Business as (un)usual? The future of informal care networks in The Netherlands.

[Note for editorial board: this is the leader text]

This article presents the results of a survey amongst 100 stakeholders in and around the informal care sector in The Netherlands. The survey was conducted by SMO promovendi, an interdisciplinary group of young PhD researchers, who investigate the long term future of the Dutch informal care sector. The survey addresses the following questions: What does the informal care network look like today and what could it look like in the future? Who are the relevant players now, and who will become (more) relevant in the coming years? How and to what extent do these players collaborate?

In 2040, the ageing population in the Netherland will be reaching its highest point in 2040, which puts pressure on the current healthcare system. The prognosis for the year 2040: for every 10 working Dutch citizens, there will be 9.1 non-working Dutch citizens. Remarkably, despite the intention by policymakers to limit the role of government, the municipal government is perceived by our interviewees as the most important player in the informal care sector. Both now and in the future. Another finding is that networks in and around the informal care sector are currently highly fragmented. Moreover, a substantial number of actors in informal care networks are *unusual suspects*. These are actors, such as technology companies, online services providers, and citizen initiatives, which are often not fully recognized as (relevant) stakeholders in current research and policy making. However, these *unusual suspects* are expected to become even more important players in the informal care sector in the coming 25 years. In summary it can be said that future-proof informal care networks are highly dependent on strong connections between these *usual* and the *unusual suspects.*

[Note for editorial board: this is the article text]

In 2040, the ageing population in the Netherlands will reach its highest point: for every 10 working Dutch citizens there will be 9.1 non-working Dutch citizens. Assuming that elderly citizens require more healthcare than younger citizens, and that the rising healthcare costs are to be covered by the working population, this prognosis has major implications for the Dutch welfare state.[1] This is an important reason why Dutch public authorities have implemented the concept of the 'participation society' [*participatiesamenleving*] in their welfare policies.[2] It means that citizens are expected to take on more responsibilities and organize their own social and financial safety nets by activating their own informal network.[3] In other words: this relative shift of reliance on professional care to informal caregivers (by family, friends, neighbours, and/or volunteers) should help reduce costs and should provide a way to cope with the challenges impacting the welfare state.[4]

Despite this focus on informal care as a solution to the ageing population, there is still insufficient research on the long-term future of informal care networks.[5] SMO Promovendi, an interdisciplinary group of young PhD researchers interested in the long-term future of the informal care sector, explores this by asking the following questions: What does the informal care network look like today and what will it look like in the future? Who are the relevant players now, and who will become (more) relevant in the coming years? Do they collaborate, and if so: how and to what extent?

To answer these questions we interviewed 100 stakeholders in the informal care sector as part of an exploratory research on the long term future of the informal care sector in The Netherlands. Our interviewees are affiliated to the informal care sector in different ways, ranging from people working at hospitals, health insurance companies, and health technology companies, to people who provide informal care themselves. In this article we show that the informal care network is highly fragmented, and that it is necessary to build more and stronger network connections in order to create strong, future proof informal care networks.

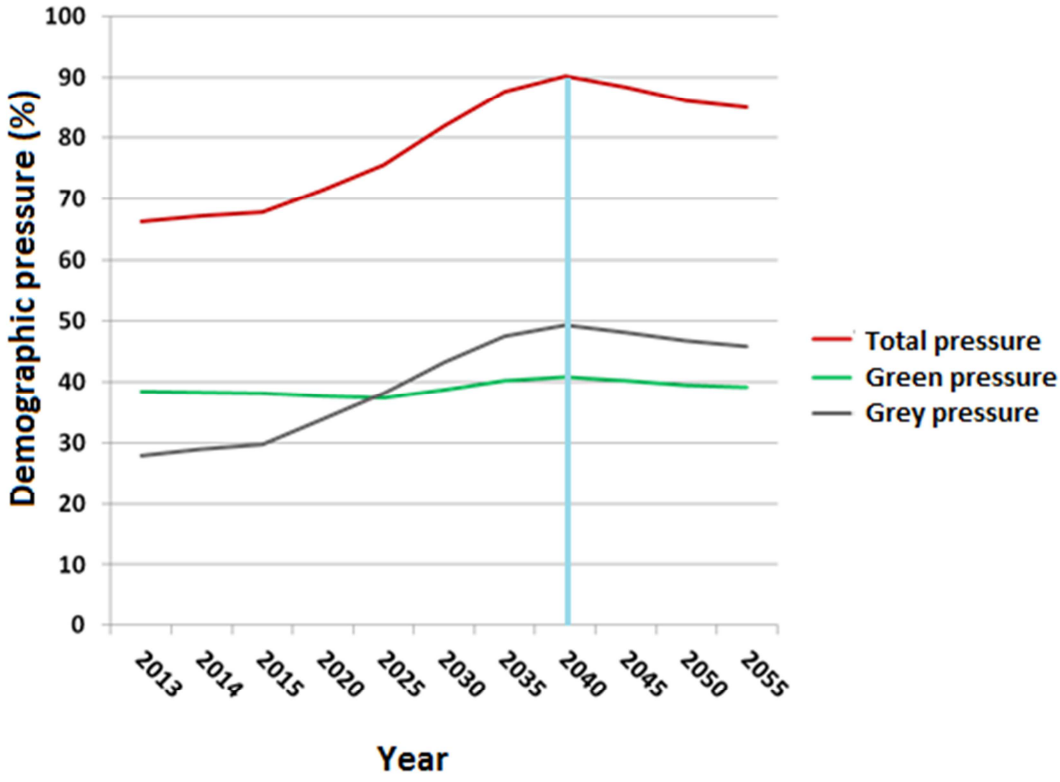

Figure 1: prognosis of demographic developments in The Netherlands between 2013 and 2055, with the 'ageing peak' in 2040. The green line indicates the ratio of people of 0-20 and 20-65 years old. The grey line shows the proportion between the number of people of >65 and 20-65 years old (source: CBS, Statistics Netherlands).[6]

The five main findings of our survey are as follows:

Currently…

1) … the municipal government is a key player in informal care networks;
2) … widespread and intensive collaboration between different types of actors in informal care networks is largely lacking;
3) ... half of the number of players in informal care networks are *unusual suspects*; actors which are not fully recognized in current research and policy making as (relevant) stakeholders.

In the future…

4) … the municipal government is expected to become an even more important player in the informal care sector, yet it remains unclear what type of role it will adopt;
5) … the *unusual suspects* are expected to play an increasingly important role in informal care networks.

1. Currently, the municipal government is a key player in informal care networks

To get an impression of the current configuration of the informal care network, we wanted to know how different stakeholders are connected to each other. The exchange of knowledge and information is generally regarded as an important element of network relations.[7] Therefore, we asked our respondents the following question: "What are the most important organizations which you exchange knowledge and information with regarding informal care?" From the answers we are able to form a top-4. The municipalities lead the list (9.69%), followed by knowledge and research institutions (8.65%), organizations of family and voluntary caregivers (together 8.31%), and welfare organizations (7.27%).

[plaatje invoegen: Exchange of knowledge and information]

In the survey we also incorporated a question on the level of dependence on other organizations to reach own organizational goals. Respondents indicate that they are first and foremost dependent on municipal governments (11%), followed by healthcare insurance companies (7%) and platforms and branch organizations (7%).

[plaatje invoegen Top-3 dependence]

Based on the data of these two questions, it seems that the municipality currently is a key player in the informal care network.

2. Currently, widespread and intensive collaboration between different types of actors in informal care networks is largely lacking

Exchanging knowledge and information is one way to collaborate, yet this does not immediately mean intensive collaboration between stakeholders. Developing policies together, however, can be regarded as an indicator of a more intensive form of collaboration.[8] When we take a look at how different stakeholders are working together in order to formulate policy, we see that they are rather reticent. The majority of our respondents indicate that they work independently when formulating policies (58.34%). Although there is no collective policy making, a large proportion of respondents from this group acknowledges that they do exchange knowledge and information with external parties about policy issues (18.06%). Or they collaborate with other actors with regards to executing policies (15.28%). In case of collective policy making (41.67%), a small minority says this occurs through a shared platform (5.56%). In addition, 26.39% of the respondents states that they cooperate with three or more parties in executing policies, but this happens in a rather isolated way through bilateral relations (mutual relations between two parties).

In summary it can be stated that there is some exchange of knowledge and information, but it does seem that widespread and intensive collaboration between different types of actors is largely lacking. All in all, these results convey an image of a rather fragmented informal care sector. We will come back to this matter in the sections below.

3. Currently, half of the number of players in informal care networks are *unusual suspects*; actors which are not fully recognized in current research and policy making as (relevant) stakeholders

In (the transition to) a 'participation society', a lot is expected and demanded from the informal care network. When assessing research and discussions on the informal care sector, we see that they tend to be about a fixed set of 'standard categories' of stakeholders. Examples of organizations that are commonly associated with informal care are welfare organizations, home care organizations, municipalities, family caregiver and voluntary work organizations (see for instance the list of the The Netherlands Institute for Social Research).[9] These *usual suspects* are mentioned in 39% of the cases when we asked our respondents about their dependence on other organizations to reach their own goals. However, in 50.5% of the cases, an organization or actor is mentioned that does *not* neatly fit in a 'standard category'. These *unusual suspects* are for example platforms and branch organizations (7%), financial institutions such as pension funds and banks (6%), knowledge institutions (5%), second

line healthcare (5%), and the private sector in general (5%). Many of our interviewees currently consider these *unusual suspects* to be essential players with regards to the informal care sector.

In other words: many actors and organizations in the informal care sector depend on stakeholders that are often left out in research and debates.[10] Thus, based on our research we suggest adding new categories of stakeholders, so that these can be taken into account in future research on informal care in The Netherlands (the list below contains the types of stakeholders that should also be incorporated, in addition to the already existing categories).

USUAL SUSPECTS	*UNUSUAL SUSPECTS*
Provincial governments	**Online services / platforms**
Transportation operators	**Healthcare technology companies**
Housing corporations	**Knowledge and research institutions**
Regional funding agencies	**Citizen initiatives (health care platforms and partnerships)**
Care assessment agency (CIZ)	**Public-private partnerships**
Home care organizations	**Second line healthcare (peripheral hospitals)**
Public Health Service (GGD)	**Third line healthcare (academic hospitals)**
Primary healthcare (GP; psychologist; physiotherapist)	**Respite care organizations and informal care organizations**
Nursing homes	**Supervisory authorities / independent advisory bodies**
Rehabilitation care facilities and mental health care facilities	**Consultation platforms / forums / networks / branch organizations**
Institutions for the disabled	**Private companies / industry**
City Bank, debt and income support centers	**Consultancy firms**
Welfare organizations	**Charities**

Comunity shelters, women's refuges	**Financial institutions (banks; pension funds; subsidy organizations)**
Youth care organizations	**Freelancers / independent contractors in healthcare**
Day care organizations	
Schools	
Police	
Religious instituions	
Family caregiver organizations	
Voluntary work organizations	
MEE Foundation	
Elderly councils	
Patient associations / client councils	
Local community platforms, local councils and village councils	
Healthcare insurers	
Municipal governments	

4. In the future, the municipal government is expected to become even more important in the informal care sector, yet it remains unclear what type of role it will assume

While the previous elements deal with current aspects of the informal care sector, it is also very important to look at the long-term future of informal care, due to the lack of attention thereof. According to our respondents, the following actors form the top-3 of actors that are expected to become increasingly important for the informal care sector in the coming 25 years: municipal governments (14%), followed by home care volunteer organizations (9.32%), and thirdly, healthcare technology companies (5.93%). The figure below adds two more actors and presents a top-5.

[plaatje invoegen infogram: Top-5 actors that will become more relevant in the future]

The fact that the municipality is mostly mentioned seems like a paradox when we look at the current policy measures in favor of the participation society wherein the government takes a less prominent role and stands back. This finding raises interesting questions about the design of the healthcare system and its networks. On the one hand we see budget cuts and a different role of government, on the other hand we see that the interviewed stakeholders expect municipalities to become more important in the future. This highlights the question of what the respondents expect of the government within the field of informal care and whether these expectations are justified. When it comes to informal care governance, will the government adopt a renounced structure or a coordinative structure? In other words: which governance model fits the future informal care network? These are questions which our research does not answer, yet these are important questions that should be considered when developing a sustainable care system.

5. In the future, the *unusual suspects* are expected to play an increasingly important role in informal care networks

Looking at the expected roles of *usual* and *unusual suspects* in the informal care network, respondents see the *unusual suspects* as important players in the future. Almost 48.73% of the given answers include *unusual suspects.* Within this category, health technology companies (5.93%), citizens' initiatives (4.24%) and knowledge institutions (3.81%) are mostly mentioned. It is important to point out that at this moment, there is no extensive collaboration between *usual* and *unusual suspects* in informal care (see point 3). But if we want more healthcare to be organized by the informal care network, more has to be done to establish durable relationships between these two categories. How these relationships will be set into place and what the opportunities are within the informal care network still remains unclear. Therefore, if we want a sustainable healthcare system which is largely dependent on informal care networks, it is of great importance to investigate the possibility of a flexible ('agile') care system that takes into account multiple possible future scenarios.

Conclusion

This survey study aims to contribute to research and debates about the future of the Dutch welfare state, bearing in mind the long-term demographic developments. Significant changes are needed in order to cope with the impact of the ageing population of the Dutch welfare state. Policymakers perceive a 'participation society' (in which the role of the state is reduced and citizens take up more societal responsibilities) as a solution to this challenge. Be that as it may, our research shows that municipal government is currently still perceived as the most important player in the informal care

sector and it is also expected to keep this position in the future. So, one of the key questions is how the role of government will develop in the future. Another notable finding is that networks in and around the informal care sector appear to be highly fragmented. While there is some exchange of knowledge and information, it does seem that widespread and intensive collaboration between different types of actors is largely lacking.

Furthermore, a substantial number of actors in informal care networks are often overlooked or excluded in current research and policy making on informal care. These actors, such as technology companies, citizen initiatives, and online services, are the proverbial *unusual suspects* and already play an important role. And according to this survey, these *unusual suspects* are expected to become even more important players in the informal care sector in the coming 25 years. Therefore, better connections between the *usual* and the more *unusual suspects* are necessary to create strong, future proof informal care networks.

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Participating partners

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End notes

[1] See: Lindenberg, J., T. Puvill, Y. Mysyuk, S. Biggs, H. Rolden, F. Engelaer, D. van Bodegom, and R. Westendorp (year unknown) From pyramid to skyscraper: sustainable policies for a new demographic reality, *Working paper from the Leyden Academy on Vitality and Ageing* (under review). In a similar fashion, numerous other studies and reports call for fundamental reforms in order to cope with this challenge. See for example the publication by The Netherlands Scientific Council for Government Policy (2006) *De verzorgingsstaat herwogen*, WRR report nr. 76. retrieved from www.wrr.nl.

[2] See for example the King's speech from 2013, or the policy letter from the minister of the Interior and Kingdom Relations, and the minister of Health, Welfare and Sport (2014).

[3] Informal care is care that is provided by a non-professional caregiver to someone in need of care. This can be a family member, a friend, an acquaintance, colleague, neighbour, other people in one's social network, or a volunteer. The level of care exceeds that of 'normal care' and should be provided for a period longer than three months for at least eight hours a week (*cf*. De Boer and De Klerk, 2013).

[4] This is also why there is more and more academic research on networks (i.e. Torenvlied 2012; Schalk *et al.* 2010; Voets and De Rynck, 2011; Geddes *et al*. 2007; Goldsmith and Eggers 2004; Hall and O'Toole 2004; O'Toole 1997).

[5] This in stark contrast with regard to the *formal* care sector, for which future forecasts and future scenarios are widely available. Think for instance about the many reports and studies conducted by various research institutes about the prognosis of (the rise of) healthcare costs, or the long term future of hospital care and other formal care institutions. For an overview of different examples of long range forecasts in the formal care sector, see Willemse (2014). Research in the domain of *informal* care are about *mantelzorg* (see for example Rekenkamer Amsterdam, 2014; Municipality of Breda, 2012), are about volunteering (Roza en Meijs, 2014), are conducted to provide policy advice (De Boer, 2007), or offer an international comparison of current developments of formal and informal care sectors (SCP, 2014).

[6] During the last century, life expectancy in The Netherlands has risen dramatically (Engelaer *et al.*2013; Oeppen en Vaupel, 2002). At the same time, however, the number of newborn babies has decreased (Coleman, 2006). This caused a drastic change in the composition of Dutch demography. Figure 1 shows the prognosis of

the different ‘demographic pressures’ between 2013 and 2055.

[7] See Fraanje and Herweijer (2013).

[8] See Citroni *et al*. (2012).

[9] See the study of The Netherlands Institute for Social Research into the social support act (*Wet maatschappelijke ondersteuning*) of 2007 (De Klerk, Gilsing and Timmermans, 2010).

[10] Previous research published in *The Hague Governance Quarterly* shows that network collaboration between different stakeholders within the domain of youth care, but especially within the domain of work & income, were not fully developed (Schalk *et al*., 2014). Collaboration was limited only to a small number of *usual suspects*. Regarding the domain of support services for people with disabilities (such as home care services), there were more network connections between the *usual suspects* and these were more ‘sunk in’ at the local level.