

SCIENCE,  
TECHNOLOGY &  
POLICY STUDIES  
STEPS WORKING  
PAPER SERIES

**The role of user-led  
regional innovation  
networks in shaping  
responsible innovation  
in eHealth**

Konrad, Kornelia; Schulze Greiving, Verena; Benneworth, Paul

NO. 2018/01, DECEMBER 2018



# **STePS Working Paper Series „Science, Technology & Policy Studies“**

## **The role of user-led regional innovation networks in shaping responsible innovation in eHealth**

Kornelia Konrad\*, Verena Schulze Greiving\*, Paul Benneworth†

\* - Science Technology & Policy Studies (STePS), University of Twente, the Netherlands.

† - Center for Higher Education Policy Studies (CHEPS), University of Twente, the Netherlands & NORCE, Kristiansand, Norway

**Editor: Stefan Kuhlmann**

### **Department of Science, Technology, and Policy Studies (STePS)**

Faculty Behavioural, Management and Social Sciences

University of Twente

P.O. Box 217

7500 AE Enschede, NL

[www.utwente.nl/en/bms/steps/](http://www.utwente.nl/en/bms/steps/)

ISSN: 2589-2150 (print)

ISSN: 2589-2169 (online)

### **Contact**

**Kornelia Konrad**

STePS, University of Twente

[k.e.konrad@utwente.nl](mailto:k.e.konrad@utwente.nl)

## TABLE OF CONTENTS

Abstract.....	4
2. Introduction .....	5
3. Conceptual Framework.....	6
The rise of responsible research & innovation as a governance process.....	6
The regional dimension to responsible research and innovation .....	7
4. Methodology and introduction to the case study .....	8
Study methodology.....	8
The actor landscape: CareConnect in the Dutch healthcare system.....	9
5. The CareConnect innovation process .....	11
The emergence of the CareConnect concept .....	11
The adaptation of existing software .....	12
Implementation and expansion .....	13
CareConnect operating in practice .....	14
Future Perspectives .....	15
6. Discussion: Anticipation, Inclusion, Reflexivity and Responsiveness in the innovation process of CareConnect.....	15
7. Conclusion.....	17
References .....	18

## **ABSTRACT**

In this chapter we study the innovation process of an eHealth application which emerged as a user-driven, local project. The eHealth application is based on a communication platform that creates a network around a particular patient who is in need of regular care and the different parties involved in the patient's care, and is aimed at facilitating the communication and coordination of this care network. We trace the innovation and implementation process, and explore, firstly, to which extent and in which form different dimensions of responsibility, such as anticipation, reflexivity, inclusiveness and responsiveness (Stilgoe et al., 2013) were present along the innovation process. Secondly, we consider if and how the regional and partly local, bottom up nature of the innovation network was conducive to enacting dimensions of responsibility.

## 1. INTRODUCTION

Technology is increasingly penetrating every sphere of human activity, including health and social care. Many expectations are being placed upon eHealth - healthcare practices delivered or supported by information and communication technologies – to deal with a range of challenges facing providing medical coverage to an aging population. The term eHealth has become an umbrella term for a wide spectrum of technologies that vary greatly in cost, autonomy and complexity. This ranges from simple online systems for managing doctor appointments and prescriptions, through technologies for sensing vital functions and monitoring a person's lifestyle and fitness level, to complex online communication and sensing platforms (Peeters et al., 2016; Kos et al., 2016). Technological interventions via eHealth are expected to deliver a range of goals, including increasing access to healthcare, improve quality, efficiency, safety and management of the delivered healthcare, reducing treatment costs, and augmenting patient self-management capacities for elderly and chronically ill patients (Dimitrova, 2013; Horn et al., 2016; Peeters et al., 2016)

However, policy-makers' enthusiastic promotion of eHealth has not matched its uptake and implementation in primary healthcare (Peeters et al., 2016). eHealth has been plagued by concerns regarding user safety, data security and privacy, alongside problems facing General Practitioners, whether practical (internet connectivity), expertise to run these systems, technological and financial constraints (Peeters et al., 2016). Embedding and aligning eHealth innovations with existing healthcare systems that are highly regulated and vary considerable between places has proven costly and complex, involving many different actor groups. Embedding and aligning actors is critical to implementing eHealth, demanding detailed consideration of short/ long-term consequences for involved actors' needs, expectations, and practices. In short, eHealth is a perfect domain to consider how innovations can be developed responsibly, including different stakeholders, anticipating and reflecting on potential implications, and using these insights in development and implementation. In particular, we are concerned with this volume's central question, namely who should be involved and in which form in the design, implementation and societal embedding of these emerging systems and practices.

In recent years, Responsible Research and Innovation (RRI) has emerged as a concept and governance approach aimed at aligning research and technological innovation with the needs and expectations of society (Owen et al., 2013; von Schomberg, 2013). Much attention has been paid to how researchers and innovation actors may become more aware of societal expectations, of different stakeholder groups, how they can anticipate on possible impacts and integrate these insights in the research and innovation processes. However, accounting for the perspectives of different stakeholder groups in a top-down manner can be challenging; alternatively, responsible practices can be enacted at a grass-roots level to allow local communities to shape the technologies that affect their lives and for which their implicit consent is given. In this chapter we therefore ask the research question what possibilities exist for local communities to contribute to responsible innovation processes? We do this by following the implementation of one specific eHealth application and exploring how far the underlying innovation processes have been responsible. We take a single case study of a eHealth system developed to coordinate communications between health professionals and patients, exploring, (i) how different dimensions of responsibility were present during the innovation process, and (ii) whether local bottom-up networks were conducive to enacting dimensions of responsibility.

## 2. CONCEPTUAL FRAMEWORK

Concepts of responsible research and innovation have arisen in part as a response to an increasing societal unease with the pace and consequences of technological change (Ribeiro et al., 2018). This unease can be linked to uncertainties about possible uses and impacts of emerging technologies, as well as the increasing complexity and interconnectivity of many (socio-)technical systems that exacerbate the difficulty to anticipate in advance the societal effects of particular interventions and facilitates second-order effects and uses beyond initial intentions. Above all is a sense that society has little control of these technologies allowing them to be implemented in undesirable ways. This is exemplified in the ongoing discussions regarding technology companies extracting value out of user data rather than purchased functionality, something clearly potentially problematic in health innovation.

### **The rise of responsible research & innovation as a governance process**

These challenges are by no means novel, although the intensity and awareness appears to have latterly increased. In the 1960s, there was interest in the democratisation of technology, particularly in north-western Europe, in developing tools and approaches that allowed communities to determine the conditions under which new technologies would be launched. In response to a number of crises of confidence around emerging food technologies, such as genetically modified food and growth hormones for dairy cattle, public understanding of science emerged to better inform publics about the reality of the risks and opportunities of new technology developments. The 'deficit' model ("the public would agree with technology if only they understood it") implicit in PUS was rapidly critiqued leading to more emphasis on co-creation and engagement with publics in research and innovation processes. Responsible research and innovation can therefore be seen as the latest in a lineage of concepts attempting to understand the ways in which societies value and consent to technologies, and to provide tools to shape technologies in socially appropriate and desirable ways, and to eventually contribute to stronger, smarter and more socially just societies. As Stilgoe et al. define it (2013),

*"Responsible innovation means taking care of the future through collective stewardship of science and innovation in the present." (p.1570)*

In this chapter, we recognise that the concept of Responsible Research and Innovation is an emerging one, and not fully conceptually stable, whilst having a number of portmanteau characteristics not fully worked through. RRI's basis is that 'responsibility' in an innovation emerges when societal actors have opportunities to enact repertoires that influence innovators' and immediate beneficiaries' choices in translating an idea into a launched product, service or technique. Stilgoe et al. (2013) suggested anticipation, reflexivity, inclusion and responsiveness as key dimensions of responsible innovation. Anticipation refers to techniques and practices, including systematic procedures, envisaging possible impacts, relevant developments and opportunities, including a reflection on what is deemed plausible, more or less likely, and potential alternatives. Anticipation helps making choices mindful of future uncertainties and implications, allowing different stakeholders to express their preferences regarding potential trade-offs. Reflexivity involves considering one's own role, activities, value system, pre-assumptions and framings, and reflecting on the consequences that one's innovation process choices have for others, including those with other world views and value systems. Inclusion involves mobilising forums where stakeholders and citizens come together and transform dialogue into meaningful influence choices made affecting their wellbeing. Responsiveness involves innovation products and processes actually being attuned to signals coming from different stakeholders, and emerging from considering the other three dimensions.

Stilgoe et al. (2013)'s propose a set of normative process characteristics that should supposedly facilitate research and innovation processes and eventually products that address different stakeholders' needs, values and concerns. They also exemplify various techniques and approaches applicable to research and innovation to foster anticipation, reflexivity, inclusion and responsiveness, such as foresight, codes of conduct, focus groups or value-sensitive design (Stilgoe et al., 2013: 1573). The "indicative techniques and approaches" listed are all structured processes and procedures dedicated to achieving goals in line with RRI's suggested dimensions. In our study, we apply an open understanding to the types of processes and practices conducive to realizing RRI's dimensions, including systematic, dedicated processes alongside practices which may or may not be geared towards realizing specific dimensions, but in practice contribute to them.

Stilgoe et al. (2013) also question whether consideration is necessary for the institutional conditions and innovation system' characteristics enabling or constraining the suggested RRI dimensions. This concern for understanding the conditions for RRI also emerges in Walhout et al. (2016)'s approach. They suggest to study processes of "RRI in the making" indicating there are many existing 'de-facto' practices, processes and governance arrangements in current research and innovation systems contributing to features of responsible innovation, irrespective of whether these explicitly refer to the concept. Furthermore, they demand further attention for how existing actor landscapes, governance arrangements and practices condition such RRI in the making (p.48). This perspective foregrounds the specific actor constellations, governance arrangements and practices within which innovation processes unfold. Thus, following Walhout et al. (2016), we contend more attention is required for different kinds of contexts where 'responsibility in the making' is evident.

### **The regional dimension to responsible research and innovation**

Innovations unfold within networks that embody their own internal governance processes; these networks are themselves embedded within a wider, more general landscape of regional, national and international (e.g. European-level) regulatory and administrative regimes. This is particularly apparent in the domain of health care where regulatory systems, organizations, practices and actor constellations differ clearly between countries, and sometimes sub-national territories. Furthermore, it has long been recognised that locality influences innovation processes (Alderman and Thwaites, 1992) and more latterly that an important role is played by the wider landscape of innovators, intermediaries, knowledge suppliers, policy-makers and skilled workers (Cooke, 2005).

The various kinds of proximity provided by co-location within a region facilitate innovating actors working together more easily with each other and complementary actors (Boschma, 2005). This ease of interaction facilitates repeated interactions, which may acquire network properties ('I can collaborate more easily with you because I know your partners') and systemic properties ('I can collaborate more easily with an unknown actor because they are located in the same region as me). Contemporary regional innovation literature has treated innovation neutrally or positively, rationalised as innovation raising total factor productivity, thereby contributing to regional growth and improving quality of life (Temple, 1998). What has received far less attention is the governance arrangements in these networks that arise when policy-makers take decisions that shape innovators' capacities to innovate.

It is possible to regard these regional innovation networks as potential sites where various repertoires of responsibility may play out, and thereby including local & regional concerns in decision-making, and where proximity and close ties may facilitate some of these repertoires. The use of regional innovation platforms or coalitions deciding on regional priorities could potentially provide an anticipatory space where local users can reflect on what wider development trends might mean for the implementation

of particular technologies in these local contexts. Reflexivity may correspond with the input of external expertise into regional innovation strategy development processes as recommended in standard strategy guides (e.g. Foray et al., 2012), while there may be a risk to take regional concerns and values for granted. Proximity and close ties may facilitate the inclusion of some types of stakeholders, and ease routes for feedback and eventually responsiveness. Still, efforts will still be necessary to ensure that any discursive processes involve people from a range of backgrounds and with a range of value systems. Responsiveness may furthermore emerge in the ways that policy-makers incentivise and reward innovators for pursuing innovations in ways that are reactive to local societal challenges, norms and value systems.

We argue that these regional innovation networks and communities could potentially provide a governance context where it is specifically possible to explore this issue raised by Walhout *et al.* of 'responsibility in the making'. We study the emergence and implementation of an eHealth platform, which emerged from a local network of health care actors in the Dutch province of Overijssel, and subsequently diffused along regional networks. The platform was created in response to an exogenous national health system change to ensure continuity and consistency of service provision for elderly vulnerable residents. Our study asks two operational research questions:

1. to what extent this innovation process exhibited characteristics of responsible innovation and
2. whether/ in which form local / regional communities and local / regional context were influential.

We refer to local communities, networks, and contexts if these extend predominantly in a municipality. We refer to regional networks and contexts, if they extend beyond a single municipality, but still build on immediate geographical proximity. We firstly present the innovation process of creating the eHealth portal, to subsequently examine how far regional innovators were able to enact repertoires of responsibility within the overall innovation process, and to which extent local and regional network and governance aspects were influential.

### **3. METHODOLOGY AND INTRODUCTION TO THE CASE STUDY**

#### **Study methodology**

In this chapter we are concerned with whether local and regional networks influence the exercise of responsibility repertoires in an eHealth innovation process. To answer this question, it is therefore necessary to gain relatively in-depth, detailed knowledge about one or more cases that provide sufficient information to make valid claims about the ways that responsibility repertoires have been exercised, and to relate that back to networks, interests and roles of local actors as well as specific characteristics of those places and settings. We have therefore chosen for a qualitative case study approach, to produce sufficient depth of understanding about that situation.

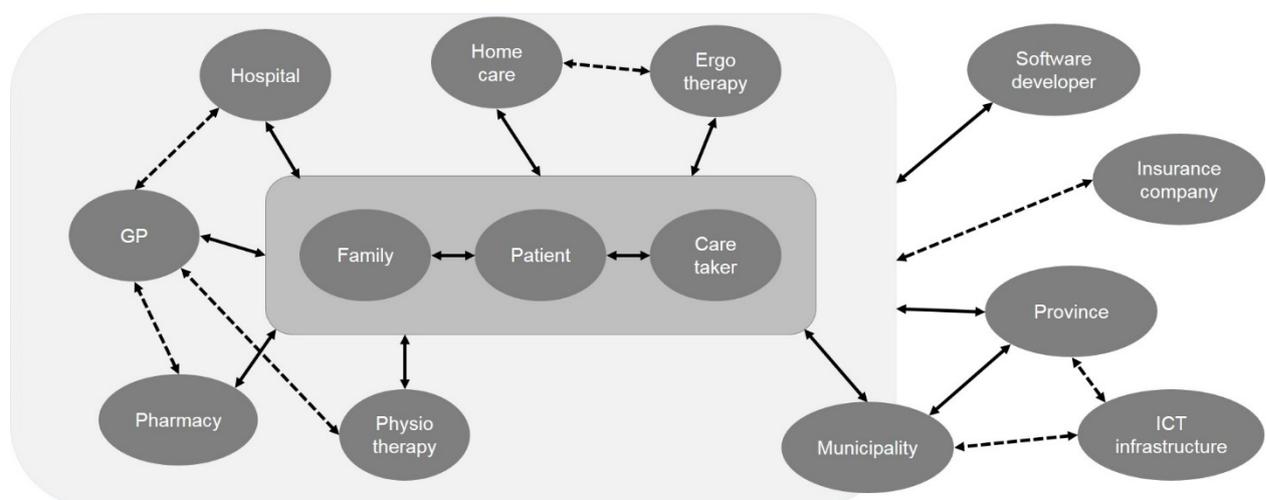
The case study, which we here refer pseudonymously to as CareConnect, builds on 10 semi-structured interviews which were carried out with key stakeholders in the development of the overall system in the summer of 2017. Seven of those directly related to CareConnect: a key innovator, a software developer, representatives of a municipality, an insurance company, and a nursing service, a general practitioner, and the project leader of a collaborative communication network in the mental health care sector. Additionally, three actors with expertise on the regional eHealth innovation system were interviewed. Interviews lasted about one to one and a half hours, were recorded and paraphrased. We analysed the data to explore how the innovation process unfolded, starting from the initial idea's

emergence, the first experimental implementation, through to the development into a full functioning system being upscaled to other localities.

### The actor landscape: CareConnect in the Dutch healthcare system

Organisationally, CareConnect was established in 2013 as an independent foundation. At the time of the research, around 400 organizations and institutions were actively involved in CareConnect with the platform operational in more than half of Overijssel Province's municipalities. CareConnect retains operational autonomy through financing via service reimbursement by municipalities and insurance companies. CareConnect is an online communication platform that creates a network around the client (patient), linking caregivers, family members and caretakers. This platform supports elderly people (and those with chronic diseases requiring regular help/ care) to live longer at home, by enabling better communication and better aligning different parties involved in a particular patient's care. CareConnect is embedded in a website where the patient or his/her caretaker can ask a question, which is directly send to other parties in the network who can answer this question in a short time. Parties in the network include pharmacies, homecare, physiotherapists, hospitals, general practitioners and the municipality (see Figure 1). Typical messages sent via CareConnect are updates on the used medication, orders at the pharmacy or questions about care. In addition, a care plan can be defined in the system as well. This way, the involved parties are updated about the care of a particular person and about the actions of other actors with the aim to increase the quality and efficiency of the care.

Figure 1 Actor network related to CareConnect



In the Netherlands, health insurance is accessible and obligatory for everyone. Since 2006, the Dutch health insurance consists of a basic package that covers general needs and which is determined by the ministry of public health, welfare and sport (VWS) after consulting the Dutch care institute (ZiN). Local policy makers, health professionals or intended users thus have little influence on what is covered by this basic health insurance. For specific services, the insurance company however can buy additional packages. Services are offered by caregivers who can make special deals with insurance companies. These deals lead to a high competition on the market between caregivers and insurance companies and offers some choice for insured persons. Next to this health insurance law, there is a specific law for societal support. This law regulates the support for people who are living at home but are dependent on regular care (e.g., help in the household, more protected living, mobility aids, re-integration, etc.). For this particular law, the municipality, instead of the government, is responsible for the funding

of care and takes over the role of the health insurer, selects services and makes contacts with caregivers as shown in the graphics (Janssen, 2014). In this way, local actors have an important role in defining how care services are provided. Furthermore, Dutch health insurers are regionally organized, with specific insurers playing a more central role in some regions than in others.

Figure 2 The Dutch Health Insurance System linking patients to care providers

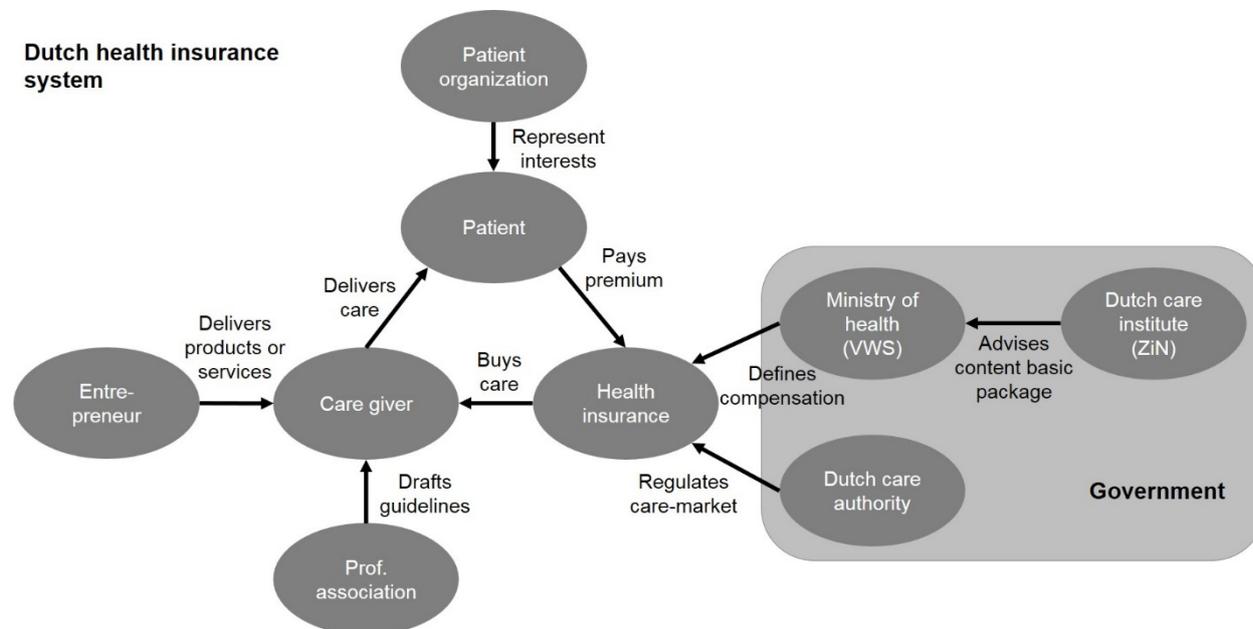
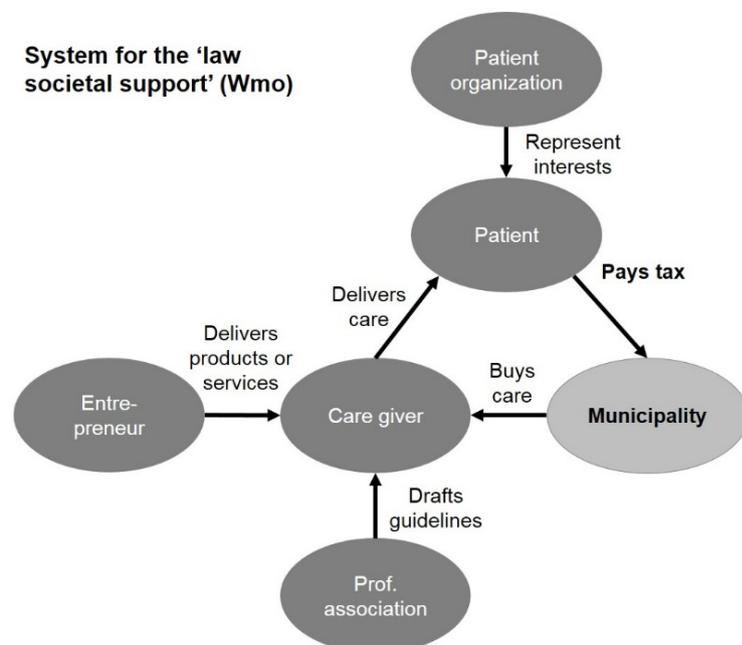


Figure 3 System introduced by the Law of Societal Support (WMO)



#### **4. THE CARECONNECT INNOVATION PROCESS**

In this section, we present an overview of the innovation journey through which CareConnect has unfolded. Firstly, the emergence of an idea for a platform along with a consensus for action is described. Secondly, we describe the guiding design principles and how user feedback was incorporated. Thirdly, we address the launch of the platform amongst the initial user group, followed by the subsequent operation and expansion amongst a number of wider users. This is not a fully sequential process, as development and adaptation continued throughout implementation and expansion. This section provides the basis for a subsequent analysis in which we look at the extent to which it was possible to observe responsible repertoires across these four stages, which in turn provides the basis upon which we can answer our operational question and contribute to the wider discussion within this volume as a whole.

##### **The emergence of the CareConnect concept**

The idea of CareConnect originated in a small village in the East of the Netherlands in response to a 2011/2012 change to Dutch health care regulations which raised the eligibility criteria for subsidized care home places for elderly residents. This reduced the demand for care home places across the Netherlands, and led to the closure of the care home in this village at the end of 2012. In the village, that care home had worked closely with a local health centre, which included general practitioners, nursing services, a physiotherapist and a pharmacy, who were able to coordinate with each other when providing more complex care services to care home residents. In late 2012, when the care home was to be closed, the carers discussed among themselves and with others what exactly was considered so difficult about having elderly clients staying longer at home. They concluded that the key problem was a lack of communication and coordination of the activities of the different parties involved in the care. In addition, the newly appointed carers at home, often relatives (the so-called 'mantelzorgers'), were typically not integrated well in the communications around the client and didn't know well whom to address in case of need. Actually, the family carers were usually more concerned and in need of communication than the clients themselves. Using email as a means of communication was considered too insecure and reaching others by phone too time-consuming to guarantee that patient-critical knowledge would be effectively shared. Thus, as a potential solution a digital communications platform was envisaged.

From the beginning, the initiators of the platform determined that the patients should be central to the system and own all their data. This decision was not the result of a long discussion or a systematic consultation with other stakeholders, but an approach that felt intuitively right to take, not only for reasons of ensuring the autonomy of the patients, but also due to functional-pragmatic considerations and to avoid to take sides with one particular party, potentially discouraging others from joining. Existing systems, for instance of GPs or physiotherapists, are directed at the needs and interests of the particular professional group, but are not oriented at facilitating the communication in a heterogeneous care network. Hence, they may include data that are not appropriate for sharing, or the information lacks elements necessary from the perspective of the patient or care network. However, many actors involved in discussions, such as further GPs, were also sceptical, fearing that the use of the system would be too time-consuming.

An independent foundation was established, CareConnect, which ensured that it remained organizationally separate from the other care providers who all had their own care systems. The establishment of the foundation was followed by creating a supervisory board with municipality representatives, regional nursing services in the region, carers and GPs to ensure the system fitted into the overall

Dutch health system. Furthermore, team members and advisors of the foundation mostly have a background in various roles in the care sector. The foundation received important support in the organizational and administrative set-up from a local resident providing his expertise on a voluntary basis. The foundation initially received a small subsidy from a regional care service organization, the local municipality and a local nursing service, to run a pilot in a part of the municipality. The subsidy also provided CareConnect with the aim to extend it to the whole municipality if the pilot turned out successful. During an official ceremony, CareConnect was opened by the municipality Director, with the first client present.

### **The adaptation of existing software**

Once the idea for a digital platform had emerged, the consortium sought for an off-the-shelf solution that could meet their various requirements. The foundation searched on the internet for potential tools, and identified a platform that had already been developed by a software developer who had himself provided care for his disabled daughter and had learned about communication struggles between carers and care professionals experienced by friends. His platform provided a solution to this problem by allowing messaging services between the client, family and care providers, and by providing the possibility to set up a care plan for the client as a more systematic way to communicate and coordinate the necessary care actions.

Initially, CareConnect used the software in its original form, but it soon became apparent that clients and the nursing service used the system differently. Examples of these deviations included clients uploading daily blood sugar curves in the system, or nursing services placing pharmacy orders via the system. Following the actual use of the system and the feedback of the users, the system was adapted to facilitate those interactions.

A key decision forum in the evolution of the platform related to the choice of which functionalities would be added to the system. CareConnect advocates strictly a 'less is more' approach, allowing a new client record to be opened simply by linking a patient, carer and GP in the system. This record can later be augmented by creating a care plan or by adding additional users, allowing the system to be set in place as quickly as possible. This approach differed clearly from those of former clients of the software developer, who first required to enter a complete care plan, which however often prolonged the process of getting a new client account operational. Simplicity in the system design, however, was not easy to achieve, as the system has to be accessible for very diverse user groups. Elderly clients and their carers often have a low digital literacy and little knowledge of the medical terms, whilst young health professionals by contrast tended to have a high technological affinity and a professional medical education. This implied that the software development required much more effort in designing for simplicity than for additional functionalities.

In the development process, the project director of the foundation served as an intermediary between the software developer and the users. When potential improvements were proposed on the basis of user feedback, they were incorporated into a concept version that was then piloted and tested in a number of locations. If the modifications were positively evaluated after the pilot, they were translated into a software update that was released to all users. Furthermore, problems were regularly identified at the annual user meeting bringing together all people that coordinate the implementation of the CareConnect system (e.g., district nurses, GPs, or employees of CareConnect). These meetings were arranged to encourage more people to provide feedback to the Director-Developer group, as well as to allow users to exchange experiences and facilitate peer learning.

Prior to CareConnect becoming a client of the software, the software had been acquired by a company who was already in the market of healthcare software and systems, and thus better equipped than the developer to handle the juridical and commercial aspects. In the meantime, all sales and first line customer support is handled by CareConnect, as they are better able to facilitate the local cooperation and communications necessary between the various parties involved when setting up a new application of CareConnect than the developer or the company owning the software. The software developer is mainly contacted for specific technical problems and development, and the health care systems company advises on the growth strategy and provides support through their network of contacts with GPs and pharmacies.

### **Implementation and expansion**

The implementation of CareConnect started in 2013/14 with a pilot in the above mentioned village, and it was then broadened to the municipality the village is part of. These first steps were supported by a small subsidy from a local care organization, the municipality and a nursing service. Since 2015 CareConnect has subsequently spread to more than the half of the municipalities in the province, and to a smaller degree beyond. Initially this was supported by a public research grant, investigating the conditions for upscaling, and the benefits and costs for the different user groups, with the further effect of raising broader attention for CareConnect. Already the first expansion step from the village to the municipality built on the support of local networks. Initially there was scepticism amongst GPs in the municipality, but the system was championed by the local out-of-hours practice who had encountered CareConnect in the pilot phase. These doctors were sufficiently positive about their experiences and the benefits for care as to persuade other providers to be willing to do it. The kinds of positive experiences that were related by this out-of-hours group related to the fact that it was regarded as saving both time on an ongoing basis as well as demanding less time to be implemented. The vector for the spread of these messages was not formal, but rather came through the different employments that a number of these doctors had, working in other practices or policlinics alongside their out-of-hours work. Certainly, there was little active promotion by the foundation of the platform, although they did find themselves responding to requests for more information from people in other regions who had heard (positively) of the system and sought to introduce it in their municipality.

One of the key decisions taken with the roll-out and expansion of the product to other municipalities outside its 'home location' is the agreement of a reimbursement compact. As explained above (see section 3.2), according to the Dutch health care system the reimbursement of health services for elderly in need of regular care is partly determined by the regionally organized health insurances and partly by the local municipalities. A health insurance involved early on, decided in 2015 to allow for reimbursement of costs for the system via the GPs, and considers further possibilities involving the care personnel, whereas municipalities support the CareConnect foundation directly. As a key condition for starting the implementation of the system, CareConnect, the municipalities and health insurers required that all relevant parties in a local care network would be willing to communicate with each other and join the platform. Similar to the initial experience, it was the GPs who often were decisive in this process, because when GPs either actively promoted or were passively willing to use the platform then it proved easier to get other parties involved. Respondents noted that this related to a particular feature of the region, with its strongly rural character, which was that the GPs often had a dominant position in the care network and often accompany a patient and whole families throughout their live. Alongside GPs, nursing services were also important drivers for the implementation, and in those villages where the nursing service was very busy or short staffed then implementation typically progressed very slowly.

## CareConnect operating in practice

We will now consider the extent to which the system has been able to live up to the initial intentions and promise to create a client-centred care system that leads to better patient treatment by facilitating better communication between multiple care providers involved in providing care for a particular patient. In this section, we consider the ways that the interests of three groups have become implemented through the innovation process, namely those responsible for organizing and financing the provision of care (municipalities and health insurers), health care professionals, and the recipients of care (clients and their families).

*Municipalities and health insurances* regarded the system as very positive. Health insurances have been extremely worried about the implications of a growing elderly population (along with limited opportunities for premium growth) since their creation in 2006, recognizing the time intensiveness of elderly care and thus the additional costs this will bring for GP-led care and the need for cooperation. However, the care sector has been relatively poor at proposing innovative solutions, and one of the features of CareConnect that attracted the interest and attention of one health insurer was precisely this feature, as an innovation emerging from health care practitioners and addressing this problem. The strong position of the client respectively family members was considered as a very strong point as well, as it ensures the legitimate interests of the clients, and facilitates the acceptability of the system.

In a similar way, one of the municipalities that joined CareConnect later on, was specifically attracted by the fact that the initiative was supported bottom-up by the GPs and promised to facilitate the communication with this group that was considered as highly important for the care process. In addition, family carers were very positive about the system, a group of carers municipalities had become responsible for after a change of law in 2007. The municipality appreciated in particular the effect it had on ensuring care quality and reducing the need for emergency respite care or cover to fill or repair short-term health problems arising from communication problems. According to the head of the responsible department, some employees of the municipality complained about not being included in the CareConnect network by some of the clients, whilst she considered this choice as a legitimate right of the patients and saw the task with the municipality to convince clients of the usefulness of adding the municipality to the network where necessary.

In terms of the *health care professionals*, the system embodied a number of their wishes. GPs found that it helped to alleviate work pressure, as they could complete reporting off-site and at times which were suitable to them, it saved time in communicating with pharmacies, and it allowed to substitute some face-to-face and phone encounters which could be handled more efficiently via CareConnect. The system is also perceived as improving the quality of care, as it facilitates consultation with a specialist before finalizing a report and because it allows a more intense communication with the family carers, which was only scarce before. It was, however, also mentioned that setting up the system and convincing all parties to participate is a time-intensive task. Finally, the interviewed GP experienced strong differences in the interest to engage with ICT-based innovations between the different regionally organized care organizations.

Likewise, the nurses found the system useful. The nurses certainly appreciated the fact that they were better informed prior to arriving at patients, that it facilitated handling situations which required action within short time, that it facilitates the communication exchange between different people involved in the care network who do not meet regularly. In particular, the contact with family members

typically arriving when the professional cares are gone, has improved. Before, communication happened mainly in moments of crisis, whereas now family carers can share their observations and concerns. The system furthermore helps to avoid the loss of information, which may happen if only transmitted via different parties, and to receive information from pharmacies and doctors when needed.

The *care recipients'* experience of CareConnect was somewhat patchier, because they tended to consult the system less regularly, for instance at moments of change or uncertainty. However, the system did bring changes that were appreciated by the clients, such as allowing them to follow the communications between the care providers (who were the more active system users). The system also provided a mechanism to allow clients to empower their next-of-kin to also track care provision; previously, client family were dependent on a client's memory and comprehension of what they had been told to relate their treatment back to their family whilst the CareConnect system allowed clients to empower their family to view communications and their care plan. An additional advantage that emerged was that it allowed for small issues to be communicated between nurses, clients and families; these were important in situations such as identifying at an early stage behavioural irregularities around medicine intake or physical activity that might otherwise be unnoticed and which if necessary can then be translated into a notification for the attention of the GP. As a limiting factor, a part of the clients do not use computers, but can still be involved in a more passive mode when carers show the messages they send or the communications which have occurred. There is, however, also a group of potential clients that is not interested in using the system.

### **Future Perspectives**

There are a number of possible developments of the platform which are explored or discussed as possible future directions. Currently, new types of settings beyond elderly care are being explored and tested, such as psychiatric care and youth care, each posing different challenges, requirements and questions, as the typical structure of the care networks and the types of cares differs. In the case of youth care, it is furthermore not evident if the system should be organized around the child or the family. In addition, making the system more accessible for particular user groups, as low literate people, adding new types of parties as hospitals, and integrating additional features as video calling or the integration of measuring devices are explored as well. It has been stressed in the interviews that an extension of functionalities may not so much be a technical challenge, but that it requires careful considerations on the use value for CareConnect, with a view on the current and future situations. As a general vision, most interviewees envisage the availability of an independent communication platform for the Netherlands, which may, but doesn't have to be based on the CareConnect platform. In order to enable this, standards for data exchange, involvement of larger parties, and a clear system for reimbursements are considered as conducive.

## **5. DISCUSSION: ANTICIPATION, INCLUSION, REFLEXIVITY AND RESPONSIVENESS IN THE INNOVATION PROCESS OF CARECONNECT**

In this section, we discuss if and in which form characteristics of responsible innovation are visible in the way the innovation process of CareConnect unfolded and in the way the system has been designed and used. In addition, we trace if and how the local / regional nature of the innovation network and the regional characteristics of the institutional environment have been influential.

At first sight, the strength of the innovation process of CareConnect is characterized by the ability to respond to and make use of imminent challenges and opportunities, rather than by explicit considerations about potential mid- to long-term future developments and impacts. An element of short-term

anticipation is however visible from the very beginning. At the time the local impact of the national policy changes became apparent, the initiators of CareConnect did not wait to cope with the new situation until it occurred, but envisaged what would be the challenges and what might be ways to cope with them. Along the innovation journey, more systematic forms of anticipation have been triggered, still focusing on imminent challenges ahead, as the study conducted after the launch in the first municipality, investigating the conditions for upscaling the system, and the costs and benefits the platform was likely to entail for different user groups. At the time of writing, multiple directions for the further development are envisaged, also these perspectives emanating along the journey rather than being the result of dedicated anticipatory procedures. Actually, one of the interviewees advocated a more systematic approach towards reflecting on future possibilities. Thus, we conclude that overall in the CareConnect innovation process anticipation played a moderate role; at the same time, we see that the anticipatory elements which did occur, clearly informed the development process, in this way constituting an element of responsiveness.

Reflexivity is arguably the most ambiguous of the dimensions, entailing multiple meanings (Stilgoe et al. 2013: 1571). Reflexivity in the form of awareness and reflection on the values guiding activities is clearly visible in the reflection on the core values guiding the design and organizational embedding of the platform, such as autonomy of the clients and patient- respectively user-centeredness. Interviewees stressed that also this consideration emanated rather intuitively from the initializing discussions among the core group of initiators, and not from a structured deliberative process. It should be noted, that the considerations for deciding to put these values central and the way how these were translated in concrete technical and organizational decisions, built on a deep and varied knowledge of the use field incorporated by the core actors of CareConnect. Related to these core guiding values, we clearly observe mindfulness for the implications the platform has for different parties. Throughout the development and implementation process, dedicated attempts at learning about the perspectives of the different user groups have been undertaken. Furthermore, we find multiple instances that actors consider critically their own role and priorities, for instances when developers embrace the less-is-more approach in the design, or when municipality or health insurance employees embrace the principle of autonomy of clients, even if this may result in a certain loss of control for them. Overall, throughout the interviews we see that actors reflect on the effects the system has on own and others practices. We argue that the close-knit, local and regional networks which carry the development and use of CareConnect are conducive for these forms of reflexivity, in particular for the more intuitive and interaction-based elements, as it facilitates becoming aware of the multiplicity of perspectives, values, roles and conditions of and impacts for different actors.

The RRI dimensions which are most evident in our case, are inclusion and responsiveness. CareConnect can be considered as a case of a user-led innovation (Truffer, 2003; von Hippel, 2005). Actors who represent multiple – though not all - of the future user groups are the initiators of the platform, responding to what is perceived as a pressing societal and professional problem. Some of the initiators took over a key role in the foundation which carries CareConnect, and further actors rooted in the care sector joined the foundation in different roles. This bottom-up process developed further along networks characterized by proximity, co-location and organizational ties, in this way mobilizing a broader set of actors. Dedicated procedures for generating user feedback, particularly from those groups, who are less likely to provide feedback proactively, and to allow for social learning among users are organized as well. While our methodological approach based on a small number of interviews can only provide limited or indirect evidence of the broader appreciation of CareConnect among the multitude of involved actors, it appears that precisely this inclusive and bottom-up approach is

appreciated by many of the involved stakeholders and considered as an essential success factor, even by actors for whom this may imply a certain loss of control or increased complexity, as the already mentioned representatives of the municipality and health insurance. The expansion along existing social networks is also considered as important for creating interest among potential users that would else be sceptical about the use value of the platform.

Responsiveness is apparent as well, with the design having been adjusted continuously in line with the feedback received for use experience and feedback. It has been stressed by some of the interviewees that the platform is considered as rather flexible in allowing for adjustments. It has furthermore been highlighted that another important element in enabling the uptake and use of the system has been the fact that support for the system has been provided by the CareConnect foundation with its experience in the world of care, and close links to the different user groups, rather than by the owners of the software. The stepwise, bottom-up process, proceeding along comparatively small steps, with a focus on creating immediate use value rather than complex functionalities has furthermore facilitated quick implementation and learning processes.

## **6. CONCLUSION**

To summarize, we see all four RRI dimensions put forward by Stilgoe et al. (2013) embodied in the innovation journey of CareConnect, though arguably to different degrees. It became also apparent that the regional, and partly local, structure of the actor networks carrying the innovation, implementation and use of CareConnect played a decisive role, both for the success of the system in a more general sense and the way elements of anticipation, reflexivity, inclusion and responsiveness featured in the process. At first sight, it may seem almost evident that a user-initiated innovation process shows a certain inclusiveness; still, we would like to highlight that inclusiveness was not confined to those participating in the innovation network, but that active steps were taken to involve relevant stakeholders more broadly. On the other hand, a stronger anticipatory approach, which for instance envisages in a structured way how further developments in the health care system could change the conditions for CareConnect to develop and discuss perspectives for new forms of usage, could possibly add relevant perspectives. While somewhat speculative, it may well be that precisely the focus on imminent needs and local conditions may have been conducive to taking such a perspective.

The regional and partly local character of most of the actors and networks involved in our case has been largely a result of the strong regional elements in the organization of the Dutch health care system, such as the responsibility of local municipalities for home care, the regional distribution of health insurers and the local and regional organization of a number of health services. It would be an interesting point for comparison, which is however beyond the scope of this paper, to study to which extent and in which form regional innovation networks and processes unfold in differently structured health care systems.

Overall, we can conclude that the strong role of local bottom-up networks firmly rooted in the world of care facilitated the design and implementation of this eHealth application by targeting the application to user needs, mobilizing networks in the use domain throughout the implementation process, by allowing for flexible, rather agile experimentation and user involvement. In principle, one might expect that this approach should also enable adjustment to local variety, even though this has been less apparent in the process so far. In our case, the need for variety and tailoring the system to different conditions has predominantly been perceived with respect to applying the system to different care situations beyond elderly care.

We would furthermore like to highlight that the innovative potential of CareConnect is not so much linked to technical innovation, but rather to the societal challenge or problem, which has been identified as primarily an issue of coordination and information exchange, and the active societal embedding of the platform in use networks, practices and institutional frameworks. This is not to say that the specific technical design has not been an essential and complex issue, but complexity resided more in finding an appropriate design in an iterative process, rather than building on an innovative technology per se. This seems important to highlight against the background that despite the turn to societal challenges as a major reference point in research and innovation policy, it is still common, also within the context of RRI, to approach an innovation process with a focus on a particular technology or a focus on innovative technology (Kuhlmann and Rip, 2014). It seems remarkable, that when asked about future perspectives of CareConnect, a number of the interviewees pointed to the vision of a communication platform available on a national level, irrespective of the underlying technical system.

Finally, we would like to point out that the potential of improving health care by means of eHealth resides in this case in the societal organization of networks of patients and carers, rather than in monitoring and 'improving' individual patients or specific bodily functions of patients, a perspective which seems to be more common in many of the currently proliferating eHealth applications. We suggest that these social and organizational aspects of health care deserve broader attention in the development of eHealth.

## REFERENCES

- Alderman N and Thwaites AT. (1992) The Regional Dimension to the adoption of Innovations. In: Townroe P and Martin R (eds) *Regional Development in the 1990s: The UK in Transition*. London: Jessica Kingsley.
- Boschma R. (2005) Proximity and Innovation: A Critical Assessment. *Regional Studies* 39: 61-74.
- Cooke P. (2005) Regionally asymmetric knowledge capabilities and open innovation: Exploring 'Globalisation 2' - A new model of industry organisation. *Regionalization of Innovation Policy* 34: 1128-1149.
- Dimitrova R. (2013) Growth in the intersection of eHealth and active and healthy ageing. *Technology and Health Care* 21: 169-172.
- Foray D, Goddard J, Goenaga Beldarrain X, Landabaso M, McCann P, Morgan K, Nauwelaers C and Ortega-Argilés R. (2012) Guide to Research and Innovation Strategies for Smart Specialisation Strategies. Sevilla: JRC. Available online at [http://ec.europa.eu/regional\\_policy/sources/docgener/presenta/smart\\_specialisation/smart\\_ris3\\_2012.pdf](http://ec.europa.eu/regional_policy/sources/docgener/presenta/smart_specialisation/smart_ris3_2012.pdf)
- Horn G, Eliassen F, Taherkordi A, et al. (2016) An architecture for using commodity devices and smart phones in health systems. *2016 IEEE Symposium on Computers and Communication (ISCC)*. 255-260.
- Janssen R. (2014) Innovatieroutes in de zorg. netwerkbijeenkomst 'decentraliseren=innoveren', Utrecht: Zorg voor innoveren.
- Kos A, Sedlar U and Pustisek M. (2016) Research and Innovation in ICT With Examples in the Field of eHealth and Wellbeing. In: Loshkovska S and Koceski S (eds) *Ict Innovations 2015: Emerging Technologies for Better Living*. Berlin: Springer-Verlag Berlin, 1-10.

- Kuhlmann S and Rip A. (2014) The challenge of addressing Grand Challenges. A think piece on how innovation can be driven towards the “Grand Challenges” as defined under the prospective European Union Framework Programme Horizon 2020. Report to the European Research and Innovation Area Board (ERIAB).
- Peeters JM, Krijgsman JW, Brabers AE, et al. (2016) Use and Uptake of eHealth in General Practice: A Cross-Sectional Survey and Focus Group Study Among Health Care Users and General Practitioners. *JMIR Medical Informatics* 4: e11.
- Ribeiro B, Bengtsson L, Benneworth P, Bühner S, Castro-Martínez E, Hansen M, Jarmai K, Lindner R, Olmos-Peñuela J, Ott C, Shapira P. (2018) Introducing the dilemma of societal alignment for inclusive and responsible research and innovation. *Journal of Responsible Innovation* 5: 316-331.
- Owen R, Stilgoe J, Macnaghten P, Gorman M, Fisher E, Guston D. (2013) A Framework for Responsible Innovation. In: Owen R, Bessant J, Heintz M (ed) *Responsible innovation*. West Sussex, United Kingdom: John Wiley & Sons, Ltd.
- Stilgoe J, Owen R and Macnaghten P. (2013) Developing a framework for responsible innovation. *Research Policy* 42: 1568-1580.
- Temple J. (1998) The new growth evidence. *Journal of Economic Literature* 37: 112-156.
- Truffer B. (2003) User-led Innovation Processes: The Development of Professional Car Sharing by Environmentally Concerned Citizens. *Innovation: The European Journal of Social Science Research* 16: 139-154.
- von Hippel E. (2005) *Democratizing Innovation*, Cambridge: MIT Press.
- von Schomberg R. (2013) A Vision of Responsible Research and Innovation. *Responsible Innovation*. John Wiley & Sons, Ltd, 51-74.
- Walhout B, Kuhlmann S, Ordóñez Matamoros G, et al. (2016) ResAGoraA Concepts and Approach. In: Lindner R, Kuhlmann S, Randles S, et al. (eds) *Navigating towards Shared Responsibility*. Karlsruhe.

UNIVERSITEIT TWENTE  
Drienerlolaan 5  
7522 NB Enschede

Postbus 217  
7500 AE Enschede

053 489 9111  
info@utwente.nl



**UNIVERSITY OF TWENTE.**