definition of services differ from one state to another. This includes institutional long-term facilities, home care and home nursing, and others. The majority of older individuals who are ill or disabled or need support/help use mobile services (for instance, home nursing, home care, home help and mobile meals) in their private homes. All of these services are offered by the communities, states or welfare (Garms-Homolova, 2013).

The following principle is put forward in Austria when it comes to home care: "*Everybody who needs care shall have the opportunity to organize his/her care according to his/her own needs".* Care benefits are the most important contribution to this aim. Care benefits are not intended to cover the full amount of needs and are considered as a contribution to an independent life in a community. Even if the regulation on care benefits is uniform for the entire country, its principles are interpreted differently in every Austrian state (Garms-Homolova, 2013).

In Austria, home nursing and personal care are different services and are also reimbursed and regulated differently. Health care insurance covers home nursing (which is a health service) if the need is verified by the physician (Garms-Homolova, 2013). Personal care and domestic aid are social services and are not covered by health insurance but by care benefits according to the federal law or one of the acts of each federal state.

Home-based services are mostly provided by non-profit organizations: Caritas, Hilfswerk, Red Cross and Volkshilfe. Services include home care, home nursing care, mobile therapeutic services, meals on wheels, transport services, home cleaning, laundry services and weekend help. The second type of the services of LTC are institutional care services that are mainly provided by provinces and municipalities and also by religious and non-profit organizations. These services include residential homes, nursing homes, day-care centres and night-care centres (Riedel and Kraus, 2010).

Austria imports nurses from abroad. From 2004 to 2011 the Austrian labour market was protected from high migration and the care profession was rare. In May 2011 the restrictions were taken away and there

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2 See the indicator *People at risk of poverty or social exclusion* (regional data). Retrieved from https://ec.europa.eu/eurostat/web/income-and-living-conditions/data/main-tables.

was a rush of immigrants. Unlike medical staff, a shortage of care staff is still typical of the long-term care sector (Hofmarcher, 2013).

Coordination and integration of services

As Leichsenring and Ruppe (2016) explain, integrated care has gained importance over the past decade in Austria with a strong focus on integration and coordination within the health care system. A discharge management in hospitals and sporadic disease management initiative were implemented. Long term care has also been shaped as a sector, with distinct funding mechanisms and by creating new links with the health system, e.g. by the new types of job profiles. Still, barriers are identified regarding a person-centred care, continuity and systemic prevention, with palliative care and care for persons with dementia being especially problematic.

Communities in some federal states have created "Integrated social health services" (ISGS) that have been co-ordinating long-term care since 2004. In other parts of Austria, links have been developed since 2000 between the primary care by the physician and the mobile services (home care) for the purpose of providing palliative care. In 2005, the federal government and the governments of federal states have signed a contract that regulates the provision of social services by charity organizations, federal states, and municipalities (Garms-Homolova, 2013).

Informal carers

According to the Wave 6 of the Survey of Health, Aging and Retirement in Europe (SHARE), there are 8% of Austrians (aged 50 or more) providing informal care daily and another 8% providing it weekly (OECD, 2017b).

Families are seen as responsible for the care of their older members and around 80% of all individuals get care and support by their relatives at home. However, domestic violence against the elderly (especially women) seems to thrive in this context (Garms-Homolova, 2013).

In Austria, children also have formal liability to maintain both parents and their grandparents if the following criteria are met:

- Parents are not able to care for themselves.
- If their ability is reduced only partially, their children have to cover only one part of the obligation.
- The parent does not have any other relatives who are committed to care for her/his daily life.
- The child is able to cover his/her own basic expenses.

Various forms of support for informal caregivers are also available, such as: training, counselling, a respite person, subsidised holidays and contribution to the social insurance. They vary from one federal state to another. An important type of support is also the leave for employees who are providing hospice care for a family member. The payment in these cases depends on the entire income of the household (Garms-Homolova, 2013).

Disparities and concerns in the process of home care

Huge regional disparities remain due to the fact that philosophy, organization and care provision are different in each federal state. The biggest regional differences supposedly exist with regard to the quality of services. One of the often-exposed issues is also the shortage of staff and stressful work in the home care. A frequent cause of distress is also communication with clients' relatives. The absence rates of nursing staff and semi-professional caregivers are therefore very high (Garms-Homolova, 2013).

2.2. Italy (Piedmont, Liguria)

Italy's healthcare system is characterised by public medical service financed through general taxation. At the national level, the Ministry of Health (supported by several specialized agencies) sets the key principles of the national health system, determines the core benefit package of health services guaranteed across the country, and allocates national funds to Italy's regions. The National Health Service is financed by direct taxation (95%) and indirect taxation. The National Health Fund (NHF) is divided among regions and local health authorities. The remaining costs are covered by the revenues of local health authorities and client co-payment. The organization and provision of healthcare is a regional responsibility. At the local level, geographically based local health authorities (ASL - *Aziende Sanitarie Locali*) deliver community health services, public health and primary care directly, assuring the so-called *'essential benefit services'* defined by the Ministry of Health (LEA - *Livelli Essenziali di Assistenza*). Primary care is provided by self-employed and independent physicians, general practitioners etc., paid according to capitation fee based on how many patients they have on their lists. The ASL can also pay additional allowances for the planned care for specific patients, for reaching performance targets or for giving additional treatments (Donatini, 2017). Secondary and specialized care can be provided either by the ASL's district hospitals or through public hospital trusts or by accredited private providers.

General statistics

In 2014, Italy spent 29.9% of GDP on social protection (Eurostat, 2014). Health expenditure as a share of GDP accounts to 8.9% (out of which 2.2 percentage points is voluntary/out-of-pocket payment) (OECD, 2017a). The need for care in Italy is already very large, however it will only increase in the following years. Italy is one of the countries where demographic changes are most prominent. Between 2015 and 2050 the old age ratio[3] is expected to increase from 33.7 to 62.5 (Eurostat, 2018), meaning less than two persons of working age for one elderly person. The most intensive growth is evident in the age group 85 or more who will more than triple until 2050. The two CONSENSO regions seem to be affected significantly by the aging challenges: Liguria has the highest share of population 65+ in Italy (28.5%), and the share in Piedmont is also above average (25%). According to ISTAT and the aging index, Italy ranked first among the EU countries in 2016. At the same time, as ISTAT reports, Italy was among those with the highest index of dependency ratio, closely following France, Sweden, Finland and Denmark.

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3 This indicator is the ratio between the projected number of persons aged 65 or more (the age when they are generally economically inactive) and the projected number of persons aged between 15 and 64. The value is expressed per 100 persons of working age (15-64) (Eurostat, 2018).

Figure 2.1: Aging index in Italy (comparison Liguria and Italy), data for all Italian regions
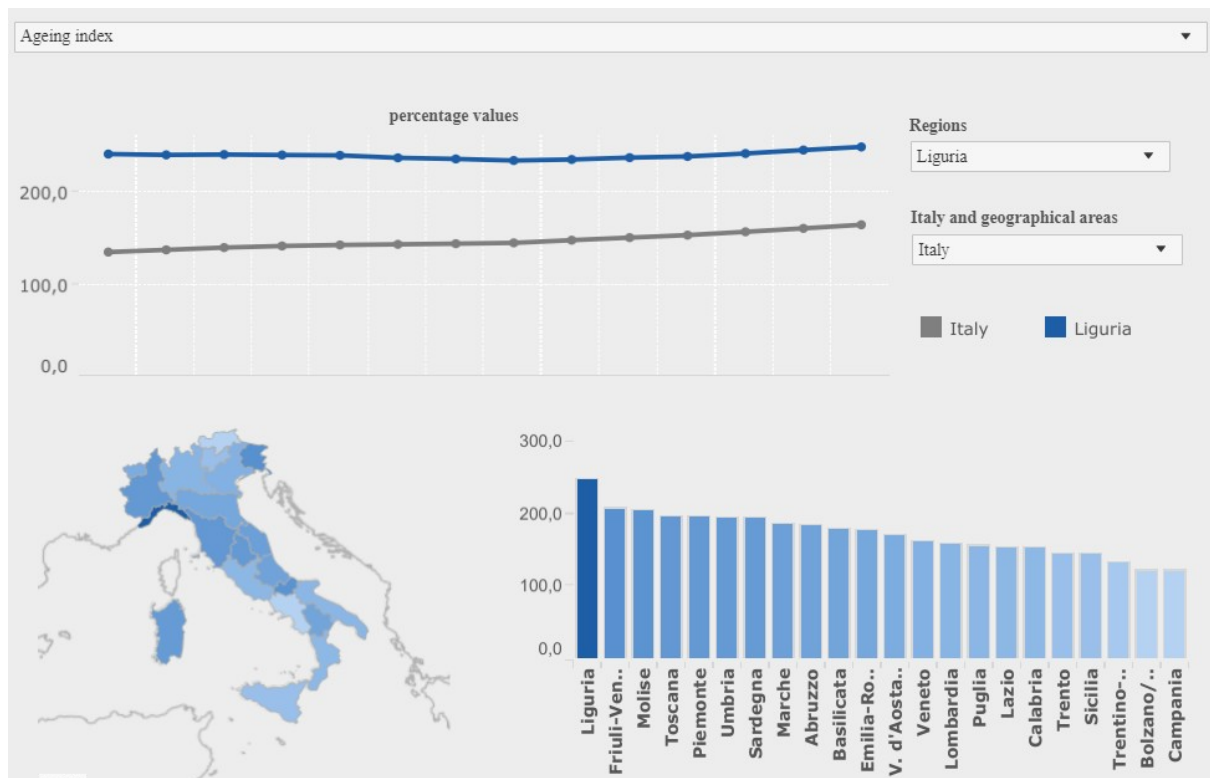
Source: ISTAT (www.istat.it)

According to ISTAT, 46% of population in Italy (18+) are overweight or obese, but the percentage is slightly lower in the two CONSENSO regions (41%). There were 19.7% of smokers in Italy in 2017, but smoking was a bigger problem in the two CONSENSO regions (20.7% in Piedmont and 21.5% in Liguria).

In 2016, healthy life expectancy[4] at birth in Italy was estimated to be 67.2 for females and 67.6 for males (Eurostat 2017), while in Liguria and Piedmont the data are significantly lower - around 59 years (ISTAT).

OECD health statistics (2017a) show very high prevalence of dementia in Italy (22.5 cases per 1.000 in a population in comparison to average 14.8 in OECD countries). There is 20% of population smoking daily in Italy (obesity is a lesser issue - 9.8% in comparison to 19.4% in OECD countries) (OECD, 2017a). On average, Italy has 3.8 physicians and 5.4 nurses per 1.000 persons. The number of physicians is slightly above average (3.4 in OECD countries), but the number of nurses is significantly under average (9 in OECD countries). The overall volume of antibiotics prescribed is also very high (to nearly 30 patients per 1.000 per day) (OECD, 2017a).

According to Eurostat, there were 22.4% of population at risk of poverty or social exclusion in EU-28[5]. The percentage is higher in Italy (28.9%), but around average in the two CONSENSO regions (22% in Piedmont and 23% in Liguria) (Eurostat, 2018).

Most OECD countries conduct regular health surveys which allow respondents to report on various aspects of their health. A commonly asked question is: "How is your health in general?" Despite the

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4 The life expectancy indicator cannot fully answer the question if extra years of life gained through increased longevity are spent in good or bad health. To answer this question, the "healthy life years" indicator (also called "disability-free life expectancy") has been developed. The focus is on the quality of life spent in health, rather than the number of years — as measured by life expectancy (Eurostat, 2017).

5 See the indicator *People at risk of poverty or social exclusion*. Retrieved from https://ec.europa.eu/eurostat/web/income-and-living-conditions/data/main-tables.

subjective nature of this question, the indicators of perceived general health are a good predictor of future health care use and mortality (Palladino et al., 2016 and OECD, 2017a). In Italy, 65.6% of population perceive they are in good or very good health (OECD, 2017a). The percentage was slightly lower in two Italian CONSENSO regions (ISTAT).

The employment rate of women is relatively low (52.5% in 2017 compared to 66.5% in EU-28), but it is slowly growing (for 4 percentage points since 2005) and together with the demographic growth that implies the needs for care are and will be increasing (Eurostat, 2018a)). The unemployment rate in 2017 (November) for EU-28 was 7.3%, in Italy 11%, while in Piedmont and Liguria the unemployment rate amounted to around 9% (Eurostat, 2018).

Home care

The Italian system is predominantly cash oriented, through disability/invalidity pensions, and the majority of care is expected to be conducted by the family. According to Eurobarometer study (European Commission, 2007), more than half of Italians believe that elderly persons should stay at home and receive regular care visits from home care service providers and from their children. With growing labour participation of women, the care has been shifted in a great extent to foreign immigrants as live-in caregivers (*badante).*

Home care has been an official policy in Italy since the beginning of the 1990s (Law 833/1978 SSN) and is divided between *home nursing* and *home help*. The Law 328/2000 aimed at promoting an integrated system of health and social services and the document *The new definition of home nursing* in 2006 defined and updated the Essential Levels of Health Assistance (LEA) (see Melchiorre et al, 2013).

Three categories of nursing care are identified: occasional, integrated and palliative. Home nursing is the responsibility of the Ministry of Health and it includes home nursing service (SID), integrated social-health home care (ADI), home hospitalisation service, and programmed home care assistance by GPs. *The new definition of home nursing* (prepared by the Ministry of Health) defines uniform eligibility criteria and is *needs-tested,* with the information on informal carers carefully considered. Persons with minimum income and those aged 65 or more, those with chronic disabling diseases, terminal cancer patients and persons during intensive post-acute phase are entitled to home nursing services for free. Otherwise co-payment is requested (Melchiorre et al, 2013).

Home help is means-tested and co-paid by clients. There are no uniform rules for determining eligibility as they differ between municipalities. The Ministry of Work and Social Policy is responsible for delivering home help. Municipalities define their own criteria of eligibility. Home help is defined as help with personal care (personal hygiene, getting up and going to bed, dressing, eating, administrative tasks etc.) and domestic work (Melchiorre et al, 2013).

Preventive home visits are not available (Melchiorre et al, 2013).

Coordination and integration of services

As stated by Melchiorre et al (2013), "*It should be noted that although the Law 328/2000 aimed at promoting an integrated system of services, many regions (mainly in the south of Italy) have not set the rules for organizational and financial integration yet."* Social and home health services are provided by different organisations, but there are local exceptions. In some regions (mainly in the central-northern Italy) there are agreements between municipalities and local health authorities on an integrated provision (ADI) (Melchiorre et al, 2013). In a few cases, home nursing services (SID) and integrated social-health care (ADI) are also provided, free of charge, for intensive post-acute phase (protected discharge from hospital). There are also some professional profiles already regulated by the law:

- The case manager nurse; often there is a professional nurse as a coordinator, but always with the collaboration of a GP. The nurse organizes the process of patient care. The coordination between home care and nursing homes often takes place when it comes to integrated home care (ADI). In case of other types of home care, the coordination is less frequent.
- The home care nurse; they provide the continuity of care by aiding at the patient's home. They perform some tasks such as blood sampling, complex dressings, bladder catheter management, health care delivery, and family health education.

Informal carers

Even though the data on informal carers are limited and unreliable, they are extremely important in Italian social protection system. Italy has a strong tradition of family care. Women provide a high share of informal care. According to the Wave 6 of the Survey of Health, Aging and Retirement in Europe (SHARE), there are 7% of Italians (aged 50 or more) providing informal care daily and another 4% providing it weekly (OECD, 2017b).

Key issues

Melchiorre et al (2013) define the following key concerns related to Italian home care:

- Demographic changes and issues with long term funding and cuts in social spending, possible restructuring of welfare state and questionable future possibilities of supplying the service of home care.
- Difficult integration between health and social services, mainly in southern Italy.
- A lack of common tools in client evaluation and quality monitoring.
- A lack of care continuity after hospital discharge; in many cases it is not provided.

2.3. France (Provence-Alpes-Côte d'Azur)

The provision of health care in France is the responsibility of the state. The Ministry of Social Affairs, Health, and Women's Rights is responsible for defining national strategy. Health expenditures are funded by statutory health insurance (SHI). In addition to setting the national strategy, the responsibilities of the central government include allocating budgeted expenditures among different sectors (hospitals, ambulatory care, mental health, and services for disabled residents) and, regarding hospitals, among regions. In individual regions, the ministry is represented by regional health agencies, which are responsible for the population's health and health care, including prevention and care delivery, public health, and social care. Health and social care for elderly and disabled persons come under the jurisdiction of general councils, which are the governing bodies at the local (departmental) level (Somme and de Stampa, 2011).

General statistics

In 2014, France spent 34.3% of GDP on social protection (Eurostat, 2014). Health expenditure as a share of GDP accounted to 11% (out of which 2.3 percentage points is voluntary/out-of-pocket payment) in 2016 (OECD, 2017a). In France, demographic state and trends are relatively stable, with lower old age dependency ratio (compared to other European countries) (45.1 in 2050) (Eurostat, 2018).

Healthy life expectancy at birth for females in France was 64.1 years in 2016, and 62.6 years for males (Eurostat, 2017).

Behavioural risk factors, especially alcohol consumption, are a public health issue in France. The French are also prescribed a higher number of antibiotics, comparing to other OECD countries (29.9 per 1.000 population, comparing to 20.6 in OECD).

On average, France has 3.3 physicians and 9.9 nurses per 1.000 persons, which is similar to OECD average (OECD, 2017a).

Most OECD countries conduct regular health surveys which allow respondents to report on different aspects of their health. A commonly asked question is: "How is your health in general?" Despite the subjective nature of this question, indicators of perceived general health are a good predictor of future health care use and mortality (Palladino et al., 2016 and OECD, 2017a). In France, 67.8% of population perceive they are in good or very good health (OECD, 2017a).

According to Eurostat, there were 22.4% of population at risk of poverty or social exclusion in EU-28. In France, this percentage is lower (17.1%)[6] (Eurostat, 2018)[7].

The employment rate of women is above average in comparison to EU-28 (70.6% in 2017 compared to 66.5% in EU-28) (Eurostat 2018a). The unemployment rate in 2017 (November) for EU-28 was 7.3%, in France 9.1%, and in Var 10.2% (Eurostat, 2018).

Home care

The overall delivery of care is under the responsibility of agencies at regional level (ARS), which work in close collaboration with the social services sector (Somme and de Stampa, 2011). Two schemes, financed by the state and by local authorities, provide social benefits to the dependent elderly and persons with disabilities to help them meet the cost of care that is not covered by the health insurance. For the elderly, the Elderly Dependency Act was adopted in 2001, which introduces "allocation personalisée d'autonomie" (individual attendance allowance) known as APA. This allowance, paid to dependent persons over the age of 60, is intended to cover the costs of any assistance they need due to the loss of their ability to care for themselves. They must also have their main residence in France and be dependent according to the AGGIR scale (Autonomie Gérontologique - Groupes Iso-Ressources). Since 2006, some aspects of the regulation of care are under the control of a GP. Patients that want to use care services must be referred by GP, in case they want to be reimbursed (this is called the 'coordinated care pathway') (Somme and de Stampa, 2011).

Home care for the elderly is provided mainly by self-employed physicians and nurses and, to a lesser extent, by community nursing services. Professionals in home care are: home helpers/home aids (level 1) that provide mainly IADL related tasks, Auxiliaire de Vie Sociale (AVS) (level 2/3), additionally performing personal care services (same tasks as a nurse assistant, but not to persons with disabilities linked to chronic illness), nurse assistants, providing help with IADL, and allowed to perform personal care but under nurse's supervision and registered nurses, providing personal care but mostly technical services licensed after training) (100).

Coordination and integration of services

Somme and de Stampa (2011) identified fragmentation between health and social services: between institutional (hospital and long-term care) and community based-services; private/non-profit and public services, and various payment systems (insurances, fees etc.). The fragmentation is noticeable at all levels of responsibility.

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6 See the indicator People at risk of poverty or social exclusion. Retrieved from https://ec.europa.eu/eurostat/web/income-and-living-conditions/data/main-tables.

7 No data available for Var region.

However, the French system has developed two main structures to address the lack of coordination within and between sectors: the CLIC (Local Centre for Information and Coordination) in the social sector and the Gerontology Health Network in the health sector. They represent the early beginnings of the case manager concept in France (Blanchard et al, 2009). CLICs were introduced to rethink our provision (home support policies) and to strive to make it more coherent through the creation of gerontology coordination network organizing the linkages in national provision from local level upwards (Ministere de l'Emploi et de la Solidarité, see Somme and de Stampa, 2011). Kodner and Kyriacouc (in Somme and de Stampa, 2011) describe the role of CLICs as providing help to the elderly in daily life in terms of care, personal support, quality and user-friendliness of the built environment and social, cultural, civic life. They should reinforce the links between professionals at clinical and service levels by providing a single-entry point function and by creating a framework of joint responsibility between the main stakeholders. However, as Somme and de Stampa (2011) warn, the state withdrew from funding in 2004 and CLICs were assessed as unsatisfactory in achieving their goals. Gerontology Health Network was designed to promote access to care, coordination, continuity and the interdisciplinary work of those responsible for health. The gerontology health networks are mainly focused on the clinical level, to provide better connection between services and the needs of the elderly, and create multidisciplinary teams of nurses and geriatricians for older persons with complex needs. There is, however, a lack of GPs participation and significant competition between care providers.

An important part of French system are case managers, who address the needs of the elderly with complex health situations. The purpose of this method of action (abbreviated as MAIA) is the integration of care and assistance services in the field of autonomy, which makes it possible to provide an open, harmonized, comprehensive and adapted response to the needs of older people and their caregivers, whatever the situation. MAIA is based on a coordination-type model and has six components:

- Coordination between stakeholders
- The case management process
- A single entry point
- Standardized multidimensional assessment
- An individual plan
- A shared information system.

Informal carers

Informal carers are called "natural helpers" so they are considered more as "co-workers" then clients whose needs and preferences should be acknowledged and answered. They have no voice in the assessment process and cannot apply directly or respite care. Even if it is acknowledged that their health may be at risk, they are "morally blamed" if they refuse to intervene in the caring process. Consequently, little support used to be given to help them reconcile work and caring. In general, flexible working arrangement are not formally authorised or favoured by firms, even if carers may take work leave in order to care. In case of terminal illness, informal carers are entitled to a paid work leave, but only for 3 weeks. The care provided by formal carers is also usually not coordinated so the family will frequently be forced to take the role of "informal coordinator" with a weak legitimacy and thus with very little support from professionals (Naiditch, 2013).

According to civil code, children also have the legal obligation to furnish economic support in case their genitors are financially needy. The "family and social action code" stipulates that the state shall assume responsibility and substitute for the family only if the latter can prove their inability to pay (Naiditch, 2013).

According to the Wave 6 of Survey of Health, Aging and Retirement in Europe (SHARE), there are 7% of French (aged 50 or more) providing informal care daily and another 7% providing it weekly (OECD, 2017b).

Disparities and concerns in the process of home care

Discrepancies between theory and reality are relatively important in France. Although any client can apply (in many ways) for home care, there are important differences in the information people have regarding their rights but also in how the overall system functions. Furthermore, the process of assessment is not conducted reliably at the national level although teams use the same instrument. Therefore, old persons with comparable needs may be granted different levels or types of care while not all clients generally receive the care that they are entitled to as some restriction applies when informal carers are potentially present. There are large social inequalities in home care as financial incentives are biased toward the rich and the latter are also more flexible in using services at their will (Naiditch, 2013).

Surveys have also shown that for APA recipients with the highest disability level, the care plan does not cover their real needs. Therefore, some services may not be delivered unless gaps are filled by subsidies (e.g. from General Councils) other than APA. Next to a lack of financial resources, there are shortages in professional human resources, entailing unmet needs for persons with no informal carers in their families or/and communities. In some areas, there is also a lack of home help and care agencies, leading to obstructions in timely hospital discharge (Naiditch, 2013).

Current concerns are numerous and relate to at least six domains:

- Insufficient funding
- Poor assessment instruments
- A lack of equity due to territorial disparities in home care services provision and financial access
- A shortage of qualified workers, related to difficult working conditions and low levels of remuneration and social recognition
- A lack of quality monitoring
- A lack of informal care support (Naiditch, 2013).

2.4. Slovenia (the Coastal-Karst region)

Slovenian social security system is based on the Bismarckian model. The system of health insurance consists of compulsory health insurance, voluntary health insurance for additional coverage, and insurance for services that are not a constituent part of compulsory insurance. The compulsory health insurance scheme covers the whole population, either on the basis of employment and self-employment or residence (insured persons and their family members).

The health care system in Slovenia is the responsibility of the state (the Ministry of Health). The state, through legislative and executive bodies, has administrative and regulatory functions. They are currently principally responsible for granting concessions to private health care providers who wish to work within the publicly operated primary health care system. The Slovene health care system remains relatively centralized and the responsibility of local communities is still limited. All administrative and regulatory functions of the system take place at the national level. Primary health care services are organised locally, so that they are equally accessible to all people. Both public and private care providers deliver primary health care. Among public providers there are health care centres and health stations. There are 64 health care centres, which are responsible also for ensuring and providing home nursing. The municipality is the founder of health care centres (outpatient clinics), which operate on the primary health care level. Within each health care centre, there is a special department of community/family nursing, with the aim to perform preventive and curative health care to the entire population. It works according to the regulations on the implementation of the preventive health programme at the primary health care level. The elderly are visited at home by nurses, when the physician prescribes the visits. In addition, nurses can

preventively visit elderly patients with chronic diseases or the socially impaired elderly twice a year. Nurses can autonomously decide to perform these two visits.

The social care system is the responsibility of the state (the Ministry of Labour, Family, Social Affairs and Equal Opportunities) and municipalities. The ministry is responsible for policy making, legislation, the administration of various benefits as well as for the payment or co-payment of the benefits. Social care services are, as mentioned, partly financed from state and municipal budgets, and partly paid by the users (recipients and their families). Out-of-the-pocket payments for social care services depend on the financial situation of a person in need.

General statistics

In 2014, Slovenia spent 24.1% of GDP on social protection (Eurostat, 2014). Health expenditure as a share of GDP accounted to 8.6% (out of which 2.4 percentage points is voluntary/out-of-pocket payment) in 2016 (OECD, 2017a). The need for care is already high, and it will only increase in the following years. Slovenia is one of the countries where demographic changes are most prominent and old age dependency ratio for 2050 is higher than EU-28 average (50.9) (Eurostat, 2018).

Healthy life expectancy at birth for females in Slovenia was 57.9 years in 2016, and 58.7 years for males (Eurostat, 2017).

Behavioural risk factors, related to smoking, alcohol consumption and obesity are similar to OECD average (OECD, 2017a).

On average, Slovenia has 2.8 physicians and 8.8 nurses per 1.000 persons. The number of nurses is similar to OECD average (9.0), while the number of practising physicians is significantly lower (3.4) (OECD, 2017a).

Most OECD countries conduct regular health surveys which allow respondents to report on various aspects of their health. A commonly asked question is "How is your health in general?" Despite the subjective nature of this question, indicators of perceived general health are a good predictor of future health care use and mortality (Palladino et al, 2016 in OECD, 2017a). In Slovenia, 64.8% of population perceive they are in good or very good health (OECD, 2017a).

According to Eurostat, there were 22.4% of population at risk of poverty or social exclusion in EU-28. The percentage is lower in Slovenia (17.1%) and low in the western parts of Slovenia (14%)[8] (Eurostat, 2018).

The employment rate of women is slightly above average in comparison to EU-28 (69.7% in 2017 compared to 66.5% in EU-28) (Eurostat, 2018a)). The unemployment rate in 2017 (November) for EU-28 was 7.3%, while in Slovenia it was 5.7%.

Home care

In Slovenia, governance on home care is fragmented. Partly, this is due to many different types of home care, i.e. domestic aid, social servicing, home nursing, family care assistance, personal assistance and tele-care (social alarms). Furthermore, the responsibility is split over two ministries. Home nursing falls under the Ministry of Health and is governed by the Law on Health Care Provision and Health Care Coverage, and Health Insurance Act (Genet, Smolej, Boerma, 2013). Personal care, domestic aid and social care, encompassing all other home care services, are the responsibility of the Ministry of Labour, Family and Social Affairs (MLFS) and are governed by the Social Security Act. Home care is a policy objective in Slovenia as far as personal care and domestic aid are concerned. The Slovenian government

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8 See the indicator People at risk of poverty or social exclusion. Retrieved from https://ec.europa.eu/eurostat/web/income-and-living-conditions/data/main-tables.

aims to stimulate programmes and services enabling old people to stay in their own environment as long as possible (Genet et al, 2013).

Home nursing (also preventive home visits) and technical aids are funded through compulsory health insurance and, in case of some technical aids, through co-payments. The basic costs of municipal health care centres are partially paid by municipalities. Social home care is mostly financed through municipal budgets and out-of-pocket payments and, additionally, by the state budget and charitable organisations (through donations and voluntary contributions). Municipalities are legally obliged to subsidise social home help for at least 50% (Genet et al, 2013).

Coordination and integration in home care

Formal coordination between different types of home care services is practically non-existent. Coordination between hospitals and the community services takes place via hospital social workers referring patients to home help or home nursing services. In small municipalities some old people's homes provide social home help. Social home help providers are also obliged to prepare the recipient for institutional care when necessary (Genet et al, 2013).

Care coordination is, however, anticipated in the law of long-term care that is currently being prepared in Slovenia. Predicted care planner will perform different tasks regarding the planning of long-term care, advising users and relatives, cooperation between different service providers, preparing an individual care plan, monitoring the implementation of the individual plan, offering support and help with the choosing of service providers, and similar tasks.

Informal carers

Informal carers assigned as family assistants can be compensated for their lost income, build up a pension and get a health insurance. Support services that are partially funded by the government are counselling and advising family carers and self-help support groups.

According to the Wave 6 of Survey of Health, Aging and Retirement in Europe (SHARE), there are 9% of Slovenians (aged 50 or more) providing informal care daily and another 5% providing it weekly (OECD, 2017b).

Disparities and concerns in the process of home care

Client pathways to home care depend on which type of care is needed. The application process for home nursing differs from the one for social home care. Furthermore, patients leaving hospital may be helped with application while in other cases they may not. There may also be differences across municipalities. Some services are not available (to the same extent or price) in all municipalities. Especially in rural areas these services may not be available. The following major problems can be identified in home care in Slovenia:

- Inability to cover currently identified needs.
- A lack of public funding for essential services.
- Geographical inequality regarding prices for social home help and social servicing
- A lack of structural coordination between the types of home care, in particular between the social and health care sector. These are governed by different organisations and programmes.
- The insufficient quality of care as a result of a lack of human resources and overburdened workers (Genet et al, 2013).

3. Methodology

In selected Alpine communities, the project validated a model of transnational governance of processes required in the fields of healthcare, prevention, care coordination and active ageing. The Alpine area, characterised by significant differences in health care models and cultures, was an ideal area to test a simple concept: a model of care that maximises the effect of human relationships between older people and dedicated professionals.

3.1. Micro level analysis

Micro level data equals information collected at the level of **individual respondents**. The data collected had two purposes: on the one hand it was used for the assessment of the needs and abilities of the individual, and on the other hand, it was suitable for evaluation purposes.

The mixed method was used when collecting data on the individual level. Mixed method research is a research design with philosophical assumptions as well as the methods of inquiry. It focuses on collecting, analysing and combining quantitative and qualitative data in a single study. Its central premise is that the use of combined quantitative and qualitative approaches provides better understanding of research problems than either approach alone (Creswell and Plano Clark, 2007). It refers to the application and combination of qualitative and quantitative data, where quantitative data include close-ended information and qualitative data open-ended information.

In the study, the embedded design was used (Creswell and Plano Clark, 2007): **QUAN (qual),** which indicates that qualitative methods are embedded within a quantitative design; a qualitative dataset provides a supportive, secondary role in a study, based primarily on the quantitative type. In impact evaluation, a two-phased embedded experimental model was used.

Picture 3: Two-phased embedded experimental model
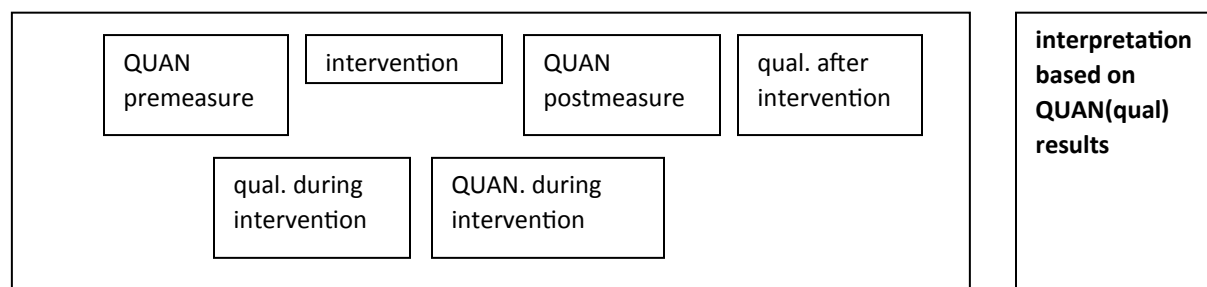
The data on the individual level was collected through the CONSENSO app, individual plans and interviews with clients.

3.1.1. The "CONSENSO app" and datasets

In the beginning of the project, the CONSENSO app was developed by a partner, Accademia Nazionale di Medicina (ACCMED). The CONSENSO application was developed for tablets used by FCNs, where key data on clients were collected. The CONSENSO app was launched in December 2016 and tested for some months at the beginning of 2017 by all FCNs, in order to correct bugs and refine the final version. After some meetings and debates with the app users, underlining the pros and cons faced during the

experimental phase on the field, ACCMED slightly altered the logic of the software and modified the database structure to meet new emerging needs. The final app was composed of the following six parts:

- Clients (data on the elderly)
- The first visit, the first interview
- An individual action plan (described in the following subchapter)
- Visits
- Events
- The closing interview.

Despite the fact that our goal was not to collect too much data and overburden our clients and nurses, the datasets turned out pretty long and complicated. The key reason for that was simply a very ambitious project application and the sheer number of activities and outputs. This fact did not allow enough time to extensively develop all evaluation instruments, the web application itself, its proper on-field testing and proper training of FCNs regarding common understanding of indicators and the implementation of the web app in the field. For instance, partners had less than one year for all these activities. The amount of administrative work and incoherent understanding of the indicators by nurses in different regions (as well as within the same region) led to (in some parts) missing values and incoherent data. There were also some mistakes in the process of the app development, most notably that the data for the indicators that should be measured multiple times during testing (i.e. client's life quality) copied itself from the first to the final interview. Therefore, the data in both time points were the same, and consequently the comparisons were not possible. Because of the above-mentioned reasons accompanied by the fact that the web app had several uses - it was designed also as an agenda planning tool for nurses (interventions), and not only evaluation - some data are not analysed in this report.

The data on the elderly included their gender and age, the town of residence, the number of inhabitants in the town, the place of living, the type of living, the floor, the number of steps to be climbed, the (non)availability of the elevator.

The first visit, the first interview included the place of living, the type of living, the floor where the client lives, the number of steps that they need to climb, the (non)availability of the elevator, household information, social networks and informal carers, data on individual autonomy, daily activities, socialization, the already established formal network around the client, health history, lifestyles, symptoms, frailty, the use of aids, personal wellbeing, the source of income. On one hand, these data were used for evaluation purposes, and on the other (and more commonly), to record clients' needs (which was mainly used by FCNs).

Visits and events were developed in order to record all activities of a nurse that were implemented in addition to the first and the final visit - all the visits in between (visits), telephone calls (events), coordination activities and all other work that was done by FCNs. This part was not communicated enough with nurses, since their approaches to using these two parts were very different, especially the qualitative parts. However, during each **visit** they recorded the client's height [cm], weight [kg], waist [cm], fasting blood sugar value [mg/dl], diastolic blood pressure [mm/hg], systolic blood pressure [mm/hg], the BMI, a reported lack of energy, fatigue, dizziness, prolonged morning stiffness, insomnia, chronic pain, urinary incontinence, faecal incontinence, constipation, allergies, the shortness of breath during activity, concerns/ anxiety, the type of activity (direct, activation of other services, educational), pulse and the date of visit. In the case of events, it was recorded what the type of event was, who was contacted and why. However, events were rarely used by FCNs.

The closing interview, some data from the first interview were collected again (the client's wellbeing, lifestyle); the activities defined in the individual plans were assessed (for each activity, an answer had to be provided - assessed, partially assessed, not assessed).

Univariate, bivariate and multivariate analyses were performed in the report. A univariate analysis is the simplest form of analysis, where data contain only one variable, therefore we do not observe any causes or relationships. The purpose of the univariate analysis was to describe the data in different regions. A bivariate analysis is used to find the relation between two different variables. A multivariate analysis (in our case, binary logistic regression) is the analysis of three or more variables.

3.1.2. The analysis of individual plans

The idea behind the analysis of individual action plans which are an integral part of the CONSENSO app is to find out more about the activities of the FCNs and to identify the differences in the intervention by the FCNs according to different regions of the CONSENSO project. Here, it is again worth mentioning that, even though designed and promoted within project activities, in practice (and to different extents) the CONSENSO model of intervention was modified to regional and national contexts and adopted to meet the needs of each participating region. The selection of the model of intervention in the field therefore depends on broader systemic features of each country, specific development within its social and health sectors and corresponding policies, and, even more specifically, on the role of FCNs within these systems. Furthermore, intervention is determined by the selection of the sample of senior citizens included in the CONSENSO project. This is evident from the quantitative results of the CONSENSO app and should be further mirrored in individual action plans designed by FCNs for the vast majority of their CONSENSO clients.

How to design an individual action plan had been discussed throughout the CONSENSO project and especially before the pilot phase began. A common understanding of the role of an individual action plan was determined in the common training received by FCNs. In the CONSENSO, an individual action plan is defined as a tool/method for helping a client and the FCN to achieve commonly set goals. It is drafted by the FCN on the basis of needs assessment and finalised in cooperation with the client. The activities of the individual action plan consist of phrasing the client's aims, assessing the need for support, drafting suitable actions and possible support network.

In spite of this common understanding of the role, goals and design of individual action plans, a brief overview of individual action plans uncovers extreme heterogeneity. These differences in the implementation of individual action plans in practice can again be ascribed to national, regional and professional differences. From the point of view of conducting a textual analysis of individual action plans, which is the method we use, it is therefore very difficult to design a common coding system which could be applied across region-specific individual action plans and would enable the textual comparison between the plans, giving an additional comparable insight into the actions taken by the FCNs.

But first, let us shed some light on the methods enabling the textual analysis of individual action plans.

How to analyse open ended questions in the CONSENSO app is challenging on different levels. These are some of the challenges and imitations an evaluation team needed to tackle:

- The majority of the open-ended questions in the app come in the form of individual plans. As mentioned above, the plans lack a common structure and it was up to FCNs to design the plans according to their experience, skills, the model of intervention etc.
- Nearly 5.000 individual action plans were designed.
- Individual action plans are written in national languages of CONSENSO partners. This means that the textual analysis was conducted in 5 different languages (Italian, English, German, French and Slovene), making it even more complicated and challenging.

The evaluation team used the Research Software for Qualitative, Quantitative & Mixed Methods Research (MAXQDA). The goal here was to make the analysis of a huge amount of textual data possible, to

interpret it and link it to other app variables. This (in the end) enabled the evaluation team to answer several research questions:

- What are the topics most commonly included in individual action plans?
- How do individual plans differ according to the region included in the CONSENSO?
- Do individual plans answer the identified needs of the client/user of the CONSENSO model?

To be able to answer these research questions, several steps in the conduction of the textual analysis were made:

- Import all app data in MAXQDA.
- Separate variables (for instance demographic data of clients) from "code columns" (these are the open-ended segments of the app which are coded).
- Apply "stop lists" to all texts in individual plans in all partnership languages (this means that words without any informational value are identified and excluded).
- Apply "lemmatization". This function combines words with a common stem and consider them as one code. For instance: live, lives, lived. It is useless to have three codes, one for each of these 3 forms of the same root. "Stemming" consists in chopping the end of the words, so that in this case we would only have 'live'.
- The "minimum number" of characters function was applied to the remaining text. This means that words shorter than certain length have been excluded from the analysis.
- Word frequency count has also been applied. The most frequently used words in individual plans were extracted.
- Two/three most frequent word combinations were identified using the word frequency tool.
- In addition to that, the "words in context" tool was applied enabling the evaluators to further understand the context of the usage of a certain word or a combination of words.
- The most frequently used words in individual action plans were reviewed, communicated with the CONSENSO partners and code system was developed according to these words. The development of a code system "is the process of combing the data for themes, ideas and categories, and then marking similar text passages with a code label so that they can easily be retrieved at a later stage for further comparison and analysis. Coding the data makes it easier to search the data, make comparisons and to identify any patterns that require further investigation" (Online QDA 2017).

Codes can be based on:

- Themes, topics
- Ideas, concepts
- Terms, phrases
- Keywords found in the data.

In the case of the CONSENSO app analysis, the codes are based on keywords identified by the tools mentioned above. Codes are in English language and entail all corresponding keywords in all partners' languages. Codes consisting of different clusters of keywords were autocoded. This means that all (nearly 5.000) individual action plans were coded according to the same code system enabling the comparison between individual action plans and across different variables in the CONSENSO app. Here we cannot ignore the fact that this comparison is not exactly "water-proof" and methodologically rigorous. In spite of the fact that certain words and combinations of words and wording appear in different regions, this does not automatically mean that these words have the same meaning in different regions. Because of that, we have to be careful with the interpretation of the results, interpreting them only descriptively and as an additional insight into the activities of FCNs within the pilot.

Topics in individual action plans

This brings us to the following questions: "What kind of topics were most commonly included in individual action plans?" and "Do individual action plans differ according to regions included in the CONSENSO?"

The self-assessment of their activities according to the three pre-given categories of activities in the app can also be subject to different understanding of what these three types of activities mean. On the other hand, the textual analysis of individual action plans can reveal FCNs actions in more detail. The FCNs were asked to design individual action plans as a response to the needs assessment provided for each client at the beginning of the visit. The action plan is therefore seen as a response to the identified needs and should ideally be relatively structured, with clear goals, activities to reach these goals, and stakeholders or support network, which will enable the achievement of these goals. However, the general impression of the majority of the action plans in all CONSENSO regions is that they are rather short and unstructured. In the majority of cases, they are more a short summary of the assessment without a clear plan on how to address the client's needs. It is therefore hard to distinguish between the assessment and the identified needs and verify whether the actions to address the needs of the client were implemented by the FCNs or not.

For example, an individual action plan contains the phrase *chronic pain* and nothing else. It is very hard to conclude that an action was taken to address this chronic pain even though we can assume that is was. There are therefore considerable limitations to the explanatory nature of individual action plans textual analysis. Nevertheless, the plans do shed more light on FCNs' interventions, their perceptions of the importance of certain topics and how they have addressed the assessed needs of their clients.

The key words (and the combinations of key words) in all individual action plans were coded using the code system developed on the basis of the CONSENSO model, NANDA classification of nurses' diagnoses, insights gained from FCNs in focus groups and reading a randomly chosen sample of plans. It is this process, which has resulted in the code system consisting of 8 codes (and several sub-codes):

- Contacting
- Informing
- Monitoring
- Measuring vital functions
- Support
- Management
- Promotion
- Teaching/instructing/educating.

These codes represent a substantial part of individual action plans activities and should reveal how the FCNs understood and implemented their interventions as well as whether they responded to the needs of their clients and the characteristics of the regional samples of the elderly included in the CONSENSO. As we have already emphasised, the codes can still be too regionally specific and can mean different

activities in different regions. This is the reason we tackle the analysis with these limitations in mind and use the results only as an addition to qualitative results.

3.1.3. Interviews with clients

Interviews with clients were performed in all CONSENSO regions at the end of the piloting (in 2017). The general focus of the interviews was on gathering in-depth insights into users' personal experiences with the CONSENSO, changes during the project, and the assessment of FCNs' activities which have or have not led to desired results defined in the individual plan. More precisely, the interviews complement the study with users' perspectives. Interviews, as a qualitative method of research within the CONSENSO, identify benefits on all three levels: micro (users' perspectives), mezzo (the evaluation of FCNs' activities) and macro (CONSENSO integration within health and social care systems in each region). A manual was prepared in order to ensure similar interviewing process in all regions.

The target group for interviews were the elderly involved in the CONSENSO who differed in age, socio-economic status, health condition, and had (un)successful treatment in regard to their actual or potential issues. In Carinthia region, 9 elderly persons were interviewed, 10 in Slovenia, and 10 in Piedmont, Liguria and Provence-Alpes-Cote D'Azur, respectively. In all regions, the selection of the elderly followed the following procedures: a) the FCN selected the client according to the suggestions in the CONSENSO interviews manual, b) the FCN discussed the possibility of interviewing the client, c) if agreed with the client, the FCN suggested the date of the interview, d) the FCN informed the researcher about the selected client and the date of possible conducting the interview, e) a visit of the client by the FCN and the researcher when the latter is introduced to the client, f) the conduction of the interview where only the researcher and the client are present. The interviews were conducted in the first six months of 2018. Every interview lasted approximately one hour. All the interviews were subsequently transcribed and translated into English for analysing purposes. During the conversations between the professional and the elderly person, the planned topic often went astray, either into describing some particular events of the client's life accompanied by strong emotions or similar irrelevant facts from their life that could not help us to keep track of pre-determined objectives of the interview within the project. Quotes/stories from the interviews are inserted in the present report.

3.2. Mezzo and macro level analyses

In the CONSENSO project, the mezzo level dataset will include the information on the environment (experimental area), the stakeholders and FCNs themselves, and macro level with a focus on the national level data (the comparison of social/health/long term care systems, SHARE/EUROSTAT/OECD etc. data).

3.2.1. Focus groups with FCNs

A group of 6 to 10 persons who share common characteristics (e.g. experts working on same issue, position in the work hierarchy, same age, social background etc.) are asked about their attitudes, feelings, and experiences regarding certain topics (e.g. the CONSENSO pilot intervention). The questions are asked in an interactive group, where the facilitator uses probing questions to animate discussion.

The focus groups were conducted in all involved regions of the CONSENSO project (Piedmont, Liguria, Var, Slovenia and Carinthia) by researchers from the Social Protection Institute of Republic of Slovenia. Focus groups had been conducted separately during last months before participants finished their main work on the field. In France, two FCNs worked in the region but only one was present in the focus group. In Slovenia, 4 FCNs, 5 nurses (supervisors) and 1 external co-worker participated in the focus group. In Carinthia and Piedmont 4 FCNs participated in the focus group. In Liguria, in the beginning there were 4 FCNs, but because of personal and professional reasons only 2 attended the focus group.

The focus groups intended to explore FCNs' general and specific experiences of the project divided in different topics in the analysis: policy context and preparation, promotion, the stakeholders' network, contact with clients, the assessment phase, the individual plan, specific clients, coordination and support work, evaluation phase, app.

In all regions, the work of focus groups was based on a questionnaire that aimed to thoroughly encompass FCNs' work in pre-pilot and pilot phase of the CONSENSO. The facilitators of the focus groups followed the semi-structured questionnaire in order to provide a cohesive thread of the discussion and get as much information as possible about the main topics: policy context, stakeholders, the assessment phase, the individual action plan, the support network, the FCN's evaluation phase.

Policy context and preparation

Before FCNs started with their pilots, they had (or at least they should have had) a certain level of knowledge about the state of the health and social system in their country, especially in the region where they were supposed to work with clients involved in the CONSENSO. Whatever knowledge FCNs had possessed about their health and social system, they had trainings that provided information on a broader view of the CONSENSO on a macro level as well as specific methods for their role as FCNs. FCNs' preparation for work on the field was part of the pre-pilot phase of the project.

Promotion

Promoting the CONSENSO was an important activity of FCNs in order to involve as many individuals over 65 as possible in the project. As promotion we consider any method that FCNs have used to present and draw the project nearer to potential elders.

The stakeholders network

Stakeholders are important agents in the CONSENSO. Their roles differ within the group.

Contact with clients

This was the first step made by a FCN in the pilot phase of the project. Here we are interested in how the contact between the elderly individual and the FCN was established and how the first visit proceeded.

The assessment phase

In each region where the CONSENSO was running, the elderly had certain needs that bothered them the most. Here we highlight what kinds of needs were standing out in each region.

The individual plan

Based on the needs of the elderly, FCNs prepared individual plans to gradually meet potential or actual difficulties that their clients had to deal with. In most cases, the individual plan was formed mutually. FCNs reported how the individual action plan was agreed between them and their clients.

Specific clients

FCNs often faced complex cases either regarding health or social condition of the elderly. Specific clients, mentioned by FCNs, revealed a chosen target group or deviations of the ideal target group of the CONSENSO model in the region as well as the limits of the CONSENSO's impact of the interventional activities.

Coordination and support work

Here we discuss the core of the FCNs' role and their relationship among themselves. Their internal relationships were crucial for every step towards efficient intervention: promotion, building the stakeholders network, finding clients and so on.

The evaluation phase

FCNs trusted their perspective on their intervention, how they were organized individually or as a team, and shared their impression about the CONSENSO in general and its future potential.

The qualitative thematic analysis is based on two phases: the pre-pilot (preparatory) phase and the pilot phase; it shows the nurses' perception of different approaches and issues.

3.2.2. Stakeholder mapping and the stakeholder satisfaction survey

As already mentioned in the introductory chapter, the issue that required our attention is not just how to measure the results but how to measure the results that are attributable only to the intervention. The project's intervention was set in very complex social and economic local, regional and national environments. One of the most important parts of FCNs work was creating a support network for the client. Engaging the environment was an important part of pre-piloting activities.

The project partners therefore prepared stakeholder mapping: a broad list of stakeholders in each region, including relevant ministries, municipalities, regional authorities, national institutes of public health/social protection, centres of social work, health centres, existing nurses, representatives of (nursing) homes for the elderly, sheltered housing, providers of home help/meals on wheels, providers of other social/health services, and NGOs. Identified stakeholders were regularly notified or actively involved in project activities. Stakeholder mapping was prepared in order to prepare stakeholder satisfaction survey that was conducted twice in the end of the project, in order to find out a) whether they were notified about the project; b) their satisfaction level with FCNs and the project's idea. The whole collection of data provided the evaluators with the information on how intensively the stakeholders were included to the project.

4. The CONSENSO model

This chapter describes the CONSENSO model as anticipated during the project and agreed upon among partners.

The CONSENSO was designed for Alpine Space's rural and remote areas, which on the one hand experience more pronounced population ageing than urban areas, and are on the other hand less equipped to tackle this challenge. Lower population density and more dispersed population make it difficult to create and maintain service infrastructure (such as health care, social services, programmes, transport), which leads to reduced mobility of the elderly population, a lack of support, care, services shortages, social exclusion and poorer socio-economic conditions. The standards of service provision, generally typical of urban areas, are often not met; there tend to be fewer nurses, hospital beds and doctors, and the distances to basic care services are longer. *"The urban/rural divide in access to needed services puts older people who have lived, worked and aged in rural areas at risk of experiencing the effects of accumulated disadvantage in their old age compared to those living in urban areas. They may face higher risks of old-age poverty, poorer health status, less supportive environments in terms of access to transport services, opportunities for social participation, and access to health and care services."* (UNECE, 2017).

Community nursing has a vital role in helping older people to maintain their physical, psychological and social health and wellbeing. The quality of and success in caring for senior citizens rely on well-trained professionals. The CONSENSO's principal **objective is to allow the elderly to remain living at home as long as possible.** Through periodical visits, FCNs should evaluate risk factors, manage minor health and social needs, promote healthier lifestyles and coordinate the network of stakeholders (governmental/regional, communal, nongovernmental, informal) and their programmes, services, and activities. This holistically designed intervention approach tailored to the individual's needs **should lead to the improvement of life quality and consequently enable senior citizens to live independently at home.** The overall operating approach was inspired by **case management** and should increase the chances of a goal-oriented and structured method of working with seniors and their surrounding networks. In addition to the elderly as the main target group, relevant target group are family members or close relatives and broader community. Additional help should come from social network that includes neighbours, mayors and municipal administration, volunteers and so on.

The CONSENSO tries to respond to numerous challenges older adults are faced with in rural and remote areas with different strategies, i. e. by providing clients with better access to health and social care services, by providing information and health promotion, by searching for cost-effective service provision and access to services, by coordinating services, by improving housing and community conditions to allow clients to live at home as long as possible, and by developing volunteering and community-based initiatives to improve social integration of older population.

The CONSENSO model generally anticipated that:
- People aged 65 or more will be included to the CONSENSO project (approximately 500 per FCN).
- Nurses obtain a list of clients (65+) and cover the entire area (include every client on that list or in that area: health status was not seen as relevant).
- Nurses perform public promotional activities, send out letters/leaflets to clients and inform them about their visiting time.

- Nurses pay attention to clients' individual needs and act upon those needs, with individualized preventive activities, the coordination of care and direct actions.
- A home visit will last on average 75 minutes; additional 15 minutes were anticipated for transfer (longer visits will on one hand burden the client and on the other hand cause organizational issues).
- A nurse should pay 4 home visits per day (and also dedicate some time to daily management of information collected, agenda organisations, case discussions, integration and coordination activities, administration etc.).
- Nurses collect the data at the first interview and prepare an individual plan with clients.

The first phase in field work included the first meeting of the FCN and the client and all the consequent meetings before the setting up of an individual support plan. The initial first phase meetings are characterised by deepening the relationship among the FCN and the client (and his/her family) and building the relationship based on trust and mutual understanding. The first phase should result in:

- The analysis of client's problems and resources.
- The assessment of the situation by the FCN.
- The assessment of the situation by the client him/herself.
- The first interview.
- The identification of issues in need of urgent action.

The second phase is built around designing an **individual plan.** The plan is drafted by the FCN on the basis of the first phase (needs assessment) and finalised in cooperation with the client. The activities of the second phase should include:

- Phrasing the client's aims together.
- Assessing the need for support.
- A draft of suitable and necessary support network.

The third phase represents all activities/events which put the individual plan into action and contribute to the realisation of set objectives and goals. It builds upon and uses all benefits from previous activities such as advocating, sensitising and the engagement of stakeholders and the broader community (from the pre-pilot phase) in building an effective and efficient support network, the efforts by the client and of course the actions taken by the FCN. In this phase, the coordination and the organisational role of the FCN as well as her ingenuity in addressing the client's needs in an innovative way is the most exposed trait and presents the added value to the project and the original FCN model.

The activities of the third phase should include:

- Coordinating and interlinking different activities by different stakeholders of the support network.
- Validating the effects of achieving goals
- Validating the client's acceptance of the support.
- Validating the success of the cooperation.
- Updating or changing the individual support plan.

The **fourth phase** of the client-FCN process focuses on the evaluation of the results of the intervention. It includes assessing (together with the client) whether the actions taken by the FCN, by the client and by

the established and activated support network have been successful and have attributed to the resolution of the issues identified in the initial assessment questionnaire (first assessment phase).

5. Results

5.1. The CONSENSO app analysis (the first interview)

In this chapter, the quantitative data of CONSENSO project evaluation is presented. It includes data collected in all five pilot areas of the project (in which the CONSENSO model was implemented and tested). FCNs started their activities in late November/early December 2016 in almost all areas. The data used for this report were downloaded on 20 June 2018, when nearly all the partners already finished their pilot activities. The data uploaded to the app after this date are therefore not included in analysis.

In this chapter, only very basic data interpretation data is provided. As shown in the following figures, differences between regions and general national statistics are sometimes striking. While this is sometimes a result of methodology and a diverse understanding of different concepts/notions, it is also a result of different approaches to implementing the CONSENSO model in various regions. More thorough interpretations for each individual region, together with qualitative results and possible environmental factors are therefore presented in the next chapter.

1.1.1. The description of pilot areas

Figure 5.1: Map of the testing area of the model with basic information

VAR (FR)

Areas	6 towns in Golfe de Saint-Tropez
Total residents	13,115
Residents >65	3,001 (23 %)
FCN team	2 nurses

PIEDMONT (IT)

Areas	Valle Maira, 12 villages	Valle Grana, 5 villages
Total residents	4,536	1,863
Residents >65	1,101 (24 %)	484 (26 %)
FCN team	1 senior + 3 junior nurses	

LIGURIA (IT)

Areas	Alta Val Trebbia
Total residents	3,816
Residents >65	1,297 (34 %)
FCN team	2 nurses

CARINTHIA (AT)

Areas	Nockberge, 3 towns	SüdKärten, 4 towns
Total residents	5,960	9,807
Residents >65	1,150 (19 %)	1,961 (20 %)
FCN team	7 nurses	

SLOVENIA (SI)

Areas	8 towns & villages around Piran municipality
Total residents	18,425
Residents >65	3,500 (19 %)
FCN team	9 nurses

The testing area of the CONSENSO model covers four Alpine Space countries: Austria, Italy, France and Slovenia. From around one fifth (e.g. Slovenia and Carinthia) to one third (e.g. Liguria) of the population in all covered areas is older than 65 years. In Austria, Carinthia Region was covered by seven FCNs, more precisely they visited three towns in Nockberge and four towns in SüdKärnten. In Slovenia, eight towns and villages around Piran municipality were visited by nine FCNs (with only four of them entering data to the app and five of them providing support and counselling). Two French nurses visited six towns in Golfe de Saint-Tropez (Var). Alta Val Trebbia, eight municipalities and 82 hamlets situated across 200 square kilometres, was covered in Liguria region. In Piedmont, project activities were implemented in two areas, Valle Maira with twelve villages and Valle Grana with five villages. Activities in these two valleys were largely financed from the CONSENSO project. The project in Piedmont, however, attracted additional areas (Asti, Novara and Verbania) which joined and implemented (or, rather, are still implementing) project activities (following the same project structure/ideas) with additional (i.e. their own) funds. Nurses working in these regions were also recording data to the CONSENSO app and these were analysed together with the data from Cuneo. As a result, as seen in the next chart, clients from Piedmont amount for almost half of all the clients involved: however, this is the work of 16 nurses (two from Asti, four from Cuneo, five from Novara and five from Verbania). FCNs from Cuneo recorded altogether 598 clients.

In total, there were **4.878 clients participating in the project** in all five regions (Carinthia, Liguria, Piedmont, Slovenia, Var) combined. There were nearly 4.000 clients who got their individual plan prepared (note that each client usually had more than one and up to seven plans). Especially in Italian regions Liguria and Piedmont, the number of clients with individual plans prepared by FCNs is noticeably lower than the initial number of the clients involved.

Figure 5.2: Number of individual plans vs. the number of clients involved, by region
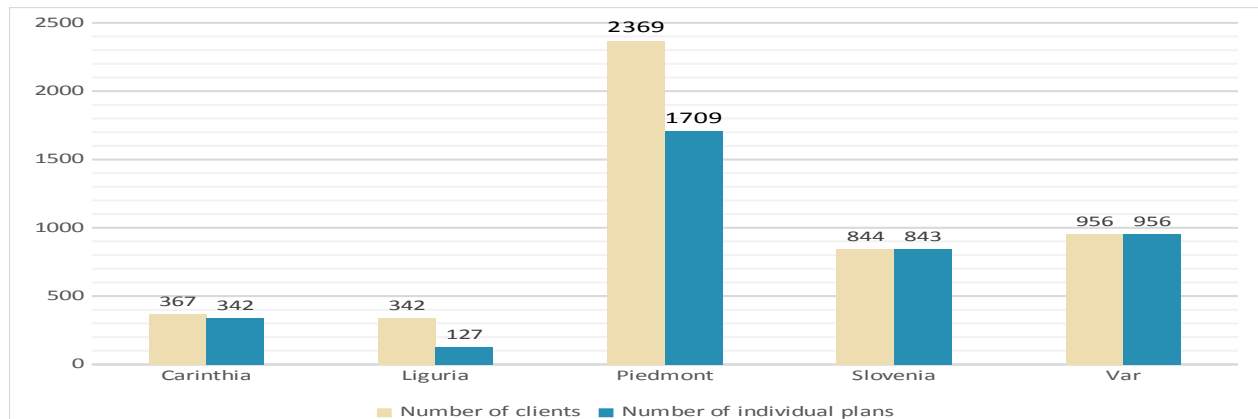
Figure 5.3: Percentage of clients participating in the project, by region (N: 4.878)

33
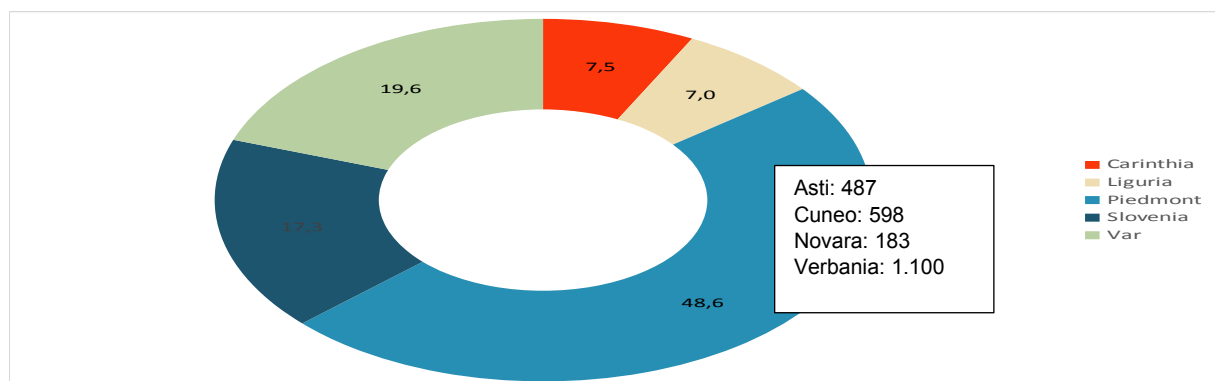
Altogether, **31 nurses were actively implementing CONSENSO activities**. Each nurse, on average, visited 157 clients and performed 340 visits. The average number of clients per nurse and the average number of visits per nurse were highest in Var. The average number of clients per nurse was lowest in Carinthia and the average number of visits per nurse was lowest in Liguria.

Figure 5.4: Average share of clients per FCN & the average share of visits per FCN, by region
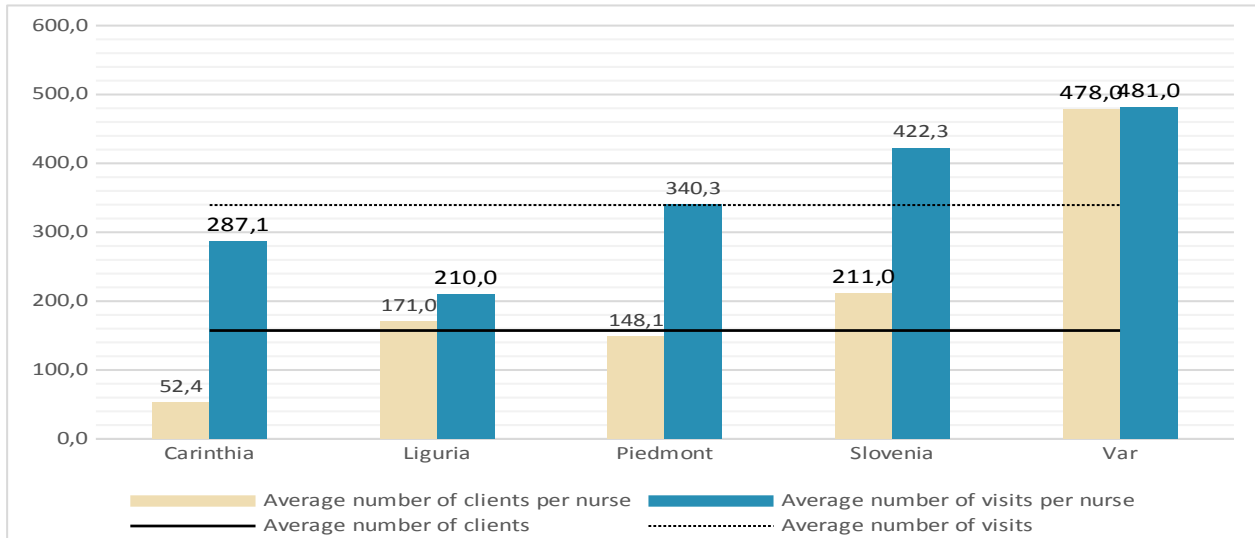
1.1.2. Visits to clients

The total number of visits by FCNs in all five regions combined was 10.526. More than half of the visits were recorded in Piedmont (5.445), followed by Carinthia (2.010), Slovenia (1.689), Var (962) and Liguria (420). The visits consisted of direct activities[9], activation/coordination of other services[10] and educational/preventive activities[11] (single visit did not necessarily include all three). On average, the number of visits significantly exceeded average in Carinthia (nearly six visits per client). On the other hand, the elderly in Var were visited just about once on average.

Figure 5.5: Average number of visits to clients (with minimum and maximum number of visits), by region

(N1=2.010, N2=420; N3=5.445; N4=1.689; N5=962)

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9 Activities performed by the nurse herself (managing minor health and social needs).

10 Contacting/involving other stakeholders in order to manage the identified need, coordination of stakeholders.

11 Different types of prevention, counselling, health education etc.

Generally, the visits containing direct activities were prevailing. Nearly 90% of visits contained some sort of direct activity by the nurse. However, vast differences are seen among regions. Var and Slovenia stand out with more than 85% of visits that included prevention. Activation/coordination of other services was most frequent in Carinthia and Var (in more than 13% of all visits), while it was rare in Piedmont and Slovenia (with only around 3%).

Figure 5.6: Type of visits, by region (%)
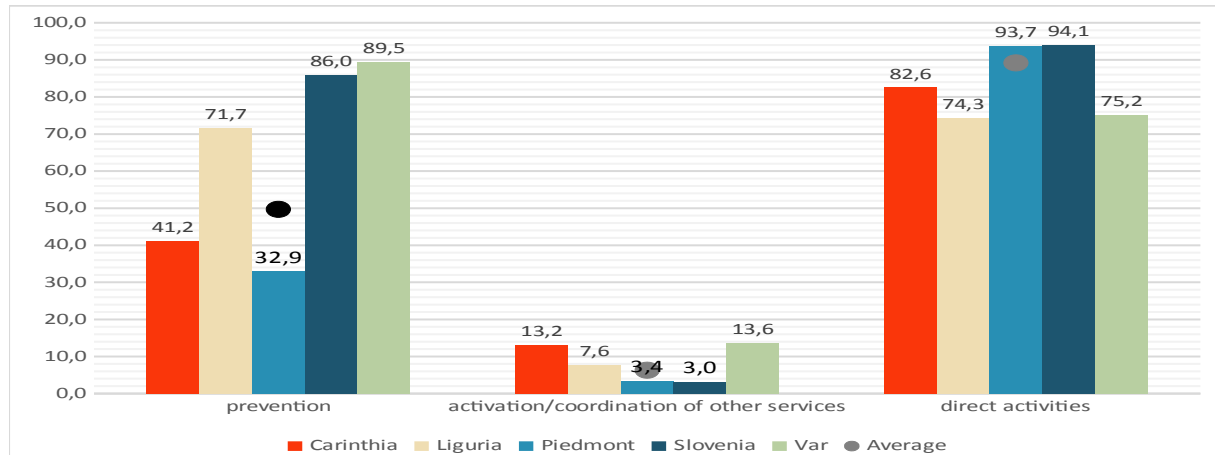
(N1=2.010, N2=420; N3=5.445; N4=1.689; N5=962)

1.1.3. The basic demographics of participants

Looking at the overall demographics, there were more female than male clients (58.8% and 41.2%). For 36 clients no gender was selected.

Figure 5.7: Percentage of clients, by gender (N: 4.842)
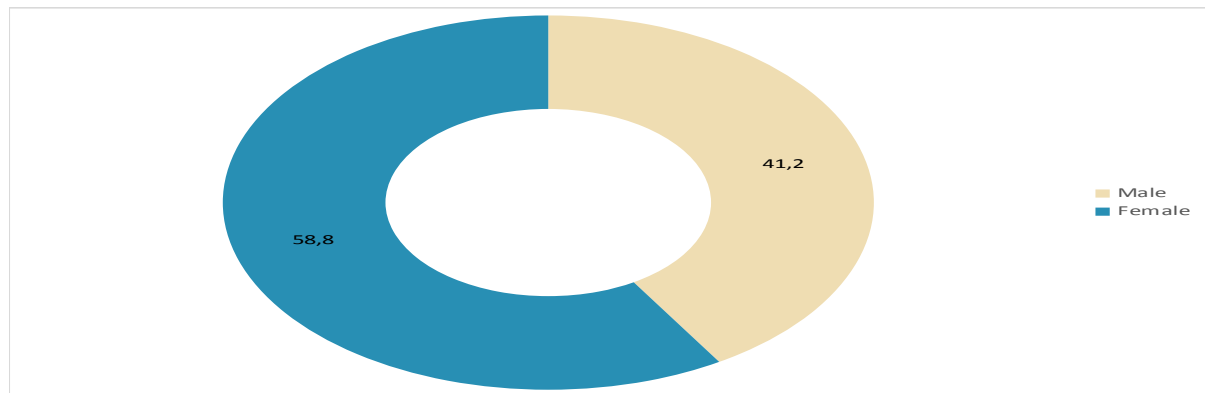
The ratio of female and male clients participating in the project does not differ vastly among the five regions, with a larger share of female clients (above half of all elderly persons involved in Liguria vs. almost two thirds in Slovenia) compared to male clients.

Figure 5.8: Gender of clients involved (%, by region)
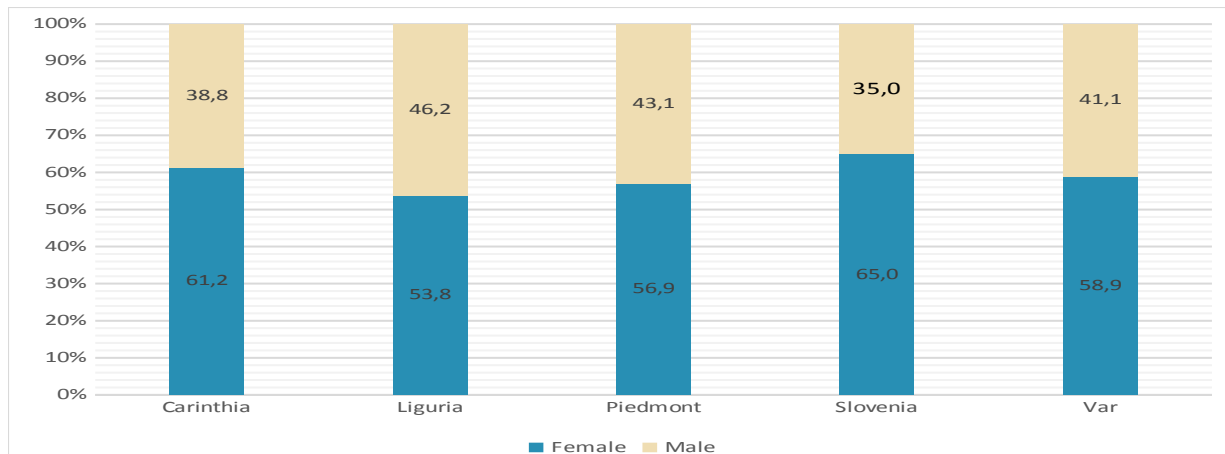
(N1=361, N2=342; N3=2.361; N4=842; N5=936)

The average age of clients is 77.25 years, with a median of 77 years of age. Youngest client was 60 years old, while the oldest was 104 years old. Majority of clients is between 65 and 87 years old. Approximately 2% of clients were 60 – 64 years old.

At almost 79 years of age, clients in Carinthia were the oldest, while the elderly in Slovenia were the youngest (on average 76.7 years).

Figure 5.9: Age of clients participating in the project, by region (average, min, max)
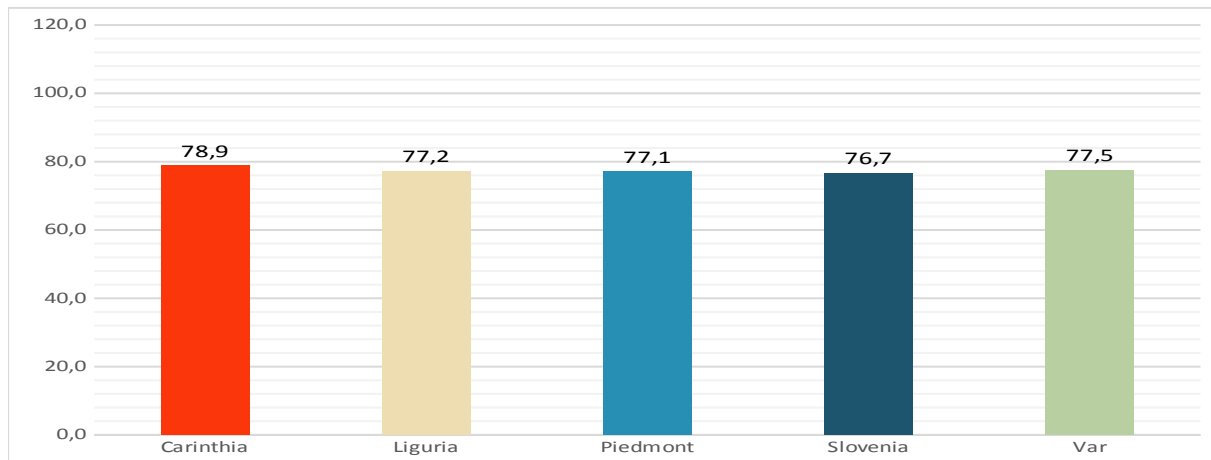
(N1=366, N2=340; N3=2.362; N4=843; N5=955)

The majority of clients lived in isolated houses or groups of houses (up to 100 residents), except in Slovenia where 85% of clients participating in the project lived in villages or towns with more than 100 residents. Slovenia stands out with a different geographical setting (coastal, lowland region) of the area covered by the visiting FCNs. The elderly in other regions (other than Slovenia) live in smaller settlements (which are often difficult to access), at high altitudes with hilly or mountain surroundings.

Figure 5.10: Place of living by number of residents, by region
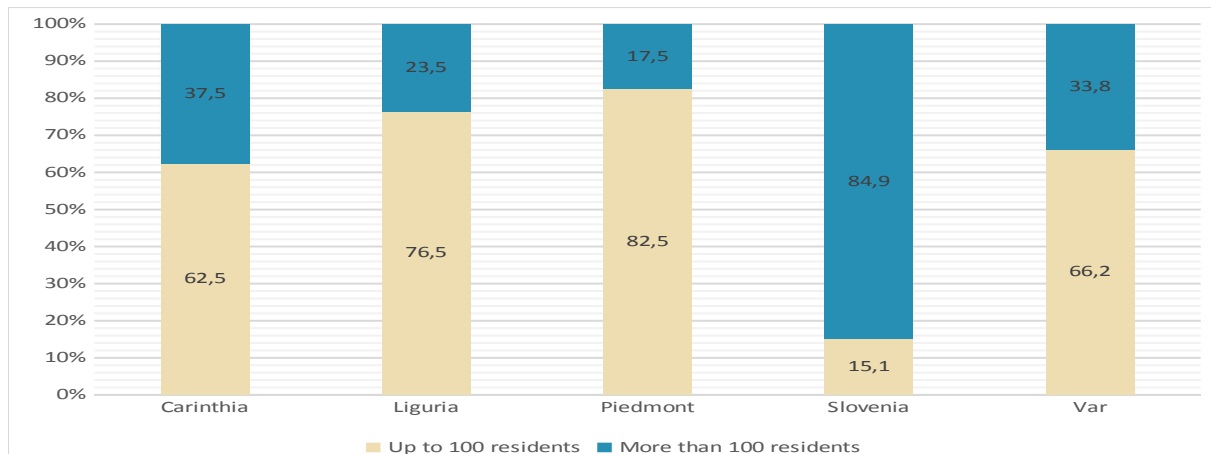
(N1=360, N2=336; N3=2.334; N4=829; N5=943)

The majority of the clients lived in houses (81.6%). The percentage is below average in Slovenia (64.7%) and in Liguria (69.8%), where more clients live in apartments than in other regions. Carinthia stood out with nearly five percent of clients that lived in alternative housing options (e.g. guarded apartments).

Figure 5.11: Type of living, by region
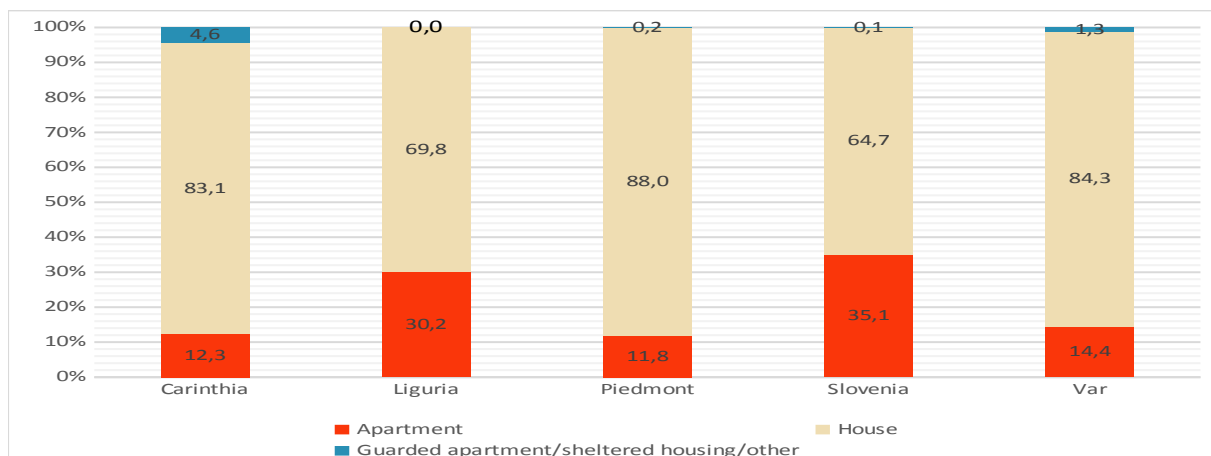
(N1=349, N2=328; N3=2.320; N4=828; N5=932)

More than a half of all elderly persons (on average 57.7%) participating in the CONSENSO were married or living in a domestic partnership. On average nearly one third (30.1%) of them were widowed, while single or divorced clients were in minority. Slovenian clients less often lived alone in comparison to other countries. The elderly from Liguria more often identified themselves as a single (13.2%).

Figure 5.12: Marital status, by regions (%)
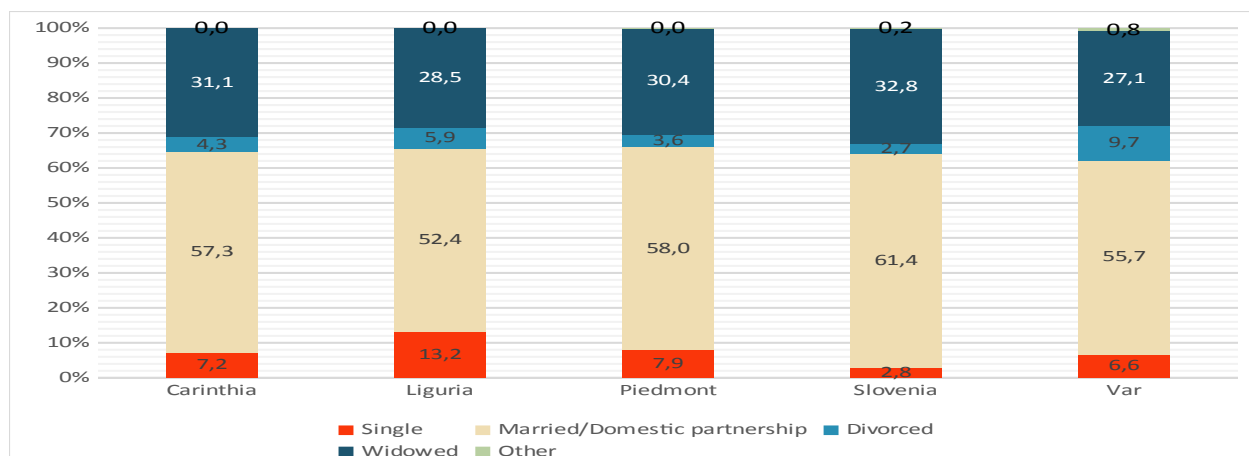
(N1=347, N2=340; N3=2.353; N4=822; N5=954)

Most of the clients completed no formal schooling, while only about 10% of clients had post-secondary education or more. Surprisingly, two thirds of clients in Piedmont (67.4%) and more than a half in Liguria (56%) did not complete formal schooling of any kind. In the five regions, primary education was the highest level achieved by around one fifth, except in Liguria, where primary education is the highest educational level achieved by more than a quarter of the elderly involved. The elderly in Var reported the highest levels of educational attainment with 14.1% of clients with post-secondary non-tertiary education and 29.4% with short cycle tertiary education or more.

Figure 5.13: Highest educational level achieved, by regions (%)
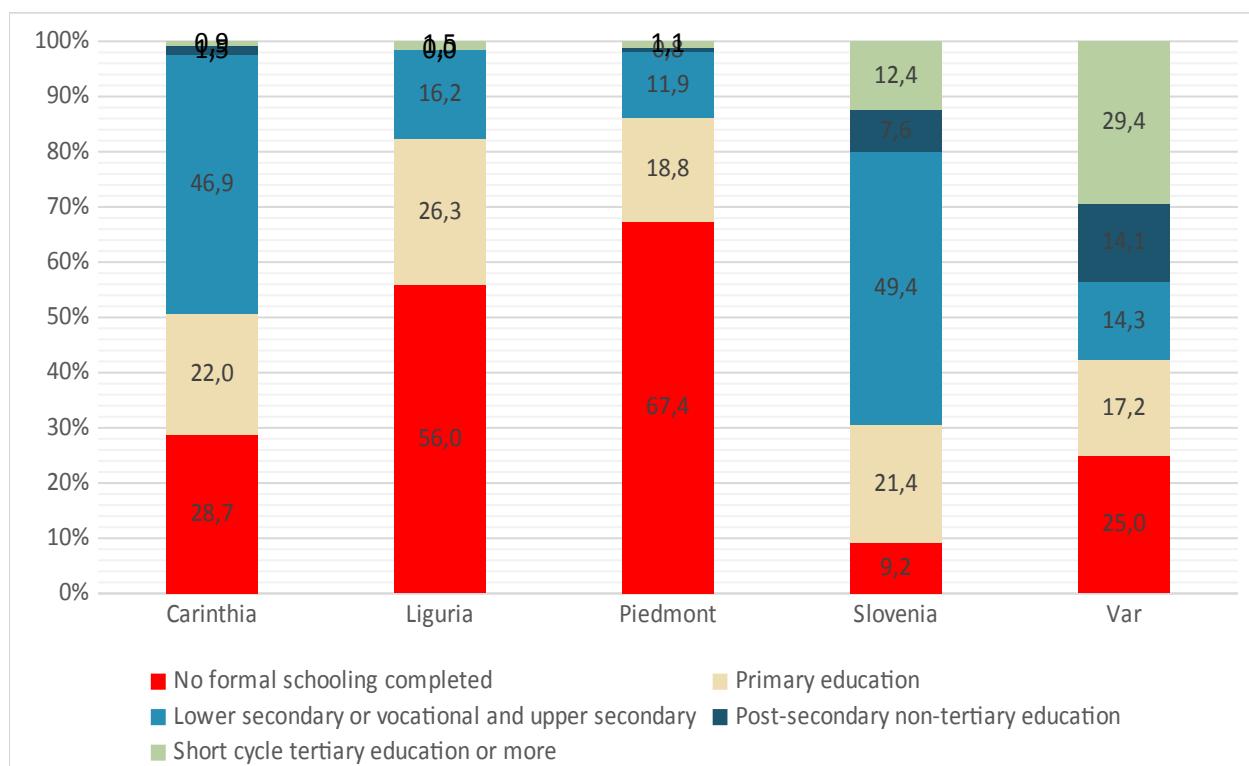
(N1=341, N2=327; N3=2.271; N4=709; N5=841)

CONSENSO clients had from 0 (13.2%) to 12 children, on average 1.8 child. This average is the highest in Carinthia (2.5) and the lowest in Liguria (1.4).

Figure 5.14: Average number of children in clients, by region
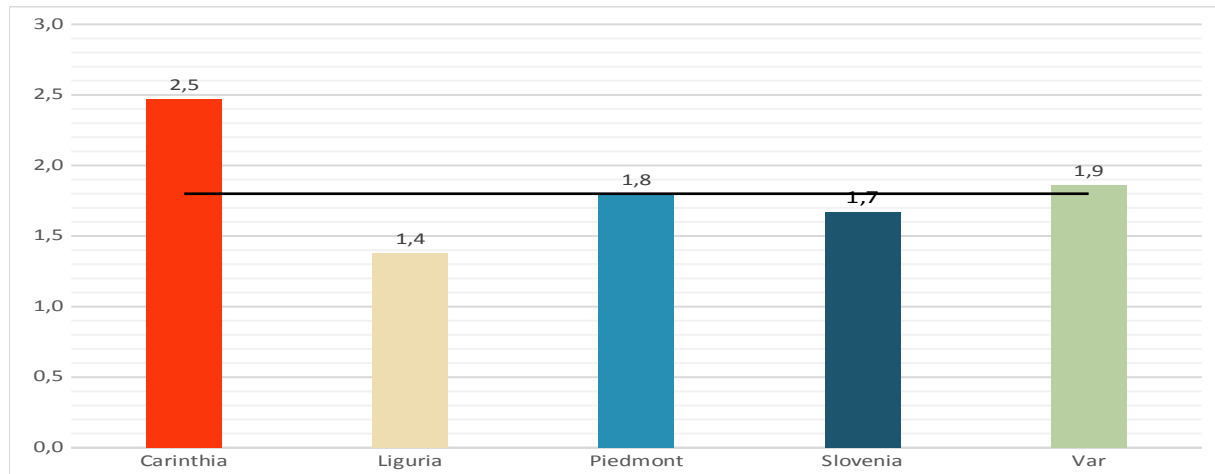
(N1=344, N2=330; N3=2.298; N4=805; N5=952)

5.1.1.   FCN activities and clients

One important part of client-FCN relationship was the design of an individual plan. FCNs and clients together selected different goals[12] (up to seven per client) that should be achieved (at least partially) during the CONSENSO project or even after its end. Towards the end of the project, clients and FCNs reviewed selected goals to see whether these were addressed/partially addressed/not addressed. Altogether 65% of goals were addressed, 19.1% were partially addressed and 15.9% were not addressed.

In Piedmont, the share of successfully addressed goals was the highest (nearly 80%), followed by Var (74.3%). In Slovenia, nearly half of the goals were not addressed.

Figure 5.15: Assessment of goals, by region (%)
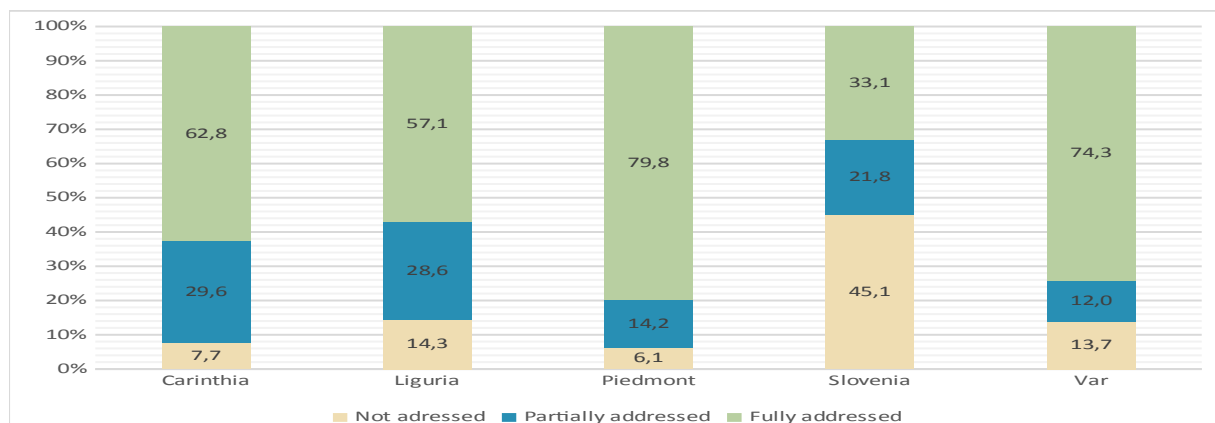
(N1=1.176, N2=42; N3=1.385; N4=889; N5=1.181)

We used binary logistic regression to predict the probability of assessing the activity as successful. Dependent variables in our case were the assessment variables with values 1 - not addressed, 2 - partially addressed and 3 - fully addressed. Variable was recoded as such: values 1, 2 into 0 - not

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12 See Methodology for methodological limitations.

addressed and 3 into 1 - addressed. Once our dependent variables were dichotomous, we randomly selected one value for each case from one of the 7 assessment variables. If an individual case had only one assessment variable that was not missing, then that value was selected. The new dichotomous variable "assessment" had now a randomly selected value from the previous 7 assessment variables for each case. We paired each assessment with a value from one of the 7 domains assessed in the closing interview. A case that had been randomly assigned a value from the fourth assessment in the closing interview was also assigned the value from the fourth domain variable in the closing interview. For the domain, variable values ranged from 1 - health, 2 - health promotion and empowerment, 3 - everyday life issue, 4 - social issue and 5 - socialization. Values 4 and 5 were recoded into a single value - social issues and socialization.

The new paired "domain" variable was our first independent variable. The rest of our independent variables or predictors in binary logistic regression were: gender, age (as interval), GP - Have you been evaluated by your GP during the past year? (yes/no), memory decline - Have you experienced memory decline during the past year? (yes/no), weight loss - Have you lost weight during the past year so that your clothing has become looser? (yes/no), walking less - Have you recently walked less because of your physical state? (yes/no), falling - Have you fallen one or more times during the past year? (yes/no), economic difficulty - have you had any economic difficulty in settling basic expenses and health care costs? (yes/no), health index with 3 values (1 - very mild or no health problems, 2 - mild health problems, 3 - severe health problems) and independence index with 3 values (1 - independent, 2 - partial help, 3 - total help).

Figure 5.16: Model of binary logistic regression
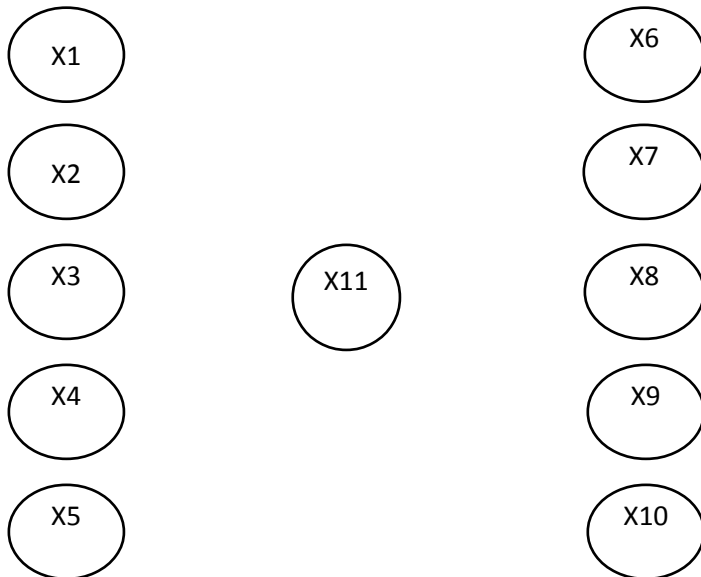
(X_1=gender, X_2=age; X_3=GP evaluation; X_4=memory decline; X_5=weight loss; X_6=less walking; X_7=falling; X_8=economic difficulty; X_9=health index; X_{10}=independence index; X_{11}=dependent variable - paired domain)

First, the binary regression was run on all countries together. Included in the analysis were 1858 cases. Nagelkerke R square was 0.12 and the classification algorithm correctly predicted 72.28% of cases. Statistically significant at the 5% level were variables age, domain 2 paired, domain 4 paired, falling and economic difficulty.

The interpretation of the coefficients is as follows: for age, each additional year increases the odds ratio of evaluating the assessment as addressed for a factor of 1.02. Clients that had **health promotion and**

empowerment assessed in the domain variable had for a factor of 2.4 higher odds that their assessment was "addressed" than those who did not have health promotion and empowerment assessed in the domain variable. Clients who had **social issues and socialization** assessed in the domain variable had by a factor of 7.1 higher odds that their assessment was "addressed" than those who did not have social issues and socialization addressed in the domain variable. Clients who **have not fallen one or more times** in the past year had for a factor of 1.46 higher odds ratio that their assessment was "addressed" than those who did. Clients that **did not experience economic difficulty** in the past year had for a factor of 1.55 higher odds ratio that their assessment was addressed than those who did experience economic difficulty.

Binary logistic regression was repeated with the same dependent variable and independent variables for each of the participating regions. For Liguria, the analysis was not possible as there were only 22 cases where the assessment variable was not missing.

In Carinthia, there were 287 cases in the analysis. Nagelkerke R square was 0.11 and the classification algorithm correctly predicted 63.07% of cases. Statistically significant were two independent variables: age and domain 2 paired. Regarding **age, each additional year increases the odds ratio** of evaluating the assessment as addressed for a factor of 1.06. Domain 2 paired was opposite to other countries, **clients who did not have health promotion and empowerment** assessed in the domain variable had for a factor 3.28 higher odds that their assessment was "addressed" than the clients who had health promotion and empowerment assessed in the domain variable.

In Var, there were 841 cases included in the analysis with Nagelkerke R square of 0.29. The classification algorithm correctly predicted 80.7% of cases. Statistically significant at the 5% level were variables domain 1 paired, domain 2 paired, weight loss, fallen and GP. For domain 1, clients who had **health assessed in the domain** had for a factor of 4.76 higher odds that their assessment was "addressed" than clients who did not have health assessed in the domain variable. Clients **that had health promotion and empowerment** assessed in the domain variable had for a factor of 12.5 higher odds than those who had not. Clients who **did not experience weight loss** in the last year had for a factor of 1.62 higher odds that their assessment was "addressed" than clients who experienced weight loss in the last year. Clients that **did not fall** in the past year had for a factor of 1.68 higher odds that their assessment was "addressed" than clients who did fall in the past year. Clients who **were evaluated by their GP** in the past year had for a factor of 2.58 higher odds of having an assessment as "addressed" than clients who were not evaluated by their GP in the past year.

In Piedmont, 484 cases were included in the analysis. Nagelkerke R square was 0.18 and the classification algorithm correctly predicted 82.02% of cases. Statistically significant at the 5% level were variables domain 1 paired and GP. Clients that had **health assessed** in the domain variable had for a factor of 5 higher odds of having an assessment as "addressed" than those who had not. Clients that **were not been evaluated by their GP** in the past year had for a factor of 4.17 higher odds of having an assessment as "addressed" than clients that were evaluated by their GP in the past year.

In Slovenia, 225 cases were included in the analysis. Nagelkerke R square was 0.17 and the classification algorithm correctly predicted 63.11% of cases. Statistically significant at the 5% level was group 1 in the health index. Comparing group 1 in health index (mild or no health problems) to our reference category of group 3 (severe health problems) showed **that clients with very mild or no health problems** had for a factor of 9.04 higher odds of having an assessment as "addressed" than those who had severe health problems.

5.1.2. Health status of CONSENSO participants

The following figure highlights *present* health issues, as reported by CONSENSO clients in different regions. Clients from Carinthia seemed to be facing health problems more prominently; in comparison to other regions, diabetes, arterial hypertension, osteoporosis, chronic renal failure, heart failure, depression, dementia, COPD, angina pectoris, and stroke were (significantly) more frequently reported in comparison to clients from other CONSENSO regions. CONSENSO clients reported different present health issues; nearly half of all clients participating in the project reported having arterial hypertension (49.3%); the percentage was highest in Carinthia, followed by Liguria, and lowest in Slovenia, as demonstrated in the following figure. Almost 40% of all clients also faced visual disturbances (38.3%), the problem was most prominent in Slovenia (53.1%). More than every fifth client (22.6%) was facing hypercholesterolemia.

Figure 5.17: Percentage of clients reporting the present issues with listed diseases, by region

	Carinthia		Liguria		Piedmont		Slovenia		France	
	N	Row N %	N	Row N %	N	Row N %	N	Row N %	N	Row N %
Diabetes	92	25,1%	47	13,7%	334	14,1%	121	14,3%	131	13,7%
Arterial hypertension	225	61,3%	199	58,2%	1257	53,1%	306	36,3%	418	43,7%
Visual disturbances	157	42,8%	114	33,3%	998	42,1%	448	53,1%	150	15,7%
Hypercholesterolemia	76	20,7%	108	31,6%	455	19,2%	226	26,8%	238	24,9%
Rheumatic disease	50	13,6%	125	36,5%	257	10,8%	60	7,1%	249	26,0%
Osteoporosis	82	22,3%	66	19,3%	249	10,5%	87	10,3%	62	6,5%
Stomach disease	16	4,4%	66	19,3%	223	9,4%	45	5,3%	57	6,0%
Chronic renal failure	30	8,2%	15	4,4%	59	2,5%	6	0,7%	24	2,5%
Asthma	11	3,0%	15	4,4%	66	2,8%	51	6,0%	21	2,2%
Chronic bronchitis	13	3,5%	16	4,7%	63	2,7%	8	0,9%	16	1,7%
Bone fracture	6	1,6%	5	1,5%	32	1,4%	7	0,8%	20	2,1%
Heart failure	100	27,2%	55	16,1%	305	12,9%	102	12,1%	218	22,8%
Depression	74	20,2%	45	13,2%	207	8,7%	30	3,6%	57	6,0%
Dementia	47	12,8%	15	4,4%	87	3,7%	35	4,1%	24	2,5%
Cancer disease	19	5,2%	13	3,8%	84	3,5%	32	3,8%	52	5,4%
COPD	28	7,6%	11	3,2%	79	3,3%	17	2,0%	27	2,8%
Parkinson's disease	8	2,2%	7	2,0%	31	1,3%	9	1,1%	15	1,6%
Angina pectoris	19	5,2%	5	1,5%	16	0,7%	31	3,7%	3	0,3%
Stroke	16	4,4%	3	0,9%	4	0,2%	4	0,5%	12	1,3%
Myocardial infarction	2	0,5%	3	0,9%	6	0,3%	1	0,1%	7	0,7%
TIA	7	1,9%	0	0,0%	8	0,3%	1	0,1%	2	0,2%

(N1=2–225, N2=0–199; N3=4–1.257; N4=1–448; N5=2–418)

A "health index" was calculated. Despite measuring *past and present* conditions in the CONSENSO app, we decided to take into account exclusively present conditions and drop past conditions. We decided that the information on past conditions was much less reliable for possible memory bias and because it was hard to estimate how much past conditions may still affect the present status.

The conditions were afterwards weighted. We put a weight of 2 to those conditions that may severely affect the daily life of the elderly, requiring monitoring and much more medical assistance (heart failure, depression, dementia, cancer, COPD, Parkinson's disease, angina pectoris, stroke, myocardial infarction,

TIA) and a weight of 1 to others. Therefore, when the condition was reported as a present condition, it was coded as 1 in case of a mild condition and as 2 in case of a severe condition.

Then we made the ∑ of present conditions, i.e. the ∑ of the values in each record (Arterial hypertension + Visual disturbances + Hypercholesterolemia + Diabetes + Heart failure + Rheumatic disease + Osteoporosis + Depression+ Stomach disease (ulcer, gastritis) + Dementia + Cancer + Chronic renal failure + COPD + Asthma + Chronic bronchitis + Parkinson's disease + Angina pectoris + Bone fracture + Stroke + Myocardial infarction + TIA).
Sum of weights was recoded to: 0-2 (very mild or no health problems); 3-5 (mild health problems) and 6 or more (severe health problems).

There **were 57.3% of clients with very mild or no health problems**. One third of clients had mild health problems and remaining **8.2% had severe health problems**. However, differences between regions are again striking, with Carinthia having nearly one quarter of clients with severe health issues (24.3%), followed by Liguria with 13.5% of clients with most prominent issues. Percentages were much lower in other regions (between 5 and 7%).

Figure 5.18: Health status of CONSENSO participants (%), by region
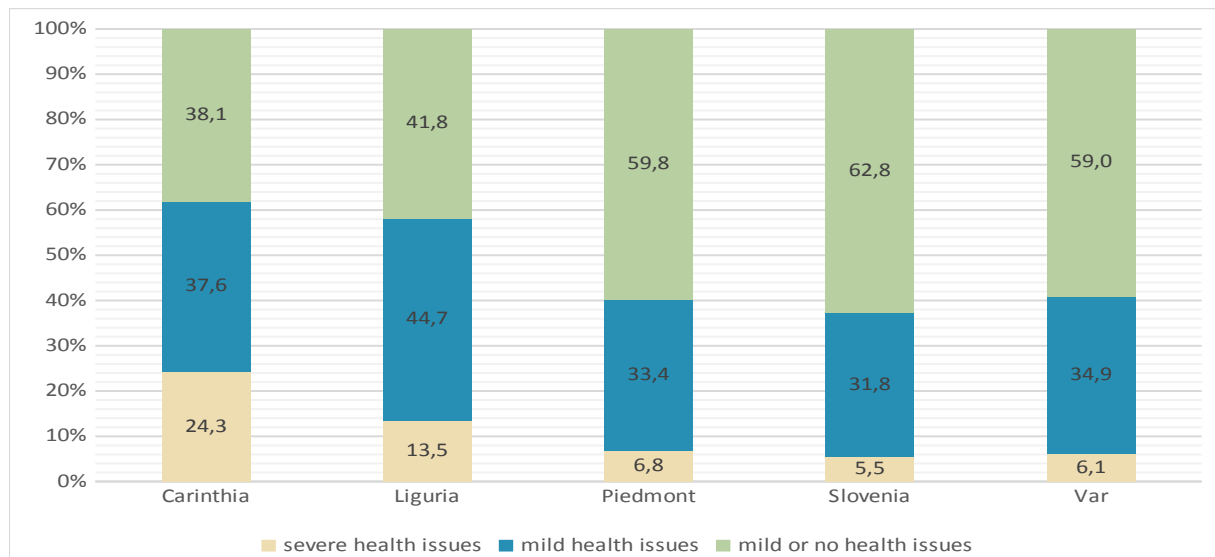
(N1=367, N2=342; N3=2.369; N4=844; N5=956)

Looking at the overall picture, male clients were slightly healthier on average, having less severe and mild health issues overall than female clients.

Figure 5.19: Health status of CONSENSO participants (%), by gender (N:4842)
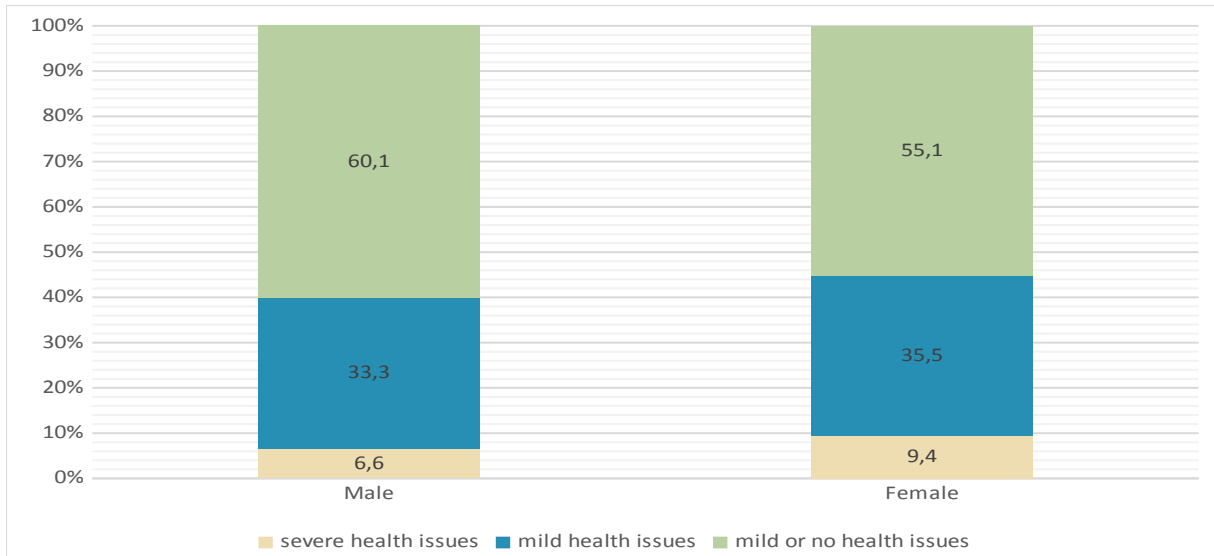
Three age groups were used when comparing differences - clients were split into groups as follows: 70 years or less (group 1), 80 years or less (group 2) and over 80 years (group 3).

Clients over 80 years of age had more severe health issues than the group of clients between 71 and 80 years of age who in turn had more mild and severe health issues than the group of clients below or equal to 70 years of age.

Figure 5.20: Health status of CONSENSO participants (%), by age group (N:4866)
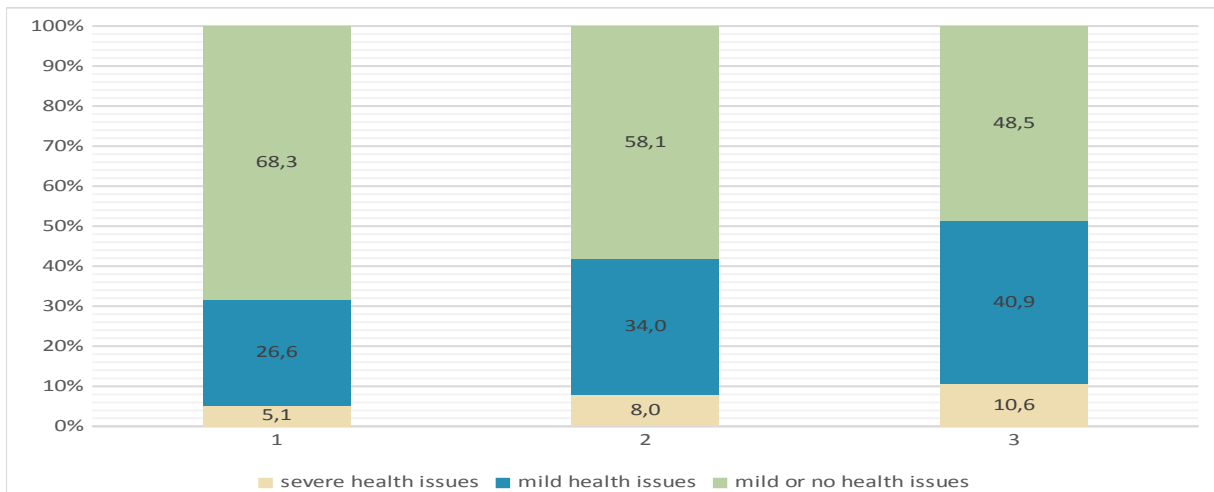
Clients with at least post-secondary education have on average less mild and severe health issues than clients with lower levels of education. Clients in the post-secondary non-tertiary education group represent the smallest overall number of clients (N: 196) and on average they have less severe health issues than any other group of clients.

Figure 5.21: Health status of CONSENSO participants (%), by education (N:4489)
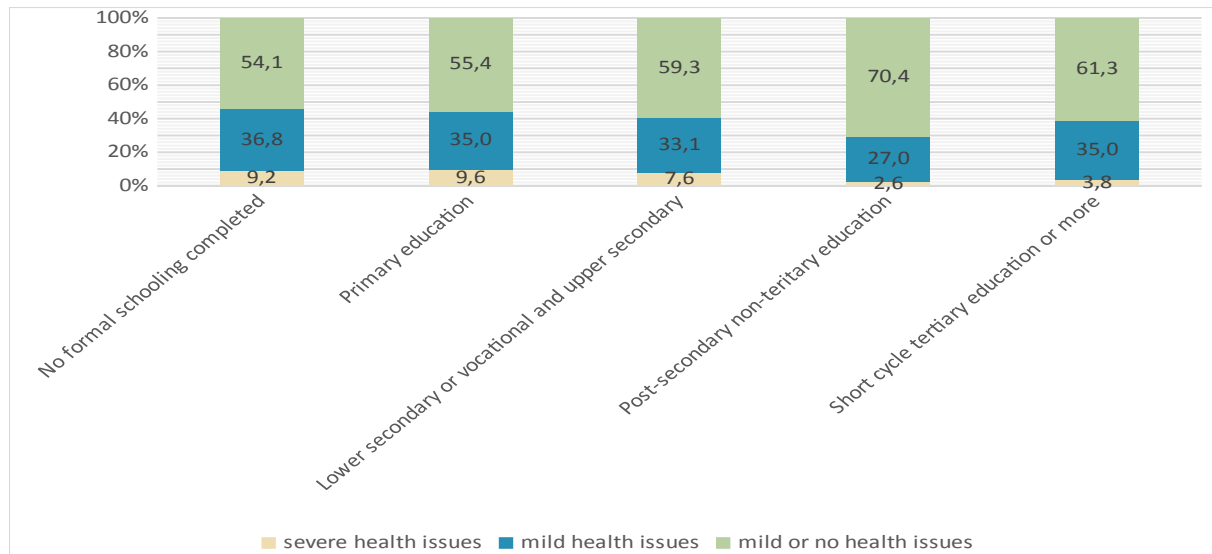
With the exception of Carinthia, where the percentage of those who use various aids stands out (except in the case of glasses), there are no major differences among other four regions. Glasses are expectedly the most common aid used by the elderly in all five areas.

Figure 5.22: Percentage of clients who use various aids, by region

	Carinthia		Liguria		Piedmont		Slovenia		Var	
	N	Row N %	N	Row N %	N	Row N %	N	Row N %	N	Row N %
Glasses	354	83,9	305	79,7	2274	86,0	822	88,3	939	91,1
Walking stick	344	38,7	259	23,2	2060	18,3	777	11,3	789	20,3
Crutches	338	9,5	238	2,5	2011	3,0	778	6,8	763	5,9
Walker	344	18,0	240	2,1	2032	4,2	771	4,3	767	6,4
Wheelchair	344	10,8	242	3,7	2028	3,7	773	1,9	762	3,0
Hearing aid	344	14,8	242	3,7	2016	6,4	777	4,6	784	9,4

(N1=344–354, N2=238–305; N3=2.011–2.274; N4=771–822; N5=762–939)

5.1.3. (In)dependence of CONSENSO participants

The following figures show clients' (in)dependence in performing different ADL and IADL activities. The compound variable was calculated in order to create a one-dimensional array of variables, related to clients' (in)dependence. The ADL activities (personal hygiene, toileting, feeding/drinking, (un)dressing, taking medication) and IADL activities (food preparation, shopping, going out for a walk or meeting) were scored with 0 (the client can perform listed activities independently), 1 (the client needs partial help in performing listed activities) or 2 (the client needs total help in performing listed activities). Since ADL activities are more complex and point to a higher level of dependence, they end up with greater weight in an index. ADL amounts to the 65.0% of the final index rating and IADL amounts to the remaining 35%.

The following two figures clearly show that the elderly in Carinthia are the least independent (with only half of them being independent in comparison to other regions where this percentage varies between 83% and 86%). The share of clients who are dependent is the highest in Carinthia (15.6%) and the lowest in Slovenia (3.3%) and Var (5.2%) (see Figure 4.24).

Figure 5.23: Percentage of independent clients in performing the following activities, by region (%)

	Carinthia		Liguria		Piedmont		Slovenia		Var	
	N	Row N %	N	Row N %	N	Row N %	N	Row N %	N	Row N %
Personal hygiene	358	61,5	317	86,4	2309	89,3	832	91,8	950	88,7
Toileting	355	84,2	314	93,3	2308	93,8	832	98,3	947	96,5
Feeding/drinking	354	88,4	313	96,8	2305	96,1	832	98,1	947	96,8
Dressing/undressing	356	68,0	313	90,7	2303	91,5	832	93,3	947	90,7
Food preparation	357	47,3	319	80,6	2301	84,4	831	86,4	946	85,7
Shopping	355	38,9	315	73,7	2306	74,5	831	68,7	946	78,0
Go out for a walk	349	67,9	314	84,4	2294	86,4	828	88,5	935	82,3
Taking medication	354	60,5	314	82,8	2294	87,2	825	93,2	946	89,9
Reading	340	84,7	309	89,3	2276	94,2	827	97,8	935	97,3

(N1=340–358, N2=309–319; N3=2.276–2.309; N4=825–832; N5=935–950)

Figure 5.24: Independence index (percentage of clients who are dependent, somewhat dependent and independent), by region (%)
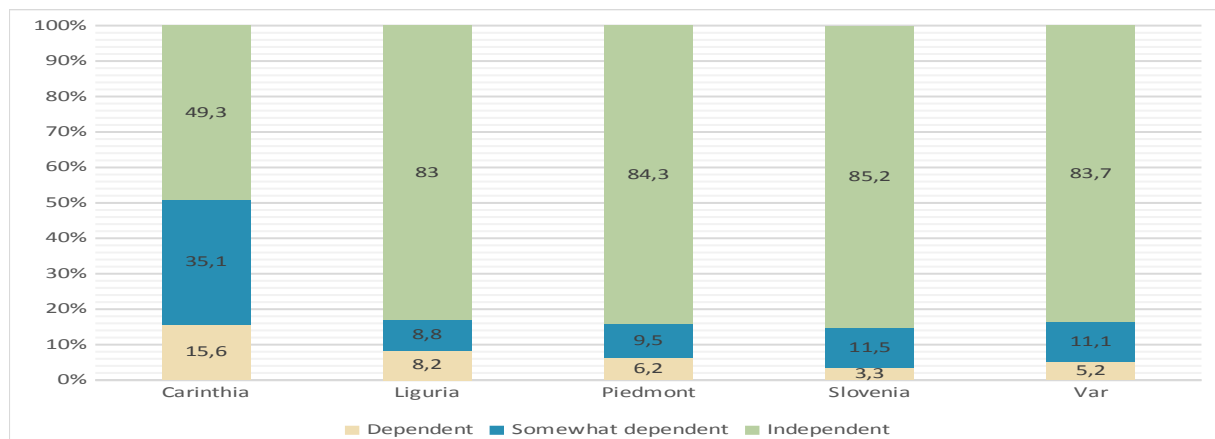
(N1=339, N2=306; N3=2.283; N4=823; N5=932)

Looking at the comparison between male and female clients we can see that male clients are on average slightly more independent (82.9% compared to 80.8%).

Figure 5.25: Independence index (percentage of clients that are dependent, somewhat dependent and independent), by gender (%) (N: 4649)
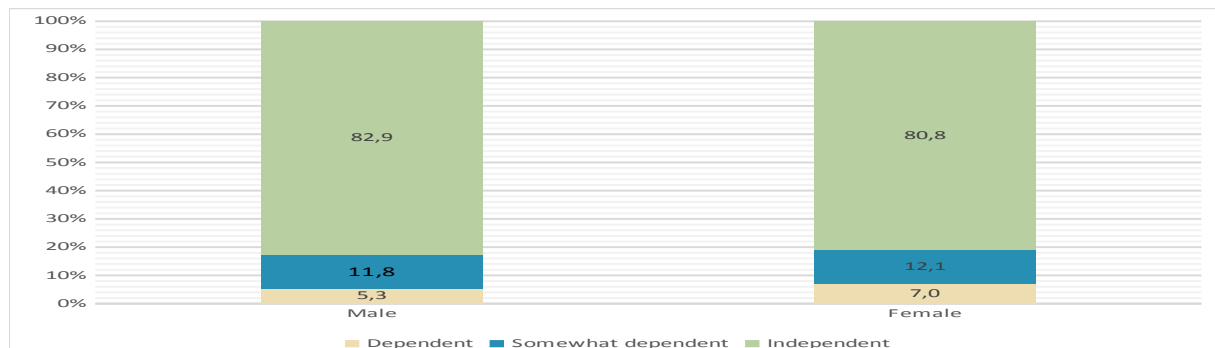
Three age groups were used when comparing differences - clients were split into groups as follows: 70 years or less (group 1), 80 years or less (group 2) and over 80 years (group 3).

Evaluating independence index based on age groups we can see that the differences between groups are significant; 95.2% of clients aged 70 or less are independent, while 89.3% of clients aged between 71 and 80 are independent. Among our oldest clients, aged 81 or more, only 63.3% are totally independent, with 13.5% being totally dependent.

Figure 5.26: Independence index (percentage of clients that are dependent, somewhat dependent and independent), by age group (%) (N: 4672)
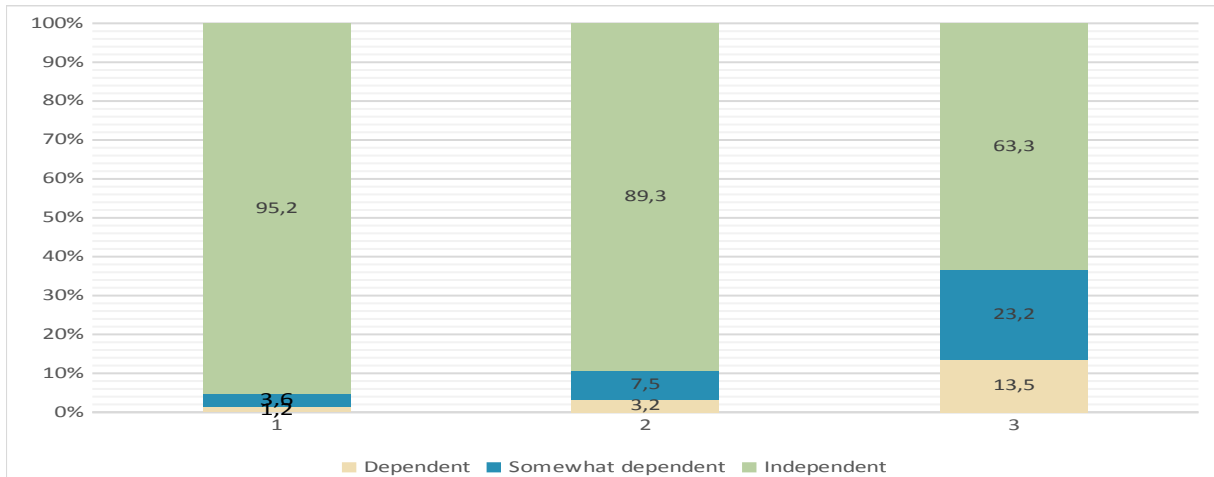
Independence index was lowest for the clients with no formal schooling completed, it is the only group with below 80% of totally independent clients. All other groups had at least or close to 85% of totally independent clients.

Figure 5.27: Independence index (percentage of clients who are dependent, somewhat dependent and independent), by education (%) (N: 4341)

The following figure demonstrates higher average dependence in Carinthian clients. In comparison to other regions, they less frequently got involved in cooking, housekeeping and shopping, which showed higher dependence on IADL activities. Clients from Var were more vulnerable in activities related to socialization (going out for leisure and meeting others), as well as performing sport and physical activities (which is a prevailing problem also in Liguria and Piedmont). Clients from Slovenia appeared to be least dependent (i.e. in cooking, housekeeping, going shopping, meeting others and performing sport/physical activities), but had the highest percentage of clients that did not go out for leisure at all (nearly one half).

Figure 5.28: Percentage of clients reporting they never perform selected activity (%), by region

	Carinthia		Liguria		Piedmont		Slovenia		Var	
	N	Row N %	N	Row N %	N	Row N %	N	Row N %	N	Row N %
Cooking	356	48,9	337	30,6	2316	23,3	823	15,7	947	18,4
Housekeeping	356	45,2	337	30,0	2316	30,0	823	16,0	946	30,1
Going out for duties	356	39,3	337	19,0	2314	12,5	821	8,4	947	13,9
Going out for leisure	342	34,2	337	9,5	2316	8,7	821	41,4	943	27,3
Meeting others	342	6,7	338	4,1	2314	4,4	822	3,9	944	15,6
Sport/physical activity	340	39,7	334	54,2	2303	45,2	819	30,9	943	49,9

(N1=340–356, N2=334–338; N3=2.314–2.303; N4=819–823; N5=943–947)

5.1.4.   The frailty level of CONSENSO participants

In order to measure the frailty level of clients, the Sunfrail tool was adopted[13]. The Sunfrail tool is one of the results of the EU project SUNFRAIL (Reference Sites Network for Prevention and Care of Frailty and Chronic Conditions in community dwelling persons of EU Countries). Innovative toolkits for the prediction of frailty and multimorbidity, focusing on community-based prevention and avoidable hospitalisations were developed. The Sunfrail tool is focused on assessing the risks of frailty through physical and performance measures. Developers of the tool focused on the bio-psycho-social paradigm. Nine items were included to the scale that was based on the bio-physical (five items), psychological-cognitive (two items) and socio-economic (two items) domains, and on the questions already available in the instruments adopted in literature. The Sunfrail tool was further adapted and tested in the CONSENSO project. Out of nine items, only seven were used,[14] socio-economic domain is therefore measured with only one item, bio-physical domain only with four. The diction of items also slightly differed in comparison to the original Sunfrail scale. The item "Do you feel lonely most of the time" was measured on the scale 1 - never, 2 - sometimes, 3 - often, 4 - every day and was further recoded to: 0 - no (never, sometimes), 1 - yes (often or every day). The question "Have you had any economic difficulties in facing dental care and health care costs during the last year?" was rephrased to "Have you had any economic difficulty in facing the basic expenses and the health care costs?". These adaptations were made in order to be more useful for CONSENSO assessment and evaluation purposes and probably had impact on the results (especially when we speak of universal health care systems, "basic expenses and health care costs" is a much broader concept in comparison to "dental care and health care costs", therefore a higher percentage of clients with such problems was expected). This item was measured on a scale from 1 to 5 (1 - with great difficulty, 2 - with difficulty, 3 - neither, 4 - easily, 5 - very easily) and was further recoded to 0 (very easily, easily or neither) and 1 (with difficulty or great difficulty).

The original Sunfrail scale did not anticipate a calculation of an index, however, for the purposes of this report, an index was calculated in order to present the data in a more cohesive way. Items were summed up in the "Sunfrail index".

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13 See www.sunfrail.eu.

14 The questions "In case of need, can you count on someone close to you?" and »Do you regularly take five or more medications per day« were not included to present analysis due to some issues in the data collection process.

Table 5.1:Adapted Sunfrail index (items)

Adapted Sunfrail items	Answers used in the index	No. of points
Do you feel lonely most of the time?	Often or every day	1 point
Have you lost weight during the past year such that your clothing has become looser?	Yes	1 point
Have you recently walked less because of your physical state?	Yes	1 point
Have you been evaluated by your GP during the past year?	No	1 point
Have you fallen one or more times during the past year?	Yes	1 point
Have you experienced memory decline during the past year?	Yes	1 point
Have you had any economic difficulty in facing the basic expenses and the health care costs?	With great difficulty or with difficulty	1 point

Significant differences are observable between regions, with clients in Carinthia being most frail (on average 2.5 on the scale from 0 to 7), followed by clients in Liguria (2.3). Clients from Carinthia seem to be struggling with the basic expenses and health care costs, with more than half reporting difficulties or great difficulties in facing them. Clients from Liguria also less often visited GP in the previous year (nearly 40% did not pay a visit to a GP).

The elderly visited in Slovenia were the least frail (on average 1.3 on an adapted Sunfrail scale), however, they do seem to be more vulnerable on the socio-economic part of the scale, with more than 30% experiencing economic difficulty in facing the basic expenses and the health care costs. Clients in Piedmont on average scored 1.4 on the Sunfrail scale. Only 75.9% were evaluated by a GP in the previous year, in comparison to more than 90% in Var, Carinthia and Slovenia.

Figure 5.29: Percentage of clients who answered with "yes" (adapted Sunfrail scale), by region

	Carinthia		Liguria		Piedmont		Slovenia		Var	
	N	Row N %	N	Row N %	N	Row N %	N	Row N %	N	Row N %
Evaluted by GP (B)	356	92,1	326	64,7	2340	75,9	832	92,4	945	96,1
Experienced a memory decline (P)	355	40,6	322	47,8	2336	25,0	828	34,2	941	42,5
Lost weight (B)	355	19,2	323	20,1	2336	10,8	828	6,8	941	23,8
Walked less (B)	355	57,2	324	49,7	2337	31,1	826	37,9	944	41,6
Fallen (B)	355	29,3	323	24,5	2333	16,6	822	19,0	941	29,6
Economic difficulty (S)	350	56,6	334	25,7	2260	21,0	740	31,1	943	27,9
Feels lonely (P)	157	19,1	179	12,8	1666	6,3	244	10,7	362	9,4

(N1=157–356, N2=179–334; N3=1.666–2.340; N4=244–832; N5=362–945)

B-item measures bio-physical domain; P-item measures psycho-cognitive domain; S-item measures socio-economic domain. The item "Have you been evaluated by your GP during the past year?" was not recoded and a higher number indicates lower frailty.

Figure 5.30: Adapted Sunfrail index, by region (average, min, max)
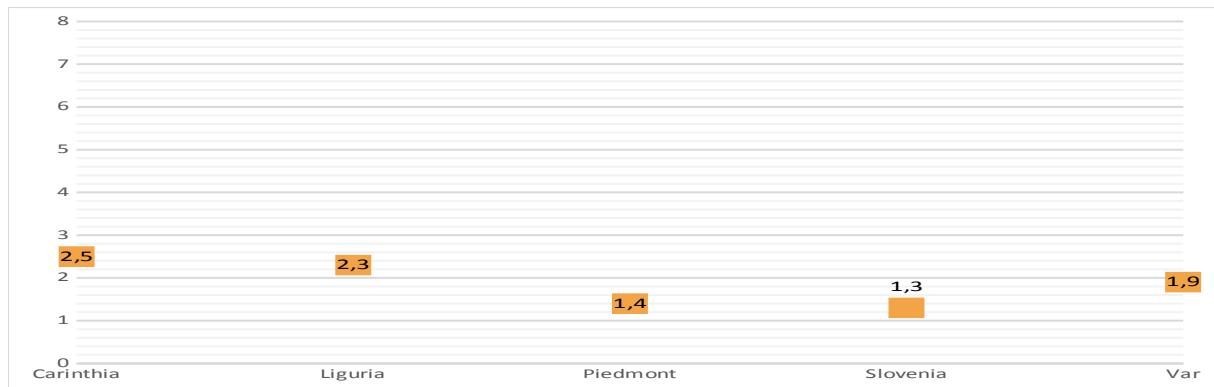
(N1=151, N2=174; N3=1.594; N4=189; N5=359);

On average 6.2% of clients experienced not being able to receive health or social services in the past 12 months. The percentage is particularly high in Carinthia and Slovenia (approximately 14%), but significantly lower in both Italian regions (around 3%). Also, 7.9% of clients on average reported feeling like they were treated badly by public institutions. This was more problematic in Liguria and Carinthia (nearly 20%), but less significant particularly in Piedmont (3.3%) and Slovenia (7.4%). Almost 10% of the clients also reported feeling left out of society most of the time, most prominently in Carinthia (16.5%) and Var (12.4%).

Figure 5.31: Percentage of clients a) not being able to receive different health or social services when needed in past 12 months; b) often feeling they were treated badly by public institutions and c) feeling left out of society most of the time, by region (%, average)
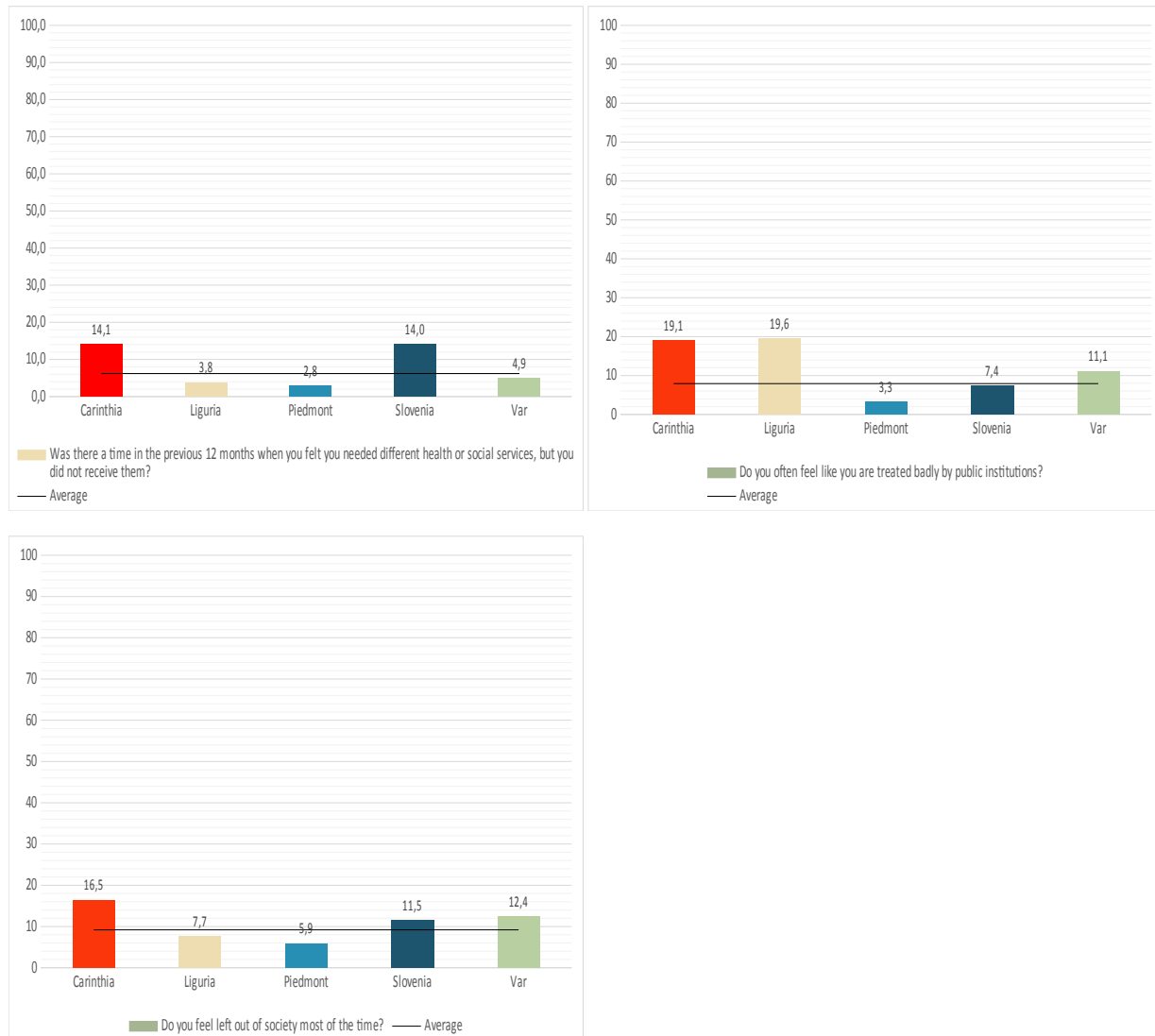
5.1.5. Social networks of CONSENSO participants

A name generator was used in order to determine the social network of the target population. Name generators were first used by McCallister and Fisher (1978), and were adapted by Van der Poel (1993). The name generator was used in order to determine the social network of our target population + the potential informal carers. With the name generator, an exhaustive list of alters (persons) with whom the respondent (ego) has some type of relationship will be identified. Termed a name generator, the respondent might be asked to list alters who occupy certain social roles (e.g. neighbours, kin, friends, co-workers), those with whom they interact (e.g. discuss important matters with, have sex with, etc.), or those with whom he exchanges support (e.g., borrowed money from, provide emotional support to). This approach is used in many classic studies of personal networks.

For the purposes of the CONSENSO project, we measured three different areas of support:

-        Minor material support

From time to time people borrow something from others, e.g. a piece of equipment, or ask for help with small chores in or around the house (e.g. easy household tasks). Who are the people you usually ask for this kind of help?

-        Support in case of illness

Suppose you become seriously ill or you are generally very weak and cannot leave home, for instance, to do the shopping or fetch medicine in the pharmacy. Who are the people you usually ask for this kind of help?

-        Emotional support

From time to time, most people discuss important personal matters with others, for instance if they quarrel with someone, when they have problems at work, family problems or similar. Who are the persons with whom you discuss personal matters that are important to you?

For each name generator, a respondent (by default) can name as many persons as he/she wants to; however, only up to three persons were added to the CONSENSO app. The networks of the elderly are usually small. Respondent (ego) identifies persons (alters) by first name only. After the respondent named all alters for all name generators, he was asked to answer "name interpreter" questions. Name interpreter questions were organized in "alter-wise" blocks consisting of all questions about each alter.

Name interpreter questions are:

-        Relationship with ego (i.e. partner, parent, child, friend etc.)

-        Satisfaction with help/relationship provided

-        The amount of help provided

Unfortunately, some data errors appeared when the level of clients' support data were collected. Option 0 was not explicitly provided in the application. That led to the lack of information on whether an answer to the particular question is missing (missing value) or is 0. Therefore, all the missing values were coded as 0, except in a few situations where nurses explicitly wrote down that there is no support. Generally, clients named between one and two persons in different support situations. On average, clients from Slovenia named the highest number of persons to which they can turn to in different situations. The elderly from Liguria follow closely. On the other hand, the elderly from Var region stand out with the lowest number of persons they can turn to in various situations.

Figure 5.32: The number of persons that the elderly can ask for help (scale 0-3), by region

	Carinthia		Liguria		Piedmont		Slovenia		Var	
	N	Row N %	N	Row N %	N	Row N %	N	Row N %	N	Row N %
Emotional support	323	1,4	300	1,59	2095	1,31	685	1,47	835	1,05
Support in case of ilness	318	1,53	284	1,64	1952	1,47	724	1,67	831	1,06
Minor material support	316	1,57	283	1,57	1561	1,39	663	1,67	683	1,01

(N1=316–323, N2=283–300; N3=1.561–2.095; N4=663–724; N5=683–835)

5.1.6. The quality of life (QOL)

The clients involved in all regions were asked to rate satisfaction with their life on a scale of 1 to 10[15]. If we look at the average ratings, we can see that Italian regions Liguria and Piedmont stand out with the highest ratings, while the elderly in Carinthia are on average the least satisfied with their life (in general).

Figure 5.33: Average rating of quality of life assessment by clients, per region (scale 0-10)

	Carinthia	Liguria	Piedmont	Slovenia	Var
standard of living	7,5	8,2	8,1	7,4	7,8
health	6,5	7,7	7,9	7,3	7,0
life achievements	7,7	8,4	8,4	8,3	7,5
personal relationships	7,7	8,6	8,3	8,5	7,4
feeling safe	7,0	8,3	7,9	8,1	8,0
feeling part of the community	6,9	8,2	8,1	8,1	7,4
future security	6,5	8,1	7,6	7,8	6,6
spirituality or religion	7,3	8,2	8,1	8,5	7,6
life as a whole	7,2	8,3	8,3	7,9	7,7

(N1=275–335, N2=166–280; N3=1.805–1.957; N4=431–611; N5=45–931)

5.2. Results (a comparison of the first and the final interview)

Some data in the CONSENSO were measured twice (see Methodology for more information). Despite some obvious limitations to this type of data collection during CONSENSO pilots, some results were observable and are presented with the following figures.

Firstly, we observed the participants' weight during the first and the last visit. The data show slight (from 74.8 to 74.4) but statistically significant[16] drop in weight for 627 participants that provided us with this piece of information at the first and this last visit. Since p value is low (<0.05), it can be accepted that the median of the differences between the paired observations is statistically significantly different from 0.

Differences between regions were observed. However, due to a very small number of cases in Carinthia (18) and Liguria (11) and invalid data from Var, only data from Piedmont and Slovenia are shown. It is evident that in both regions the weight of participants dropped (from 72.6 to 71.3 in Piedmont and from 75.1 to 74.9 in Slovenia). Differences are statistically significant (p<0.05). The FCNs also measured waist circumference, which is an indicator of health risk associated with excess fat around the waist. The data available for 347 clients show no statistically significant differences[17] between the two measurements (100.8 and 100.6 cm).

The BMI (Body Mass Index) is a measure of body fat based on height and weight and is an indicator of a healthy weight range. BMI classification developed by the WHO consists of four groups: underweight (<18.5), normal (18.5 – 24.9), overweight (>25) and obese (30). However, there is strong emerging evidence that WHO cut-offs may not be appropriate in increasing age, therefore cuts were adapted (for example) to: underweight (<23), healthy weight (24-30) and overweight (>30). The data show a statistically significantly lower BMI in Piedmont[18]; however, no change was observed in Slovenia.

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15 The questionnaire was based on the *Personal Wellbeing Index: 5th Edition (2013) by International Wellbeing Group. Melbourne: Australian Centre on Quality of Life, Deakin University*
(http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/index.php).

16 The Wilcoxon signed rank test was used.

17 The data for clients with at least two measured values was reported. The Wilcoxon signed rank test was used.

18 The data for clients with at least two measured values was reported. The Wilcoxon signed rank test was used.

Figure 5.34: Average weight and BMI among clients, comparison of first and closing interview, by region
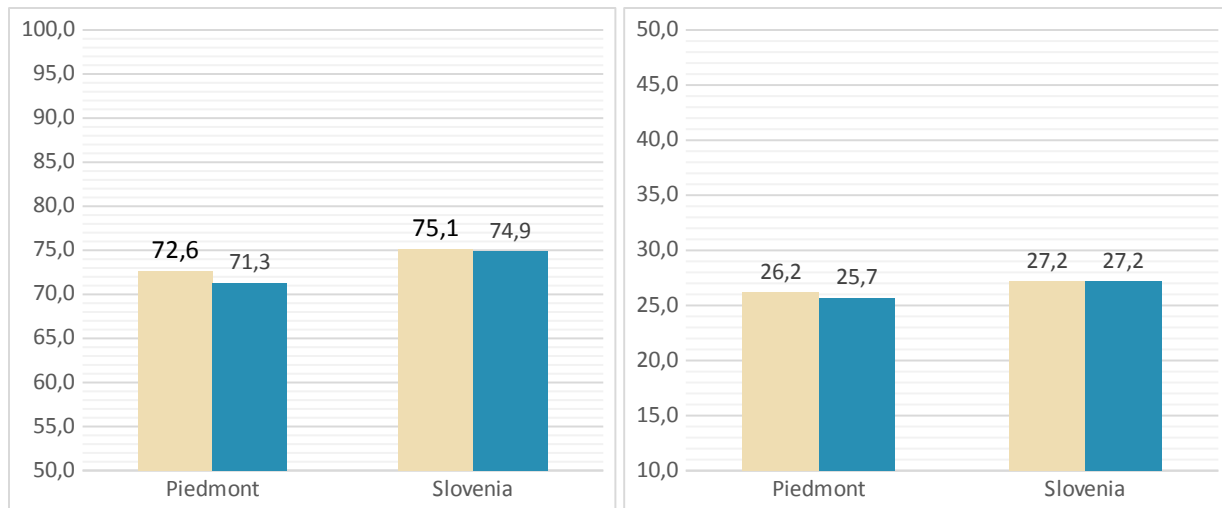
(N3=60; N4=538)   (N3=45; N4=533)

Systolic and diastolic blood pressure were regularly measured in all regions but Var. In three out of four regions, a slight drop in (diastolic and systolic) blood pressure is noticeable if we compare the first and the final measurements. The change in systolic blood pressure is statistically significant in the case of Piedmont and also if we combine measurements of all five areas[19].

Figure 5.35: Average blood pressure (diastolic and systolic), comparison of the first and the closing interview, by region
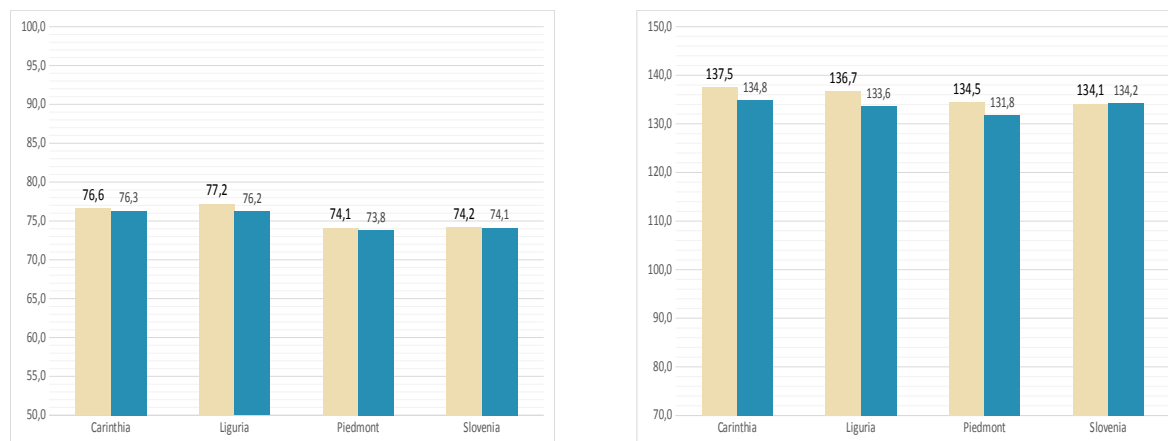
(N1=144, N2=33; N3=456; N4=681)   (N1=145, N2=32; N3=455; N4=681)

Data in the entire sample (N=4.433, the first interview) show that 90% of clients were non-smokers. This percentage varies between 85.9% (N=269) in Liguria to 94.8% (N=324) in Carinthia. There are no statistically significant differences between the first and the final measurements in the number of cigarettes smoked per day (entire sample and regional samples). If we observe only data for smokers (reported smoking at least one cigarette per day) we can see a slight, yet statistically insignificant drop in the average number of cigarettes (from 12.7 to 12.6)[20].

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19 Data for clients with at least two measured values was reported. The Wilcoxon signed rank test has been used.

20 Data for clients with at least two measured values was reported. The Wilcoxon signed rank test has been used.

Alcohol abuse was identified in 3.9% of clients (N=4.715, first interview). The percentage was highest in Piedmont (5.5%, N=2.278) and lowest in Slovenia (1.3%; N=825). There are no major differences between the share of clients with alcohol consumption issues in the first and final measurements (entire sample and regional samples) (drop from 3.9 to 3.8%)[21].

Figure 5.36: Average number of cigarettes smoked per day (left chart) and percentage of clients with alcohol consumption problems (right chart), comparison of the first and the closing interview, by region

(N1=307, N2=26; N3=822; N4=671; N5=940)   (N1=323, N2=31; N3=908; N4=683; N5=943)
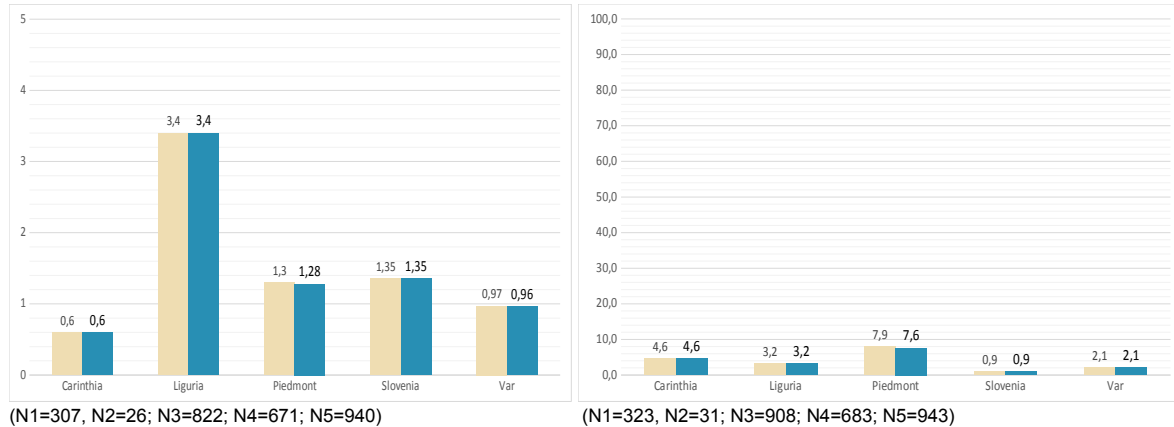
A lack of sufficient physical activity was identified in nearly one third of clients (31.7%) participating in CONSENSO, less in Piedmont (24.4%) and more in Slovenia (50.7%). There is a slight, yet statistically significant drop in the share of clients with problems with physical activities (from 32.7% to 31.9%) observed in the sample (N=2.894), but mainly in Piedmont, where difference between the first and the final measurement was statistically significant[22]. Similarly, the data on problems with nutrition show a statistically significant drop in problems (from 12.7% to 9.5% in the entire sample). However, it also shows a significant difference between Liguria and other regions in identifying such problems (which might be the consequence of the methodological understanding of the concept). Nearly one third (30.9%) of clients in Liguria had problems with nutrition. The share was the lowest in Var (5.7%). The drop between the first and the final measurement was statistically significant in Piedmont (from 15.3 to 13.2%)[23].

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21 Data for clients with at least two measured values was reported. McNemar test was used.

22 Data for clients with at least two measured values was reported. McNemar test was used.

23 Data for clients with at least two measured values was reported. McNemar test was used.

Figure 5.37: Percentage of the elderly with problems with physical activities (left chart) and nutrition (right chart), comparison of the first and the closing interview, by region
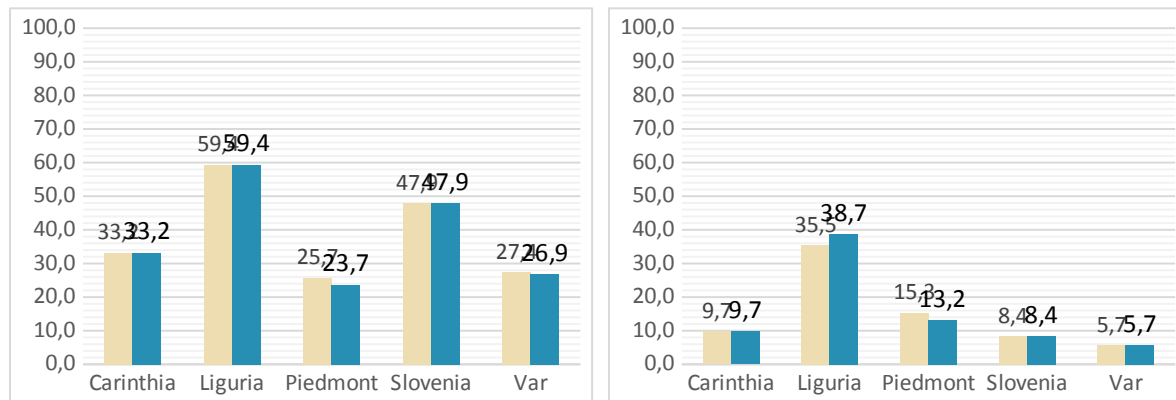
(N1=322, N2=32; N3=913; N4=682; N5=945) (N1=321, N2=31; N3=911; N4=682; N5=941)

Even though we cannot claim that all these differences are directly correlated to the interventions by CONSENSO FCNs (at least not in such short period of time), they generally show (albeit small) slight improvements among the elderly after a few months of visits from FCNs. The data (with differences and deviations among regions) presented in this chapter are systematically interpreted in the next part of the report.

6. The implementation of the CONSENSO project in different regions

In this chapter, regional descriptions of CONSENSO models and results are presented. Regional descriptions are mainly composed of the results of focus groups, together with quotes from interviews and literature review. Focus groups were conducted by FCNs who provided thorough descriptions of their activities during the project and thus contributed to detailed reports on implementation in their respective regions.

6.1. Carinthia

Carinthia (German: Kärnten) is the southernmost Austrian state or *Land*. Situated within the area of Eastern Alps, it is noted for its mountains and lakes. With a total of 561,077 inhabitants (Eurostat, 2018) it ranks as the sixth among the nine federal states of Austria (6.4% of Austria's population). With a surface of 9,537km², population density in Carinthia is 59/km². Carinthia's main industries are tourism, electronics, engineering, forestry, and agriculture. With GDP of €19.3b in 2016, Carinthia accounts for 5.5% of Austrian GDP (Eurostat, 2018). GDP per capita in Carinthia (€31,600) reaches 84.9% of the Austrian average (Eurostat, 2018). In terms of GDP growth since 2000, Carinthia could not keep up with the average of Austria's federal states. Carinthia is one of the four regions under Austrian average, others being Styria (88.7%), Lower Austria (91.7%) and Burgenland (69.1%) (Eurostat, 2018).

The CONSENSO pilot in Carinthia was implemented in the region Nockberge, Wolsberg and Voelkermarkt. This geographical area borders to Slovenia to the South, the area is bilingual, both German and Slovene are official languages.

In Austria in general the availability of services for the elderly depends on federal state. This is true for the institutional long-term care but for other services as well, including home care and home nursing. In Carinthia (as well as in other federal states) the majority of older people who are ill or disabled or need support and help receive so-called "mobile services" (for instance, home nursing, home care, home help

and mobile meals) in their private homes. Additionally, counselling by a social worker or a nurse, support for the family caregivers, and other services are offered (Genet et al, 2013).

The CONSENSO project in Austria was seen as a welcome platform to address some of the disadvantages of the existent health and social system. As most of the nurses in CONSENSO were previously employed by the mobile services, they were very well acquainted with the needs of the elderly population in the region. One of the most discussed topics in regard to the limitations of the system in Carinthia was that the elderly, especially those who are the most disadvantaged in terms of being poor, could not afford services they needed to support their independent living and/or increase their quality of life. The CONSENSO was used to address these shortages of the system and improve the life of CONSENSO target group.

Pre-pilot activities in Carinthia

Pre-pilot activities linked to the CONSENSO's goal to promote additional services financed by the project were organised solely by the Carinthian federal government. The nurses were not involved in the formal promotional activities from the beginning of the project although they feel that this could have been useful and efficient to get more impetus for the successful beginning of the project. Nevertheless, the nurses were involved in the pre-pilot activities in a more informal way, namely by their own initiative spreading the information about the project by word of mouth as they were active in small and interconnected geographical areas. The pre-pilot activities were rather successful as the word about the CONSENSO project spread also to other regions of Austria, and the CONSENSO nurses have even been contacted by other nurses working in the field inquiring about the project.

The predominant view in Carinthia was that it is hard to lead a successful promotional campaign of the project prior to the project as the target group does not have sufficient practical experiences with the CONSENSO model to be able to truly understand the benefits of their potential involvement with the project. This is the reason why some of the promotional activities were extended to the pilot implementation phase of the project.

No additional training was provided for the nurses apart from the general nurses training in Izola, Slovenia. In the focus group in which all Austrian nurses participated they expressed the view that at the beginning of the piloting no strict protocol of intervention was developed (or made clear to them) and they had to resort to improvisation, their experiences and professional know-how. Participants in the focus group with nurses expressed that they missed the official presentation of the project by responsible authorities

> "…/ it would have been very useful if we had a presentation of the project where we could get all necessary information for our work" (focus group).

This meant that the nurses themselves were not included in the pre-pilot activities. Consequently, the nurses were not involved as much as they would like to with other relevant stakeholders and were not aware of them being involved in the project. Austrian nurses therefore lacked the support from stakeholders before starting their field work. Respondents in the focus group even discussed a pre-pilot phase to be discouraging.

However, this does not mean that relevant stakeholders were not included in the project. According to the multistakeholders analysis, several (up to 36) stakeholders were included in the project. More than half of them were identified as key players and not just project partners who had merely been informed about the project (we had 16 of such stakeholders i Carinthia). Regarding the category of needs of the elderly these stakeholders address, 31 of them were focusing on social needs, four on health needs and one on financial needs (the following division was provided by project partners):

- Key players:

- o Social needs: Communities Bad Kleinkirchheim, Malta, Reichenau, St. Paul/Lav., St. Georgen/Lav, Lavamünd, Sittersdorf, Bad Eisenkappel, Österreichisches Rotes Kreuz Kärnten, Arbeitsvereinigung der Sozialhilfe Kärntens.
  - o Financial needs: Amt der Kärntner Landesregierung.
- Kept informed:
  - o Health needs: Allgemein Öffentliches Krankenhaus Spittal/Drau, Akademie für Weiterbildung der FHOÖ, Schule für Gesundheits- und Krankenpflege Klagenfurt am Wörthersee, Landeskrankenhaus Wolfsberg.
  - o Social needs: Regionalverband Nockregion, Österreichisches Rotes Kreuz Kärnten, RML Regionalmanagement Lavanttal GmbH, Verein Regionalentwicklung Südkärnten, LAG Unterkärnten, Arbeitsvereinigung der Sozialhilfe Kärntens, Gesundheits-, Pflege- und Sozialservice.

<u>Pilot activities in Carinthia</u>

a) Contact with clients

There were three methods of building clients' list:

a. attendance at public events when FCNs were already in the field,
b. FCNs' visits of nursing homes,
c. potential users who found the project by themselves and ask for help and want to participate.

According to the participants of the focus group with Austrian nurses, there was slight dissatisfaction with the lack of efficiency in the pre-pilot activities, which (in their opinion) could have been implemented in greater cooperation with nurses. This influenced the beginning of the pilot phase which could have been conducted more in line with project's general plan if the nurses would have been involved in the previous phase − the pre-pilot phase. As this was not the case, the nurses expressed the view that a lot of time was spent in the pilot phase also for the promotion of the project and their services and explaining the clients about their role.

> *"If we would have started with the training before starting the field work, we had had more time for each client or more clients"* (focus group).

From that we can conclude that FCNs learned about the CONSENSO model after they had already started to work in the field. This meant that they "learned by doing", combining their previous work and professional experiences. They approached their tasks combining work with new clients and learning about the project simultaneously (for instance how to use CONSENSO app).

In their opinion, the best way to establish a relationship with clients was to give them space and time to talk without asking detailed questions (these detailed questions were otherwise part of the needs assessment included in the CONSENSO app). In order to be more successful and build trust with their clients, the nurses improvised and designed their own general protocols (which were discussed among them) for the first and subsequent visits which were in line with CONSENSO model but were adapted to better suit the goal of gaining trust of the clients.

The first set of questions when starting the "intervention" were usually dedicated to clients' home and only afterwards about health and social conditions and possible issues clients faced in these areas. The nurses avoided discussing the needs of the client too directly. General conversation alone gave the nurses a broad overview of users' issues and needs, these were followed by the CONSENSO app thorough needs assessment.

Interview 1, Carinthia:

> *"She arrived to my house and introduced herself and I found her to be very nice, I liked her from the beginning. I trusted her and it worked from the beginning."*
>
> *"I told the nurse about my problems, about the fact that I cannot manage alone, and she understood right away and helped me."*

Interview 8, Carinthia:

> *"She did not talk so much about the CONSENSO, but what she did mention about the project was not that important to me. The most important was that we could talk and chat and that way we started to talk about my family issues."*
>
> *"Personal, personal, we discussed personal issues but it is important that nurse was very well educated when asking me these questions. I did not know how to arrange services for myself … how could I have known? It is all so complicated."*

b) Clients' needs

The participants of the focus group estimated that on average the conversation with a client lasted approximately 2 hours. In spite of the fact that all visits generally had a common form, each FCN had a relatively unique experience with their clients, dependent on their needs since some clients needed more time to talk openly than others. One FCN even emphasized that she had her first meeting with a client in the street where they met and had a discussion related to the CONSENSO project. Generally, Austrian FCNs agreed that only more self-confident elderly individuals participated in the project.

In spite of that claim the Carinthian sample of clients included in the project shows that (as indicated above) the Austrian FCNs used the project CONSENSO to address the needs of the most vulnerable elderly population in Carinthia, providing free services to those who have hard time paying for already existent services (for instance mobile help or additional mobile help). These clients also faced the most complex medical and social circumstances requiring well-coordinated and sustained intervention. This is evident from the prevalent types of intervention:

- Management (reflecting coordination efforts of FCNs to design a support network as well as efforts to address social aspects of their clients showing their inability to handle administrative processes on their own).

- The assessment of needs indicating a variety of clients' needs which nurses had to address; for instance: clients' lack of independence and poor health mainly described in NANDA diagnoses.

- Activities related to clients' needs to be represented (in front of the authorities), instructed, taught and educated, all with the aim to improve their lives and enable them to stay at home as long as possible.

FCNs in Carinthia reported that the assessment showed several very different unmet needs of their CONSENSO clients (from clients needing instructions on how to use medication to family mediation and organizing transport). What is interesting is the resistance of some clients still claiming they did not need any help or service from the FCNs in spite of obvious and identified needs. Such clients needed even more attention and persuasion.

In general, the most prolific need of Carinthian clients was clients' distress because their **relatives could not provide care** for them due to different personal reasons (for instance they had moved to the city). Another important issue which influences the fact that clients' needs were unmet prior to the CONSENSO project are the geographic characteristics of the region (mountainous terrain, semi-deserted villages) which made accessibility very difficult for already existent social and health services but also for CONSENSO nurses. Another very common problem was clients' **loneliness**. The elderly in remote geographical locations have lived alone for a number of years without their grownup children who have

moved to the cities. This, combined with the fact that some of them did not have driving license (or were too old to drive), was a serious obstacle for their mobility. One FCN reported how she delivered food to one of her clients and sometimes had to call a local baker and ask him to bring the client the meal instead of her because the client's house was not accessible due to snow etc. There were rare cases when the elderly did not want to accept FCNs' help. For instance, some felt they would lose the feeling of control and self-worth if the nurse helped them.

What kind of clients' needs were tackled within the pilot is also evident from individual action plans which were designed for each client individually as part of the CONSENSO app. The analysis of the plans shows that almost all clients in Carinthia received the first individual action plan, after that the share of clients with subsequent action plans steadily declined - to 78.76% of clients receiving also subsequent action plan, 61% with the third, 45% with the fourth plan, 35% with the fifth, 24% with six plans and almost 19% of clients with seven action plans. This does correspond to the complexity of the cases and severity of the health and social issues dealt by CONSENSO nurses in Carinthia as the shares of clients with more than one or two plans is higher than in other CONSENSO regions.

Judging from the share of clients with subsequent individual action plans Carinthia opted for much more sustained intervention which is in fact more in line with the ideal CONSENSO model. Carinthia also has the highest number of visits averaging more than five visits per client. The qualitative analysis of individual action plans in Carinthia support these findings as it shows that the adapted and implemented CONSENSO model bet on the importance of continuous and in-depth intervention − taking more time with a single client, visiting the client, monitoring the client in multiple visits following the goals set in the first and also subsequent action plans, but not writing a new action plan every visit.

This brings us to the question of what topics were most commonly included in individual action plans in Carinthia? As mentioned before, the FCNs were asked to design individual action plans as a response to the needs assessment provided for each client at the beginning of the visit. The action plan is therefore seen as a response to the identified needs and should ideally be relatively structured, with clear goals, activities to reach these goals and stakeholders or support network, which will enable the realisation of these goals. However, the first general impression of the majority of action plans in Carinthia shows this is not the case - individual action plans are rather short and not structured. One reason behind this is that in Carinthia, individual action plans were used more as a tool to write down the results of the assessment and diagnoses and not solely to plan FCN's activities. This is also evident from the prevalence of the so-called NANDA codes in individual action plans. The textual analysis of individual action plans in Carinthia can therefore shed the light on FCNs actions in more detail but with the knowledge of the context explained above being limiting factor.

If we focus merely on NANDA codes, we learn much more about the assessment phase and less about the planning phase of the intervention. Nevertheless, it is important to understand what issues the FCN's focused on in Carinthia. The topic (linked to NANDA codes) most at the forefront in the individual action plans is clients' inabilities to deal with administrative issues. This topic appears in almost one third of all action plans, it is followed by deficient knowledge, impaired walking, the risk of unstable glucose level, impaired home maintenance, bathing self-care deficit, feeding self-care deficit and dressing self-care deficit. These are all diagnoses. Logical consequences of such diagnoses are the actions taken by nurses to address the needs of the clients related to these diagnoses. Here, we observe addressing these issues with their management (over 30% of all individual action plans contain such code) and teaching/instruction/educating clients (inhabited in over 44% of all individual action plans). Both of these actions include a vast array of tailor-made responses, from building and managing clients' support network, managing administrative issues they might have, instructions on how to adapt clients' homes in order to prevent falls, how to lead healthier lifestyle etc.

Interview 2, Carinthia:

"She measured my blood pressure and did a short health check. She told me that I have to be careful and

> *take my medication regularly and as the doctor has prescribed it. She discussed the medication with my doctor. We discussed where I could have some other medical issues."*

Interview 3, Carinthia:

> *"I now have a positive outlook on life, I am also very happy whenever I see her. She has helped me a lot with the paperwork; I am not able to arrange these administrative issues on my own any more."*

Interview 4, Carinthia:

> *"And she … she arranged everything what was to be arranged…for instance she even took me shopping…and took all the groceries into the house…and she accompanied me to the doctors and when I had to get my injections for ten weeks straight , she was always there, right on time every time."*

c) Follow-up

The analysis of the interviews with clients in Carinthia show that imagining a future without a CONSENSO nurse is hard. The level of clients' satisfaction with and even gratitude for Carinthian FCNs, not just the intervention but also their approach, treating each client as an individual - listening to them, discussing certain social, medical and even personal and family issues - is very high. We can ascribe this to the fact that the relationship with client was not forced but built over longer period of time and many visits where clients could observe that FCN's activity did have positive results.

Interview 1, Carinthia:

> *"Oh, I will miss this a lot. To whom should I then turn to? I don't know. I will be left alone then, yes, I will be all alone."*

Interview 2, Carinthia:

> *"I am very burdened by the thought that the project could just end. I simply do not understand why it should end. I don't understand that. Why should we try to find some other solution if this one works really well? It does not make any sense. I don't even know what to say. We have to try and keep old people in their homes. I don't want to go to an institution. It is over for me then."*

Interview 8, Carinthia:

> *"When the nurse is here, I am doing well. She gives me so much hope. Without her … I will be dependent again on my family and they do not even live here, or I will have to pay somebody to take care of me but I cannot afford that!"*

It was in great interest of Carinthian regional government to regulate family and community nursing within their legislation. They have intended to measure whether the costs of institutional care can be reduced by strengthening community care. CONSENSO's activities in Carinthia were primarily provided to clients that were at risk of being moved to nursing homes. During the project, FCNs were recording the number of clients that would have been institutionalized without CONSENSO's activities (the perception of clients themselves was measured). Altogether, 80 clients were not able to receive enough or the appropriate kind of help in the community with existing services provided. Project partners have calculated that the cost for these clients in the institutional setting would be 1.540.800 EUR. Overall costs of FCNs were 852.091 EUR. Project partners calculated savings if community care would be strengthened with FCNs, which amounted to 688.709 EUR in Carinthia.

d) Conclusions and discussion

In the case of Carinthia, we can observe several elements which influenced the pilot phase of the CONSENSO project. These elements contributed to observed adaptations of the so-called ideal model of

CONSENSO and derive from broader characteristics of social and health system, values and professional characteristics of participating nurses, understanding of the project and the characteristics of the sample of clients the FCNs worked with.

In Carinthia we can see that the sample of participants in the CONSENSO was carefully chosen to address the shortcomings of the current health and social system. This in fact influenced the type of intervention by the nurses as they dealt with the population which was considerably more vulnerable from the social, health and independence perspectives than in other CONSENSO regions. The designers of the CONSENSO model in Carinthia had seen a niche in how the needs of the most vulnerable population of the elderly are addressed in the current system and capitalised on the project by amending that.

The selection of the sample of senior citizens included in the CONSENSO project therefore determined the intervention. This is evident from the quantitative results of the CONSENSO app and was further mirrored in the analysis of individual action plans designed by FCNs, the analysis of the interviews with CONSENSO clients and focus groups with Carinthian FCNs. The sample of participants in Carinthia is poorer, has more health issues and is less independent than in other regions. Therefore, much more complex issues were at the forefront. The intervention was subsequently characterised by more visits on average, more individual action plans designed and more nurses' activities which were not focused predominantly on preventative issues and the promotion of healthy lifestyle but more on actively managing the case they were dealing with through designing a broad support network and dedicating considerable time and efforts to improving the situation of their client. In regard to that, the intervention had to be tailored to each elderly individual as they faced different challenges within particular circumstances. These efforts were recognised and are evident in clients' interviews.

Some deviations from the common CONSENSO model should therefore not be subject to criticism and should instead be celebrated as they answered the needs which had not been addressed before and therefore contributed greatly to the improvement of the situation of the elderly in pilot geographical areas. Even more, the Carinthian CONSENSO model is one of the closest models (if not *the* closest) to the ideal model, especially if we include the considerable importance of case management approach within the ideal model.

6.2. Liguria

Liguria is a coastal region in north-western Italy, the capital is Genoa. It is bordered by France (Provence-Alpes-Cote d'Azur) to the west, Piedmont to the north, and Emilia-Romagna and Tuscany to the east. In Liguria, in the beginning of the project there were four FCNs, but because of personal and professional reasons only two were left and implemented planned activities till the end of the project.

In Italy, nurses' training programmes were introduced in 1992 and 1994, when old regional nursing courses came to the end and new students could choose this study only after two years of high school. The main objective of legislation for the nurse was to make the profile more autonomous and active with new responsibilities. Nurses are required to have obtained a three-year university degree and pass the state examination. But development went further in 2000 when the role of the nurse as nurse management was established, accompanied by a degree in nursing sciences for training managers and teachers in nursing. In the academic year 2004/2005, a postgraduate two-year nursing specialist course began (Kringos et al 2015).

The pilots were implemented in Alta Val Trebbia in eight towns, with Torriglia (with, according to Wikipedia, around 2.500 inhabitants) being the biggest one and located in the upper Trebbia valley. It is a large, hilly, remote area with poor traffic connections, consisting of fragmented small settlements. The representatives of the focus group mention poor coverage with services; even grocery shops are not available in these towns; nurses visit inhabitants, but are not stationed in these towns. There is one health centre in Torriglia. Only one general practitioner covers the entire area. There are social services available and Red Cross is the only association covering these towns. There are two institutions providing

residential care in Torriglia and Rovegno and people often rely on informal carers. The informal care is usually accessible to some degree, if not by relatives, then by communities themselves.

<u>Pre-pilot activities in Liguria</u>

Before the field work began, FCNs had a training programme that provided a general vision of what they were supposed to do within the frame of the project and tried to emphasise the importance of paradigm changes in providing care to clients. In the focus group, one FCN discussed her traditional approach towards providing nursing care and concluded that the training was instrumental in helping her to be more open in her point of view and approach. *"The overall training was useful because it provided a new vision, a change of paradigm"* (focus group). The main method FCNs learned during the training was how to conduct home visits and how to approach potential users included in the CONSENSO. As mentioned above, the new profile and role of the FCN had not existed before the project started in the region. Therefore, training was helpful in painting a wider picture of an ideal type of the role. FCNs agree that the training lacked information on practical tools to work as a FCN.

The FCNs were the ones building the network in this area, not project managers. The most important stakeholders identified by FCNs were: mayors, nurses and other staff from the local health unit, Red Cross, social workers, and general practitioners. The role of mayors was the most relevant as they contributed the most of all the stakeholders (*"That is why the role of mayor is crucial; they do everything for the community. In some cases, mayors directly/personally contacted people living in their community"* (focus group)). Many times, FCNs contacted staff who did not have an institutional role but had an influence within the community (former mayors or professionals from associations, people promoting tourism in the area and others). Although in Italy health services and social services are usually divided, some regions (Emilia Romagna, Toscana and Liguria) manage them in an integrated way. The regions are in charge of both types of service but the responsibility for social services rests with the municipalities while health services are run by local health authorities (*ASL-aziende saniatarie locali*) (Tediosi and Gabriele 2010). In Alta Val Trebbia the integration is not yet visible, but the process of integration was initiated by the project; social workers were supporting the project and more constant relationship with them was maintained.

Project partners identified the following stakeholders in the region:

- Key players:
  - Health needs: ASL 3 GENOVESE, Dipartimento di Prevenzione Asl 3 Liguria ambulatori specialistici ASL 3 Genovese, Alisa (Azienda sanitaria Ligure) Area Socio Sanitaria, Ambulatorio salute mentale ASL3, comune di Torriglia, Comune di Rovegno Comune di Fontanigorda, Comune di Fascia, Comune di Montebruno, Comune di Gorreto Comune di Rondanina, Comune di Propata, MMG, Associazione Polisportiva Torrigliese Servizi Sociali di ATS 45.
  - Social needs: Distretto Socio-Sanitario, Comune di Bargagli Servizi Sociali.
  - Experts: Università degli Studi di Torino.
- Kept satisfied:
  - Health needs: ASL3 Genovese, OPI Genova, Ambulatorio Diabetologico ASL3genovese Ambulatorio cure Palliative ASL3Genovese, associazione Polisportiva Torrigliese associazione Anziani Oggi, associazione ASLIDIA (associazione ligure diabetici) MMG.
  - Social needs: Comune di Bargagli Distretto sociosanitario.
- Kept informed:
  - Health needs: Associazione Anziani Oggi, Dipartimento di Prevenzione ASL3 Ambulatorio Cure Palliative Asl3 Genovese, IPASVI Genova, SSD ENDOCRINOLOGIA, DIABET. E MALAT.METAB.-ASLIDIA.
  - Social needs: MMG, sindaci comuni valtrebbia.

FCNs agreed to start building a network in the peripheral areas and then moving to bigger towns. They informed everyone interested in the project with letters and organized public events in each town where they introduced themselves and the project itself. We can notice distrust of the elderly in the region and how important was that FCNs have shown themselves ("*It was very important to show our faces and introduce ourselves*" (focus group)). FCNs prepared personal cards and posters and hung them in eight towns across the region. In addition to the public meeting, there was also a presentation for scientific purposes. A specific way of promotion was the presentation of the project in a church during the mass ("*Even during the mass, during the speech, the priest has talked about the project, telling people, inviting people, visiting them… talking about peripheral towns, remote ones*" (focus group)).

FCNs also organized the work amongst themselves. They decided to discuss all cases together, "*because four heads are better than one*" (focus group).

Pilot activities

    a)   Contact with client

In the beginning FCNs obtained the lists of all their clients (65+) in every small town. "*We had a list of everybody residing in the valley, in the area*" (focus group). The list was later updated by removing the clients that had moved or died. "*One of the problems was to look for their telephone numbers - this was very time-consuming, because the lists were not updated. We now have a clear idea of who the residents in these towns are*" (focus group). Firstly, FCNs sent letters to clients in the area. Sometimes the letters did not arrive so individuals were contacted by the phone as well. FCNs then set a meeting with clients (not more than four clients per day). There were also some important specifics in Liguria regarding the time of visits. Usually, FCNs could not visit the elderly before 10 am (because of sleeping time until then) and after 11:30 am (lunchtime till 2 pm, when they did not want to be disturbed). Thus, there was a time window in between for visiting them personally. The second part of the visits was then done after 2 pm. Their visits lasted 1 or 1.5 hours. According to FCNs, such long visits were the only chance to strengthen the relationship with the client. A true relationship between the FCN and the elderly person began with an informal discussion in order to get to know each other and it continued with more specific questions following the app questionnaire.

We can notice that the new approach of contacting clients in Liguria was quite a fresh idea for the inhabitants ("*We work with people who do not request anything. We go to their homes, but they do not ask for that. It is a change of paradigm. People are not used to that; they do not understand what this is all about*" (focus group)).

Interview 3, Liguria:

> *A man lives by himself in a rented apartment in suitable conditions. He spends his time mostly watching TV and reading books. He has good relationship with his son and a neighbour. He was informed about the COSENSO by his family doctor and was extremely happy about it. The nurse made the contact by directly coming to him. The nurse had a clear and informal approach to him and he felt fine during the process. He did not find the process to be intrusive. He trusted the nurse immediately. He was able to express his needs to the nurse and felt he was heard. He was otherwise happy with Consenso service and is feeling better after they helped him with treating a wound.*

    b)   The individual plan and clients' needs

The individual plan in Liguria region was done reciprocally and progressively between the elderly and the FCN during visits. "*We insist little by little to increase awareness*" (focus group). The first indicator in making an individual plan and assessing needs was the measurement of vital functions and general health and social-economical state of the elderly. Despite them claiming they do not need much, numerous untreated issues were identified.

Because of geographical relief and insufficient traffic route connections between villages and towns, **isolation** seemed to be the biggest issue that had a strong impact on users' daily life in Liguria, especially among women. Traditionally, "*women are more attached to home and their social life is limited to Sunday*

mass. Apart from that, they have fewer opportunities of social life, even in bigger towns" (focus group). Despite their very strong informal (family or community) care orientation, as a representative of focus groups suggested, this is not friendship, therefore the exchange of emotions and truly friendly conversation are not an option. "*They know they can count on people outside for help, but not for conversation, emotional conversation. No wonder that when we came, it was easy for them to talk to us, because we were from the outside and there were no prejudices so they could open and speak freely*" (focus group).

The method of tackling the isolation problem was very simple, yet very effective, and has also strengthened health prevention. Numerous walking groups were organized, and only women attended these walking groups (men were invited, and two even attended at one point, but soon gave up). In the walking groups nurses *"have experienced how important and how valuable it is to focus on promotion in small groups; not only to promote physical activity, but to solve other issues as well, especially isolation"* (focus group). The walking groups were organized according to guidelines that had been established before the CONSENSO. FCNs contacted mayors, who helped them organize a public event and invite persons who had already been involved in walking groups. They even provided them with T-shirts and hats. "*We started with five participants, after two months we had 14 or 15 people from everywhere*" (focus group). For the sustainability of the project and its idea of health promotion, they trained clients to be team leaders and provided them with necessary skills to organize such events by themselves.

Interview 4, Liguria:

> *An old lady who had finished commercial school lives with her husband in suitable conditions. She is mostly in bed, due to her health condition that makes her unable to walk. She needs permanent assistance in everything. Except for her husband who helps in most cases she has no social life. She receives home help twice a week and is also helped by her daughter. She has positive feelings about the process of joining CONSENSO. The FCN came to her home and asked about her needs in a very positive manner. She hopes that the presence of the FCN will be as positive in the future, too. She feels comfortable with the work of the FCN and does not find the process to be intrusive or too long. She understands the meaning of the individual plan that the FCN made for her and would not change anything about it. The professionalism of the FCN helped her to achieve her goals. She is completely satisfied with the help of FCNs, they provided support in different sanitary and social problems.*

In Liguria, there were different kinds of complex cases. At a focus group meeting, FCNs reported communication problems in families, psychiatric problems, medical and physical problems. It happened that during the FCN's visit family members were arguing so the conversation was hardly possible. Psychiatric problems were harder to solve since they required health professionals (looking for them was time consuming). The problem related to medical issues was most users' forgetfulness or sloppiness as regards taking medication (they tended to take double dosages or wrong medication). There was a case when a user had a physical problem but resisted to receive help. FCNs visited clients with complex issues numerous times (two or three times per week) and kept contact by telephone. All clients had their numbers and could contact them in case of need.

Interview 6, Liguria:

> *An old lady lives alone in a suitable rented apartment. She spends time cleaning, shopping, meeting friends, watching TV, reading. She gets most help from her daughter when she needs transport or buying groceries. She found out about the CONSENSO from her neighbour. She had a wonderful first impression of the program and expected support in case of emergencies or necessities. Her relationship with the FCN was informal and simple, quite comfortable. The FCN helped her with blood pressure measurements and she was happy with the results (blood pressure subsided). She was also encouraged into more socializing. She currently feels physically fine but a bit sad. Her social life was good until 2 years ago but recently she has lost friends. She is overall pleased with the FCN activities.*

   c) Follow-up

In the discussion, FCNs expressed their interest in how CONSENSO would have worked in metropolitan areas, e.g. in Genoa. They believe that in big cities there should be a shift of the focus; social networks in Alta Val Trebbia are already established (in a sense of awareness that the community needs to take care of its members; more due to need, not as much due to forming friendly relationships), however, this is not at all common in Genoa. "*Here* [in Alta Val Trebbia] *a lady lives alone in a very little town. I suggested her to write my telephone number on a big sheet of paper in case of need. However, her trick is simply not to open the window, and people outside will understand that she needs help. In Genoa, people can die in their apartments and nobody in the same building will know*" (focus group).

However, CONSENSO activities will continue to be implemented after the project finishes, with one nurse. The financing was already ensured. "*We will continue in the same way as in the CONSENSO*" (focus group).

d) <u>Conclusions and discussions</u>

Pilot activities in Liguria started in December 2016 and ended in March 2018. Initially, four nurses worked on the CONSENSO model, but only two performed field work from the middle till the end of the project.

FCNs in Liguria visited 342 clients and they prepared the least number of individual plans (127). The reason for that could be found in the above described situation with the absence of nurses during the implementation. Consequently, there was the least number of visits of the elderly per nurse (210) among all regions.

Before the beginning of field work, FCNs were well prepared thanks to training they attended. Although it lacked more practical information and guidelines it offered knowledge of a wider policy context. FCNs were closely connected to municipal administration and local health unit who gave them the list of the elderly in the area and basic information about them. They were responsible for the official promotion of the project, attracting as many users as possible. When we compare the discussions of the focus groups in all regions involved in the CONSENSO, we can notice that FCNs from Liguria were the among most active during pre-pilot activities. They contacted every mayor, organized public events and promoted CONSENSO in every way possible (even during masses).

When pilot activities began, contacts with clients were established either personally or by phone calls. The average age of clients was relatively low (77.2). The lowest percentage that stands out denotes direct activities (74.3%), but on the other hand, we can see that FCNs worked more on prevention (71.7%, third highest place) and activation/coordination (7.6%, third highest place). This corresponds with the index of independence of the elderly which is relatively high (83%) and indicates that issues of the elderly in Liguria are connected with services (transport, medical problems) that can be offered by others than FCNs. The CONSENSO model was well integrated and successfully adapted according to region legislation and specific needs of the target population. The elderly in Liguria are, from the territorial perspective, definitely in a great need of CONSENSO interventions. They live in remote areas with a lack of transport connection between the villages and towns which is essential for making health and social services more accessible and available. From the interviews with the elderly, we can see that the CONSENSO importantly contributed to providing transportation service for those in need or emergency. The elderly needed transport either for shopping groceries, going to hospital or pharmacy, and it was provided by their neighbours or family members. This highlights the important fact that the greatest issue of the elderly was isolation and the We can say that isolation was tackled in different ways, by walking groups, but also by the FCNs visits themselves which were (based on the focus group results) very well accepted and helped clients open up and talk about their issues without prejudices. need for socializing, which could be seen from the interviews and discussion in the focus group with FCNs. According to available information, it seems that the CONSENSO connected communities, not only in terms of the coordination of services (that too), but also and especially in terms of connection with the people living in the area. A very good practice in Liguria was the organization of walking groups.

6.3. Piedmont

Piedmont is one of the 20 regions in Italy. The capital is Turin. It borders to Liguria region to the south, the Aosta Valley region to the northwest and the Lombardy and Emilia-Romagna regions to the east. Piedmont has significant industrial tradition, with specialization in the automotive industry (FIAT is the largest Italian company), but in recent years, new specializations have emerged, for instance in ICT and telecommunications. The service sector and agriculture significantly contribute to regional GDP. GDP per capita PPS (Purchasing Power Standards) was equal to 30.000€ in 2016 (Eurostat, 2018), slightly above the Italian (28.200€) and European (29.200€) average. In 2017, the employment rate (63.8%) was in line with the national average. The unemployment rate increased considerably in the recent years, from 5.1% in 2008 to 9.1% in 2017 (Eurostat 2018). Nevertheless, Piedmont is still one of the regions with the lowest level of unemployment in Italy.

The CONSENSO project was perhaps the most important for Piedmont, since it has a strong tradition of family and community nursing. The University of Turin was the first university in Italy to organize the first level master's degree in family and community nursing. Thanks to previous experience carried out by Turin University with the innovative program 'Family and community nurses advanced learning program', Regional Health Authority of Piedmont (RHAP) was in 2013 recognized as Reference Site (EIP-AHA), a programme launched by the European Commission in 2012. Piedmont region therefore strongly supported the initiative and saw it as a project that "represents an intervention of regional interest with regard to the reorganization of community services."

The main motivation behind piloting the CONSENSO project in Piedmont was to strengthen primary care by introducing the profile of a family and community nurse, whose focus of work is less on technical tasks and more on their autonomous and proactive roles. The peculiarity of the CONSENSO FCNs work in comparison to traditional work of nurses in Italy is their proactivity that manifests in the attention to prevention, in the support to clients' families and in the promotion of healthy and active aging.

Pilot activities in Piedmont took place in two mountain valleys - Maira Valley and Grana Valley, altogether in 18 small municipalities in the Province of Cuneo. The following towns were involved in the study: Acceglio, Canosio, Cartignano, Castelmagno, Celle di Macra, Elva, Marmora, Montemale di Cuneo, Monterosso Grana, Pradleves, Prazzo, Roccabruna, San Damiano Macra, Stroppo, Valgrana and Villar San Costanzo with 6.399 inhabitants (1.585 of them 65 years old or older, which is 24,7%). As already mentioned, additional areas (Asti, Novara and Verbania) also implemented the same activities with their own funds (in spite of officially not being part of the project), and their results are also included in the analyses, presented in the previous chapter. Altogether (Cuneo, Asti, Novara and Verbania) 16 nurses were involved in the project. The focus group in Piedmont, as well as a thorough description of their work, however, included only nurses from Maira Valley and Grana Valley, so the care model for this region is based on their perspective and their work.

Pre-pilot activities in Piedmont

a) Promotion

Pre-pilot activities began in November 2016. In Piedmont, FCNs did not promote the CONSENSO from the beginning of its implementation. *"They [project management] have already contacted the mayors and promoted the project. We were not included in that part"* (focus group).

After being formally employed, FCNs were (also) responsible for the promotion of the project:

- FCNs prepared 15 public events, while in 3 municipalities they visited clients directly, together with mayors.
- They made a leaflet with enlarged letters (due to clients' sight problems) and pictures of nurses (to make the recognition of nurses easier).

- FCNs hung posters in shops, pharmacies and other public places.
- More than 1.000 letters were sent to clients that included a personal invitation to a COSENSO event.
- FCNs called clients who did not attend the public event or knocked on their door, which was a less promising approach: *"They have not seen us before so most of them refused …"* (focus group).
- The promotion of CONSENSO spread also by word of mouth.

FCNs in Piedmont were measuring the degree of response. In the areas of higher altitudes, the response rate was generally better in comparison to that in the foothills. In Alta Valle Amira the response rate was 77.1%, in Valle Grana 59.1%. The refusal to join the project was, according to FCNs, mainly a result of distorted perception of clients' needs or a proximity to the services already active in the lower parts of the valley.

b) Stakeholder mapping

In the beginning of the project, the following stakeholders were identified in Piedmont by the project partners:

- Key players:
  o Health needs: ASL Cuneo 1, ASL Torino 1, IPASVI Torino, IPASVI, Ministero della Salute, Ordine dei Medici Chirurghi e Odontoiatri della Provincia di Torino, PROMIS.
  o Social needs: IRES Piemonte.
  o Experts: Università degli Studi di Torino.
- Kept satisfied:
  o Health needs: ASL Alessandria, ASL Asti, ASL Biella, ASL Cuneo 2, ASL Novara, ASL Torino 2, ASL Torino 3, ASL Torino 4, ASL Torino 5, ASL Vercelli, ASL VCO, AO Ordine Mauriziano di Torino, AO SS Antonio, Biagio e C. Arrigo di Alessandria, AO S. Croce e Carle di Cuneo, AOU Città della Salute e della Scienza di Torino, AOU San Luigi di Orbassano, AOU Maggiore della Carità di Novara, Federsalute, IPASVI Cuneo, Istituto Superiore di Sanità.
  o Social needs: Comune di Acceglio, Federsanità ANCI, Italia Longeva, Polo di Innovazione bioPmed, SiTI Istituto Superiore sui Sistemi Territoriali per l'Innovazione, UNCEM Piemonte.
  o Experts: Fondazione Torino Wireless, SIGG, Scuola di Medicina Università di Torino, Unione Industriale Torino.
- Kept informed:
  o Health needs: IPASVI Alessandria, IPASVI Asti, IPASVI Novara, IPASVI Vercelli, Istituto Superiore Mario Boella.
  o Social needs: Città Metropolitana di Torino, Compagnia di San Paolo di TorinoComune di Torino, Comunità montana Valli Grana e Maira, Confederazione Associazioni Regionali di Distretto, CSP innovazione nelle ICT, Unione Montana Valle Grana, Unione Montana Valle Maira.
  o Housing needs: ANASTE Piemonte.
  o Experts: Politecnico di Torino, Università degli Studi di Torino 2i3T Incubatore di Impresa, Università degli Studi del Piemonte Orientale "Amedeo Avogadro".

FCNs actively worked with relevant stakeholders in the area. The most important stakeholders were mayors, medical doctors, NGOs and social workers. Close relationships were established with mayors who were generally very supportive of the project. The mayors attended public events and helped to explain the project and introduce the nurses to the target group. Local authorities gave suggestions about how to contact these people: *"We let the local authorities choose the best way to get to know people. Some of them brought us to people's homes directly, and it made sense, because there were only ten inhabitants or so. However, this was not the best way to introduce the project - public events were"* (focus group). City halls also provided conference rooms for public events and helped FCNs with the list of the

clients. The lists were firstly obtained from health centres (with clients' short health and social history) and later updated/compared with data collected by municipality.

At the focus group meetings in Piedmont, relationships with doctors as one of the more important groups stakeholders were mentioned, especially since nursing (in Italy) has historically been subjected to forms of medical dominance and conflicts (e.g. Allen, 2007). According to project partners, general practitioners in the beginning expressed doubts, mistrust and fear that certain responsibilities were taken from them, however, through the piloting of the project, the majority of them realized that under no circumstances FCNs want to replace them but rather take a complementary role that clearly contributes to the health of clients. FCNs in the focus group confirmed that not all doctors wanted to collaborate with them and be part of the CONSENSO, however, it was possible to establish fair collaboration with some of them (when contacts were more frequent and constant). For instance, issues occurred when physicians learned about the project for the first time from the newspapers (*"//… They were not informed officially. They were not happy about the fact that we went to their areas in the mountains where physicians are the only providers of health services"* (focus group)). In some cases, they remained unsupportive until the end of the project. *"Not everybody changes their mind. But it is not just because of the project, it is a general issue in this area. There are some doctors that are open-minded and want to collaborate with nurses, while some of them are not able to change"* (focus group).

The third stakeholder were home care nurses, employed in public health centres, which were especially relevant where general practitioners were not willing to cooperate (*"They help us have a better relationship with doctors, because they have been working with them for a long time"* (focus group)). FCNs had weekly meetings with nurses in health centres.

Project was presented broadly, also to other private and voluntary bodies. In particular, meetings were held with the director of the Socio-welfare Consortium of the Valleys Maira and Grana, the director and staff of the "Pensionato Vittoria" senior care facility in Monterosso Grana, the president and the psychologist of the Alzheimer Café di Dronero, the volunteers of the old centre of Valgrana, the volunteers of the Red Cross of Acceglio, the director of the Rest Home Alessandro Riberi "di Stroppo, the president of the Acceglio Foundation and a volunteer from the Raffaella Rinaudo Association. It was thus possible to establish good cooperation with some of these institutions, especially in case of need. Unfortunately, the lack of volunteers in the field has emerged and, in some cases, caused the difficulties in responding to the clients' issues.

c) Additional tools and scales

FCNs in Piedmont used:

- Additional scales for needs assessment (for risk of falls, dementia, the mental state, ADL, IADL)
- Specially designed individual plan
- Flow charts for the region with instructions what measures to take in different situations (related to health, frailty, social problems, socialization etc.)
- Flyers with instructions related to healthy life styles.

Pilot activities in Piedmont

In order to implement pilot activities successfully, FCNs established their own rules of communication, as described in detail in the focus group in Piedmont. They had regular meetings in order to help each other and coordinate all possible services for clients in the field. In each municipality there were two FCNs in case that one would be unable to visit a client and clients could then rely on at least one nurse being available all the time. FCNs decided to start working in those municipalities where they had the most support from mayors. They also found support in neighbours and other professionals for small tasks (*"We cannot go there every day if they need to control blood pressure, we activate neighbours and social service"* (focus group)).

a) Contact with clients

As already described, due many promotional activities the presence of FCNs was well-known. The clients were directly contacted by letters and/or by phone calls and at public events. After the first meeting with clients in Piedmont region, FCNs were often called by users in order to provide or organize different services for them.

FCNs believe that 500 clients (this number was agreed within the project initially but unofficially) per nurse is too much: *"If we also include younger clients, families, then 500 is appropriate, however, if you monitor only older clients, then it takes more time. We have around 120 clients each and this number is already hard to handle"* (focus group).

Interview 2, Piedmont:

> *A lady lived with her husband in an isolated house in a bad condition with a bathroom outside. After FCN's intervention, both moved to their daughter's and son-in-law's farm, in a house that has indoor bathroom and does not have stairs. Their son helps her with shopping and accompanies her when she needs to see her doctor. She first heard about the COSENSO through flyer she got after mass in the church. She always felt calm as she trusted FCNs. She was included in the activities of Alzheimer Café that were suggested to her by a FCN.*

b) Assessment of elder individuals' needs

In order to assess the needs of the clients, FCNs had to use additional scales and tools and they made flow charts with instructions about necessary measures in different situations. After assessing the needs, the individual plan was written down by the nurse and discussed with the client. They were relatively flexible in preparing individual plans, however, the user's perspective was usually taken into account in the cases of changing lifestyle (but not when health issues were discussed).

The most prominent needs in Piedmont region were related to a lack of available transport which caused issues with socialising, especially in remote areas. *"As I said, the transport is one thing and socialization in the areas on higher altitudes is another thing. The elderly there are actually healthier, however, they need more socialising because of their isolation. They can stay there because they are well and can walk around"* (focus group). Both needs were often found in relation to seniors living alone and/or who are not self-sufficient any more. In some cases, the elderly did not have good friendship support network (paid or not paid). They hesitated to express their social needs because in the long run, the same users found it difficult to ask the same persons who are helping them for continuous help. These social and health needs stay unmet also because of difficult access to general practitioners' clinics, the supply of medicines and basic necessities. They also affect the need for socialising (going to the nursing home, the market etc.) for seniors who live in an isolated area and are more at risk of becoming depressed. FCNs were very proactive when they identified this particular need. Numerous meetings with mayors took place and the local administrators' awareness of the relevance of the problem was raised. Some possible measures for the resolution of this issue were identified. One of such measures is to increase the numbers of volunteers working in the field directly with the elderly. A project was being developed between the ASLCN1 and the ANTEAS association (based in Cuneo), in agreement with the Mountain Union president Valle Maira, to respond to the need of transport in the two valleys. This would be a service offered 5 days a week that would offer a weekly visit to the market for a group of elderly persons, participation in educational activities (e.g. walking groups), and visits to general practitioners and specialists.

Interview 5, Piedmont:

> *A lady lives in a house with her husband, daughter and her family. She enjoys living in the countryside, however, she feels she is burdening her daughter too much. She knew about the COSENSO via letter*

received from the mayor and the FCN who visited her. In the beginning she did not feel that the project could help her, but afterwards she changed her mind. The FCN organized her activities of daily living and helped her find a nursing home for her mother.

FNCs also tried to tackle dementia issues and collaborated closely with Alzheimer Café from Dronero. Clients in need were therefore offered new, effective and free services. Throughout the experimental period, contacts with the psychologist from the association were constant, the clients were discussed together and many times joint visits were made. This collaboration has produced important positive results especially where informal carers were overburdened and an extreme need for family reorganization was identified.

c) Interventions and activities

During the project's implementation period there was an attempt to create new initiatives for the communities with the main purpose of promoting healthy lifestyles, as reported by FCNs. The group initiative aimed at promoting greater participation, to increase opportunities for socialization, to seek out and enhance the help and involvement of stakeholders. In particular, as part of the implementation in the Valleys Maira and Grana, the initiatives promoted were as follows.

Walking groups

Two walking groups were organized and promoted in the whole community by FCNs in the summer of 2017, one in Valle Grana and one in Valle Maira. Walking groups were organized in places with the appropriate characteristics in terms of space, security and accessibility for all: circular, safe, with the possibility of sitting down, on flat terrain. Once the suitable place was identified, FCNs have prepared and posted the posters with the place and relevant contacts to publicize the beginning of the walking group. Clients were also invited to participate by telephone. Collaboration with a physiotherapist was established; she led a class with 20 to 25 attendants.

The groups started with a certain number of users, mostly elderly ones, who participated constantly throughout the summer period. At the end of summer, the mayor was again involved to allow the continuation of the activity in an indoor place, provided free of charge by local administration, which was then used throughout the winter. In fact, in both cases it was possible to continue the initiative thanks to volunteers who were identified by the FCNs as suitable for becoming the leaders of the walking group. Two groups continued under the FCNs' supervision once a month. In the summer of 2018, two new walking groups were expected to start, one in Valle Maira and one in Valle Grana.

"Healthy eating to live better" lectures

Another initiative for group education in the community were discussions of healthy diet. This initiative was promoted within the CONSENSO in collaboration with the S.S.D Diabetology and Endocrinology of the ASLCN1. To give more complete and exhaustive information, specialized professionals in the field of nutrition were involved. After presenting the COSENSO project and its aims to the Director of the S.S.D Diabetology and Endocrinology of the ASLCN1, collaboration with the Dietician Technical doctor was agreed on.

Chronic Disease Self-Management Program

This programme was created in 1991 by the Stanford University Patient Education Research Centre as a research project in collaboration with the Northern California Kaiser Permanent Medical Care Program. In order to implement the programme, it was necessary to purchase the license from the Stanford University by the ASLCN1. The nurses then took part in a specific two-day training course. As part of the ASLCN1, the initiative called "Insieme per di bene", open to all, started in six areas, two of which are the two areas involved in CONSENSO: Valle Grana on 13 March 2018 and Valle Maira on 12 April 2018, with the aim of offering an important opportunity for health and socialization to the community. The proposal: six group

meetings lasting two and a half hours each week to reinforce the self-management of chronic pathology. The course was held by two FCNs and was aimed at both chronic patients and caregivers (maximum 20 participants).

    d)   Analysis of individual action plans

As already noted in the CONSENSO app analysis, the number of individual plans prepared by FCNs in Piedmont for their clients is lower than the total number of clients. 2369 clients were included and 1709 individual plans were prepared. This can be attributed to the fact that some other Italian regions unofficially joined the project and followed the agreed project "rules" regarding nurses' intervention more loosely as they were not present at the training. Otherwise, the nurses carried out on average 2.3 visits per client. The textual analysis of all prepared plans and planned activities mirrors, in some respect, the above described overall approach of the pilot implementation in Piedmont. We can observe a considerable amount of attention paid to physical activities such as exercising: these activities were planned for more than 20% of all clients. Another prominent activity evident from the action plans is a direct activity and could be classified as health intervention (more than a third of all clients). It is understandable that activities linked to monitoring of clients' health are also very prominent and were received almost by half of the clients. Less frequent (but still important) were activities related to health promotion and informing received by more than 20% of all clients.

Interview 7, Piedmont:

> *A couple lives in a village where all inhabitants know each other. The husband first heard of the CONSENSO through a letter from the mayor and a flyer. He was impressed by the project since he was given assistance without moving from home. He agreed about the goals set in the individual plan suggested by the FCN. The results showed that he lost weight and his blood test was better than at the beginning of the project. He emphasized the FCN's approach and behaviour towards him that helped him most. He noticed that overall situation improved after the FCN's intervention.*

    e)   Conclusion and discussion

In Cuneo, 598 clients were officially included as participants in the pilot, each nurse on average actively worked with nearly 150 clients and performed 340 visits during the project implementation. As statistics from the CONSENSO app shows, FCN's in Piedmont mainly provided direct activities, there was less prevention and activation of other services. However, the discussions from focus groups with nurses and the list of activities which were organized by FCNs (and provided to the evaluators) show that those two types of activities were actually at the centre of their work. FCNs did not work directly only with clients but (as foreseen in the COSENSO model) also with the community. As believed in Piedmont, the sustainability of the CONSENSO model is strongly linked to the ability of nurses to empower clients to cope with their own needs (empowerment and health literacy), but the model can be beneficial as well as sustainable if the nurse increased the social capital in the community in which she is active (strengthening the feeling of belonging to the community, integration). FCNs performed really prominent work in pre-pilot activities and during the implementation they also held regular meetings with mayors, with nurses employed in health centres, and with Alzheimer Café.

The relationships with physicians were less promising, since they were often unavailable for communication. FCNs highlighted the importance of team work: *"We think that a team should be composed not only of us, nurses, but also of psychologists, physiotherapists and social workers. We do not know everything about what we can offer to a client, we always have to ask"* (focus group).

FCNs in Piedmont were taking a proactive approach; they began to establish themselves as key persons to their clients: *"This is the biggest difference between us and the physicians - the pro-active approach. If*

you do not call or contact your clients, you simply do not know them or their problems. It is not the same if you do not go to their house and see the place and how someone lives" (focus group).

6.4. Slovenia

The **Coastal-Karst statistical region** (Slovene: *Obalno-kraška statistična regija*) is situated in south-west Slovenia. It covers the regions of Slovenian Istria and most of the Karst Plateau. The region has sub-Mediterranean climate and is Slovenia's only statistical region bordering the sea. As reported by the Statistical Office of the Republic of Slovenia, Obalno-kraška statistical region had 5% of Slovenia's population in 2016. The region stood out with the highest share of foreign citizens in total population (9.7%) and with the largest number of persons emigrating abroad (10 per 1.000 population). The unemployment rate in September 2018 was below national average (7% vs 7.8%) (Employment Service of Slovenia). Every fifth inhabitant in the region is 65 years old or older (SURS, 2018).

The pilot in Slovenia was implemented in the municipality of Piran, which is one of the eight municipalities in the region. Piran is the administrative centre of the local area and one of Slovenia's major tourist attractions. It borders Croatia to the south, and the municipalities of Izola and Koper to the east and faces Italy across the Gulf of Trieste and the Adriatic Sea. The municipality is bilingual, both Slovene and Italian are official languages. Municipality comprises of numerous towns: Dragonja/Dragogna, Lucija/Lucia, Nova vas/Villanova di Pirano, Padna/Padena, Parecag/Parezzago, Piran/Pirano, Portorož/Portorose, Seča/Sezza, Sečovlje/Sicciole, Strunjan/Strugnano, Sveti Peter/San Pietro dell'Amata. In the centre of the city of Piran, cars are generally not allowed, there is parking available outside of the town centre. The city provides a free shuttle bus to and from the parking lot. The city has characteristic narrow streets and tall buildings with several floors. The surrounding villages are situated on a hilly landscape. Among the five CONSENSO regions, Slovenia is therefore the only one covering coastal (not mountain) terrain.

Community care for older adults is more or less limited to nursing care and home help. The CONSENSO project was closely connected with home nursing staff, who, in accordance with the law, already implement a majority of the activities anticipated in the CONSENSO model.

Home nursing services are 100% financed from compulsory health care insurance. Home nursing is organized as an independent organizational unit within primary health care institutions. Nurses are usually employed in the primary health care institutions. The curative nursing is carried out according to the physician's working orders. Preventive activities in home visiting can be carried out by a nurse, in accordance with the applicable legislation, independently of doctor's orders.

Older adults are marked as an in-risk group and nurses provide them with curative and preventive visits at home. The preventive nursing care model is similar to the CONSENSO's:

- Nurses visit families, focusing on pregnant women, new-borns, babies, small children, the chronically ill, and older adults.
- The approach is holistic; together with the client they try to identify their needs and promote health, prevent disease through education-driven voluntary behaviour changing activities.
- When visiting older adults, a contact is also made with the family and community; social, economic, hygiene and health conditions of the family are identified.
- Before the first visit, nurses need to be familiarized with the area which they are responsible for, its demographics, major health/social statistics and issues, as well as its geographical and cultural characteristics and its economy.
- Nurses counsel the clients about healthy lifestyles and warn about risk factors; nurses are also the coordinators between clients and their general physicians.

With older adults, nurses are allowed two preventive visits per year, but only for those clients who live alone and are socially vulnerable. Krajnc (2018) discusses the issue of the "loneliness and social vulnerability" criterion, since it is not precisely defined. The practice in recent years shows that preventive visits are not covered by the insurance, and consequently fewer preventive visits to older adults at home are carried out. The goal is to keep/improve the level of independence, prevent diseases and allow for independent living at home for as long as possible. Health education work is adapted to the particular circumstances of the individual, their illness and the possibility of help from informal carers. If she, for example, finds out that someone with chronic disease is not sufficiently aware of healthy lifestyle or there are other factors or symptoms that may be endangering their health, she will - in line with professional competences - implement measures at all levels of prevention. Independent preventive visits are due to recent issues with insurance rare, but preventive measures are provided together with the main (curative) cause of the visit.

Pre-pilot activities in Slovenia

There were altogether nine nurses involved in the project: a) four family and community nurses (employed part time, 75%); b) five senior nurses, employed in the Community Health Centre Piran, also working part time (20%). CONSENSO nurses were following the newly designed CONSENSO model of care, the role of senior nurses was focused on advising and introducing younger nurses to the community. *"The four of us selected a mentor nurse. Senior nurses already treat inhabitants in designated areas and are known in the community. With their help, it was easier for us to enter the house, because the seniors are usually very suspicious of new people"* (focus group). Since senior nurses worked only as supervisors and advisors, and FCNs worked with older adults, only the work of FCNs is recorded in the CONSENSO app.

The first steps of the project implementation involved:

a) contacting the Municipality of Piran, which provided the CONSENSO team with the list of older adults with all necessary information such as address, date of birth etc.
b) CONSENSO training of FCNs.

Two FCNs and five senior nurses were involved in training in Izola (June 2016) while others did not decide to be part of the project. The more thorough trainings were implemented after September 2016.

c) Working with the community and stakeholders, the promotion of the project (activities carried out less by the nurses, more by the project team members).

The following stakeholders were identified as important by project partners:

- Key players:
  - Health needs: Health centre Piran (Zdravstveni dom Piran).
  - Financial needs: Local public authority.
- Kept informed:
  - Health needs: Ministry of Health of Republic of Slovenia, Nurses and Midwives Association of Slovenia.
  - Social needs: Center za socialno delo Piran.
  - Housing needs: Center za socialno delo Piran.
  - Family/friends and others: NGO's dealing with the elderly and long term care: Društvo HOSPIC; Rdeči križ Slovenije (Red Cross Slovenia), Karitas, Društvo upokojencev Piran, Društvo Svetilnik, local authorities.

According to the focus groups with nurses, the CONSENSO project was presented on many different occasions before the start of the pilot: a) in local communities to citizens of Piran; b) at events (i.e. the Health Day in Piran); c) to different stakeholders (general practitioners, the Association of Persons with Disabilities, the Association of Pensioners and others who attended events). Nurses sent 3.000

notifications to the retirement home and knocked on their doors to present the project. Flyers were designed and handed out during events. At focus groups, they mentioned they regret not having visited local priests who could be important stakeholders and promoters of the project. No contact between local social workers and the newly employed nurses was established, senior nurses contacted them, too. Nevertheless, social workers were well informed about FCNs' work and the CONSENSO project. A potential veto stakeholder of the project was an NGO program "The elderly for the elderly" (organised and implemented by Slovene Association of Pensioners - ZDUS, the largest NGO in Slovenia) which covers the whole country and provides coordination activities which are similar to those of the CONSENSO. Nurses had a great support from doctors and mayors. Municipality administration provided a list of potential users, but FCNs found most of the help in nurses who already knew the territory and the majority of clients.

<u>Pilot activities in Slovenia</u>

Field work started on 6 December 2016.

  a) Contact with clients

Making contact with a client was the first step made by a FCN in the pilot phase of the project. Here we were interested in how the contact between an older adult and the FCN was established and how the first visits of the elderly proceeded. During their first visits, Slovenian FCNs tried to strictly follow the questions from the app, but they afterwards decided to change that strategy with more locally adjusted manner of speaking to the elderly in order to be closer to them and create a more relaxed atmosphere resulting in a more genuine relationship. They estimated that around 40% of the elderly from the list provided by municipality got actively involved in the project (some were already deceased, some moved to institutional care or other cities and some refused to cooperate). Nurses emphasised good practices in their work:

- When visiting someone for the first time, it worked best to just knock on their doors (sending letters did not work as efficiently).
- The topic to include when introducing themselves: ("*//…I collaborate with nurses, we do a research, you will tell me about your health state, we will measure your blood pressure…// //… Everything is anonymous, we work for municipality…//*" (focus group)). The most important moment of building trust was a one-minute presentation in front of clients' doors. "*The biggest issue was getting in the house; once we were in, they agreed to participate, gave us their life story. But it was difficult to establish trust*" (focus group).
- Making conversations less formal, encouraging the elderly to talk freely about their social and health conditions.
- To learn the questionnaire by heart. FCNs recognized that simply reading questions to the client is not a good practice ("*//…You do not ask them directly, sometimes he do not tell you the truth. Afterwards, you change the question and they will tell you the whole story*" (focus group))
- The questionnaire was too long, so one had to be very focused to get the necessary information. Some questions were more sensitive, especially those related to religion, the perception of safety, relationships, finance. Some activities were not appreciated by clients (measurements of the waist).
- It is important to explain everything clearly to other family members, too. There were cases when they did not approve of their parent's involvement in the project.
- According to the participants of the focus group, it was more difficult to get into the house where the elderly lived close together in the city centre than in the countryside.

  b) Assessment of elder individuals' needs

According to the views expressed by the nurses in the focus group, there was no need which could be seen as predominant. The nurses summarise the expressed needs as follows:

- Younger clients (65-70) usually do not have prominent unmet needs - the nurses' activities are focused on counselling (advice about activities supporting and promoting health - health education. Clients usually ignored suggestions referring to changes in their homes. "*I do not want to give away my rug. I certainly will not fall*" (focus group). Numerous people at that age, according to nurses, are still completely functional and do not like to think about the future.
- People with chronic diseases - the nurses' activities focused on lifestyle changes (limited alcohol intake and smoking, weight reduction, reduced salt intake), demonstrating to clients how to regularly monitor their blood pressure. "*Due to preventive work, one client lost 22 kilograms. He even thanked me later*" (focus group).
- Complex cases: complex or unsolvable cases were rare in Slovenia. There were two situations when emergency had to be contacted. One FCN reported holding a client when he wanted to go shopping. The FCN measured blood pressure and it was 210 (she had recognized his dizziness before). She called the doctor and the client was taken to hospital.

After assessing the needs through the questionnaire, FCNs prepared an individual plan for each client. The individual plan was designed together with the client. They did not set the final objective but rather took small steps so the client had a feeling they could achieve it. An individual plan was a consensus between FCN's findings of client's health and social state and his/her objective. It was a gradual process. When FCNs showed the elderly the content of health education work where the needs and potential solutions are written, FCNs helped them to go through the document in case that they did not see well or were not very motivated.

Interview 1, Slovenia:

> *An old lady lived in the house together with her son and his wife. She had several problems which made it difficult for her to carry out everyday activities. She got help from her son, especially when she needed a ride to the hospital. The FCN visited her twice, assessed her needs and offered her help. When she fell and broke her shoulder, she called the FCN who came and helped her with contacting the hospital and arranging the appointment.*
>
> *"I would also ask for help my daughter-in-law but she is busy with her work as well and does not feel well; I really appreciate that they [FCNs] are very attentive. //… they are very sensitive, hard-working, working from their heart, listen well."*

The analysis of individual plans showed an above average share of individual plans which followed the approach where the majority of clients had their vital functions measured, where they were actively listened to or received some form of emotional support, and where their identified needs were managed. We can assume that in Slovenia individual action plans were designed in order to address clients' multiple needs during a relatively small number of visits. This is also confirmed by the focus group with Slovene nurses, where nurses said that they often recorded two needs by default: first, measuring the vital functions of the elderly and, second, socialization which referred to the presentation of associations to the elderly. Furthermore, considerable emphasis was placed on instructing the elderly on how to perform certain tasks, on informing them about the meaning of health education and other promotional activities (the promotion of healthy lifestyle, encouraging physical activity etc.) echoing Slovene agenda from the beginning of the project - to use the project to intensify these activities within existing FCN services. Coordination activities were rare and provided by senior nurses. FCNs usually solved problems by themselves when this was possible. Frequently requested services in the region were related to everyday

activities: cleaning, cooking, shopping, bathing. This is also in line with the Slovenian sample. Slovene seniors included in the pilot are the youngest and the healthiest, a majority of them not having complex issues needing complex and coordinated sustained measures by FCNs.

c) Follow-up

The majority of clients in Slovenia were visited twice by FCNs. At their second visit they checked whether plan(s) as defined in the CONSENSO app were being implemented. Phone calls from clients were rare ("*I think I had two or three calls. We did not give the elderly our personal numbers*" (focus group)), but some were visited multiple times. "*A few clients asked me to visit them more often, so I did, just to chat and measure the vital functions. Sometimes they just needed some emotional support*" (focus group).

Interview 2, Slovenia:

> *A man lived with his wife who helped him with everyday care. He needed to visit his doctor at least once a month. His wife gave him an insulin shot every day. When the FCN visited him, she gave advice related to changes in the apartment (i.e. to remove the cushion at the entrance door since it increased the risk of fall). He and his wife removed every carpet from their apartment. They both trusted FCNs and saw them as experts.*

d) Conclusions and discussion

To sum up, four nurses actively worked on the CONSENSO model with the support of senior nurses. Older adults participating in the project were (in comparison to other regions) younger, more commonly living in areas with higher number of residents, healthier and less dependent. Altogether, the four CONSENSO nurses took care of 844 older adults, who were on average visited twice each in a period of approximately one year. Predominantly, nurses provided them with direct activities and health prevention. The coordination of stakeholders was rare, coordination activities were not identified as necessary in the local environment, based on the data in the CONSENSO app, individual plans and based on the analysis of focus groups. However, when coordination was necessary, it was performed by senior nurses. This is coherent with the target population in Slovenia; among all regions, Slovenian nurses were the most successful in involving younger seniors (65-70 years old), which is coherent with their preventive function.

FCNs generally welcomed new approaches to their work, especially a broader focus on preventive care for the elderly. Since the CONSENSO model was predominantly based on Slovenian example, they see its main benefits in expanding the role of community nurses with more frequent and elaborate preventive visits to the elderly. "*The legislation limited preventive visits to the elderly to those that are vulnerable and lonely. With the CONSENSO, we were again able to take care of the entire population*" (focus group). Therefore, in order to incorporate CONSENSO activities to Slovenian health and social system, the role of nurses in caring for the elderly needs to be strengthened by enhancing their preventive functions. A major goal of the health promotion and disease prevention approach is to identify health and other problems for which preventive efforts can result in a more appropriate utilization of services and the improvement of wellbeing. Data show that nurses were more successful in involving younger seniors (65-70 years old), which is consistent with the activities they were providing. As Golinowska et al (2016) show, exercising, quitting smoking, limiting alcohol consumption, participating in learning activities and integrating into the community can help preventing the loss of functional capacity, therefore improve the quality of life. These activities are more appropriate for relatively young seniors, while activities for those aged 85+ should receive more medical attention from physicians and caregivers (Golinowska et al, 2016).

The CONSENSO project was very useful for municipalities in a sense of strengthening preventive care activities, which was highlighted in their work. The CONSENSO also brought forward some new activities,

especially work with other providers and NGOs in a community, the coordination of care, as well as closer relationships with municipality of Piran.

6.5. Var

Var is a department in the Provence-Alpes-Côte d'Azur region in south-eastern France. On the east, it borders to the department of Alpes-Maritimes, on the west to Bouches-du-Rhône, on the north to the river Verdon to the department of Alpes-de-Haute-Provence and to the south by the Mediterranean Sea. In Var, two FCNs covered older adults in six towns, however, three nurses were trained (one resigned in the middle of the project). One FCN has attended focus group and shared her experience during the CONSENSO. The pilots were being implemented in six towns in Golfe de Saint-Tropez, in a coastal and rural area with limited transportation connections (there are no public transport or highways).

As Naiditch (2013) reports, registered home nurses in France are usually self-employed (*infirmier liberal*) and paid fee for service. These nurses are highly supported by the public, but need to work more hours (50) on average to get a fair income. Since FCNs, employed with the CONSENSO project, with their free service represented the competition to the private-sector nurses, they decided to take a different role in a project. "*In the beginning of the project we tried to define what the work of a CONSENSO nurse should be. We decided that we do not have to provide care to the elderly, not even measuring blood pressure. We do not even tell them we are nurses, we are coordinators. Because of that they are not expecting nursing but merely information. Our work is to coordinate. The elderly do not know we are nurses; sometimes they know, but really, we are not allowed to do this service. It's forbidden for us to be nurses, because of the competition*" (focus group).

By positioning themselves as coordinators, the French FCNs bridged an important gap in French social and healthcare system. Coordination in the home of the recipient of services is usually weak and so is coordination between home and residential care (even when one organisation runs both). The same can be said for so called discharge management which is not frequent − employment of nurses, called "liaisons" and other services (MAIA) are an exception. Links between all types of home help and care agencies on one hand and self-employed nurses and GPs on the other are not formally organised (Naiditch, 2013). *"There is already a service in France that provides help after discharge from hospitals (MAIA), but they are understaffed, there is only one person for a very large area... and MAIA service is also very new and they are happy to receive help. MAIA started in January this year /…/ And also, we are better than MAIA because our service is not so conditional - if you want to get MAIA services, you have to be alone, isolated or have a chronic condition, which is a lot of requirements. We help everyone"* (focus group). In addition to the coordination of already existing social and health services, the French FCNs offered health prevention, suggestions about adaptations in their homes and other information important for their clients.

Pre-pilot activities in Var

Despite their role as coordinators, FCNs were professional nurses by occupation. Because of that they expressed their lack of knowledge and familiarity with social policy measures, programmes etc. In order to obtain further knowledge, they started to collaborate with the Red Cross. "*We do not know much about social issues in France, so we started to learn about the rights of the elderly. This was the first part of the project*" (focus group). The help from the Red Cross was provided throughout the entire duration of the pilot. *"I need additional education. That's why I sometimes call the Red Cross. When I am near a burnout, I call them for help. I think it is very important to have the support to do the job. My previous education is not enough. Training in the project still continues"* (focus group). French nurses emphasized the lack of their experiences and competences as well as knowledge of social policy, social work, or case management, which were all integral and important concepts and approaches of the CONSENSO model.

Similarly, they were often asked questions by their clients regarding legal matters, making it necessary to include a lawyer in the clients support network. In spite of their efforts, they did not manage to include one.

During pre-pilot activities, nurses studied the geographical territory they will be responsible for and made a map trying to identify weak and strong points in terms of which professionals already provide services for elderly population. They also build a socio-demographic profile of the elderly in the region. They searched for doctors and nurses and they made a list of all relevant professionals active in the field. It seems that FCNs had two groups of stakeholders divided between health and social department. "*There are 203 persons in the network. These are only health professionals. We meet with social workers separately*" (focus group). All health and social work professionals were notified about the project by mayors. FCNs emphasized the importance of the role of mayors who were truly supportive of the project, they helped with communication with professionals and clients, as well as by additional co-financing of the project. However, not all professionals were willing to cooperate with FCNs at first. *"In the beginning I noticed that not all professionals wanted to be our partners; they thought we would only increase their workload. Now it is a real team work with some of them, they discovered that we do not give them more work but make their work easier since we provide information to our users"* (focus group). Care providers were reluctant regarding the project and opposed it as they perceived the FCNs as their competition.

Mayors provided FCNs with a list of persons over 70. Nurses had to re-check the list and add those from 65-69. *"In fact, in France there is Christmas tradition that mayors send a gift for Christmas to everyone older than 70. They had the list of those aged 70+, but not 65-69. So we searched for these, we prepared an excel file with gender, name, surname, telephone number ... We had to clean the list, because sometimes women were recorded twice (also with their maiden names). We also had to find couples so that we could visit them at the same time. We had to search for 3000 phone numbers, one by one, on the Internet. In one particular town, they gave us only handwritten names, so we had to retype all the names"* (focus group).

Interview 2, Var:

> *An otherwise independent lady received basic IADL help from her brother. She heard about the CONSENSO on TV and was impressed by the project. She was very satisfied with the first visit, she did not find it too long or too intrusive. She felt she trusted the FCN.*

During the preparatory phase, a formal strategy and methodology of visiting clients were developed − FCNs prepared Excel sheets and communication tools to regularly update mayors regarding the needs in particular municipalities.

According to the multistakeholder analysis, up to 16 stakeholders were included in the project. Seven of them were identified as key players while others stayed unidentified. Regarding the category of needs of the elderly these stakeholders address, five of them were focusing on social needs, one on housing needs, one on health needs and five on financial needs.

- Key players:
    - Health needs: ARS /Alsace Esanté, ARS Provence Alpes Côte d'Azur, Syndicat des infirmiers libéraux du Var [Union of independent nurses: Union of independent nurses of the Var], Conseil départemental de l'ordre des infirmiers du Var [departmental council of the order of nurses of the Var], ESA 83 [specialised team for Alzheimer's disease in the home], SSIAD 83 [service for nursing care in the home].
    - Social needs: CD 83, CD 67, CD 68, Eurométropole Strasbourg, Local authorities (towns).
    - Housing needs: Social housing companies, Réseaux EHPAD.
    - Financial needs: CPAM, Mutuelles : MGEN AG2 R la Mondiale, CARSAT.

- o Family/friends and others: Association Française des Aidants, La Maison des aidants, Réseau café des aidants, UDAF 67.
- Kept satisfied:
  - o Health needs: Ordre des médecins, Ordre National des infirmiers, The Red Cross, Syndicat national d'infirmiers libéraux (ONSIL), Convergence Infirmière, Syndicat National des infirmières et infirmiers libéraux (Sniil).
  - o Housing needs: Fédération Nationale des associations de directeurs d'établissements et services pour personnes âgées (FNADEPA).
  - o Family/friends and others: Associations de Familles, Famille de France, Familles rurales.
- Kept informed:
  - o Social needs: Monalisa Association [national mobilisation against the isolation of older persons], Restos du Cœur, Associations de services d'aide à domicile SAAD [home assistance service associations].
  - o Family/friends and others: Family care givers.

<u>Pilot activities in Var</u>

The pilot phase started in December 2016. The first contact was usually made by telephone in order to set the time and date of the visit. For the majority of clients, the first visit was preventive. Because of that, the first visit was usually also the last. The follow-up was usually performed three months after the last visit by telephone call in which nurses checked with clients whether the identified issues were successfully dealt with. If this was the case, the case was closed. If not, FCNs reopened the file and kept working with the client. But all FCNs did not work in that way ("*I always call after three months, even if there was only prevention, but Kathy does not work in the same way. Kathy - if she just gave prevention, she closed the case*" (focus group)). After the first intervention, 70% of the cases were closed. Nurses tried not to pressure clients into participating in the project, however, all the clients received a flyer with additional information (*//…I do not force them. I just leave them the flyer and tell them to call me if they change their mind*" (focus group)).

e) Contact with clients

Clients were at first contacted by mayors; there were 3.000 letters sent at the same time, which resulted in numerous (around 100) phone calls. Since nurses were not ready to start working (the web application was not yet available), they prepared a priority list and promised the clients to visit them as soon as the pilot officially started. *"To people that really needed help it was difficult to say 'wait'. Because they received this letter in September, so they had to wait until December"* (focus group).

Interview 1, Var:

> *A lady lived alone in the apartment. Nurses, home helpers and family members were involved in her daily care. Her first contact with a FCN was over the telephone. Generally, she had great communication with the FCN, she felt listened to and could express her (dis)agreements easily. In her opinion, the overall situation was better after the intervention of the FCN, especially when all objectives were achieved.*

f) Assessment of elder individuals' needs

In the case of Var, the individual plan analysis shows that the recorded interventions were rather brief. Judging from the individual action plans, the most prevalent issue addressed in Var are financial issues. This is explicitly clear from the textual analysis of the individual plans as more than 41% of these plans contain this code. It seems that certain socio-economic issues were high on the agenda in Var. This is

further confirmed by the considerable presence of codes like *supporting*, *management* in individual plans, the focus group with nurses and interviews with clients. Another topic or area of interest in the intervention is promotion. Promotion activities feature relatively high in Var. This finding is supported by the fact that more than 89% of all visits in Var were described as having been of preventative nature.

Interview 3, Var:

> *A lady reported some financial issues and troubles with paying bills on time. She described the relationship with the FCN as very good; she listened to her suggestions regarding adaptations in the apartment in order to prevent falls. However, she would need daily home help, but unfortunately could not afford it. So far the FCN has not yet find a way to help her overcome her financial troubles.*

FCNs in focus groups, however, highlighted that the most commonly identified needs were linked to isolation and loneliness. Usually, FCNs managed to find a nurse or other caregivers to meet different needs: help with the cleaning, cooking, shopping etc., but many times they did not find a "service provider" to solve the problem of isolation ("*In this territory, no one is talking about the issue of the elderly being alone - not even NGOs. Associations do not go, it is too far for them. //…We do not want to send just anyone, we want to have competent volunteers, so we often cannot find them*" (focus group)). Nurses informed policy makers in local areas about the issues and they responded with two volunteers, who afterwards visited clients.

Interview 10, Var:

> *A lady who lived alone in a rented apartment had quite prominent health issues. Her apartment was adapted to her needs, she got regular visits from physiotherapist, nurses and home help service. She first heard of the CONSENSO by mail. She stated that without the CONSENSO she would always face problems with paperwork. She described the relationship with FCNs as very good and felt that the goals set during the project were achieved and her overall situation improved.*

In Var, the nurses and the clients designed client's individual action plans together. FCNs gave the client the space in order for him/her to feel comfortable to express his/her real needs. Clients usually set their objectives by themselves. The analysis of the individual plans and discussing them in the focus group with French nurses reveals that the most important activities of the FCNs in Var were informing the client. FCNs emphasized that clients were not familiar with available services or financial rights, therefore their work was needed and appreciated. In the focus groups, nurses estimated that approximately 5% of cases were urgent and needed very complex coordination. Usually, the complex cases demanded quick intervention (up to 48 hours) in Var. "*When I started visiting, I encountered a client with dementia. Relatives were too afraid to leave her alone at home, therefore they took her with them and lock her in the car in front of the supermarket. I was shocked. I later found out they did not know about human help service which was available in the area. Informal carers burnout is a big problem in France. In Toulon and other bigger cities, day care for the elderly is available, but not in these isolated villages*" (focus group).

Interview 9, Var:

> *A lady and her husband heard of the CONSENSO at the Communal Centre of Social Action. They were in contact with the FCN, who provided them with the cards for persons with disabilities. The objectives that were set were subsequently achieved. The CONSENSO was a big help for them and their overall situation improved.*

In the focus groups nurses emphasised the importance of timely intervention. It was important that when an organisation was made part of clients' support network, it was trustworthy, reliable and responsive.

This was not always the case. "*They said yes, but 2 weeks after - nothing. No one came. So I called again, and heard many excuses. I told them that I do not want to cooperate with them again. And they were blacklisted*" (focus group). After complex coordination, a re-visit or a phone call from the FCN was performed. When asked to describe successful coordination, a FCN mentioned a 74 year old woman who broke her right arm and went to hospital. Since she lived alone, she was not able to take care of herself properly, and after four days, a neighbour called, informing city hall that lady cannot eat or wash herself, because her hand is immobilised. The city hall contacted the FCN who visited the lady and coordinated meals on wheels service and human help, as well as a nurse. Afterwards, the client completely recovered. Without the CONSENSO, the coordination would have taken more time because the communication would have been less successful.

Interview 4, Var:

> *An elderly couple reported they had financial issues. The FCN helped them to find allowance fund so that they could pay for home help services but they did not obtain a favourable response from the administration regarding eligibility to financial assistance. The husband reported that overall situation unfortunately did not change in spite of the CONSENSO project.*

Health prevention, especially exercise, was not highlighted in FCNs' approach in Var as much as in other regions. "*I think health professionals need good people skills. In France, actually, we do not have this prevention-oriented culture; there are NOs everywhere (do not eat fats, do not smoke, do not drink ...). People do not really like to hear that*" (focus group). In line with that, Cartier and Bourguil (2015) argue that FCNs' role in health education and prevention is generally limited in France. They are mostly conducted at the single-patient level. Some health networks, health centres or multidisciplinary team practices are doing group health education. But these forms of organization in primary care are currently rare. Most health education practice is concentrated in hospitals.

Interview 5, Var:

> *A man who lived together with his son was relatively independent and only needed assistance with administrative tasks. His first contact with the FCN was via phone. He observed that the CONSENSO was very beneficial for elderly population, but since he was healthy, he did not need any help at that moment.*

g) Conclusion and discussion

There were 956 clients participating in the CONSENSO in Var; 962 visits were recorded in the web application altogether. Firstly, despite a lower number of visits and rather scarce descriptions in the individual plan section, a large amount of work and activities was done by telephone. The nurses were available for phone calls and did numerous follow-ups by phone. This was recorded in the "events" section in the web application, which was broadly used by Var nurses, more than by nurses in other regions. In this section, FCNs recorded 366 events (follow-ups, newly proposed visits, administrative work/paperwork, as well as identified issues and notes for further work, client's health and social state, hospitalization status etc.). It is evident from the web application that the majority of these "events" (approximately 70%) were initiated by the nurses themselves. Among these events, approximately three quarters are related to communication (follow-ups, telephone calls, mail, e-mail) and were completed in the office. The rest were related to the visits of clients.

The average age of clients was relatively high in Var (77.5), second highest among the five regions. In accordance with their socially oriented philosophy and approaches to work, the analysis of the app shows the highest level of coordination activities in Var (13.6% of all the visits were aiming at the activation of other networks and coordination of services). A vast majority (89.5%) of visits also aimed at prevention

which is more surprising, since nurses in focus groups explicitly mention that prevention was not their primary focus; however, *prevention* was most likely interpreted with *providing information* (as a source of prevention) and this explains the results. Direct activities were less prominent. Health and independence indexes show that clients from Var more often had very mild or no health issues (59%), which is similar to Slovenia and Piedmont, and were less dependent.

From all available data (individual plans, focus groups, quantitative data and especially events section in the application), it is clear that FCNs from Var approached the CONSENSO from social, instead of medical point of view. Medical model focuses on something that needs to be fixed or changed with the individual, and has proven indispensable in many contexts. According to the medical model, medical treatment, wherever possible, should be directed at the underlying pathology in an attempt to correct the abnormality and cure the disease. However, FCNs in Var did not focus as much on "fixing the individual's habits", which is shown in less prominent focus on exercise and healthy lifestyle promotion, but more on providing support in clients' current ways of living. Care was more customized according to client's needs and values and client was the source of control (which is shown in nurses' attitude - they did not force the clients to participate or suggest how to change their lives, and individual plans were based on the wishes of the clients). They focused on providing information, removing barriers, support and care coordination. Following that ideology, they closed cases quicker than nurses in other regions, but provided clients with phone number. This is, from the perspective of empowerment, very beneficial for the clients (gives them the power to contact when they feel the need), however, in some cases it probably did not lead to a continuous care / relationship. The relationship of closeness and trust between the nurse and the client was not established in some parts. The focus group, however, shows that clients were very proactive in contacting the nurses. "*Today I had seven calls, I think I spent one hour on the phone. On Friday, Saturday, Sunday, Monday, Tuesday and Wednesday I was not able to answer my phone, so I got 12 messages. But professionals call me, too*" (focus group)*.*

7. Discussion and conclusion

The goal of the evaluation report was to systematically present the results of the project CONSENSO and the key benefits that the project brought to local communities and their older residents. As the project activities implemented in each region were described in great detail in the previous chapters, this final chapter provides a summary of the most important results of the project and highlights the key challenges for our further work.

In the study, the mixed-method design was used when collecting data. Qualitative methods were embedded within the quantitative design and played a role of supporting and additionally interpreting quantitative results. Since scientific research of experiments such as the CONSENSO pilot should be executed according to rigorous criteria, the control and experimental group should have been an essential part of the scientific method. In the CONSENSO, outcome indicators in both the control and experimental group as well as covariates in matched areas, were expected to be gathered from the institutional sources of information (National/Regional/Local statistics). Although French and Austrian partners did have access to such data sources, data protection rules did not allow them to make record linkage among different data sources. To be clear, it was not possible to link the list of names from demographic files to the list of names from hospital discharge files, from mortality lists etc. Moreover, in Slovenia most of relevant data sources were not available. This was not the case in the two Italian regions, where data sources were appropriate and available. Therefore, CONSENSO project ensured comparative analysis of the control and experimental group in the region of Piedmont. However, comparative analysis is not in the centre of this report. Findings from the analysis of the control and experimental group can be found in separate stand-alone report.

This report presents only the short-term project results. Pilot activities in the majority of regions lasted only 12-18 months and prominent changes on national/municipal level were not expected to be observed in national statistical data. However, differences in the everyday lives of the individuals were expected and described throughout this report.

The CONSENSO project's overarching goal was to enable and empower the elderly to live at home as long as possible by introducing a FCN in their lives as a key person who can identify the needs of the elderly and intervene or organise support in the form of various services. In order to achieve this goal, project partners developed the CONSENSO model of intervention and tested it in five different Alpine Space regions - Carinthia, Liguria, Piedmont, Slovenia and Var. The main target group of the CONSENSO were older adults (aged 65 years or more), living predominantly in rural/remote areas. On the one hand, these areas experience more pronounced population ageing in comparison to urban areas, and on the other hand they are less equipped to tackle challenges linked to this process. Additionally, the services infrastructure (transport, health and social services, programmes, NGOs) in these is inadequate and have caused reduced mobility, a lack of support and care, social isolation and unfavourable socio-economic conditions. The CONSENSO project therefore began to identify the most vulnerable parts of this population and worked actively with individuals with different needs and conditions.

In the three years of project implementation (December 2015 – December 2018), partners had a challenging task of designing a new model of care, preparing an application for collecting data on tablets from scratch, delivering tools and evaluation instruments, organizing field work, sensitizing local communities, promoting the project and interventions and performing numerous visits to clients with an ambitious goal of improving their lives. The initial part of the project was especially demanding since the project partners had to combine various ideas, national (macro level) needs and characteristics, legislations, interdisciplinary differences in the understanding of the community care, all in order to

develop a uniform model of interventions at home. Some methodological issues, related to the common understanding of indicators, occurred in this initial period that had somewhat impacted the differences in our findings, described in the previous chapters. Some of the differences between CONSENSO regions occurred partly due to app design, partly due to the fact that not enough time was devoted to the training for the evaluation and the usage of CONSENSO app, and partly because our interviewers were FNCs and not professional interviewers. The latter issue would be hard to avoid in the context of the CONSENSO project, however it did cause some of the bias in the data. The communication between a professional interviewer and client is different from that of a health interview. Health practitioners who think that they have experiences with interviewing might face issues when working with older persons because assessment interviews and research interviews are hardly synonyms. The first two identified issues are however more problematic. Despite the fact that the app was tested by project partners and FCNs and indicators explained, some issues remained until the end of the project's implementation. Our recommendation for the future work is therefore to allow more time for the preparatory phase of the project; for the development of the indicators, development of the app, the model itself and also more comprehensive evaluation training.

Altogether 31 nurses were actively implementing CONSENSO activities. Until 20 June 2018, there were 4.878 clients participating in the project in all five regions (Carinthia, Liguria, Piedmont, Slovenia, Var) combined. Individual plans were designed for nearly 4.000 clients. Each nurse, on average, worked closely with 157 clients and performed 340 visits. The total number of visits by FCNs in all five regions combined was 10.526. In addition to the visits, the FCNs were available to clients by telephones, in their offices and through numerous events they organized (i. e. walking groups, local promotions, conferences etc.). Eight percent of the clients faced complex health problems which required more demanding treatment and numerous visits. In the beginning, the initial idea was to reach up to 500 clients per nurse, which soon proved to be too ambitious. Consequently, the consortium decided to lower the recommended number of clients per nurse in order to improve the quality of the field work. This decision meant that the CONSENSO model shifted more towards in-depth intervention, more towards a case management approach which demanded from the FCNs more proactive and support network building approach. This in fact led to the key result of the project which is the identification and treatment of the most vulnerable groups of the population with nearly 4.000 individual plans prepared and followed up, developed protocols for data management, counselling, coordination and other approaches that were tailor made for each participant.

The data described in this report indicate not only the immense efforts of the FCNs but also the differences between the regions (even between the two Italian regions where the model was implemented in a similar policy and socio-economic environment). For instance, the clients in Carinthia were the most materially underprivileged and the most socially excluded. They were on average the oldest, the least independent, had the worst health status, were facing the most as well as the most severe social and economic circumstances. Thus, the Austrian FCNs had to perform numerous client's visits (average 5 per client) in order to maintain their independence and prevent the institutionalisation. Clients in Slovenia, however, were (in comparison to other regions) younger, healthier, less dependent, more of them lived in more populated geographical areas. This reflects different approaches to selecting the target group, which was based on the partner's understanding of the CONSENSO model and shaped according to either national or local priorities and needs. Sectoral priorities and the philosophies of the nurse as a profession in each participating region were also important factors in choosing different intervention approaches and activities predominantly pursued by FCNs. For example, in Var, where social care was highlighted and promoted especially by NGOs, the intervention did not focus on changing clients' risk prone behaviours and/or lifestyle. On one hand, this is evident in less prominent focus on exercise and healthy lifestyle promotion and, on the other hand, on more provision of support and empowering clients to remove whatever barriers they face. In the regions where the ideal of health prevention was more prominent, FCNs tried to encourage clients in changing their lifestyles, which meant less emphasis on the client's perspective as an integral part of the CONSENSO intervention model.

From the data that we collected, four different ideal types of FCNs can be identified:

- proactive FCN,
- preventive FCN,
- curative FCN and
- case manager.

Project partners in Slovenia saw the CONSENSO as an opportunity to provide more preventive health care (with focus on health education, promotion, measuring vital functions) to their clients and to highlight its importance. Austrian partners wanted to bridge the shortages in the system, which omits the most vulnerable population, and provided predominantly curative care. Partners in Var tried to enhance social care and case management in the area. Italian partners focused on proactive (instead of reactive) approach in nursing, i.e. taking control (anticipating autonomous role), anticipating and preventing problems as well as seizing opportunities. The project partners therefore discovered that regional introduction of a common ideal-type trans-national model of health and social intervention for the elderly was not an easy task. One could even argue that the project was not successful in this regard. Evaluation results namely show that each region adopted the proposed common model but also adapted it to better fit their own national and regional needs in this field, professional competences, existent policy environment and, most importantly, to the needs of the elderly the nurses worked with. These unintended consequences have, however, further enriched the project.

Key recommendation to consider before adapting or implementing the CoNSENSo model

Our first, general recommendation is that it is important to **provide enough time** for preparatory phase. Better or clearer organisation of work in the beginning ensures that the final implementation matches its purpose, and increases the likelihood of its success. Firstly, model of intervention needs to be adapted in order to better correspond to regional needs. To do that, **macro and meso level analyses** need to be performed. These analyses should provide us with regional specificities, key needs, barriers and burning issues, and should help us consider how intervention can respond to these issues or how to embed it to the legislation. The macro level includes health and social systems within which the family and community nurses operate, the meso level focuses on institutional decision making and generally the work with stakeholders.

In this part, **stakeholder mapping** should be performed, for two main reasons: a) building a network of support / services around the client; b) higher visibility and promotion of the project.

A collaborative process of research, debate and discussion should help determine a key list of stakeholders across the entire stakeholder spectrum in the local area, and should include relevant ministries, municipalities, regional authorities, national institutes of public health/social protection, centres of social work, health centres, nurses, representatives of (nursing) homes for the elderly, sheltered housing, providers of home help/meals on wheels, providers of other social/health services, and NGOs and volunteers, even priests, lawyers etc. After the identification of main stakeholders, one should work out their power, influence and interest, and support or opposition to the intervention, in order to build a stakeholder management strategy.

After clearly defining the intervention in a region, **training** should be provided to nurses. CONSENSO intervention combines provision of case management, social and health (integrated) services, and proposes a change in paradigm with more proactive, user-centred approaches. We propose to separate training into two parts: a) CONSENSO intervention, where the model and its philosophy are presented, together with FCNs activities and daily tasks; common understanding of the model and its aims should be established; b) the use of app and data entry (understanding of the indicators, methods, understanding and usage of individual plan). As CONSENSO project clearly showed, both trainings are extremely important and should be extensive and frequently repeated. Written manuals for nurses and constant support from supervisors should be provided.

Actively promoting the intervention is another important recommendation. Promotion should be done on two levels:

- Promotion to the stakeholders; stakeholder will take an active role in the implementation of the intervention (especially in connection with coordination activities) and can be supporters and promoters of the project among the clients. Contact with representatives of regional authorities should be maintained in order to achieve sustainability of the intervention.
- Promotion to the general public to reach the potential clients (through local media channels, other stakeholders, promotional events, consultations etc); direct notification of the clients in the intervention area (through letters and telephone calls).

For the second, <u>implementation phase</u>, **the type of the intervention performed** should be decided between:

1. an in-depth intervention (meaning less clients per nurse, but highly proactive work and numerous (curative) visits) or
2. prevention-oriented intervention (meaning more/healthier clients, more focus on health prevention, almost no curative work).

This decision must be reflected in the organisation of nurses' weekly activities. When organising the pilot, the following should be considered:

- which nurses will be employed (as practice has shown preferably senior nurses should assist junior nurses as mentors),
- which clients will be visited (a well-defined intervention area should be selected for each family and community nurse);
- the number of clients per nurse (depending on the selected depth of the intervention, approximately 300 should be sufficient),
- data protection issues, authorisation for collecting personal information of clients;
- time of each visit (for first visit approximately 1,5h).

List of all the clients with their telephone numbers should be obtained (usually from municipalities) and updated.

During the implementation, the agenda should allow the nurse to visit clients, to get regular training, to keep up with the administrative work, to (depends on the model) provide as regular support to clients as possible (i. e. also by telephone), but also to actively work with stakeholders and client's families, neighbours and community itself, in order to make it as self-sufficient and empowered as possible.

Due to different, sometimes very complex issues faced by clients, it is important **to strengthen the autonomous, flexible, innovative aspect of nurses' role**. As in the pre-pilot phase, also during the implementation phase, **regular trainings** should be provided. It is also important to **ensure continuity** in the work of family and community nurses who should build long lasting (at least 5 to 10 years) relationships with clients. Changes in staff are very undesirable. Working closely with same clients can create trust and leads to a continuous fruitful relationship.

Finally, we also propose to **adapt the app**. Currently, the app serves different purposes (needs assessment, individual plan, impact evaluation). Part of the applications that was designed to gather data for impact evaluation should be removed. Needs assessment could be also simplified. The app should be simplified to better support FCNs in easier monitoring of the progress of the clients.

<p align="center">***</p>

In spite of some methodological issues the evaluation process has faced, we can conclude that the project intervention was successful. It has delivered on its promise to improve the quality of life of the elderly and

enable them to stay longer in their familiar environment if this is supported by the introduction of a key person being actively involved in seniors' lives, promoting healthy lifestyles and organising the support network when needed. The CONSENSO has succeeded in showing exactly that.

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9. Appendences

9.1. Appendix 1: Consenso interviews manual

Background info

The general aim of in-depth interviews with CONSENSO users

to complement the study with user perspective;

to complement the study with approximate cost-benefit calculations on the individual cases;

to show for which cases is FCN useful from a financial and social perspective;

to identify the benefits of CONSENSO on a micro level;

to identify the issues unsolvable by CONSENSO model (and to suggest modifications to the model);

to show how the project (CONSENSO) integrates within already established health and social care systems.

Target group

4 of the interviewees are elderly with at least three (curative) visits (within CONSENSO project); with either numerous untreated symptoms/poor health condition; at least two with low socio-economic status and at least one with prevented hospitalizations/nursing care admissions, where activation of other networks or other interventions went successfully.

2 of elderly with at least three (curative) visits; with either numerous untreated symptoms/poor health condition; at least one with low socio-economic status and at least one with prevented hospitalizations/nursing care admissions, where activation of other networks or other interventions were not successful.

2 (younger) elderly in need of change in lifestyle, with successful health prevention activities.

1 (younger) elderly in need of change in lifestyle, with unsuccessful health prevention activities.

The process

In-depth interviews are meant to be conducted with clients in all regions included in CONSENSO.

Estimated start of conducting interviews is January 2018 and should be finished by the end of February 2018. Interviews need to be recorded, transcribed, translated to English and send to IRSSV.

It is important that interviews are conducted by qualitative analysis professionals and not FCNs, in order to avoid potential bias and assure a higher level of research standards. The communication between the researcher and participant is different from that of a health interview and requires a change in perspective. Health practitioners who have already undertaken a considerable about of interviewing might consider themselves as experienced interviewers, however especially when working with older people there are questions and issues arising from research interviews that are different from assessment and interventionist interviews.

Nurses will suggest clients for the interview. The ethics of the recruitment is important; we have to make sure that clients know they are not forced to participate in the interview. The principles of non-coercion (free participation, no fears of losing services if decline etc.) and non-manipulation (interpreted as the

clients must be fully informed at all stages during the interview) must be applied. Fully informed consent and assurance of confidentially must be signed

Every region is expected to conduct 10 interviews with 10 different interviewees.

The interview guidelines

In-depth interview guide has been designed according to the outline of the CONSENSO Impact Evaluation Plan. The guide consists of five main scopes of questions which are related to different phases of CONSENSO model and different activities of FCNs (pre-pilot activities and pilot activities (needs assessment, individual plan, activities). The general focus of the interviews is on gathering in-depth insights into personal experiences of users with CONSENSO, changes brought by CONSENSO and assessment of FCN's activities which have led or have not led to desired results defined in the individual plans.

The interview must consist of three important categories: establishing rapport and credibility as a researcher, developing the relationship, and storytelling as a strategy to integrate the participant's personal context with the researcher's questions. The communication between the researcher and participant must be different from that of a health interview and requires a change in perspective. While it can be time consuming and frustrating to listen to long stories about personal experiences, such story telling leads the way to establishing mutual respect. Additionally, relevant information is often woven into the fabric of these stories.

Establishing the relationship

The research needs credibility which comes from a clear understanding of the research and the part played by the client and the researcher. So, the first steps to establishing a relationship need to be considered carefully. We suggest the following procedure:

> FCN selects the clients, according to the suggestions, provided in the section target group;

> FCN discusses the possibility of interviewing with clients, providing them with short description of the process;

> if clients give their consent, FCN discusses some possible dates of home visit;

> FCN informs the researchers about selected clients and together they determine the date/time of the visit;

> FCN and researcher visit client together, researcher is introduced to client;

> during the interview, only researcher and client are present due to the risk of bias.

The method

The method must be a semi-structured interview. The interview should be dialogic, egalitarian, which means there's an equal power relationship. We should focus on the perspective of the participants and their experiences.

Timeframe

The timeframe is an important factor when interviewing older people; on the one hand, it is essential to give the person the opportunity to tell you what they think it's important (even though it is not always the answer to our questions), however on the other hand we have to make sure the interview is not too long, too tiring for the participant and also too expensive for our budgets. About one hour should be sufficient to obtain important information, however certain flexibility must be applied at this point.

The questions

In the first step, we write the client's short life story. Further on the client is asked about experiences with pre-pilot phase, needs assessment process, the individual plan and other FCN activities.

In the beginning we ask the client to share with us his or her life story. This has many purposes: to obtain his or her background information and context, to introduce us to the person, his or her status and social position and the living environment (past, youth, social networks, living conditions etc.), to obtain a client's trust, to allow him/her to relax, so it, later on, becomes easier to answer our questions. Such method draws the researcher into the client's world which is important to understand to see what might influence his or her responses. Observing, participating and listening are thus important interviewing strategies because they provide insights into the world of older people. As Mason emphasized (see Robertson and Hale 2011) in telling us about where they have lived and why, people not only provide their residential histories, but in the process, they also construct personal biographical narratives which bring into play key features in their life stories: their identities, their sense of self and their values.

The interviewer encourages the client to tell the story by himself, without many interruptions. However, the following topics should be at least partly covered. Interviewer can try to direct the course of conversation into the desired direction, however in doing so, he does not need to follow the order of questions, listed below:

> when and where was he/she born, what was the youth like,
>
> what is a typical day like? How does he/she spend the time?
>
> the education status (where did he/she go to school, formal status, skills), -
>
> where and with whom this person lives now, who owns the dwelling, suitability of housing,
>
> social networks (relatives, friends, who provides help, what kind of help they provide, what kind of help is missing, how they resolve understandings, conflicts,…),
>
> participation in the community (is he or she a member of associations, groups, religious groups, does he or she participate in community events and social activities, politics, volunteer work ..);
>
> concrete life goals and future expectations? What does he or she need to achieve these goals?

In the second step, the interviewer should direct the conversation to FCNs and his/her work.

How did you find out about CONSENSO? (flyers, media, TV, internet, events, word of mouth etc.)

What was your initial impression of such a project?

How did FCN make the contact?

Please describe your first contact with a FCN?

What were your expectations from the project?

This third step is very important and will help us with preparation of the individual plan and later on with the cost-benefit analysis. This part will be divided into two sections: a) in the first section, we remind our clients about the needs assessment process, provided by FCNs, and ask for their satisfaction assessment; b) in the second part, we try to list their current needs and formal and informal carers and service providers, who are currently managing identified needs. This will be necessary for the preparation of the per-user cost benefit analysis.

At least for the first section, please allow the process to be informal, let the client speak for himself or herself, provide the guidelines, but not necessarily in the given order. The second part must be more structured and demands a higher level of precision.

It would be very beneficial if results from the APP are available to the researcher for that particular user, so they can be more concrete while asking the questions.

<div align="center">Needs assessment – section 1</div>

In the first visit, the nurse tried to list your health and social needs and see, whether these needs were already being taken care of or additional help was required. Please describe the process where FCN assessed what your needs were (was it formal, informal)?

How did you feel during this process?

Was the process short or long, according to you?

Was the process intrusive?

How did FCN build the trust between you and her?

Did FCN present the results of the assessment in the end of the process?

Did you agree with the results?

Could you express your disagreement?

Did you feel heard during this process?

Could you express your needs to FCN?

Did the nurse, in the end, prepare a plan for working with you? (individual plan)

What was the procedure of preparation like?

Did the FCN explain what an individual plan is and why it is important for you?

Did you agree on the goals set in an individual plan?

Did you agree on the activities which need to be taken in order to achieve the goals?

Have your goals been achieved?

What helped achieve your goals? Which actors, organisations?

What prevented your goals being achieved? Which actors, organisations?

Could you please give us a detailed example of some of the activities and goals agreed on by you and FCN?

What would you have changed in CONSENSO in regard to individual plan

Needs assessment – section 2

General remark: Some of these questions were probably already answered in the description of a life story or other parts of the interview. You do not need to repeat them, however if you need further clarifications, you should ask for them:

Now let's go over your needs systematically again. How would you describe the state of your current health, physical and psychosocial, related to i. e. disease management, mobility, nutrition, use of medical devices, ability to take care for yourself, adaptation of the living environment, general feelings, attitudes towards life, stress, sense of security, threats…?

How would you describe your current social life? Who is a part of your social network, how they help, support you, where the support is missing, how do you resolve misunderstandings and conflicts?

Are there any activities/issues that you need help with (please, include all the needs, those that are already being covered by a professional or a relative, and those that no one is helping you with), i. e. help with cooking, cleaning, dressing, going to the toilet, transport (mobility), feeding or any other activities that you would like to do in your daily life? Who helps you with these activities? How often? Do you pay for services when you need them? How much? Can you afford them?

(FOR THE INTERVIEWERS: PLEASE USE INDIVIDUAL PLAN TEMPLATE BELOW FOR LISTING THE ACTIVITIES)

Do you get help from relatives? Do you get help from friends and/or neighbours? How much help are they providing? Would you prefer someone else taking care of you, or are you happy with current carers? What is the psycho-physical condition of your friend/helper while helping you? Does he/she have any issues while helping you?

The final steps of the interviewing process are other FCN activities. For this part, it is important that client is allowed to speak freely about the focal points listed below. It is important to describe their experience with FCN in their own words:

How would you rate your overall situation before and after you were helped by FCN?

What would you have done if there would be no CONSENSO services?

What do you think about coordination of providing services?

Did you have the feeling that the FCN organised and coordinated activities to support you to achieve your goal?

Could you give us an example?

How was your communication with the FCN?

Do you prefer to have a more open conversation with a coordinator or service provider (close relationship)?

Do you think that FCN pays more attention to the patient than a nurse in a nursing home? Please explain.

What is the future role of CONSENSO role?

9.2. Appendix 2: List of information collected in the first interview

Demographics and other elderly information		
1	Name	
2	Family name	
3	Gender	1. female 2. male
4	Date of birth	
5	Address	
6	Town of residence	
7	Town, number of inhabitants	
8	Place of living	1. isolated house 2. group of houses (up to 100 people) 3. village (up to 500 people) 4. town (more than 500 people)
9	Type of living	1. Apartment; 2. House; 3. Guarded apartment/sheltered housing/other (describe)
10	Floor where the elderly lives, including the ground floor	0-ground floor; 1-first floor: 2-second floor, etc.
11	Number of steps to be climbed (up or down) to get to the main entrance of the household?	
12	Elevator	
13	Number of persons living in the same household	
14	List name and type of relationship of persons living in the household	household member codes:1-husband; 2-wife; 3-son; 4-daughter, 5-sister; 6-brother; 7-grandchild; 8-other relative; 9-friend; 10-badante; 11-other (specify) _____
15	Marital status	marital status codes: 1-Single; 2-Married/Domestic partnership; 3-Divorced; 4-Widowed; 5-Other (specify) _____
16	Highest educational level achieved	ISCED codes: 0-No formal schooling completed (ISCED level 0); 1-Primary education (ISCED level 1); 2-Lower secondary education (ISCED level 2; 3-Vocational and upper secondary education (ISCED level 3); 4-Post-secondary non-tertiary education (ISCED level 4); 5-Short cycle tertiary education (ISCED level 5); 6-Bachelor's degree (ISCED level 6);

			7-Master's degree (ISCED levels 7) 8-higher than Master's degree (ISCED levels 8) Client will not answer with the ISCED level, but nurse will assign him/her to the appropriate level, based on his answer. ISCED level rules are available in all countries
17	Working activity (past or present if not pensioned)		
18	Retired		
19	How many children do you have?		
20	How far does your closest child live?		
Name generator			
21	*From time to time people borrow something from other people, for instance a piece of equipment or ask for help with small jobs in or around the house (e.g., easy household tasks). Who are the people you usually ask for this kind of help?*		
22	*How satisfied are you with this kind of support overall?*	1-means not satisfied at all 2- 3- 4- 5-means very satisfied.	
23	*Suppose you become seriously ill or you are generally very weak and cannot leave home, for instance to do the shopping or fetch medicine in the pharmacy. Who are the people you usually ask for this kind of help?*		
24	*How satisfied are you with this kind of support overall?*	1-means not satisfied at all 2- 3- 4- 5-means very satisfied.	
25	*From time to time, most people discuss important personal matters with other people, for instance if they quarrel with someone, when they have problems at their work, family problems or similar. Who are the people with whom you discuss personal matters that are important to you?*		
26	*How satisfied are you with this kind of support overall?*	1-means not satisfied at all 2- 3- 4- 5-means very satisfied.	
27	name1	who is name1 codes:1-husband; 2-wife; 3-son; 4-daughter, 5-sister; 6-brother; 7-grandchild; 8-other relative; 9-friend; 10-badante; 11-other (specify) _____amount of help: 1. sometimes (less than once per week)2. often (once per week or more)3. every	

		day
28	name2	who is name2 codes: etc.
29	name3	same
30	name4	same
31	name5	same
32	name6	same
33	name7	same
34	name8	same
35	name9	same
36	name10	same
37	name11	same
38	name12	same
39	name13	same
40	name14	same
41	name15	same
Autonomy and socialization		
42	Personal hygiene (bathing, trimming.)	1. independent; 2. need partial help; 3. need total help; help provider codes:1-husband; 2-wife; 3-son; 4-daughter, 5-sister; 6-brother; 7-grandchild; 8-other relative; 9-friend; 10-badante; 11-other (specify) _____12-nobody at presentamount of help: 1. sometimes (less than once per week)2. often (once per week or more)3. every day
43	Toileting	same
44	Feeding/drinking	same
45	Dressing/Undressing	same
46	Food preparation	same
47	Shopping	same
48	Go out for walking or for meeting with friends, relatives, or visit the doctor…	same
49	Taking medication (dosage, correct time…)	same
50	Reading, because of sight problems!!!	same
51	Cooking	1. never 2. sometimes (less than once per week) 3. often (once per week or more) 4. every day
52	Housekeeping	same
53	Going out for duties/shopping	same
54	Going out for leisure	same
55	Meeting others (relatives, friends…)	same
56	Sport/physical activity	same
Current formal support network		
59	Elderly's GP name	
60	Elderly's GP telephone number	
61	Elderly's nurse name	
62	Elderly's nurse telephone number	
63	Eledrly's home health service	
64	Eledrly's home health service telephone n.	
65	Eledrly's home social service	
66	Eledrly's home social service telephone n.	

67	Eledrly's home help service	
68	Eledrly's home help service telephone n.	
Health history		
69	Diabetes	1. past; 2. present
70	Arterial hypertension	1. past; 2. present
71	Angina pectoris	1. past; 2. present
72	Heart failure	1. past; 2. present
73	Condition after myocardial infarction	1. past; 2. present
74	Stroke	1. past; 2. present
75	TIA	1. past; 2. present
76	Hypercholesterolemia	1. past; 2. present
77	Chronic bronchitis	1. past; 2. present
78	Asthma	1. past; 2. present
79	COPD	1. past; 2. present
80	Chronic renal failure	1. past; 2. present
81	Rheumatic disease	1. past; 2. present
82	Osteoporosis	1. past; 2. present
83	Condition after a fracture	1. past; 2. present
84	Parkinson's disease	1. past; 2. present
85	Stomach disease (ulcer, gastritis)	1. past; 2. present
86	Cancer disease	1. past; 2. present
87	Depression	1. past; 2. present
88	Dementia	1. past; 2. present
89	Visual disturbances	1. past; 2. present
90	Other (specify)	1. past; 2. present
91	List name and dose of elderly's medications	name_____ dose _____ name_____ dose _____ name_____ dose _____ name_____ dose _____ name_____ dose _____ name_____ dose _____ etc. (up to ten lines, i.e. ten medications)
92	Elderly's number of hospitalisations in the past year	
93	Elderly's last hospitalisations in the past year	date of discharge nb of days of hospitalisation diagnosis at discharge
Lifestyles		
94	number of cigarettes	
95	problematic alcohol consumption (describe)	
96	problematic coffee consumption (describe)	
97	problematic sugar or food consumption (describe)	
Current symptoms		
98	Lack of energy	
99	Fatigue	

100	Dizziness	
101	Prolonged morning stiffness	
102	Insomnia	
103	Chronic pain	
104	Urinary incontinence	
105	Faecal incontinence	
106	Constipation	
107	Allergies	
108	Shortness of breath during activity (e.g. walking up the stairs)	
109	Concerns/Anxiety	
114	Other (specify)	
Current aids		
115	Glasses	1-does not need 2-needs, but does not has 3-has, but does not use 4-uses
116	Walking stick	1-does not need 2-needs, but does not has 3-has, but does not use 4-uses
117	Crutches	1-does not need 2-needs, but does not has 3-has, but does not use 4-uses
118	Walker	1-does not need 2-needs, but does not has 3-has, but does not use 4-uses
119	Wheelchair	1-does not need 2-needs, but does not has 3-has, but does not use 4-uses
120	Hearing aid	1-does not need 2-needs, but does not has 3-has, but does not use 4-uses
121	other (specify)	
Quality of life (PWI)		
122	… your standard of living?	
123	… your health?	
124	...what you are achieving in life?	
125	...your personal relationships?	
126	...how safe you feel?	
127	...feeling part of your community?	
128	...your future security?	
129	...your spirituality or religion?	
130	"How satisfied are you with your life as a whole?"	
Socioeconomic situation		
131	Was there a time in the previous 12 months when you felt you needed different health or social services, but you did not receive them?	
132	Why were those needs for care unmet?	
133	Do you feel left out of society most of the time?	
134	Do you often feel like you are treated badly by	

	public institutions?	
135	Source of income	1. Pension; 2. Salary; 3. independent activity; 4. other sources (specify) (for example support from others, social support, etc.)
Preventive measures		
137	Height	cm
138	Weight	Kg
139	BMI	
140	Waist	cm
141	Fasting blood sugar value	mg/dl
142	Blood pressure dyastolic	mm/Hg
143	Blood pressure systolic	mm/Hg
Frailty index		
57	"Do you feel lonely most of the time? "	same
58	"Have you been eveluted by your GP during the past year?"	
136	"Have you any economic difficulty in facing the basic expenses and the health care costs?"	1- with great difficulty, 2-with difficulty, 3-neither, 4-easy, 5-very easy
110	"Have you experienced a memory decline during the past year?"	
111	"Have you lost weigth during the past year such that your clothing has become looser?"	
112	"Have you recently walked less because of physical state?"	
113	"Have you fallen one or more during the past year?"	

9.3. Appendix 3: Multi stakeholder satisfaction survey (MSSS)

Welcome to the CONSENSO stakeholder satisfaction survey!

1. *[include the name of the organisation]* is currently implementing the project COmmunity Nurse Supporting Elderly iN a changing SOciety (CONSENSO), together with project partners from Slovenia, Austria, France, Italy *[add appropriate countries].* The project is being (co)financed by *European Regional Development Fund*.

CONSENSO project is a care model that puts the elderly at the centre of health and social care. The crucial role is played by the Family and Community Nurse who helps and supports the daily activities of the elderly and their families in the entire municipality of Piran *[add appropriate area]*, by offering preventive activities and coordination of care. The project wants to create the right conditions to improve health and life quality of senior citizens in the Alpine Space enabling them to stay at home as long as possible.

Since the role of family and community nurse is versatile, with focus on coordination of care, it is necessary that he/she works hand in hand with the community and the stakeholders and service providers, already available in the area. That is why all of you were already notified about the project through different channels (i. e. public conference, private meeting, leaflet, …) and at this point, we would like to obtain your thoughts and opinions in order to better understand your experience in the project and have a chance to make the project that serves elderly, better. This survey should only take 7-8 minutes to complete.

Please, complete the survey until *[dd/mm/yyyy] [add appropriate date].* If you have any doubts or questions, please contact us on *[add e-mail and telephone number].*

INFORMATION ABOUT CONSENSO

1. How familiar are you with CONSENSO project?
*   I know the project well
*   Familiar
*   Somewhat familiar
*   I do not know what the project is about
*   N/A

2. Where did you hear about CONSENSO project?

    _____
    _____
    _____

3. Overall, how would you rate your satisfaction with information provided about the project?
*   Extremely satisfied
*   Satisfied
*   Neutral
*   Unsatisfied
*   Extremely unsatisfied
*   Not sure
*   N/A

4. When presenting CONSENSO to you, how would you rate the presentation?
*   Extremely well presented and understandable
*   Well presented and understandable
*   Sufficient presentation
*   Difficult to understand
*   Extremely bad presentation and difficult to understand
*   N/A

5. How would you rate a match between presentation of the project and its actual implementation?
*   Perfect match
*   Match with issues
*   Sufficient match

- Bad match
- Does not match at all

Why do you think so?

_____
_____
_____

COLLABORATION EXPERIENCE AND COMMUNICATION

6. How did you build a contact with project partners of the project?
- Promotion conference
- Leaflet
- Telephone
- Meetings
- Other: _____

7. If you needed to contact CONSENSO project partners again, how accessible were they?
- Very easy to access and keep in touch
- Easy to access
- Neither easy nor difficult to access
- Difficult to access
- Very difficult to access, I couldn't keep in touch
- N/A

GENERAL SATISFACTION AND IMPACT OF THE PROJECT

8. How beneficial is CONSENSO for your local community?
- Very beneficial
- Beneficial
- Somewhat beneficial
- Not beneficial
- N/A

    Please, explain your answer:
    _____
    _____
    _____
    _____

9. How would you rate CONSENSO's contribution to an already existing home-care system (health and social) for the elderly in your country?

    _____
    _____
    _____
    _____

10. Overall, how satisfied are you with CONSENSO project?
- Very satisfied
- Satisfied
- Somewhat satisfied
- Unsatisfied
- Very Unsatisfied
- N/A

11. If you could change something about CONSENSO what would it be?

    _____
    _____
    _____
    _____

[if stakeholder does not know the project: 1 →4]

2. CONSENSO project is a care model that puts the elderly at the centre of health and social care. The crucial role is played by the Family and Community Nurse who helps and supports the daily activities of the elderly and their families in the entire municipality of Piran *[add appropriate area]*, by offering preventive activities and coordination of care and represent a key person to each elderly in the area. If family and community nurse identify the unmet needs, he or she contacts the appropriate service and provides the elderly with information regarding their rights and options. The project wants to create the right conditions to improve health and life quality of senior citizens in the Alpine Space enabling them to stay at home as long as possible.

How would you rate CONSENSO model (as described also in the introductory part)?

- Excellent
- Good
- Average
- Poor
- Terrible
- N/A

How beneficial do you find this model for your local community?

- Very beneficial
- Beneficial
- Somewhat beneficial
- Not beneficial
- N/A

  Please explain your answer:

  _____
  _____
  _____
  _____

9.4. Appendix 4: Focus groups questionnaire

1. Pre-pilot phase

1.1. Policy context

Policy

- Was social and health policy context in your view favourable for CONSENSO model implementation?
- What kind of services have already been in place?
- What was your knowledge of the policy context?

Stakeholders

- How did you identify the network of services providers?
- How did you promote the CONSENSO model?
- What were your impressions on stakeholders' support for CONSENSO project?
    - Who is (has been) CONSENSO policy driver?
    - Who is (has been) CONSENSO policy opponent?
- What kind of events did you organise?
    - What worked? Why?
    - What did not work? Why?
- What actors were notified?
- What was the logic behind the notification of certain actors?
- Who made the contacts? FCNs, project managers?
- Did you have a formal strategy for promotion of CONSENSO services in the pre-pilot phase or did you improvise? What worked for certain actors/stakeholders?

2. Pilot/intervention Phase

2.1. Assessment Phase

- How did you contact the clients?
    - What were the biggest challenges?
- How did you identify the needs of the clients?
- What were the main challenges when identifying the needs?
- What were the most expressed needs of the clients
- How did you build trust with clients?

– What issues did you encounter?
- How did you identify the resources of the client? How did you determine the strength of his/her (social) network?
- What were the most complex cases (when it comes to needs of the client) and was it hard for you to identify this complexity?
  – Were clients hesitant to "open" up about their needs?

2.2. Individual action plan

- How was the individual support plan made?
- What was the process behind it?
- Did you have any experiences with designing an individual support plan?
- How did you set the goals?
- How did you negotiate the goals with your client?
- Were there any opposition in setting the goals?
- What was the process behind setting the goals? Were the goals set in cooperation with the client? Informal carers?
- What were the main challenges in setting the goals?

2.3. Support network

- How did you organise the support network in practice? What was your approach?
- Which services were (are) the most needed?
- What needs could be addressed solely by FCN? Please, give us an example of successful and unsuccessful FCN intervention.
- What needs could be addressed by activating the support network of services? Please, give us an example of successful and unsuccessful network intervention coordinated by FCN.
- What is your personal experience of the project intervention?
  – Did you feel you were able to address the needs of the clients?
  – What could have been changed, improved?

2.4. FCN's evaluation phase

- How did you verify the results of FCN's intervention?
- How did you verify the results of the FCN's led and coordinated support network intervention?

- How did you assess the project?
- How did you assess the FCN's influence on micro/mezzo/macro level?

Additional questions:

- What is your opinion on CONSENSO app?
- Issues?
- Challenges?
- What does CONSENSO model represent to you?
- CONSENSO in the future?

9.5. Appendix 5: External factors, system specifics

This final part is a proposal of data that needs to be collected in order to obtain the external factor, system specifics and background. This part needs to be filled in as soon as possible, and probably we will get back to partners with additional questions.

Especially the first part of the document – state of the art – should be filled in for both *regional (or municipal)* and *national* level.

STATE OF THE ART DOCUMENT

1. Organisation of primary health and social care

Please describe how the primary health and social care is organised both in the partner' region and at national level; please detail the levels of responsibility with specific regard to the project themes and activities that will be developed.

2. Organisation and description of care for elderly

Please describe how the care for elderly is organised both in the partner' region and at national level, describe both: professional (institutional and home/community care) and informal care.

Please, detail the most common options of care for older people when depending on assistance and care of another person.

3.   Long term care (LTC)

Please describe how the long term care is organised. Please describe the regulatory framework for long term care, both at regional and national level. Describe different forms of LTC services and benefits in kind or in cash and the current challenges at this area.

4.   Country regulatory framework

Please describe the regulatory framework, both at regional and national level: is the community and family nurse foreseen by the regional/national law? Are similar professional profiles already regulated by the law and how do they work in practise?

5. Other specifics

If you would like to point out other specifics, regarding health/social/community care in your area, please write it here.

****

9.6. Appendix 6: Working with stakeholders

Table 1: Monitoring tool for nurses

Information collected (date):	
Project partner:	
	Answer:
Nr. of nurses on the field	

Table 2: Monitoring tool (elderly)

From: __/__/___ (fill the date) To: __/__/___ (fill the date)	
	Answers:
Nr. of refusals	
Nr. of impossible to reach/absent	
Nr. of informal carer questionnaires filled in	
Nr. of letters sent to elderly	
Approximate nr. of phonecalls to elderly (choose your own unit: per day/per week/per month,…)	
Approximate nr. of phonecalls by eldery (choose your own unit: per day/per week/per month,…)	

Table 3: Monitoring tool - community

From: __/__/___ (fill the date) To: __/__/___ (fill the date)				
Stakeholder local name	Category*:	Stakeholder power/will map**	Public/private organisation	Nr. of meetings with stakeholder

*1-health needs; 2-social needs; 3-housing needs; 4-financial needs; 5-family and friends; 6-local/regional/national authority (see Alison's dissemination plan)

**1 – opponent (high power, low will), 2 – influential (high power, strong will); 3 - opponent (low power, low will); 4 – influential (low power, strong will).

Monitoring tool – other events in the community

We recommend collecting these data:

a) By the end of each month:
   a. First one: from the start of the piloting (date should be written down) until the end of February
   b. Each next: by last day in each month.

Table 4: Monitoring tool - events

Information collected:			
From: __/__/____ (fill the date)			
To: __/__/____ (fill the date)			
Project partner:			
Name of the event	Type of the event (i. e. meetings with general public, conferences, radio, …)	Nr. of attendees	Comments (if needed)