In For Care

Overview of quantitative and qualitative aspects of informal care and volunteering assistance in Europe

Country comparison: BE, DK, NL, NO, SE, UK

Interreg
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In For Care
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northsearegion.eu/in-for-care

Contents

1. Introduction

In Europe, 80% of all care is provided by informal carers – i.e. people providing usually unpaid care to someone with a chronic disease, disability or any other long-lasting health or care need, outside of a professional or formal framework. Although carers are the cornerstone of our long-term care systems, their contribution is seldom acknowledged and their needs rarely discussed. Yet, current societal trends (including notably the ageing of our societies, the increasing occurrence of comorbidity among dependent people, and the increasing mobility and changes in family structures) put informal carers under excessive pressure. The sustainability of their effort is at stake and without adequate support, these people are likely to reach a breaking point and become unable to provide quality care anymore. Some policies and practices have been developed to address this reality, mostly at local level, but they remain largely insufficient, extremely fragmented, geographically uneven and not always sustainable. Source: http://www.eurocarers.org/

EUROCARERS is the European network representing informal carers and their organisations, irrespective of the particular age or health need of the person they are caring for. This network defines a carer as a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework. On their website there are several fact sheets relevant for the project In For Care.
One of the fact sheets is about the services which have been identified as key enablers for quality informal caregiving:

- Information (What support tools and services are available? Which ICT-based solutions could help me? How can I access and use them? What are my rights and obligations as an informal carer? How can I get in contact with peers and exchange with people facing similar challenges?)
- Counselling and emotional support (How to cope with the emotional burden and contradictory feelings? How to manage my own mental and physical health? How to make choices?)
- Advice and guidance (How to organise the care of my relative? How to organise myself and juggle my responsibilities towards my family, my work, and the person I take care of? How to plan in advance?)
- Respite care (The possibility for the informal carer to be replaced so that he/she can take some time off).
- Training (The possibility to develop skills related to daily care, health care as well as transversal skills - communication, ICT literacy, coordination and planning, etc. in order to help them care

This report is designed to help all project partners of the North Sea Region Interreg project In For Care as a basis to work with during the whole project period. The content contains into an overview of quantitative and qualitative aspects of volunteering and informal care in Europe, in the participating countries: Belgium, Denmark, the Netherlands, Norway, Sweden and the United Kingdom.

1.1. About the project In For Care

The Interreg project In For Care: Informal care and voluntary assistance: innovation in service delivery in the North Sea Region is a project run within the Interreg North Sea Region Programme (www.northsearegion.eu). Ten partners from 6 different EU countries work together to innovate service delivery by optimizing informal and formal networks to address some shared challenges.
As a consequence of an ageing population, the rising costs for (health)care services and budget cuts, (national) governments in the countries around the North Sea have moved from a care system whereby the state regulates, cares and pays to one that increasingly facilitates a civil society that is based on solidarity and community. Countries with a large amount of publicly funded care and services are increasingly shifting the focus towards family or social responsibility, and towards promoting informal care. At the same time the organisation and regulation of services are increasingly being devolved to local and regional authorities, based on the assumption that if the provision of

services is organised close to the recipient, this will lead to more appropriate solutions and lower costs.

This transition in the care systems is not without risks; it may cause increasing (health-)care inequality, increasing problems with combining work and care, increase costs in relation to sick leave, etc. Furthermore, it is widely recognised that informal caregivers face a number of challenges, including poor understanding of the local health and social care systems, lack of experience and/or formal education in care, limited societal support, lack of specific tools to manage the whole care cycle, skills deficits to support the cared for with activities of daily living, lack of technical support with respect to caring aids, problems with coordinating care affecting with other 'care' employment, psychological issues such as stress, anxiety and/or depression.

To support the public sector to innovate in service delivery, innovation is needed through the right channels. Often, cooperation between SMEs, knowledge institutions, public administration and end-users to reach this goal is limited or only taking place very locally. The dissemination of good practices in this regard is lacking and only a few initiatives on European scale can be found to support informal and formal networks, while this is clearly very urgent if we want to keep social services accessible and affordable for every citizen.

The elderly citizens form a potential as well. Although ageing may cause more demanding tasks for the European municipalities, it is also true that the new generation of older citizens live longer because they have better health and meet old age with multiple and more resources than previous generations. The new generations of seniors likely have higher education, a better economic status, better living conditions and better functionality than any previous generation. They are also more familiar with technology and are rather autonomous. In this respect, it can be concluded that there are increased opportunities to also mobilize elderly people to actively contribute for the public benefit.

The project overall objective is: *to develop innovation in service delivery by optimizing informal and formal networks* (to address the challenges arising from an ageing population, budget reductions and increasing demand for health care).

The project detailed objectives are:
- To create and improve processes of voluntary work and informal care in service delivery
- Support the public sector to innovate in service delivery.
- Enhance cooperation between SMEs, knowledge institutions, public administration and end-users.

1.2. Why this report?

Differences in informal care provision in European countries are affected by differences in socio-demographic factors, and also by differences in long-term care systems between countries. We should be aware of the different definitions between and within the partner countries, views and approaches on informal care and voluntary assistance in Europe right at the start of the project In For Care.

In this document we compare and share information of the project partner countries on:
- How volunteer and informal care policies work at national and local level.
- General recruitment of volunteers and targeted to specific groups.
- Strategies for coordinating volunteers and informal carers in health organisations.
- Definitions on volunteering and informal care.

2. Methodology

This report has been created mainly by desk research, and by knowledge gained through former projects in the area of informal care or voluntary work in Europe (such as VAPE, Care for Informal Care). During and after the Kick Off meeting in February 2017 of the project, all partners were asked to add relevant information from their country, and a general agreement on views and approaches was established. In November 2017 information which took place about co-creation sessions has been added as an annex.

Desk research

The Supply of Informal Care in Europe, ISBN 978-94-6138-122-4, Available for free downloading from the CEPS website (www.ceps.eu); and the ANCIEN website (http://www.ancien-longtermcare.eu/), © Copyright 2011 Linda Pickard

General overview of the health care system in the project partner countries (formal policy papers/ Ministry/other government)

The Health Systems in Transition (HiT) series which provide detailed descriptions of health systems in the countries of the WHO European Regions as well as some additional OECD countries (updated every 5 years). Source: http://www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits

For this report the following documents were used:

- HiT BE 2010
- HiT DK 2012
- HiT NL 2016
- HiT NO 2013
- HiT SE 2012
- HiT UK 2015

Hence, in relation to issues concerning informal care and volunteering assistance, the main knowledge of project partners has been used as input.

2.1 About the content

This report presents an overview of the current situation of informal care and voluntary assistance in the participating countries within the project In For Care. Per country the content will be build up as follows:

1. Health system infrastructure.
2. Informal care and volunteering assistance landscape.
3. First identification of bottlenecks and challenges.

The final Chapter 4 will represent a general overview of all countries with a focus on: How the volunteer policies work in other participating countries at national and local level (i.e. partner countries)

- Definitions used on voluntary assistance, on volunteering, and on informal care
- General recruitment of voluntary assistance targeted to specific groups
- Strategies for coordinating voluntary assistance and informal carers in health organisations.

3. Country reports

3.1 Belgium

Belgium is a federal state with a parliamentary democracy. There are three levels of government:

- the federal government;
- the federated entities: three regions and three language communities: French, Dutch and German;
- the local governments (provinces and municipalities).

3.1.1 Health system infrastructure

Health policy is a responsibility of:

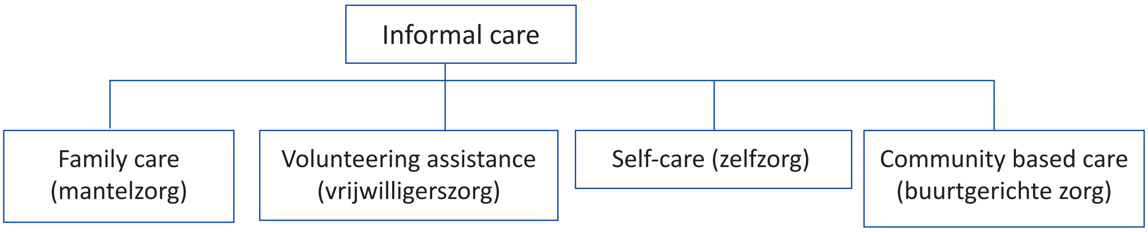
- the federal authorities are responsible for the regulation and financing of the compulsory health insurance; the determination of accreditation criteria (i.e. minimum standards for the running of hospital services); the financing of hospital budgets and heavy medical care units; legislation covering different professional qualifications; and the registration of pharmaceuticals and their price control.
- the federated entities (regions and communities) are responsible for health promotion and prevention; maternity and child health care and social services; different aspects of community care; coordination and collaboration in primary health care and palliative care; the implementation of accreditation standards and the determination of additional accreditation criteria; and the financing of hospital investment.

To facilitate cooperation between the federal authorities and the federated entities, inter-ministerial conferences are regularly organised.

The organisation of health services is characterised by the principles of therapeutic freedom for physicians, freedom of choice for patients, and remuneration based on fee-for-service payments. The compulsory health insurance is managed by the National Institute for Health and Disability Insurance.

The Belgian health system is based on the principle of social insurance characterised by horizontal solidarity (between healthy and sick people) and vertical solidarity (based to a large extent on the labour incomes) and without risk selection.

3.1.2. Informal care and volunteering assistance landscape



In Belgium informal care is the umbrella term for family care, volunteering assistance, self-care and community based care.

Family Care

In Brussels there are 7 ‘family care organisations’ - 6 Dutch speaking and 1 French speaking – who have united their knowledge in one consortium: het Mantelzorg Overleg Komité, with the main goal to inform and to support persons who provide family care. Family care is care giving to family members and also caregiving for neighbours.

According to the research of the *Studiedienst van de Vlaamse Regering* (SVR) in 2015 approximately 26% of the adult people was an informal care giver for a disabled or older family member, friend, acquaintance or neighbour. The SVR counts over 1,000,000 informal care givers in Vlaanderen. The health questionnaires of 2013 show that 9% of the Belgium people older than 15 years, provides informal care at least once a week for one or more persons. According to the OECD report of 2013 over 20% of the people older than 50 years are informal carers (weekly 60% or daily 40%).

Support for persons who provide family care:
- provide them with relevant information from Welfare organisations;
- appreciation and recognition;
- advocacy;
- respite care.

Regulations and specific measures:
- specific on leave opportunities
- on leave for medical assistance of (very close) family member(s)
- grants towards living expenses (for non-medical costs); €130,- per month allowance (national)
- cities and municipalities offer also a specific allowance (annual amount for care givers or receivers; the amount of money differs between local governments). People can spent this amount of money according to their own desires.
- palliative forfeit can be requested for palliative patients (twice; approx. €500,-)

Voluntary assistance versus voluntary work

The 2005 law on volunteering, has established a distinction between the two notions. The law officialises the term "volunteering" as being an activity defined by the law. All other non-remunerated activities would have to be qualified as bénévole. In the Dutch speaking part of Belgium, only the word *vrijwilliger* is used. It corresponds to the Anglo-Saxon terminology designating non-remunerated work. However, the meaning of the term can slightly change according to the context.

The law on the rights of volunteers has been created with the intent to set up a common definition which would be shared by all the stakeholders involved in volunteering. The 2005 Law on Volunteering describes volunteering as follows:
- Volunteering is unpaid. Volunteers can be given a limited amount of money, to reimburse their expenses or as a forfeit, for costs to be made;
- Volunteering does not involve coercion. A volunteer commits him/herself without any obligation; he or she cannot be forced to perform an activity. Although persons can-not be forced to volunteer, the moment they engage in some type of voluntary activity, a kind of (juridical) relationship (with mutual rights and duties) is established;
- Volunteering is undertaken for others or for the society. Volunteering means being of use to others who are not family or acquaintances, in an organisation or for society in general; and
- There should always be a distinction between volunteering and professional activities. A volunteer cannot perform the same activity both as an employee and as a volunteer for the same employer.

Evolution to community based care

Volunteers and family carers can help persons with chronic illness or with diminished ability of self-care. A supportive system of community based care for volunteers and family carers in the neighbourhood/community needs to be developed. The policy of the Flemish government is to appoint the local government to coordinate and implement the community based care.

3.1.3. First identification of bottlenecks and challenges

- lack of information on specific regulations and measurements (on leave; allowances etc.);
- recruitment of volunteers;

- debate about economic value of family care and the financial impact of it on health insurance (research University of Hasselt: *De economische waarde van mantelzorg en de financiële impact ervan op de ziekteverzekering), 2016*;
- the demand for informal care givers will increase further because of the amount post-war population increase (elderly people);
- the amount of care givers will decrease, since there will be less people who will be able to provide this care (demographic pressure). In the near future there is no balance between the amount of care givers and persons who request care, the rising old-age-dependency ratio;
- compartmentalization of (primary) health care;
- reform of primary health care with a directing role for the local governments in the collaboration between care actors and realisation of accesible care;
- shift in finance system towards a personal budget;
- reformation of hospitals will increase the need of home care, and increase the burden on informal carers;
- increasing diversity, so healthcare should adapt accordingly;
- marketing of healthcare.

3.2 Denmark

Denmark is a parliamentary democracy, divided into three different administrative levels:

- the state
- the regions (5)
- the municipalities (98).

3.2.1 Health system infrastructure

The health system in Denmark can be characterised as fairly decentralised, with responsibility for primary and secondary care located at local levels. Access to a wide range of health services is largely free of charge for all residents. The health system is organised according to three administrative levels: state, region and local.

The state:	overall regulatory and supervisory functions + fiscal functions but is also increasingly taking responsibility for more specific planning activities, such as quality monitoring and planning of the distribution of medical specialties at the hospital level.
5 regions:	Responsible for hospitals as well as for self-employed health care professionals.
Municipalities:	Responsible for primary care, disease prevention and health promotion.

Regarding human resources, General Practitioners (GPs) are fairly well distributed throughout the country, but practising specialists are concentrated in the capital and other urban areas.
Public health services are partly integrated with curative services and partly organised as separate activities run by special institutions. The GPs act as gatekeepers, referring patients to hospital and specialist treatment. Most secondary and tertiary care takes place in general hospitals owned and operated by the regions. Nursery homes are also part of tertiary care and operated by the municipalities.

Many actors are involved in rehabilitation care within the health care sector, the social sector, the occupational sector and the educational sector; with each sector carrying out a different aspect of work (problem of securing coherent patient pathways).

Health legislation formally provides residents with the right to easy and equal access to health care and entitles patients to choose treatment after referral at any hospital in the country. Financing mainly takes place through taxation at the state (progressive tax) and the municipal (proportional tax) level.

3.2.2 Informal care and volunteering assistance landscape

The state responsibility model is characteristic of the Scandinavian countries and therefore also for Denmark (CESEP, 2007). The long-term care falls under social care and is the responsibility of the local councils, as regards both provision and financing. The rules on long-term care are part of the Consolidation Act on Social Services (CASS). Local authorities provide care for the elderly based on the general principle of free and equal access to the assistance offered. They finance the costs of long-term care through local taxes and block grants from the state (Enepri Research Report no. 73 Contribution to WP1 of the Ancien Project, May 2010).
From the point of view of the population, personal care in particular is primarily the task of the state (municipality). Nevertheless, a great share of help with practical tasks (gardening, financial tasks, etc.) is provided by members of the family too. Actually resent research shows that 70-90% of the care of resident citizens with severe illness or disability is provided by their relatives and thus informal carers.... (Kirk and Pedersen 2014, Wiwe 2006, Lind, 2015). It might show us that the phenomenon “informal caregivers” is not common in Denmark.

Although informal caregiving by relatives is not so common in Denmark, help for family caregivers have to be supported by the local authorities. Substitute or respite care is offered as well as cash allowances for palliative care. Under specific circumstances the carer of a closely connected person can be employed by the municipality for up to six months.

Voluntary assistance versus voluntary work

In Denmark the following definitions on voluntary work are relevant (pamphlet published by the Ministry of Social Affairs/The National Volunteer Centre, 2001:5).

- Voluntary or non-obligatory, i.e. undertaken freely without physical force, legal coercion or financial pressure and no threats of financial or social sanctions (for instance being cut off from social security benefits or a social network) if the volunteer no longer wishes to continue the work.
- Unpaid. This does not preclude payment of remuneration for expenses the volunteer has incurred while carrying out the activities, such as travel and telephone expenses, or payment of a symbolic amount as compensation for the voluntary work.
- Carried out for persons other than the volunteer's own family and relatives. This distinguishes voluntary work from ordinary domestic activities and the informal care of family members.
- For the benefit of other people than the volunteer and his or her family. The value that the work has for others makes it voluntary work. This precludes participation in for instance self-help groups or participation as a mere member of sport clubs from being voluntary work.
- Formally organised – mostly in an association, although this need not be the case. However, ordinary helpfulness or spontaneous acts are not voluntary work.

42% of the population are engaged in volunteer work, placing Denmark among the countries in the world where the largest proportion of the population engaging voluntarily. Overall about 365 million hours of voluntary work was done in 2014. This is equivalent to about 190,000 full-time jobs. There are roughly equal numbers of women and men who are volunteers. There is a tendency for more people with longer further education to participate in volunteer work. The proportion of young 16-29 year-old volunteers is slightly lower than the other age groups.

Danish Voluntary work by age in 2010, 2012 and 2014 (Centre for Voluntary Work, 2014)

Years by age	2010	2012	2014
16 – 29 years	39%	40%	37%
30 – 39 years	46%	44%	41%
40 – 49 years	55%	46%	46%
50 – 59 years	41%	41%	42%
60 – 69 years	39%	36%	42%
70 years +	35%	27%	45%
Total	**43%**	**40%**	**42%**
Number	**1007**	**1007**	**1001**

Volunteers are committed for various reasons; 42% of the volunteers indicate that they want to help others and 36% say they have become volunteers because they want to be part of a community. Among young volunteers it is a motivating factor that it can strengthen their CV and future job opportunities. 39% report that they are voluntary because they were asked. 71% of non-volunteers responded that it is likely that they would volunteer if they were asked about it in a context that interests them.

A large share of volunteering takes place in an association; 49% of the voluntary work is done within the field of cultural, sports and leisure activities. 40% of the volunteer work is within the social, humanitarian, welfare, health and prevention area. 23% are engaged in local communities.

More and more municipalities establish joint projects and partnerships with social associations and include this in their policy development. Active citizenship is gaining ground and the local authorities want to involve and engage citizens in a different way than before. The traditional voluntary policies are increasingly being replaced by broader strategies to put up to civil society strategies or policies for active citizenship. As a consequence of this, we see an increase in the number of municipal employees who are employed to develop and coordinate the voluntary social work and cooperation with associations. Several municipalities organize volunteers into their own, municipal activities (Centre for voluntary work, 2014).

3.2.3 First identification of bottlenecks and challenges

- The Danish welfare state is in the process of redefining itself from being a safety net for citizens to be coordinator of cooperating across social health, employment and education system, private operators and volunteers.
- The number of hospital beds has declined since the early 1990s in the acute, long-term and psychiatric care sectors. Average length of stay has also declined through changes in treatment options, with an increase in outpatient treatment as well as a policy of deinstitutionalization in the psychiatric sector.
- Area that is attracting attention within rehabilitation and intermediate care is the problem of securing coherent patient pathways.
- Continuity of care is a concern in the rather fragmented and decentralized Danish health care structure. Various initiatives have been implemented in order to improve continuity, but lack of integration of care is still a major issue, particularly regarding chronic care.
- It can be a challenge for associations and volunteers and thus informal carers that contact to the municipality has to be taken to many different administrations. Conversely at the same time, it can also be a challenge for local councils to incorporate the voluntary initiatives into their overall strategy.
- The voluntary associations and local governments experience that it has become harder to recruit and retain volunteers for regular operational tasks, but at the same time a little easier to recruit for individual and time-limited tasks.
- The volunteers express the feeling that it is an inhibiting factor for their voluntary work that it feels more and more like paid work, mainly because of documentation requirements and objectives.
- Employees, for example in the municipal nursing homes, expresses that it may be an inhibiting factor when the tasks volunteers perform, is valued higher than the employees’ tasks.

3.3 The Netherlands

Although the Netherlands is formally headed by a king, the executive power is with the parliament and the national government, which is usually based on coalitions. The Netherlands is divided in three different governmental levels:

- the State
- 12 provinces (regions)
- Municipalities (approximately 390; reorganisation to a smaller amount is going on)

3.3.1 Health system infrastructure

The Ministry of Health, Welfare and Sport published in January 2016 “Healthcare in the Netherlands”. The content of this document has been used for this paragraph.

The philosophy underpinning the Dutch healthcare system is based on several more or less universal principles:

- access to care for all;
- solidarity through medical insurance (which is compulsory for all and available to all);
- high-quality healthcare services.

The foundation of the healthcare system is governed by four basic healthcare-related acts:

- the Health Insurance Act which provides for hospital care (*Zorgverzekeringswet*)
- the Long-Term Care Act which focuses on other types of care (*Wet langdurige zorg*)
- the Social Support Act (*Wet maatschappelijke ondersteuning*
- the Youth Act (*Jeugdwet*).

In addition, there are several general laws in place (including the Competition Act/Mededingingswet) and a number of specific healthcare acts (e.g. the Care Institutions (Quality) Act).

The Long-Term Care Act is a national act governing healthcare throughout the Netherlands. In implementing the Health Insurance Act, private health insurance companies play a key role in a system based on “regulated competition” and a number of specific public requirements. The Social Support Act and the Youth Act provide for other forms of care and support. The municipalities are primarily responsible for enforcing these two acts. Private individuals may be affected by all four healthcare-related acts.

3.3.2 Informal Care and volunteering assistance landscape

Under the Social Support Act 2015, the responsibility of providing support to people with disabilities has been transferred to the local authorities. This includes people with physical, mental or psychological disabilities, including people with learning disabilities and the elderly. The support is designed to ensure that people can continue to be productive members of society and to enable them to continue living at home. Local authorities can provide sheltered accommodation and support to people who have no other options or who are unable to live at home.

Due to demographic changes with more elderly people and a decreasing amount of younger people supporting them, there will be a growing demand for health and social services. People are being forced to work longer and should stay healthy as well. A strong focus on prevention is therefore necessary. The current challenge is how to accomplish this.

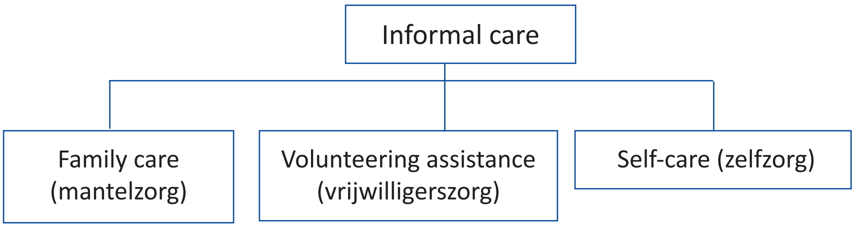
The municipal approach is focused on personalised care and inclusion. The local authorities discuss the client’s request for support together with the client and the informal care giver(s). It is then up to the local authority to provide the appropriate type of support and determine how this support is to be organised.

This includes:
- assistance and day programmes/daytime activity;
- household support;
- support by an informal carer;
- volunteers;
- a sheltered accommodation for people with long-term psychological disorders;
- support for men, women and children who are victims of domestic violence;
- social support, e.g. for people who are homeless;
- financial support for people who incur significant additional expenses on account of their chronic illness or condition.

Local authorities distinguish between general provisions and personalised provisions. General provisions are intended for the community as a whole. Personalised provisions are designed for a single person. The presence of an informal carer is often a key indicator of a person's ability to remain at home. The absence of an informal carer, he or she could be living alone, but has an informal carer, maybe daugther or son, around, is an indicator of client risk. Information on client living arrangements and informal carer availability provides an indicator of the potential in-home support and the extent to which the burden of care is absorbed by the informal caring system.

Definitions in the Netherlands

Informal care includes family care, voluntary assistance and self-care. In the project In For Care the province of Drenthe focusses on working informal care givers; in the province of Groningen the focus is on young care givers (children growing up with someone who needs care or is addicted).



Family care

A person who provides care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need. The care is given by relatives, friends, acquaintances, colleagues or neighbours because of their personal relationship with the care-receiver. It excludes care and help provided by professionals or through organised voluntary services.

Amount of informal care givers 18 years or older, duration and insensitivity in 2001 and 2008

€	2001	2008
total	3,700,000	3,500,000
> 8 hours per week	1,050,000	1,400,000
> 3 months	2,050,000	2,300,000
> 8 hours per week and/or > 3 months	2,400,000	2,600,000
> 8 hours per week and > 3 months	750,000	1,100,000

Source: SCP (Mantelzorg 2001); CBS (IH'08) SCP bewerking, translated by CMO STAMM

In the Netherlands 1 in 5 persons provides informal care longer than 3 months or 8 hours a week (20% = almost 2.6 million people). of whom 1.1 million people provide long term care and more intensive care. Most people don't call themselves a family carer. For them it's naturally and a matter of love for their family member, friend or neighbour. And most of them are women, 59% (Expertisecentrum Mantelzorg).

There are several regulations and measurements for family care givers (on leave, benefits etc.), The local government is responsible to support care givers too.

Informal care giving and labour market

Recent national research shows that employment doesn't influence being an informal care giver. Some people stop temporarily with their job, most people combine both responsibilities. Employed informal care givers supported by their management and colleagues, experience the combination of work and informal care more positive than those who are not supported. Hence, employees with a balanced combination of work and informal care have less physical complaints.

In the province of Drenthe the indicative amount of employed informal care givers are:

	Total labour force (15-65 years)	Employed labour force (15-65 jaar)	Employed informal care givers
2010	314.000	204.000	35.700
2011	312.000	202.000	35.350
2012	310.000	203.000	35.525
2013	308.000	202.000	35.350

Young informal care givers

Children who grow up in a family with a family member who is chronically ill, or with a mental or physical disability or a family member with an addiction or psychical problems (0 – 23 years). These children grow up with other worries and responsibilities than their peers. Risks of growing up in such a family are: school drop out, no social network of their own, health problems etc.

Voluntary assistance versus voluntary work

Voluntary assistance in the informal care sector is carried out by persons active as a volunteer at a (care)organisation. They provide support ranging from domestic help to personal care, respite care or support family care. Their motives to be active as a volunteer are (Scholten 2011): supporting other people; involvement in society issues; meaningful leisure time; meeting other people; personal development; practice their knowledge or to gain work experience.

It's the expectation that less people will be active as a volunteer (further higher degree of labour participation). Approximately 8 to 15% of the Dutch people is active as a volunteer. Besides traditional forms of voluntary assistance (through organisations), more citizens develop own initiatives (citizenship) with new forms of voluntary work and voluntary assistance models. The main difference between family care and voluntary assistance is that the latter is a choice of people themselves.

Current situation in the province of Groningen:

- CMO STAMM is carrying out the provincial expertise centre on informal care (social policy of the Province of Groningen to protect vulnerable citizens). CMO STAMM has a broad network of professionals and volunteering assistance organisations.
- 21 local supporting points/local expertise centres in 21 municipalities.
- 1 provincial foundation representing the needs of informal cares (Platform Hattinga Verschure).

Current situation in the province of Drenthe:

- the Province of Drenthe focusses on the delivery of informal care giving by employed people;
- 12 municipalities are responsible for coordination, facilitating and safeguarding care delivery;
- 1 umbrella organisation for local contact points representing informal care givers. It provides information and organises activities for informal care givers;
- Business cluster VPB Emmen has the expertise and contacts with SMEs. They will exchange with five other Business Park Management organisations in Drenthe.

For the project interesting recent developments:

- commercial organisations and health care insurances discovered a new market: informal care.
- awareness campaign targeted at SMEs: to ensure the health of employed informal carers.
- citizens initiatives: a care cooperation (foundation in collaboration with formal care workers).

3.3.3 First identification of bottlenecks and challenges

- Supporting informal care givers is a responsibility for all relevant stakeholders and not only for local supporting points.
- There are less opportunities for sheltered accommodations. People should rely on their own social network first. This means more pressure on informal care givers. The availability of informal carers is significant for the capacity of a person to be able to remain living at home.
- More (elderly) people live independently, with a risks of isolation and a combination of illness (comorbidity). If they need care, it's often more complex and a burden for informal carers.
- Support for volunteering work in general and volunteering assistance (informal care) are separated worlds. Citizens initiate (informal) care initiatives with new forms of voluntary assistance. Traditional and new forms of voluntary work should benefit more from each other.
- If employers become aware that they could save a large amount of money through preventing illness or sick leave of their employees, more employers would feel obliged to invest in new approaches towards informal care givers within their organisations/enterprises.

3.4 Norway

Norway's five million inhabitants are spread over nearly four hundred thousand square kilometres, making it one of the most sparsely populated countries in Europe. Norway is a parliamentary democracy, divided into three different administrative and political levels:

- the state;
- the counties (19 in 2017, reorganisation to a smaller number is going on);
- the municipalities (426 in 2017, reorganisation to a smaller number is going on).

Norway is not a member of the EU, though it is a member of the European Economic Area. It also retains close cooperation with the other Nordic countries.

Overall, Norway's population enjoys good health status, and with has a life expectancy of 84,2 years in 2014 (OECD 2016). Quality of care in Norway is generally excellent (OECD, 2015), with Norway among the countries with the biggest expenditures in the Europe. Total spending was 5862 USD per capita, while the European average was 3453 USD (OECD, 2015)

3.4.1 Health system infrastructure

Coverage is universal and automatic for all residents. It is financed through national and municipal taxes. Social security contributions finance public retirement funds, sick leave payment, and, for some patient groups, reimbursement of extra health care costs. Health legislation provides the population with the right to easy and equal access to health care services.

The Norwegian health care system can be characterized as semi-decentralized. The responsibility for specialist care lies with the state since 2002, administered by four Regional Health Authorities (RHAs). Municipalities are responsible for primary care and enjoy a great deal of freedom in organizing health services (though counties provide dental care).

Public health services are delivered at the local and national levels. They are integrated with curative services at the municipal level, but are run by separate institutions at the national level, including the National Institute of Public Health. During the past decade, the government has launched several national public health programmes and strategies focusing on risk factors such as smoking, alcohol consumption, diet, and physical activity.

Several trends can be discerned in both the infrastructure and organisation of the hospital sector. The number of hospital beds has been declining since the late 1980s, and the average length of hospital stay has also declined. At the same time, municipalities have been given increased responsibility on areas such as prevention, early intervention and for patients with chronic diseases. Municipalities also provide emergency service for somatic and psychiatric patients. In the municipalities, there has been an increased focus on the importance of people living at home for as long as possible, and to achieve this, the municipalities have made a strong development of home-based services.

The Ministry of Health is in charge of regulation and supervision of the system, but many of these tasks are delegated to various subordinate agencies, such as the Directorate of Health, the Norwegian directorate of eHealth (NDE) and the Norwegian Medicines Agency (NoMA).
Norway has a well-developed system for registering health data where diverse types of health data are collected by compulsory national registers (15 in 2012), such as national registers on cancer and cardiovascular diseases, as well as around 200 further medical registries. Overall supervision and monitoring of health services is provided by the National Board of Health Supervision.

Inter-sectoral cooperation across administrative levels has become increasingly important over the past few years, especially as a means for addressing social inequalities in health. Hence, the Government introduced the *Coordination Reform* (REF. 1) in 2012 to ensure sustainable, integrated and coordinated health and care services of high quality and tailored to the individual user. The reform focused on more cooperation in two ways, vertical between primary and secondary care, and horizontal between municipalities. In addition, it involved a greater emphasis on local authorities' role in the provision of health services and implicated greater emphasis on measures to promote health and prevent disease, on habilitation and rehabilitation, on increased user influence, on courses of treatment, and on binding agreements between municipalities and hospitals.

The availability and use of information technology (IT) continues to increase within the health care system as well as in other parts of the society. A new Directorate of eHealth, was established January 1, 2016, and is responsible for the overall setting of standards and for leading the development and application of health information technology in health care. Several national strategies for a more digitalised health care system have been launched and implementation of these strategies is now starting to gain momentum. They include an electronic health record containing critical health information (e.g. core journal), which can be accessed from all medical institutions in the country. The white paper *One citizen - one electronic health record* (REF. 2) demands a strategy for the future development in the health care sector with a special focus on the need for integration between different IT systems.

3.4.2. Informal Care and volunteering assistance landscape

Norway, just like other European countries, faces increasing challenges on the deliverance of excellent services to residents, who are growing in number, age and needs. Several official reports have addressed some of the problems and weaknesses of the care services and explored the possibility of finding innovative approaches and solutions that can turn this situation around (REF. 3, 4, 5):

- the growth of new younger user groups;
- more elderly in need of assistance;
- the shortage of volunteer care providers;
- the shortage of health and social services personnel;
- the lack of coordination and medical follow-up;
- the lack of activities and coverage related to psycho-social needs;
- the internationalisation of the market for personnel, service providers, patients and users.

Mechanisms for involving family members and volunteers have become a national focus and a government's strategic priority, where several public sources have pointed out the challenge of establishing an effective coordination of the voluntary services to support society's needs (REF. 3, 6). On this basis, a stronger political focus directed toward family members and volunteers as a resource is recommended.

In Norway, 15% provide informal care for sick, elderly or disabled (2016)[1]. The largest proportion who regularly carries out unpaid care is between 45 and 66 years. These usually provide help to their own parents. People who regularly provide help to others spend on average five hours a week on unpaid care. This level is similar to those who provide help regardless of age and gender. It is more common to provide different types of practical help to your own parents than to provide care. The proportion of unpaid help is about equal among men and women, however, there are nevertheless some differences in the type of help they provide. People in part-time work provide the most unpaid help.

The Coordination Reform (1), launched in 2012, focused on improving the utilisation of resources through collaboration between municipal health care services and specialist health services. In addition, A *second Coordination Reform* was also suggested, which should target mobilisation of resources for cooperation between families, social networks and local communities, finding innovative ways of volunteerism and informal care to empower civil society beyond the traditional public schemes (3). The goal is to focus on alternative working methods, forms of operations and

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[1] https://www.ssb.no/helse/statistikker/omsarb

organisation starting from the local level, that encourage participation of citizens.

Additionally, in the white paper, *Future care* (REF. 8), a *Programme for an active, future oriented informal care policy is* presented. The first phase of the programme focused on measures that support family members and enhance cooperation between the health and care services and family members, while the next phase explored the issues of changes in financial compensation schemes and provisions on leave of absence in cooperation with the Ministry of Labour.

In the recent white Paper, *Primary health and care services of tomorrow* (REF. 9), the government is showing how they will follow up the programme. Important future measures will include user involvement, a focus on research about informal carers, and facilitating voluntary, non-profit organisations and businesses. Some of the suggested measures include

- developing guidelines about *Carers in Health and Care Services*[2]
- giving entitlement to user-controlled personal assistance (BPA
- developing arenas where users and their families get to present their concern
- identify barriers and opportunities associated with a more formalized interaction between users and their families and service providers
- initiating efforts to reform schemes involving care pay and nursing benefits for parents with sick and disabled children

In Norway, there are many different organisations for carers. Many of these organisations are representing specific groups, but there are also established some organisations who apply to informal carers independent of special interests. One example is The *Caregivers Alliance,*[3] an independent umbrella organisation, which attends caregiver's interests and rights. This alliance collaborates with similar organisations abroad and has contributed to the development of the *Health Directorates Guidelines about Carers in Health and Care Services*. Another example is the *Centre for Carers*,[4] established in the municipality of Stavanger. This centre has developed a dedicated website for carers with information for informal carers and a telephone service where they can seek advice and guidance.

In addition to focusing on informal are, the Government has designed a National strategy for volunteering in the health and care services (REF. 10). The strategy refers to section 4 of the Public Health Act that states that the municipalities have a responsibility for cooperation with the voluntary sector by facilitating the voluntary sector, and that the municipalities should develop their own Volunteering policy. The strategy takes its point of departure in the following five components: Mobilization, Interaction and cooperation between the voluntary sector and the municipality, Expertise, Development and innovation, Simplification and facilitation.

Today, non-governmental organisations (NGOs) contribute with between 5000 and 10000 full-time positions in health/care (7). Around 2% of the population carries out voluntary work in the field where about 75% of volunteers behind this effort are over 50 years old. Volunteering outside of the NGOs is growing, however, but the extent of this form of volunteering is not yet documented (REF.7).

In an equivalent manner as for informal carers, there are also many different organisations for volunteers, some more specific and others that are more general. In 2005, *Volunteer Norway*[5] was

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[2] https://helsedirektoratet.no/retningslinjer/parorendeveileder
[3] https://parorendealliansen.no/
[4] http://www.parorendesenteret.no/hjem
[5] http://www.frivillighetnorge.no/no/english/

established as an umbrella organisation for the voluntary sector (NGO's) in Norway.
This association has a mission of coordinating the voluntary sector's dialogue with Norwegian authorities on issues that are of concern to the voluntary sector. The organisation is also concerned with producing information and providing advice to the member organisations and is responsible for a web-page that serves as a portal for connecting volunteers and persons in need of assistance.[6]

The coordination of voluntary services presents a challenge to support societal needs. For example, if an increased involvement of volunteers is desired, it is necessary to coordinate a larger number of activities, volume of information and personnel. In Norway, this has led to the establishment of *Volunteer Centres* in the municipalities, where there are employed *Volunteer coordinators* who work as a link between the volunteer sector and health and care services. The volunteer centres receive public funding from the Ministry of Culture, and there are regulations ensuring that they are organized as non-profit organisations serving the better good of the population. There are approximately 420 (2016) volunteer centres in Norway.

The volunteer centres are open to everyone, regardless of age, gender, ethnical origin, political or religious believes. The volunteers spend their free time helping people with diverse needs. It is an organisation that aims to promote a healthy and physically active lifestyle. Their target group is the entire population in the municipalities, though they arrange activities for different age groups. The volunteer centres have a board that sets the goals and purpose of the activities that the individual centre will focus on. An important goal is that the volunteers should contribute through something they find interesting and important. This means that there are differences in how they organise their activities. All the volunteer centres have a manager or coordinator who coordinates their activities together with the board and members. Many volunteer centres require that those who participate must sign a declaration of confidentiality.

3.4.3. First identification of bottlenecks and challenges

As the amount of institutional care is ever decreasing, the problems related to home-based care cannot be solved without increasing the amount and significance of informal care and volunteering assistance. However, there are several bottlenecks associated with this:

- From a municipal viewpoint, informal care is a very inexpensive form of arranging care. However, the service system has not developed to support informal care, and developments in this matter have been just the opposite
- There is a risk that adult and children who take care of elderly parents, experience inhibited work participation
- There are reported challenges related to increased interaction with volunteers and social entrepreneurs and legal aspects of the current legislation
- Many municipalities (except for some larger municipalities) have not prioritized developing goals and strategies for cooperation.
- Although the economic impacts of informal care are recognised very well, its position in home care service entity is still unstable

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[6] https://frivillig.no/

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3.5. Sweden

Sweden is a monarchy with a parliamentary form of government. There are three independent government levels:

- national government;
- 21 county councils/regions;
- 290 municipalities.

3.5.1. Health system infrastructure

Sweden has a long tradition of health care devolution: the 21 politically elected county councils are responsible for health care provision. The national health policy is filtered by county councils of numerous different political persuasions, leading to differences (how they contract with private providers depending on the importance they attach to equity of access; which is an issue with political difference). The main responsibility for the provision of health care services lies with the county councils and regions. The municipalities are responsible for care of older and disabled people. A main issue for all of Swedish welfare is the need to overcome boundaries between regional (county councils) and local (municipalities/cities) care, and to make transitions as smooth as possible with a holistic approach to the patient or user.

The Swedish health care system is a socially responsible system with an explicit public commitment to ensure the health of all citizens. Three basic principles apply to health care in Sweden:

- The principle of human dignity means that all people have an equal entitlement to dignity, and should have the same rights, regardless of their status in the community
- The principle of need and solidarity means that those in greatest need take precedence in medical care.
- The principle of cost–effectiveness means that when a choice has to be made between different health care options, there should be a reasonable relationship between the costs and the effects, measured in terms of improved health and improved quality of life.

The Health and Medical Services Act of 1982 specifies that the responsibility for ensuring that everyone living in Sweden has access to good health care lies with the county councils/regions and municipalities. The Act is designed to give county councils and municipalities considerable freedom with regard to the organisation of their health services. Local self-government has a very long tradition in Sweden. The regional and local authorities are represented by the Swedish Association of Local Authorities and Regions (Sveriges Kommuner och Landsting (SALAR).

The state, through the Ministry of Health and Social Affairs, is responsible for overall health care policy. There are eight government agencies directly involved in the area of health and care and public health: the National Board of Health and Welfare, the Medical Responsibility Board (HSAN), the Swedish Council on Technology Assessment in Health Care, the Medical Products Agency (MPA), the Dental and Pharmaceutical Benefits Agency (TLV), the Swedish Agency for Health and Care Services Analysis, the Swedish Social Insurance Agency and the National Institute for Public Health.

There is a mix of publicly and privately owned health care facilities but they are generally publicly funded.

Health care is largely financed by tax in Sweden. About 80% of all expenditures on health are public expenditures. Both the county councils and the municipalities levy proportional income taxes on the population to cover the services that they provide.

One important aim behind structural changes in Swedish health care since the 1990s has been a shift from hospital inpatient care towards outpatient care at hospitals and primary care facilities, respectively. Primary care, delivered by more than 1100 public and private primary care units throughout the country, involves services that do not require advanced medical equipment and is responsible for guiding the patient to the right level within the health system. These services include family doctors, nurses, physiotherapists, and other para medic groups. The primary care mission is being looked over in order to strengthen its role as a main contact for most patients.

3.5.2. Informal Care and volunteering assistance landscape

In Sweden, care of elderly people is a public responsibility and generally provided by the municipalities. There are comprehensive public policies and programs providing health care, social services, pensions, and other forms of social insurance. Even so, families are still the major providers of care for older people. In the 1990s, the family was “rediscovered” regarding eldercare in Sweden. New policies and legislative changes were promoted to support family caregivers. The development of services and support for caregivers at the municipal level has been stimulated through the use of national grants. As a result, family caregivers have received more recognition and are now more visible. However, the “Swedish model” of publicly financed services and universal care has difficulty addressing caregivers. Reductions in institutional care have had negative repercussions for caregivers and may explain why research shows that family caregiving is expanding. At the same time, a growing “caregivers movement” is lobbying local and national governments to provide more easily accessible, flexible, and tailored support. In 2009, the Swedish Parliament passed a new law that states: “Municipalities are obliged to offer support to persons caring for people with chronic illnesses, elderly people, or people with functional disabilities.” The question is whether the new legislation represents a movement towards a more family-orientated system. If so, what are the driving forces, motives, and consequences of this development for the different stakeholders? (https://www.researchgate.net/publication/51707386_Informal_Caregiving_for_Elders_in_Sweden_An_Analysis_of_Current_Policy_Developments)

Under Swedish law, health service staff must work in accordance with scientific knowledge and accepted standards of practice. Research results and comprehensive clinical experience should guide the delivery of health care. The National Board of Health and Welfare is commissioned by the government to provide evidence-based guidelines for the care and treatment of patients with serious chronic illness. The guidelines are produced in collaboration with other actors, most importantly the Swedish Council on Technology Assessment in Health Care, the MPA and the TLV.

Carers refer to family, close friends, significant others or neighbours, in short - anyone who provides a variety of emotional and practical help, support or care to people that suffer from a long-term illness or disability. This caring is generally unpaid and carried out on a voluntary basis.
Close to every fifth person (approximately 1.3 million – in 2012) in Sweden over 18 years of age give care, help or support to someone. 900 000 of these people are in paid employment. Caring is common in all age groups but most common between 45-65 years of age.

- Carers between 30-44 years mainly give care and support to children
- Carers between 45-65 give mainly care and support to aged parents
- Cares older than 65 years provide more extensive care to their spouse or partner.

Overall, there are no major gender differences concerning caring when it comes to time and frequency. Women’s support is mainly overseeing the caring situation, providing/arranging company and personal care while men give practical help and financial support.
The more extensive the care provided by carers the more their quality of life is adversely affected.

- Women experience to a greater extent that caregiving affects their quality of life negatively.
- The opportunity for gainful employment and studying is affected by caregiving especially in the age group 30-44 years old and women are more affected than men.
- 100 000 carers have had to shorten their paid work hours or quit their employment due to caregiving.

On the other hand, most of the carers say that they feel good about giving care to their significant other. Carers’ quality of life is enhanced when they know that the person they care for is provided with good health and social care by people whom they trust.

Carers themselves usually request information, education and support. They want to gain more knowledge about different illnesses, diseases and treatment of their significant other. For those who provide personal care, carers often request skills training to better equip them to carry out nursing tasks. They also want to know what kinds of help and support are available to them and how to get it. Carers providing care on a regular basis often require respite care together with practical help with caring. In addition, appropriate adaptations to the home environment to help facilitate daily living. Emotional support such as an understanding person to talk to is equally important.(http://www.anhoriga.se/information-in-english/facts-about-informal-carers/facts-carers-and-support-of-carers/)

3.5.3. First identification of bottlenecks and challenges

More recently in Sweden the needs of children who are "next of kin" receive serious attention. This concept is not commonly known, but is becoming used more and more. The term "young carers" is not established at all. There are, however, children with excessive burdens of responsibility and care in their families. According to a survey, about seven percent of 15-year-olds have such a responsibility. (Source: Read or download facts about children as next of kin here)

There are many people that don't see themselves as a carer and sometimes it takes time to realise that you are a carer or in a caring situation. Carers' need of support changes over time and that is why it is important to adapt the support to the specific individual carer. A first step could be helping carers to be aware of their situation and informing them about what kind of help and support they can receive from the municipalities, organisations or local community to better cope with their everyday life.

The government official investigation *Läs mig! Nationell kvalitetsplan för vård och omsorg om äldre personer SOU 2017:21 Del1* was presented in March 2017 and suggests that the Swedish government should obtain a national long-term quality policy for elderly care lasting until 2034. The governmental directive suggests an increased quality level – from a "reasonable" to a "good" living standard for the older population. At the same time there is no room for increased costs, according to the same directive. An increased competence level for the low-educated nursing home staff is one of the main suggestions. Better use of e-health technology is another key factor.
The last couple of years, conditions for civil society and it's organisations have undergone major changes. An agreement between the state and these organisations was signed in October 2008 with the main objective to strengthen the independence of the ideological organisations and their independent role as opinion makers, as well as to support the emergence of a significant greater diversity of performers and providers in health and social care: *www.överenskommelsen.se*. The aim of the national agreement is also to stimulate regional and local agreements. This could be seen as the beginning of a movement were civil society is increasingly regarded as important actors in the welfare sector.

3.6 United Kingdom

The United Kingdom, located off the northwest coast of the European mainland, comprises Great Britain (England, Scotland and Wales) and Northern Ireland. It has a population of around 64 million, 80% of whom live in England.

3.6.1 Health system infrastructure

Despite the description as a "national" health service (NHS), in practice the health system has never been the same across the four nations. This variation has increased with the transfer of powers for health care and public health to Northern Ireland, Scotland and Wales from 1997 onwards, in a process termed "devolution". Scotland, Wales and Northern Ireland have pursued an approach emphasising partnership between purchasers and providers in the health system, while market forces play a greater role in the English health system.

The United Kingdom's health care system was established in 1948 as a national system available to all residents, funded through taxation, provided using publicly owned hospitals and free at the point of use. The United Kingdom government allocates money for health care in England directly, and allocates block grants to Scotland, Wales and Northern Ireland which in turn decide their own policy for health care. Each nation funds organisations which arrange services on behalf of patients.

In England and Northern Ireland there is a split between the purchasers and providers of services, which was introduced in 1990; this split has been abolished in Scotland and Wales.

England, Scotland, Wales and Northern Ireland each have their own advisory, planning and monitoring framework for their health care system. Unlike other European countries, devolution of health powers in the United Kingdom was not accompanied by a common data or monitoring system, and so comparisons between nations within the United Kingdom are not easy to make. A key body is the National Institute for Health and Care Excellence (NICE), which advises on the cost-effectiveness of interventions, though its guidance does not automatically mean funding for a recommended treatment is available.

The health system is mainly funded through general taxation, with the remainder coming from private medical insurance and out-of-pocket payments. The number of acute hospital beds is one of the lowest in the EU; the average length of stay has also been declining.
The key elements of public health in the United Kingdom are:

- health protection programmes
- health improvement programmes
- and reducing health inequalities.

Primary care in the United Kingdom serves three main roles:

- it is the first point of contact when a person has a health concern;
- it provides ongoing care for common conditions and injuries;
- and it serves as a gatekeeper to more specialised care, which is generally provided in hospitals.

Practice-based general practitioners mainly provide primary care, with practices increasingly including other health care professionals such as nurses. Salaried specialist doctors and others who work in state-owned hospitals provide most secondary care. Tertiary services offer more specialized care, and are often linked to medical schools or teaching hospitals. Tertiary care services often focus on the most complex cases and rarer diseases and treatments.

Patient pathways are the same across the United Kingdom, with comparatively more emphasis on choice of provider in England. One of the main goals across the United Kingdom at the moment is to better integrate health and social care, in order to be more cost-effective and efficient, and to provide higher quality services to patients.

Legislation to implement health and social care integration, passed by the Scottish Parliament in February 2014, came into force on April 1, 2016. This brings together NHS and local council care services under one partnership arrangement for each area. In total 31 local partnerships have been set up across Scotland and they will manage almost £8 billion of health and social care resources. Working together, NHS and local council care services will be jointly responsible for the health and care needs of patients, to ensure that those who use services get the right care and support whatever their needs, at any point in their care journey. Integration will mean a greater emphasis on enabling people to stay in their homes, or another homely setting, where possible, sharing their lives with their family and friends, doing the things that give life meaning and value.

3.6.2. Informal Care and volunteering assistance landscape

Informal carers provide care on an unpaid basis, often to family members. Some will provide a few hours of care each week, perhaps doing the shopping for someone who finds it difficult to get out of the house; others will provide round the clock care and companionship. Formal care, in contrast, is provided in return for payment. Carers are an essential part of the workforce, in its broadest sense, contributing savings to health and social care services in Scotland of an estimated £7.68 billion every year. (Carers UK/University of Leeds, Valuing Carers, 2007)

Carers Uk policy briefing (2015) identify the 2011 Census figures for the UK show an 11% rise in the number of carers since the last Census in 2001 - increasing by over 620,000 to 6.5 million in just 10 years.

Number of carers in England, Wales, Scotland and Northern Ireland, 2011 Number of carers 2001

	Number of carers 2001	Number of carers 2011
England	4,877,060	5,430,016
Northern Ireland	185,086	213,980
Scotland	481,579	492,031
Wales	340,745	370,230
UK Total	**5,884,470**	**6,506,257**

Alternative estimates from the Scottish Household Survey indicate the number of carers in Scotland may be higher, at 759,000 (17% of the population). Carers UK estimates that we will see a 40% rise in the number of carers needed by 2037 – an extra 2.6 million carers, meaning the carer population in the UK will reach 9 million.

Key findings, research data from the Family Resources Survey (from 2011/12 to 2013/14) to describe the situation of informal carers in the UK, and how being a carer has implications for employment, income and poverty. (http://www.npi.org.uk/files/2114/6411/1359/Carers_and_poverty_in_the_UK_-_full_report.pdf)

- 5.3 million people in the UK routinely provide unpaid care to someone with a disability or health condition. Most carers (72%) provide care to immediate family, whether a parent (40%), partner (18%), son or daughter (14%). The most common arrangement was for carers to provide support to parents who were not living with them (33%).
- 1 in 10 adults provide unpaid care, rising to 20% of women and 13% of men aged between 55 and 64
- The poverty rate among working-age carers increases with the number of hours they care for, particularly after 20 hours per week.
- 2.6 million working-age carers provide less than 20 hours and have a lower poverty rate than the average non-carer (of 21%). 1.4 million working-age adults provide at least 20 hours of care and have a poverty rate of 37%.
- Despite the challenges of combining care with employment, 400.000 people are doing a full working week alongside long hours of care (20 hours or more).

- Working-age people who provide care for 20 hours or more each week tend to have lower qualification levels. Overall, 70% of those who cared for 20 hours or more had no or low qualifications compared with around half of low intensity carers (52%) or non-carers (48%).

Almost 4 million of the UK's carers care for 1-19 hours each week. But the numbers caring round the clock, for 50 or more hours or more each week, are rising faster than the general carer population - an increase of 25% in the last ten years compared to an 11% rise in the total number of carers.
The amount and type of care that carers provide varies considerably. A carer might provide a few hours of care a week - shopping, collecting medication and taking someone to medical appointments - or they may care around the clock. According to the NHS Information Centre Survey of Carers in Households :
82% provide practical help such as preparing meals, doing laundry or shopping.
76% keep an eye on the person they care for
68% keep them company
62% take the person they care for out
49% help the person they care for with financial matters
47% help the person they care for deal with care services and benefits
38% help with aspects of personal care such as
(Source: CarersUK Policy briefing 2015)

Key role of carers: future

Carers, as **equal** partners in the delivery of care, enable people with illnesses or disabilities to remain at home and in their own communities safely, independently and with dignity. Carers can, for example, prevent avoidable hospital admissions and contribute to people's overall health and well-being. Carers' role and contribution will be critical in the future due to demographic and social changes:

- Scotland's 65+ population is projected to rise by 21% between 2006 and 2016 and by 62% by 2031; and
- For the 85+ age group, a 38% rise is projected by 2016 and by 2031 the increase is a projected 144%.

(**Caring Together: The Carers Strategy for Scotland 2010-2015)**

Shifting the balance of care from residential and institutional settings to care at home and more people being cared for at home for longer has implications for carers. Carers will play an increasingly important role in the support, care and treatment of people with long-term and/or multiple conditions, disabilities, illnesses, including dementia, and alcohol and drug dependency. **However, this greater role must not place additional burdens on carers or prevent them from working, learning or having a life outside of caring. (Caring Together: The Carers Strategy for Scotland 2010-2015)**

The Carers (Scotland) Act will start on April 1, 2018. The package of provisions in the Act is designed to support carers' health and wellbeing. These include, amongst other things:

- a duty on local authorities to provide support to carers, based on the carer's identified needs which meet the local eligibility criteria. National matters which local authorities must have regard to when setting their local eligibility criteria will be set out in regulations;
- a specific Adult Carer Support Plan and Young Carer Statement to identify carers' needs and personal outcomes; and
- a requirement for each local authority to have its own information and advice service for carers which must provide information and advice on, amongst other things, emergency and future care planning, advocacy, income maximisation and carers' rights.

The Act contributes to the Scottish Government's vision of a healthier and fairer Scotland, and sits within the wider policy landscape including: integration of Health and Social Care; GP contract; new social security powers; and Fair Work agenda.

3.6.3. First identification of bottlenecks and challenges

Carers, whatever their circumstances, should enjoy the same opportunities in life as other people without caring responsibilities and should be able to achieve their full potential as citizens. (Caring Together: The Carers Strategy for Scotland 2010 – 2015).

Financial (Carers UK (2014) Caring & Family Finances Inquiry UK Report)

- The poverty rate among working-age carers increases with the number of hours they care for, particularly after 20 hours per week.
- Half of working age carers live in a household where on on is in paid work.
- Almost 1 in3 carers had seen a drop of £20000 in more a year as a result of caring.
- A third of carers had cut back on essentials like food and heating (32%).
- 45% of carers said their financial circumstances were affecting their health.

Health

- Carers providing round the clock care are more than twice as likely to be in bad health than non-carers.28
- The pressures of caring can take a toll on carers' physical and mental health.54% of carers have suffered depression because of their caring role; carers also felt more anxious (77%) and more stressed (83%) because of their caring role.

Social exclusion and personal relationships Carers UK (2015) State of Caring 2015

- 61% of carers said that they were worried about the impact of caring on their relationships with friends and family;
- In 2014, half of carers (49%) said they feel society does not think about them at all

Work and caring

- 3 million people combine informal care for a loved one with paid work.
- Over 2 million people have given up work at some point to care for loved ones, 3 million have reduced working hours;
- 70% of carers were over £10,000 worse off as a result of reduced earnings;
- Half of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours;
- Around one in nine workers in the UK has caring responsibilities.

Estimates from Age UK showed a cost of £5.3 billion a year to the economy in lost earnings and tax revenue and additional benefit payments. Age UK (2012) Care crisis wipes over £5.3 billion from the economy.

4. Summary, comparison and definitions for In For Care

In this document an overview has been presented on the health systems in participating partner countries and on their views, approaches and strategies on informal care and voluntary assistance. On the next page a summary will be given per country:

- Definitions on informal care and on voluntary assistance;
- Policies on informal care and voluntary assistance;
- Strategies for coordinating volunteers and informal carers in health organisations (i.e. partner countries

4.1 Definitions per participating country

	Participating countries In For Care					
	Belgium	**Denmark**	**Netherlands**	**Norway**	**Sweden**	**United Kingdom**
Definitions on Informal care	Family Care, Voluntary Assistance, Self-Care and community based care	Informal caregiving by relatives is not common	Family Care, Voluntary Assistance and Self-Care	Family care and voluntary assistance	Family care	Family care, voluntary assistance, self-care and community based care
Future governmental policies	Volunteers and family carers can help persons with chronic illness or with diminished ability of self-care. A supportive system of community based care for volunteers and family carers in the **neighbourhood or community** needs to be developed.	Personal care in particular is primarily the **task of the state** (muni-cipalities). Help for family care givers is to be **supported** by the local authorities. Evolution to civil society/active citizenship.	Carers **as equal partners** in the delivery of care, enable people with illness or disabilities to remain at home and in their own communities safely, independently and with dignity	**Mechanism** for **involving** family members and volunteers have become a national focus and a government's strategic priority.	Care of elderly people is a **public responsibility**, and general provided by municipalities. The development of services and support for caregivers at the municipal level has been stimulated.	Carers **as equal partners** in the delivery of care, enable people with illness or disabilities to remain at home and in their own communities safely, independently and with dignity
Strategies for coordinating volunteers and informal carers	Evolution to community based care. The local government coordinates and implements the community bases care (Flemish).	Broader strategies to put up to civil society strategies or active citizenship. Municipal employees develop and coordinate the voluntary social work and cooperation with associations.	Evolution to community based care, stimulating active citizenship. Responsibility of the municipality.	Several public sources have pointed out the challenge of establishing an effective coordination of the voluntary services to support society's needs.	Conditions for civil society and it's organisations have undergone major changes. The national agreement between them and the state: civil society is increasingly regarded as important actor in the welfare sector.	Shifting the balance of care from residential and institutional settings to care at home. This has implications for carers. They will play an increasingly important role in the support, care and treatment.

4.2 First bottlenecks and challenges per participating country

Belgium	• lack of information on specific regulations and measurements (on leave; allowances etc.) • recruitment of volunteering • debate about economic value of family care and the financial impact of it on the health insurance • the demand for informal care givers will increase further because of the amount of baby boom-generation (elderly people) • the amount of care givers will decrease, since there will be less people who will be able to provide this care (demographic pressure). In future there is no balance between the amount of care givers and persons who request this care. • Compartmentalization of (primary) health care • Reform of primary health care with a directing role for the local governments in the collaboration between care actors and realisation of approachable care • Shift in finance system towards a person following budget • Reformation of hospitals will increase the need of home care, and increase the burden on informal care. • Increasing diversity, so healthcare should adapt accordingly • Marketization of healthcare
Denmark	• The Danish welfare state is in the process of redefining itself from being a safety net for citizens to be coordinator of cooperating across social health, employment and education system, private operators and volunteers. • The number of hospital beds has declined since the early 1990s in the acute, long-term and psychiatric care sectors. Average length of stay has also declined through changes in treatment options, with an increase in outpatient treatment as well as a policy of deinstitutionalization in the psychiatric sector. • Area that is attracting attention within rehabilitation and intermediate care is the problem of securing coherent patient pathways. • Continuity of care is a concern in the rather fragmented and decentralized Danish health care structure. Various initiatives have been implemented in order to improve continuity, but lack of integration of care is still a major issue, particularly regarding chronic care. • It can be a challenge for associations and volunteers that contact to the municipality has to be taken to many different administrations. Conversely, it can also be a challenge for local councils to incorporate the voluntary initiatives into their overall strategy. • The voluntary associations and local governments experience that it has become harder to recruit and retain volunteers for regular operational tasks, but at the same time a little easier to recruit for individual and time-limited tasks. • The volunteers expresses that it is an inhibiting factor for their voluntary work that it feels more and more like paid work, mainly because of documentation requirements and objectives. • Employees, for example in the municipal nursing homes, expresses that it may be an inhibiting factor when the tasks volunteers perform, is valued higher than the employees' tasks.
Netherlands	• Supporting informal care givers is a responsibility for all (not only for municipality supporting points) • Dutch policy is that people have to live on their own as long as possible. People should rely on their own social network first. This means more pressure on relatives with a job or for children growing up in a family where care is needed. The availability of informal carers is significant in the capacity of the client to be able to remain living at home. • People who needs care live longer independently: risks of isolation and a combination of illness (comorbidity) which makes that the needed care more complex (burden for informal carers). • Support for volunteering work in general and volunteering assistance (informal care) are separated worlds. Nowadays more citizens initiate (informal) care initiatives with new forms of voluntary assistance. Traditional and new forms of voluntary assistance should benefit more from each other (strengthen each other; instead of competition). • If employers become aware that they could save a large amount of money through preventing illness or sick leaf of their employees, more employers would feel obliged to invest in new approaches towards informal care givers within their organisations/enterprises.
Norway	As the amount of institutional care is ever decreasing, the problems related to home-based care cannot be solved without increasing the amount and significance of informal care and volunteering assistance. However, there are several bottlenecks associated with this: • From a municipal viewpoint, informal care is a very inexpensive form of arranging care. However, the service system has not developed to support informal care, and developments in this matter have been just the opposite • There is a risk that adult and children who take care of elderly parents, experience inhibited work participation • There are reported challenges related to increased interaction with volunteers and social entrepreneurs and legal aspects of the current legislation • Many municipalities (except for some larger municipalities) have not prioritized developing goals and strategies for cooperation • Although the economic impacts of informal care are recognised very well, its position in home care service entity is still unstable.

Sweden	• More recently in Sweden the needs of children who are “next of kin” has begun to receive serious attention. This concept is not commonly known, but is becoming used more and more. The term “young carers” is not established at all. There are, however, children with excessive burdens of responsibility and care in their families. According to a survey, about seven percent of 15-year-olds have such a responsibility. • There are many people that don’t see themselves as a carer. Carers’ need of support changes over time and that is why it is important to adapt the support to the specific individual carer. A first step could be helping carers to be aware of their situation and informing them about what kind of help and support they can receive from the municipalities, organisations or local community to better cope with their everyday life. The government official investigation Läs mig! Nationell kvalitetsplan för vård och omsorg om äldre personer SOU 2017:21 Del1 was presented in March 2017 and suggests that the Swedish government should obtain a national long-term quality policy for elderly care lasting until 2034. The governmental directive suggests an increased quality level – from a “reasonable” to a “good” living standard for the older population. At the same time there is now room for increased costs, according to the same directive. An increased competence level for the low-educated nursing home staff is one of the main suggestions. Better use of e-health technology is another key factor. The last couple of years, conditions for civil society and it’s organisations have undergone major changes. An agreement between the state and these organisations was signed in October 2008 with the main objective to strengthen the independence of the ideological organisations and their independent role as opinion makers, as well as to support the emergence of a significant greater diversity of performers and providers in health and social care: www.överenskommelsen.se. The aim of the national agreement is also to stimulate regional and local agreements. This could be seen as the beginning of a movement were civil society is increasingly regarded as important actors in the welfare sector.
United Kingdom	Carers, whatever their circumstances, should enjoy the same opportunities in life as other people without caring responsibilities and should be able to achieve their full potential as citizens. (Caring Together: The Carers Strategy for Scotland 2010 – 2015). Financial (Carers UK (2014) Caring & Family Finances Inquiry UK Report) • The poverty rate among working-age carers increases with the number of hours they care for, particularly after 20 hours per week. • Half of working age carers live in a household where on on is in paid work. • Almost 1 in3 carers had seen a drop of £20000 in more a year as a result of caring. • A third of carers had cut back on essentials like food and heating (32%). • 45% of carers said their financial circumstances were affecting their health. Health • Carers providing round the clock care are more than twice as likely to be in bad health than non-carers.28 • The pressures of caring can take a toll on carers’ physical and mental health.54% of carers have suffered depression because of their caring role; carers also felt more anxious (77%) and more stressed (83%) because of their caring role. Social exclusion and personal relationships Carers UK (2015) State of Caring 2015 • 61% of carers said that they were worried about the impact of caring on their relationships with friends and family; • In 2014, half of carers (49%) said they feel society does not think about them at all Work and caring • 3 million people combine caring for a loved one with paid work. • Over 2 million people have given up work at some point to care for loved ones, 3 million have reduced working hours; • 70% of carers were over £10,000 worse off as a result of reduced earnings; • Half of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours; • Around one in nine workers in the UK has caring responsibilities. Estimates from Age UK showed a cost of £5.3 billion a year to the economy in lost earnings and tax revenue and additional benefit payments. Age UK (2012) Care crisis wipes over £5.3 billion from the economy.

Annexes

The annexes contains end-user needs and co-creation workshops results for a better cooperation between formal and informal networks of the partners In for Care.
The lead beneficiary partner, the University of Agder, together with two Norwegian co-beneficiaries, Grimstad municipality and the web technology company Frameworks AS, have implemented a series of workshops to collect user needs and co-create solutions for volunteers and informal carers, all in connection with formal care services. The following sections describe the method, results and additional answers to the questions prompted by the work package 3 leader CMO STAMM from Netherlands.

The results, method, participants and next steps are described in the next 5 documents.

EU Interreg V Project InforCare

Co-creation Summary

September 2017

Norway

Project Beneficiary: **University of Agder**

Project Beneficiary: **Knutepunkt Sørlandet**

Co-beneficiary: **Grimstad Kommune**

Co-beneficiary: **Frameworks AS**

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Version Control

Description	Author/s	Version	Date	Approval/Date
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Co-creation workshops summary: annex for country comparison

1. Introduction:

Norway, as other countries in the North Sea Region, faces challenges to provide quality services to older people. The EU Interreg V InforCare project focuses on the need to find innovative solutions for coordination in health care services. A Quadruple Helix model (Arnkil, Jarvensivu, Koski & Piraiinen, 2010) is used as an innovation model between academia (universities and colleges), government industry and end-users as active participants in the innovation process. The lead beneficiary partner, the University of Agder, together with two Norwegian co-beneficiaries, Grimstad municipality and the web technology company Frameworks AS, have implemented a series of workshops to collect user needs and co-create solutions for volunteers and informal carers, all in connection with formal care services. The following sections describe the method, results and additional answers to the questions prompted by the work package 3 leader CMO STAMM from Netherlands.

2. Summary of preliminary results

The results, method, participants and next step are next described.

2.1 End-user needs and co-creation workshops results for a better cooperation between formal and informal networks

Two end-user needs and two co-creation workshops were held in the University of Agder, Grimstad, Norway. Participants were the employees of the day centre and nursing home of the Frivolltun and Feviktun, both in the municipality of Grimstad, Norway. Two different scenarios were created based on the user needs collected. The description of both scenarios are included below.

Scenario 1: **Webportal**

> *The municipality of Grimstad has received funding from the Directorate of Health to develop a common internet portal for all day centers and nursing homes in the municipality.*

Scenario 1 Results Summary:

The results showed that the web portal would be implemented to be accessed from different devices (e.g., mobile, tablet, PC) and platforms (e.g., Android, iOS), user-friendly and with structured content. The portal would provide communication between the main stakeholders (employees, volunteers and informal carers). The portal would have an overview of defined events and tasks to which volunteers and relatives should be able to easily sign up and join, via Internet, SMS or physically at the centre. The communication with the employees would be bi-directional, allowing for electronic notifications from the employees and feedback from volunteers and informal carers, in addition to reminders. Each institution (e.g., day centre and nursing home) would have a dedicated space inside the portal. Volunteers and informal carers would also have a section where to provide the desired activities and potential contribution they could provide to the institutions.

Scenario 2: Recruitment and follow-up of volunteers

> *For Grimstad municipality volunteering is essential for maintaining a good welfare society. Grimstad Municipality and its volunteer centre would like to develop a new online service to recruit, register, follow up and handle volunteers in the municipalities in a easy-to-use and useful way. The system would be also used for municipal management (nursing homes and day centers) and make it easier for them to recruit volunteers to cover the current and future needs. The municipality of Grimstad has also reported that many citizens would like to voluntarily contribute, but these potential volunteers do not fully understand or get the right information about what it is needed.*

Scenario 2 Results Summary:

All the user groups involved showed interest in the scenario. The results presented included for the employees of the centres an overview of the volunteers, to know who they are and follow them up. The system would allow volunteers to define and propose activities they would be willing to contribute or had competence/experience related, together with their own interests. The system would provide relevant information regarding the people volunteers may be helping or cooperating with, giving access to personal information (such as "My personal story") written by the service receiver. In addition, contract and confidentiality agreement would be accessible and signed through the system.

Participants referred to the creation of ad-hoc training courses for volunteers to acquire the appropriate skills to help people in the centres. A database will be used to register volunter's skills and training, together with a follow-up for the activities they participate in, with post-evaluation of all parties involved. Satisfactorily reported activities would result in new ones with the same parties.

From the institutional point of view, prior to the introduction of the system for volunteer management, it would be required to offer a training course for employees for the management of the system. In addition, specific job positions (such as environmental therapist) could be created ad-hoc for follow-up and management of volunteers and their records.

2.2 Co-creation method

The co-creation method was based in the experience that the lead beneficiary members gathered in the project meeting in Karlstad, Sweden, on 29-31 May 2017, and the own experience and expertise that one member of the team, Santiago Martinez, already had on co-creation and co-design processes. There were four workshops in total, 2 for detecting and describing end-user needs and 2 for co-creation. The user need workshops gathered representatives of all user groups. These were: employees from the day centre and nursing home from Frivolltun and Feviktun, both in Grimstad municipality; informal carers; and volunteers. The workshops lasted approximately 120 minutes. The data collection included a series of general questions that facilitated the dialogue among and between participants. Hand-made annotations and voice recording were made, all under ethical approval and voluntarily signed consent to participate and being voice-recorded. After the user-needs workshops, the research team went through their annotations and discussed the information gathered, as well as different ideas and suggestions generated by the discussion with the end-users. The information was used to create two scenarios later used in the co-creation sessions.

The co-creation workshops were divided in two differentiated days. The first day, three employees with management responsibility were invited. The research team explained the two scenarios created and asked for suitability, amendments and suggestions to the participants. The agenda and the group distribution were also agreed with the participants for the second day. The second day, thirteen participants attended the workshop. They were distributed in three groups, with each group having representatives of different user groups. The groups were explained the instructions of the co-creation session. Once understood, all the groups listened to the first scenario description. Afterwards, participants broke into groups and each went to a different room and started the co-creation process. The process started with 10 minutes for discussion among the group about the ideas and priorities related to the scenario; followed by 40 minutes for creating a paper prototype of a technology solution for the scenario, using props such as coloured markers, sticky notes and other office material. Finally, each group had 5 minutes to present their solution to the rest of the groups. The scenario 2 followed identical procedure but with 35 minutes for paper prototype creation instead. The research team made notes of all the process and the audio was recorded. A summary of the findings has been described above.

2.3 Participants

In total, 19 participants joined the 2 user-need and 2 co-creation workshops. They user groups represented were employees from the day centre and nursing home from Frivolltun and Feviktun both in Grimstad, Norway. In addition, volunteers and informal carers also attended the workshops. The list of participants of the user need workshops is written below:

- Volunteer coordinator (1): *Kristin Sigmond.*
- Day centre employees (4): *Mette Liv Seljåsen* (leader for day centre), *Kirsten H. Strand, Marthe Nævisdal, Anita Bjønnum* (responsible for dementia department).
- Nursing home employees (3): *Ellen Njåmo* (responsible for dementia department), *Marthe Nævisdal, Anita Bjønnum.*
- Informal carers (6): *Gyda Haglund, Frode Mindrebø, Stein Erling Hansen, Peder Bjørklund, Birgit Tellefsdal, Reneè Cindy Roland.*
- Volunteers (6): *Åse Lahn, Mirjam Abrahamsen, Magne Aslaksen, Thomas Sørbø, Reneè Cindy Roland, Reneè Cindy Roland.*

The list of participants of the co-creation workshops is written below:

- Volunteer coordinator (1): *Kristin Sigmond.*
- Employees (7): *Ellen Njåmo, Sigrid Christoffersen, Marit Folkeman, Mette Liv Seljåsen, Marthe Nævisdal, Anita Bjønnum, Kirsten H. Strand.*
- Informal carers (3): *Peder Bjørklund, Reneè Cindy Roland, Frode Eldejard Minderbø.*
- Volunteers (3): *Mirjam Abrahamsen, Marit Folkman, Reneè Cindy Roland.*

2.4 Next steps

The results of the co-creation workshops will inform the development of a prototype solution for communication and management for voluntary assistance and informal care processes in connection with formal carers. The material co-created in the workshops serve already as a guide to the responsible for the development of the solution, the web technology company Frameworks. The testing and validation of the prototype solution will include the end-users who participated in the workshops. In addition, we are currently in an ongoing co-creation process with the municipality of Vennesla and Songdalen, Norway, to proceed through the same steps undertaken with Grimstad municipality. The results of the user-needs and co-creation workshops will be further reported.

2.5 Related policy documents

See the section 3 Targeted Questions below.

3. Targeted Questions

Following the answers to the three questions asked by the work package 3 (WP3) leader CMO STAMM from Netherlands.

3.1 How do you ensure that your activities are based upon the needs of your target group?

The design of all the activities presented in this summary were firstly addressing the detection and description of the end-user needs. These user needs were used by subsequent activities, such as co-creation, and will be further used, such as in development and testing, with the involvement of the end-users in all of them.

3.2 How you enable your target group into solutions found in the project?

The solutions developed in the project, in particular from WP3 and WP4, are targeting current and future innovative work (formal carers and other professionals involved) and daily (volunteers and informal carers) routines of the target end-users. In this way, the development of the solutions is aimed at being tested and validated by end-users in their work/daily routines.

3.3 Do these methods have a correlation with the actual policies and activities in your countries concerning informal care and voluntary assistance?

The methods and especially the information gathered through them is in direct connection with the official documents included in the country comparison as a deliverable for WP3. In particular, the Care and Cocreation Innovation document (in Norwegian, NoU 2011 Innovasjon Omsorg og samskaping) and the National strategy on voluntary assistance for health care (in Norwegian, Nasjonal strategi om frivillige arbeid på helse omsorg 2015-2020).

4. Visual Material

Co-creation workshops:

Figure 3 Co-creation workshop at UiA

Figure 2 Co-creation workshop at UiA

Annex to Country comparison, UC SYD

Due to our goal on involving the students from UC SYD, we settled the first co-creation session with students in April. We had 24 students participating in this session. We arranged it as an innovation-process, and the innovation questions were: “Why should students participate in voluntary work?” and “With what and how can students do voluntary work?” The students who attended had just started their last year of the Bachelor in Occupational Therapy.

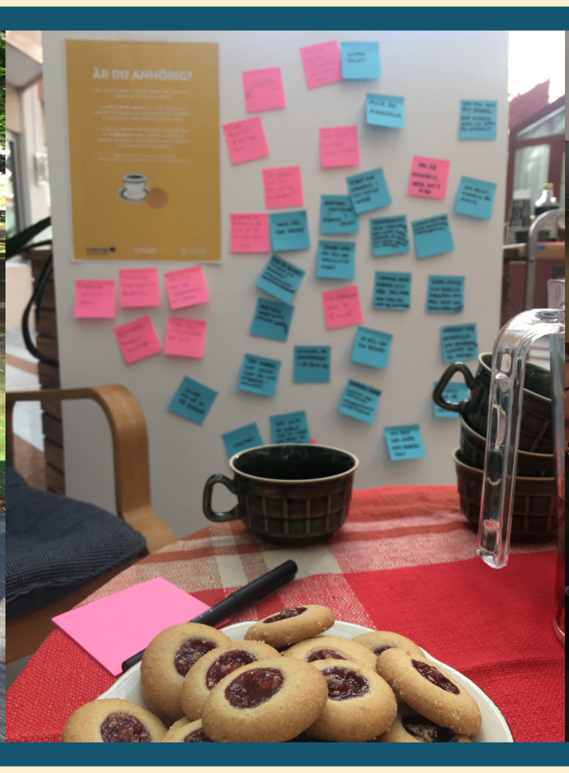
The process was facilitated using LEGO Serious Play and “Creative Platform”. We were addressing the topic “voluntary work by students” into the innovation-course at the Occupational Therapy Education. The co-creation session gave us a knowledge about how students think of themselves as volunteers. We experienced that students are very interested in doing voluntary work in the community. They want to work in flexible hours and settings, and most of them are not interested in long-term obligations. It is very important for them that the work they do is relevant to their study and it motivates them if the voluntary work will improve their chances to get a job after graduation.

After the session, three groups of students wrote their bachelor-thesis on the topic of voluntary work. The focus on voluntary work has raised an interest on the topic and students has become aware of the opportunity to involve themselves in voluntary work and also to focus on the importance of collaborating with volunteers as a supplement to the professional care in the community.

In For Care pilot

County Council of Värmland

WP3: report on co-creation sessions so far



INTRODUCTION

The County Council of Värmland is a politically elected organisation responsible to deliver good health care and dental care for everyone living in the county of Värmland. We have around 30 health centers in Värmland and three hospitals and we are an organisation with almost 7000 employees. Health care in general is under growing pressure to innovate. Aging population, increasing demands and rising costs are just a few of the many challenges the sector is facing today.

Similar to other countries with public healthcare systems, Sweden has attempted to legislate changes within healthcare, for example through the “Patient Act” passed in 2014, that requires a greater level of involvement of patients in care decisions. However, it is increasingly acknowledged that it is difficult to fully realize these policy changes in public healthcare without the appropriate methods and buy-in on the ground.

Within this context The County Council of Värmland established Experio Lab - the first embedded service design group within Swedish health care. The lab was initiated in 2013 with the dual focus of building design capabilities and driving transformation towards person-centred care. This has included creating new services to improve patients’ everyday lives and equipping health-care staff with tools to continually involve patients.

OUR CASE

In the In For Care pilot our vision is to improve life quality for older people with multiple illnesses. An improved quality of life both gives, and comes from, a better health condition, which in turn will reduce the need for health care. The hypothesis in this pilot is that this will be achieved by the development, support and integration of work done by family carers and volunteers with the formal health care system.

DESIGN METHODOLOGY

In the In For Care pilot we are building on the Experio Lab approach - to involve patients with multiple illnesses, their family caregivers, health care staff and other stakeholders in participatory design processes. Central to this approach are the four phases of the design process:

1. **Discover** insights about the problem
2. **Define** the area to focus on

Needs assessment

3. **Develop** potential solutions
4. **Deliver** solutions that work

Development and testing of solutions

Design is by its nature co-creative, and will hence be central in all parts of our pilot, it therefore makes it hard to separate co-creation as one single activity. When chosing methods for the co-creation activities we’ve had in mind that we not only want to involve users and stakeholders in single co-creation activities but focus more on building long term relationships with users and stakeholder in order to create networks from which opportunities can emerge (open innovation).

Interreg North Sea Region
In For Care
European Regional Development Fund
EUROPEAN UNION

EXPERIO LAB

Landstinget i Värmland

Interactions:

Patients, family carers and volunteers: 30 people
Health care professionals: 40 people
Other stakeholders: 10 people

Informal methods used:

”Fika dialouges”
”Walk and talks”
”Co-creation interviews”

DISCOVER PHASE

In the discovery phase we are trying to gain a deep understanding of the situation by exploring users’ needs, experiences and challenges. When talking about users’ we refer to both patients, family caregivers, volunteers, health care professionals as well as volunteer organisations. In this phase we have used a variety of methods for gathering insights about the situation for the users. Instead of seeing elderly people with multiple illnesses as one group, we try to look beyond the the norm and stereotype of an ’older person’ and address the more marginalized people within our society. So far we have interacted with 40 health care professionals, 30 patients, family carers and volunteers as well as other public sector representatives from Karlstad municipality. Our approach in interacting and building relations with these have been to use informal methods as a way of building trust, equality and mutual understanding into the process.

Our main co-creation activities took place during the National caregivers week in Sweden October 2nd to 6th. We took part in ”walk and talks” with elderly family care givers while doing Nordic walking outside in the city. We also invited people in our own organisation that are family care givers to ”fika dialouges” with coffee and cake, to talk about their situation. Currently, health care professionals (nurses and doctors) from one health center in the city of Säffle are undertaking ”co-creation interviews” with patients. They are individually meeting with two patients each to talk about their life situation and health care. The result of these will be used to identify better ways in organizing health care for the target group where family care givers are seen as a resource.

INSIGHTS ON NEEDS SO FAR

As we are still in the discovery phase and exploring needs we have not yet started the define phase where we are analysing and synthesising the data. However we can share some of the insights so far:

NEEDS AND BARRIERS OF PATIENTS AND INFORMAL CAREGIVERS

We have found that caregivers are doing a huge amount of, often invisible, work for elderly with multiple illnesses. They help their loved ones to cope with everyday activities, provide mental support and navigate the often very complex health care system.

We have found that many caregivers top priority is that the one they care for feels good and get the best health care possible. Their own mental and physical wellbeing are often neglected and finding a balance between his/her own life and informal caregiving is hard.

We have found that many elderly people don’t include themselves in the stereotypical image of the ’elderly person’, a norm that is very dominant in our society. We design solutions and services in the health care system based on this norm and these assumptions influence how patients are talked to and treated in health care situations. Instead of seing elderly people as one group we need to broaden the representation of elderly people to actually reflect the population, so that we can design solutions that works for all.

We have found that there are less accessibility to healthcare, support and other services for elderly people with multiple illnesses and their family care givers who live in rural parts of our county than for those living in urban areas.

NEEDS AND BARRIERS OF HEALTH CARE ORGANISATION (FORMAL CAREGIVER)

We have found that health care seldom look at patients and their family caregivers in a holistic way, we tend to focus on patients and their illnesses without looking to the whole life situation of the family. Family caregivers are often seen as trouble-makers by health care professionals rather than as a resource in their care.

NEEDS AND BARRIERS FOR A BETTER COOPERATION BETWEEN FORMAL AND INFORMAL CAREGIVERS

We have found that people who are caring for a elderly family member or friend with multiple illnesses often realize that they need support too late. Becoming a care giver could have a sudden start but many times it doesn’t happen from one day to another. The person with an illness might gradually begin to need more and more attention or help. It is therefor hard to notice and identify that you are in an informal care situation. We also know that social and healthcare professionals have an important role in identifying informal care situations, still today there are no systematic ways of doing this.

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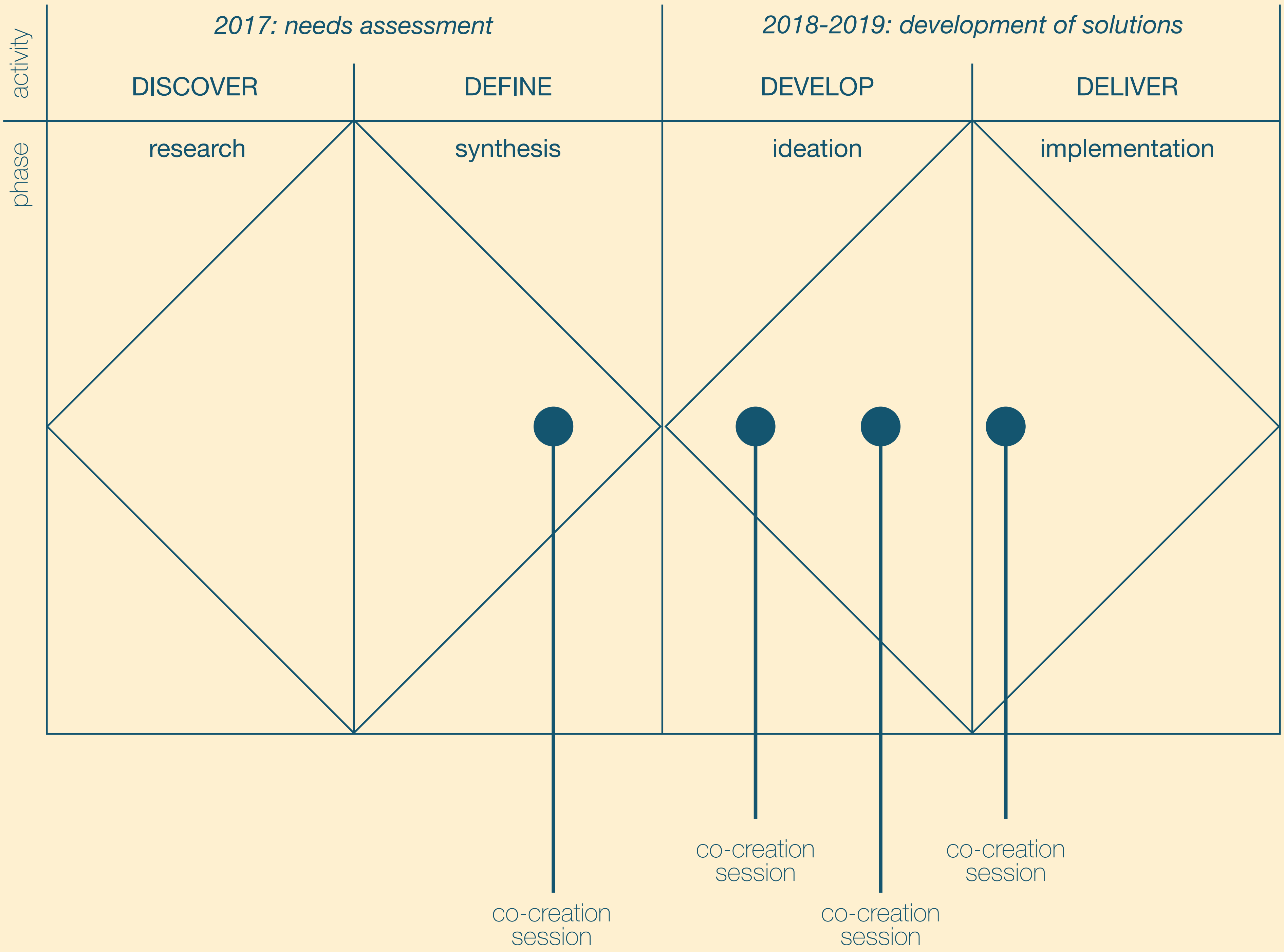
In For Care
European Regional Development Fund
EUROPEAN UNION

EXPERIO LAB

Landstinget i Värmland



NEXT STEPS

In the continuation of the pilot we will address all of these insights by organising a series of co-creation sessions on three different themes/ cases.

Themes/cases

1. How can we see family care givers as resources in health care?

2. How do we collaborate between formal and informal organisations to better reach family caregivers?

3. How can we, with the help of informal actors, increase accessibility to care in rural areas?

We will handpick and invite partners and stakeholders to participate in these co-creation sessions based on the theme/case. The co-creation sessions will follow the design process and it’s phases.

Timeplan

2017: Research and need assessment

November - December: continuation of research and need assessment. Participation in hackathon on open data.

2018: Ideation, creation and prototyping

January - February: synthesising research, preparation of themes/ cases and planning of co-creation sessions

March - May: arranging a series of co-creation sessions

August - December: prototyping and testing of ideas

2019: Implementation and evaluation

Report – Needs assessment In For Care

1) Co-creation with volunteers

Co-creation with persona's on recruiting and motivating volunteers (n=9).

a. Results

The panel prefers personal contact through e.g. letter, events with personalised contact. The main advantage of volunteering is the social contact with peers; volunteers have different ideas about keeping them motivated: if a volunteer wants to quit, then you have to let him ⬄ search for the underlying reason and work together to search for different volunteering work. Showing appreciation is essential to keep volunteers motivated.

b. Next steps

- Using the feedback to make new profiling for volunteers (e.g. for recruiting volunteers to conduct house visits – cfr supra 2))
- Using feedback to give tuition to employees working with volunteers
- Organising activities for volunteers to show appreciation (Volunteering Day in Spring 2018)

2) Elderly & Loneliness

- Interview with questionnaire to detect loneliness with elderly living at home (n= 56)
- Focusgroup with purposefull sampling (n=5), analysis with software NVIVO

a. Results

An important part of the target group suffers from small to severe feelings of loneliness. Although an important group gets daily or weekly visits, and frequently uses telephone, they feel that they have few contact with other persons than their family. Especially the eldest of elderly, singles and low-skilled elderly have high risks of loneliness. They participate less and see more barriers to participate.
Family, friends and neighbours play an important role in the life of elderly. To stimulate these relationships can play an important role in tackling feelings of loneliness.

It is especially important to conduct daily activities. Obstacles in public spaces, stimulating mobility and counteract feelings of insecurity can support this.
Internet and technology is not yet widespread as a source of information. Using technology can pose obstacles for participation. Elderly feel the need for extra tuition to use technology, but technology may not replace physical contacts.
There is need of sincere, warm and intergenerational contacts, for example by having more house visits by volunteers/ buddies.

b. Next steps

- Working out method to detect loneliness (in collaboration with University College Odisee and University of Brussels)
- Workshop – apps and technology for elderly (in collaboration with University college Odisee)

- Preparing a service delivery with volunteers for house visits

3) Interview with informal carers

a. Results

The interviews with a survey (n=15) did not give the proper information, therefore stad Aalst had contact with iDrops, an organisation specialised in co-creating social innovation. iDrops worked out a solution for informal carers through an intensive needs assessing and co-creative trajectory.
Stad Aalst wants to take these results and adjust it after interaction with local informal caregivers about the model. In addition, stad Aalst wants to collaborate with the formal caregivers to see what role they can play.

b. Next steps

Collaboration with iDrops to implement a bottom-up supportive system for informal carers, consisting of

- Tuition for first line caregivers
- Support Quest for information (introduction of a chatbot – new tool)
- Stimulate interaction between informal caregivers (caregiver café)

Report co-creation session young people, Sept. 23rd 2017

1. Introduction

In the province of Groningen the common work approach to develop policies and activities with young people, instead of deciding for them. In the project In For Care we focus on young informal care givers.

Young informal care givers are children who grow up in a family with a family member who is chronically ill, or with a mentally or physical disability or a family member with an addiction or psychical problems (0 – 23 years). Although these children don't call themselves informal care givers, and although they don't provide the care similar to adults, these children grow up with other worries and responsibilities than their peers. For example, they don't have time for friends because their mum needs support in cooking the dinner, they can't participate in leisure activities because there is no time. Risks of growing up in such a family are: drop out, no social network of their own, health problems etc.

Co-creation is essential in our work approach. In all our activities we ask young people themselves, and we let them participate, which means involve them as volunteers, give them responsibilities according to their own talents and age, and searching with them for solutions (equal voice as adults).

In the Province of Groningen there is an Expert team Young informal carers, wherein 8 local practitioners working in different municipalities collaborate with each other to raise more awareness on young informal care. Our aim: optimising the support for these young people according to their own needs. Some bottlenecks from professional point of view:

- professionals in the informal and in the formal care are focussing on the person who needs care, and therefore don't realise what the impact might be for young people living together with the person who request care;
- the group young care givers is relatively invisible, and they often want to stay rather invisible because they don't want to be different as their peers.

In 2016 we collaborated with several young carers in producing an in formative film about the impact on their daily lives. This film was launched in December 2016 for all practitioners and volunteers working with young people in the province of Groningen (50 practitioners with different backgrounds). Children form different ages and with different backgrounds just tell their story. All practitioners in the province of Groningen may use this film to raise awareness on young informal care (no costs, but on the condition that they develop a follow-up). It's our experience that professionals such as youth workers or coordinators of the local supporting system Centre for Youth and Family request the film. So, informal and formal care professionals are brought together and informed about young carers.

What are their needs according to our experience and scientific research in the Netherlands:

- leisure time for themselves;
- understanding for their living conditions by their teachers, friends etc. For example: don't assume immediately that a pupil didn't want to make his/her school assignment, but ask first why he/she didn't fulfil the assignment;
- some of the young care givers want contact with other peers living in a similar situation; others don't.
- It's important that interventions or support match the needs of a young carer, without a problematic stigmatise and with a focus on the whole family.

In September 2017 CMO STAMM and Humanitas (city of Groningen) invited young carers to participate in a 'Meeting Sphere-session' to hear their voice, this was our first co-creation session in the project In For Care. Unfortunate our second group scheduled in September 2017 in the northern part of the province of Groningen did not succeed, however we will try now to organise a second session in another part of the province (decided on the 10th of October 2017).

The outcome of the sessions will be used as input for Abertay. The Scottish partner in In For Care will develop a new digital tool to optimize the support of young carers reached out through the project In For Care. In 2018 they will present this tool, and we will test this tool in the province of Groningen.

Date:	23rd of September 2017
Amount of participants:	7 young carers aged between 15 – 22 years old
Location:	Humanitas city of Groningen
Hosts:	Janine Dijkema and Lisette Trinks (CMO STAMM)
Method:	Meeting Sphere session
An impressions also on:	https://nl-nl.facebook.com/HumanitasJMZpage/

2. About the method

A meeting sphere session is a digital way to collect views and opinions from people anonymously. Every person can answer questions on their own laptop (see pictures on the first page), and a facilitator collects all answers on a general and large screen. The method is a relative quick way to collect individual answers (anonymously), to transfer all answers in a ranking system, and presenting a result chart, which can be used for further debating or a brainstorm.

CMO STAMM provided a technical facilitator and a moderator. On 23rd of September 2017 the session was divided in 3 parts:

a) to what extent do you agree with 10 statements?
b) what is the best way to reach young care givers according to you?
c) what are your needs?

3. Outcome of theses

7 participants. Question: To what extent do you agree with the following 10 statements?

Label for scale value:

-2 = Totally Disagree -1 = Disagree 0 = Neutral 1 = Agree 2 = Totally agree

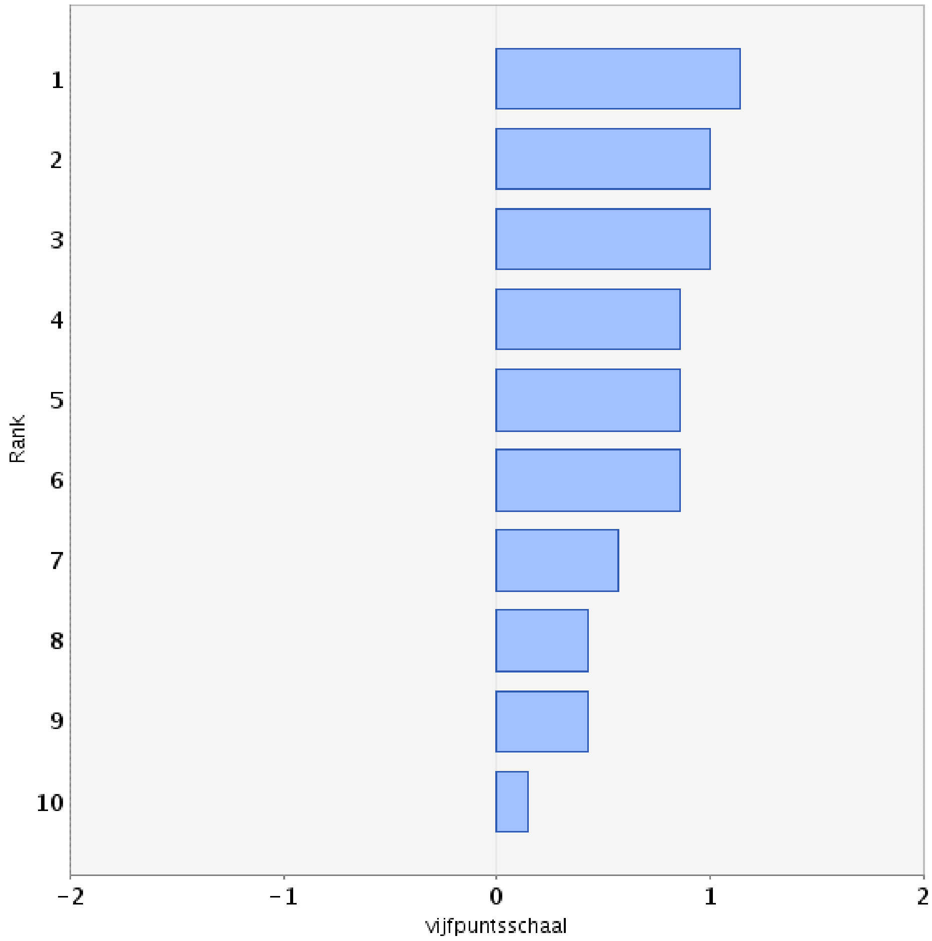
Theses (rating by numeric scale) sorted by Mean

Criterion "five poits scale". 10 items.

Scale: -2-2. Abstentions not permitted. List of items randomized.

Nr	Item	-2	-1	0	1	2	Mean	SD		n
1	A school must know which students are Young Care givers	0	0	2	2	3	1.14	0.21		7
2	It is important that school and other institutes take young care givers more into account	0	0	2	3	2	1.00	0.19		7
3	Many young people have no idea what the word “care giver/Mantelzorg” means	0	0	2	3	2	1.00	0.19		7
4	It is important that special activities are being organized for young carers	0	0	2	4	1	0.86	0.16		7
5	Young people should be more aware of the theme Young Carers	0	0	2	4	1	0.86	0.16		7
6	In general more awareness should be raised for the theme young carers	0	0	3	2	2	0.86	0.21		7
7	Every Young Carer must know that he/she is a care giver	0	0	5	0	2	0.57	0.23		7
8	Every Young Carer needs a listening ear outside the family	0	1	3	2	1	0.43	0.23		7
9	Many Young Carers are ashamed of their family situation	0	1	3	2	1	0.43	0.23		7
10	Many young carers don’t like being addressed as young carers	0	1	5	0	1	0.14	0.21		7

Results chart theses, five point scale



Remarks made by the young participants on the ten theses:

- A school must know if a pupil has problems at home, because this might be the reason why a pupil can't concentrate or less, and it might even affect the school grades. According to the participants almost no one at their school knows about the care giving situation. If they could have had more time for their assignments than it would not always be necessary to degrade a pupil to a lower level immediately after having received a bad grade.
- Young people often don't know what care giving means, even friends of the participants, although it's clear that these friends are care givers as well. Participants say that they have to explain their living situation very often.
- All participants belief that activities for young carers are necessary to relief their burden, because their mind-set is somewhere else during the activity (busy enjoying the activity instead of worrying about the family member).
- 2 participants belief it's important that young people are aware that they are a young care giver because than they will be aware of supporting systems around them, such as activities. One of the participants didn't speak about the family situation at first, through the activities of Humanitas this participant learned how to talk about this topic. Another participant had no

problems to talk about her autistic sister, but she had to coop with feelings of guilt because she knows that her sister doesn't like the fact that someone else talks about her (the sister).

- according to the participants very young carer needs a listening ear outside their family, and outside their friends. Friends often forget the home situation of the young carer and are not capable of taking him/her into account. Therefore it's nice if there is someone else to talk with.
- Many young carers don't like being addressed as young carers because they don't want to be different as their peers.

4. How to reach young carers according to participants

Participant instructions: There are many young caregivers. We would like these young people to know what's up for them. How do you think we can best achieve young caregivers? Name the five most important

We categorized the answers of the 7 participants.

- School (10)
  - **3. To talk about it at school**
  - **4. through school**
  - **6. through school**
  - **7. School**
  - **8. Make the word JMZ (young carers) more familiar**
  - **10. More familiarity with schools and other agencies**
  - **15. To tell mentors at school about it**
  - **16. Teachers have to know which students are caregivers**
  - **26. School websites**
  - **28. That people come at school and tell what it is and means**
- (Social)Media (15)
  - **1. Through teleplone**
  - **2. śocial media**
  - **5. billboard**
  - **11. Advertising on the internet**
  - **13. social media**
  - **17. Put up posters in at places where young carers come, like hospital**
  - **18. via folders to reach people**
  - **19. facebook**
  - **20. Through papers too involve eldery people who have also problems**
  - **21. Handing out folders in the city centre**
  - **22. tv advertising**
  - **24. Youtube with our vlogger Angelo (locale Vlogger)**
  - **25. Making a website where children and adults can sign up and read about it**
  - **27.Having a own paper. We can share it with other people**
  - **29. instagram**
- Social/personal contact (4)
  - **9. Other autorithies**
  - **12. Say to people on the street**
  - **14. Say it to friends and bring them over to meetings**
  - **23. Through care autorithies who comes at home (elker for example)**

According to the participating young carers there are 3 important categories to reach them: School (10), (Social) Media (14), and Social/Personal contact (5). For these young people the tool Whats App was mentioned as sufficient tool to reach them. Facebook is not sufficient; Instagram is more popular now. In order importance the ranking for these young people was: Social media, school, social/personal contact.

Prioriting Categories (rank order) sorted by Mean
Criterion: "important". Highest rank of 3 is given 3 points.
Ratings submitted: 7. List of items randomized.

Nr	Item	Mean	SD	
1	(Social)Media	2.14	0.28	
2	School	2.00	0.31	⚠
3	Social/personal contact	1.86	0.21	

5. What are your needs?

Number of participants: 7. **Participant instructions:** What do you need as Young Carer? More answers are possible. *All contributions are anonymous.*

● = Good idea (5 points per participant)

- **Not categorized (21)**
  - ●(1) **1. Listening ear**
  - **2. Find peace**
  - ●(2) **3. Listening ear**
  - ●(1) **4. recognition**
  - ●(1) **5. To tell my story**
  - **6.More understanding of people, like teachers**
  - ●(3) **7.that people take your situation into account (at school)**
  - ●(4) **8. activities**
  - ●(2) **9. Listening ear (buddy)**
  - ●(1) **10. Sometimes more peace at home**
  - ●(1) **11. peace**
  - ●(4) **12. Time for myself**
  - ●(7) **13. More understanding**
  - **14. To empty your head sometimes**
  - **15. To do something nice**
  - **16. Meet people (who have the same situation)**
  - **17. Activities for fun**
  - ●(6) **18. Activities for fun**
  - **19. Feeling that other people understand you**
  - **20. Feel that you are not the only one**

●(2) 21. To have a moment on your own

Remarks made by the young participants: they specifically need more understanding and time for fun activities (so that they can relax for a short moment).

6. Next steps

After this first co-creation session, we will organise a second one with young carers living in rural areas. Afterwards, we will:

- express the needs of these young people during a Work session (CMO Academy) on the 7th of December. Target group: policymakers at governments and organisation. Theme: supporting young carers with a family member with an addiction or psychical problems (0 – 23 years).
- express the needs of young carers to our partner in Abertay as input for the development of a tool whereby formal and informal networks around and with these young people will be developed (and tested in 2018).
- express the needs and bottlenecks for formal and informal networks around these young people in the country comparison for In For Care (including our working approach towards co-creation).