Towards learning healthcare systems

Collaboration and boundary crossing in research and practice

Debbie Vermond

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Towards learning healthcare systems

Collaboration and boundary crossing in research and practice

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Samenwerking en grensoverbrugging in onderzoek en praktijk

(met een samenvatting in het Nederlands)

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1

General introduction

Balancing perspectives

Already from Hippocrates' time providing the best possible care for every patient has been a principle concept of medicine[1]. Nowadays, this is frequently referred to as evidence based medicine (EBM): providing the best possible care for each individual patient via optimal integration of *scientific evidence* with *clinical expertise* and the *patient's experience* (**Figure 1**)[2]. Yet, at the same time the complex balance between scientific evidence, clinical expertise and the patient's experience makes healthcare systems prone to inefficiency and fragmentation[3]. Given the increasing prevalence of chronic conditions such as type 2 diabetes, chronic obstructive pulmonary disease and cancer, this is all the more pressing. Organizational and disciplinary boundaries must be crossed between researchers providing scientific evidence, healthcare professionals building their clinical expertise on that, and patients experiencing the outcome.

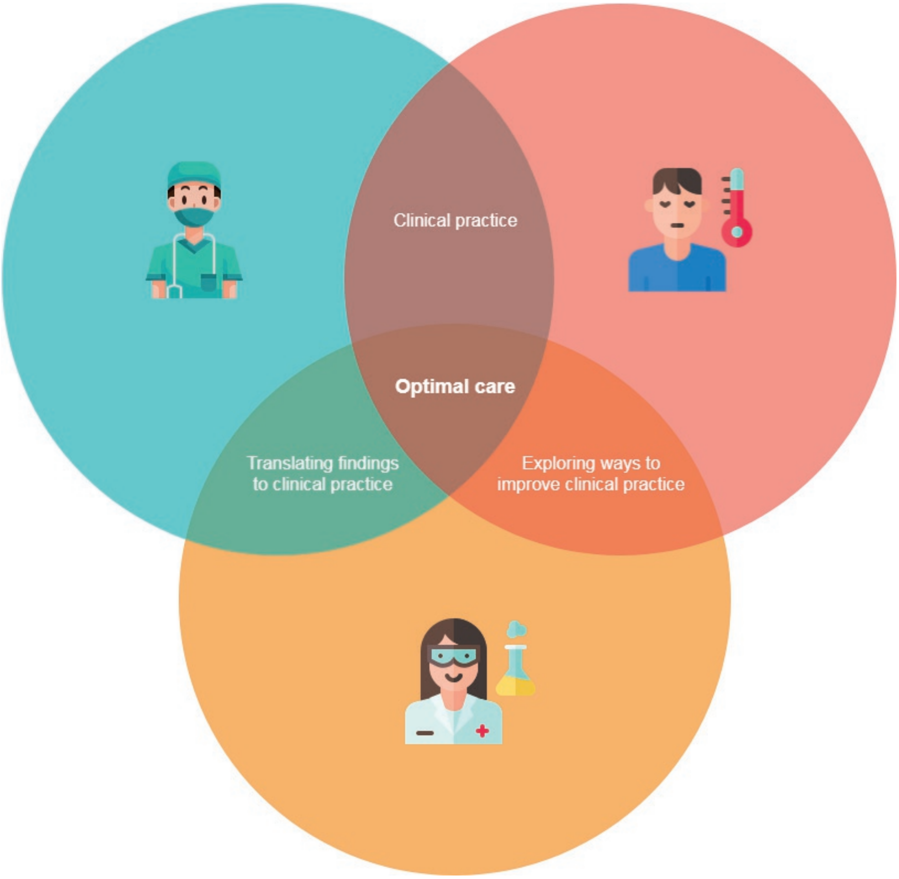


Figure 1 Healthcare systems integrating the knowledge and expertise of researchers, healthcare professionals and patients to establish optimal patient care.

Today's healthcare would benefit from a system that effectively manages to integrate these three perspectives while continuously reflecting on how they may support each other to improve patient care: a learning health care system[4]. Learning healthcare systems (LHS) are systems in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in (research on) care processes, relevant stakeholders active in all elements, and new knowledge captured as an integral by-product of care experiences. Researchers, healthcare professionals and patients all contribute to LHS provided their contribution is equally valued.

So far, however, the impact of quantitative research is dominant. Since the introduction of EBM in the early nineties some major criticisms have appeared in the scientific literature: EBM would be 'reactionary' and 'exclusive'[5]. The key criticism is that it reduces medicine to statistical interpretation and excludes reasoning, critical thinking and experiences[6,7]. In daily clinical practice, healthcare professionals and patients are not engaged in a quantifiable science, but in a real life rational, interpretative and interactive process. The question is how we may bring the two perspectives of EBM and daily clinical practice closer together.

Science in Transition

It is to be expected that many societal developments such as changing demography, financial cutbacks, and a polarized political debate will only increase the pressure to transform current healthcare in a more balanced and dynamic LHS. The founding fathers of Science in Transition (2013) address the critiques on EBM by stating that we need new checks and balances in our (scientific) system and align it better with societal health demands[8-10]. Currently, progress in science within LHS is mainly measured by individual researcher parameters of esteem such as number of publications, citations, awards won, and funding acquired. It measures and quantifies. Yet, the value of researchers who cross their boundaries and collaborate can't be captured by a quantitative expression of quality or impact[11].

Doing science is not about achieving individual excellence – at least not primarily. So much of doing science is about the people you are doing it with, and for. In other words: societal investment in science can only be legitimated by the progress it brings for the individuals in society[12].

> *"Doing science that makes a difference for society is about listening and collaborating."*
> - Frank Miedema

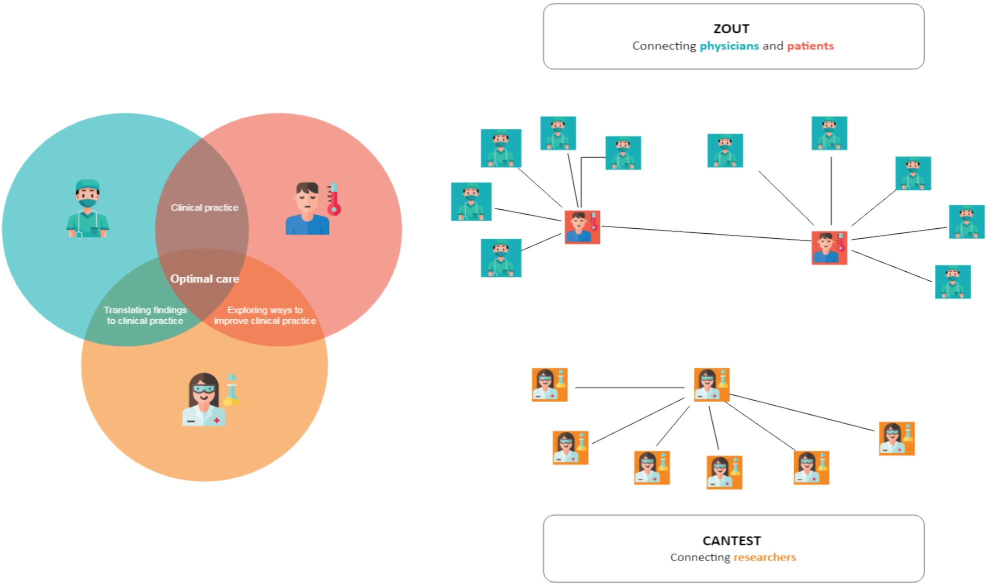


Figure 2 Two initiatives facilitating collaboration within learning healthcare systems . The first (above) focuses on understanding and connecting healthcare professionals and patients; the second (focuses on understanding and connecting researchers.

Patient centred medicine

We need new checks and balances to integrate more qualitative insights in our LHS – not the least on how patients value medicine and how they determine the context in which research and clinical practice takes place. Approximately 20 years after the emergence of EBM, a new movement called patient centred medicine (PCM) arose[13]. PCM is primarily known for putting the patient at the centre of our system[14]. Despite the fact that EBM and PCM are often perceived as two conflicting movements, they are related as two sides of the same coin[15]. It is difficult to see how one of them reaches its full potential without the other as a continuous reference: PCM should not be practiced without being based on the best available evidence and the ultimate mission of EBM is to translate evidence to the individual patient[16]. Therefore, continuing to approach researchers, healthcare professionals and patients as separated stakeholders blocks the path towards establishing the highest attainable standard of care. Equally understanding and appreciating the perspectives of researchers, healthcare professionals ánd patients is a first step towards bringing EBM and PCM closer together and stimulating the development of LHS.

Boundary crossing in learning health care systems

Researchers, healthcare professionals and patients, all from their own perspective, contribute to LHS. More insight into how they reinforce each other, by looking at their interaction and understanding their unique perspectives, may help learning healthcare systems to move forward. From their respective perspectives, how do they connect with each other, within as well as across their boundaries? Cross-boundary collaboration within LHS is the central theme in this thesis: between researchers (**Figure 2** – top right) and between professionals and patients (**Figure 2** – bottom right). We explore each of the two subthemes by using an example as a case study: the CanTest network and the ZOUT project.

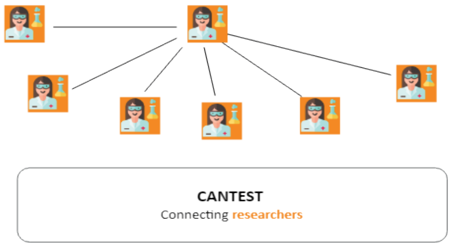
Understanding perspectives

Optimizing research Collaboration; the example of the CanTest network

The benefits of research collaboration are widely known, arguing that generating scientific evidence is most efficient when researchers with expert knowledge in different areas collaborate on a project of overlapping interest[17-19]. The overlap allows for common ground, while the respective areas of expertise cover a greater "surface area" of the possible knowledge brought to bear on a specific question. Whether it is across areas within a department, across (international) institutions, or across disciplines, there is much to be gained by bridging the divide between isolated research groups[20].

But how do researchers connect and develop?

And how may we facilitate that in the future?



The CanTest collaborative is an ongoing, international collaborative research network on optimizing cancer diagnosis in primary care, funded by Cancer Research UK (CRUK). It facilitates international collaboration in diagnostic cancer research in primary care through (1) promoting joint research, (2) providing various trainings and (3) boosting academic exchange. The network organizes the annual CanTest International School, sponsors (inter) national research collaboration and actively stimulates researcher-to-researcher interactions. The aim of CanTest closely aligns with the rationale of a LHS: integrating research efforts, while appreciating different perspectives, to build capacity for continuous quality improvement for individual patients. CanTest has developed as an educational research school in which senior researchers help junior researchers to develop themselves to reach independence.

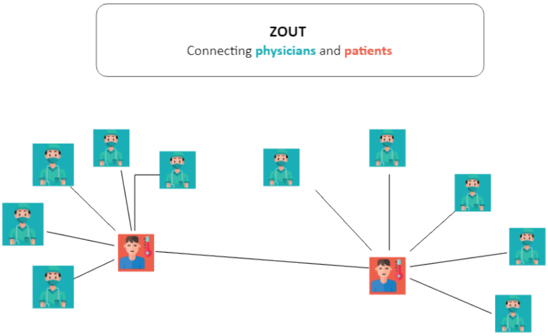
The CanTest network provides a platform for collaboration and learning amongst researchers, and accordingly offers the perfect opportunity to better understand how researchers connect, collaborate and develop in networks to move LHS forward.

Integrating the patient's and healthcare professional's perspective: the example of the ZOUT project

Bringing together the healthcare professional and patient perspective is essential to improve clinical practice[21,22]. "Learning together to work together", as Chesters *et al.* put it, is seen as increasingly important in the complex world of health care delivery[23]. Interprofessional collaboration and learning are terms that have grown in popularity and relevance over the years. Starting the dialogue between healthcare professionals from different backgrounds, while involving patients in that conversation, is increasingly considered necessary to move LHS forward[24-26].

But how do healthcare professionals and patients connect and develop?

And how may we facilitate that in the future?



ZOUT is the acronym for "The right care the right place in Utrecht". It is a project aiming to develop processes to evaluate and discuss clinical practice amongst healthcare professionals and patients in the region of Utrecht. Regularly, postgraduate learning meetings only consist of healthcare professionals, who have the tendency to discuss care plans and set goals solely from the professional perspective[27]. In order to actively integrate the patient's perspective and stimulate patient participation, the patient should join these meetings[28]. Accordingly, central aspects in this project are interprofessional learning and the (active) role of patients in healthcare. As such, the purpose of ZOUT relates closely to the philosophy of the LHS: integrating perspectives while appreciating differences, to work towards effective and innovative care that consistently adds to providing the right care at the right place.

ZOUT provides the tools to understand the roles of healthcare professionals and patients in clinical practice, and maps the dialogue between them as a fundament for LHS.

Bridging perspectives

> *"Once you see the boundaries of your environment, they are no longer the boundaries of your environment."*
>
> – Marshall McLuhan

From understanding the role of the three parties involved in LHS, we move to what may be considered the overarching goal: bridging their perspectives. As a common thread throughout the research in this thesis, the notion of boundary crossing will be used to understand how more intense and innovative collaboration between researchers, healthcare professionals and patients can increase their impact and speed up the development of LHS[29-31]. Boundary crossing is a theoretical concept defined as the efforts made by individuals or groups at boundaries to establish or restore continuity in action or interaction across practices. Boundary-crossing strategies include the use of boundary objects and brokers: objects or persons that can bring two different working practices together – or to bridge the gap between different working practices[32-34].

Boundary crossing is often considered in the study of learning and development across organizations or workplaces as it targets the connections and learning opportunities of situations in which different individuals or groups need to collaborate[35,36]. Accordingly, this thesis will build on the notion of boundary crossing to understand the collaboration and learning between researchers, healthcare professionals and patients. In our methods, we zoom in on the different levels at which their perspectives need to be balanced, understood and bridged. The individual, group and network level (units of analysis) represent the development of our LHS, in all its facets, as closely as possible.

Methodological concepts to analyse collaboration: SNA and CHAT

Individuals, groups and networks differ primarily in their level of aggregation: from no aggregation (individuals) to more (groups) and more aggregation (networks)[37]. Groups often have formal lines of authority and roles, and are often structured around particular tasks or activities. Networks rather connect distributed individuals; individuals in networks may be connected to other individuals either directly or indirectly and may not even be aware of all those who form part of the wider network[38].

Where CanTest primarily focuses on individual researchers in networks, ZOUT zooms in on individual healthcare professionals and patients in groups. Relationships between individuals in networks can efficiently be studied using the method of Social Network Analysis (SNA). So for CanTest we used SNA to structure the research network in terms of nodes (individual researchers) and the ties, edges or links (relationships or interactions) that connected them[39].

SNA is not a formal or unitary theory. It is rather a loose federation of approaches that all aim to study the relationships between actors and the patterns of those relationships[40,41]. SNA helps to describe the role of individuals within a network while it also enables a collective-level analysis[42]. As such, it is a helpful way to study how researchers cross their boundaries and connect with other researchers. When looking at networks, it is important to realize that, like photographs, they are snapshots of how these networks have formed. Capturing networks at different points in time allows for simulation of network change and provides insight into how or why different people connect to each other[43]. Do researchers, for example, create new connections because of their individual characteristics, or in response to new opportunities from their network?

A well-suited analytic foundation to explore how and why individuals in groups establish relationships (ZOUT), is the Cultural Historical Activity Theory. This theory is often used to understand the boundary crossing within and between groups. In essence, Cultural Historical Activity Theory (CHAT) places groups in context: it emphasizes the different contexts at different sides of the boundary to promote mutual understanding[44]. To help this process, groups are portrayed as so-called ‘activity systems’. An activity system refers to the entire context in which interaction occurs, including the individuals involved, but also the problems they are addressing, the desired outcomes, the artefacts that mediate their interaction (e.g., forms of communication, tools, technologies), the rules that shape their behaviour (including provider policies and shared policies), the communities in which they operate (including the social environment), and the ways in which the work is distributed among them. One way to utilize CHAT is to identify structural tensions (contradictions) within and between different activity systems (e.g. from healthcare professionals and patients), as there is emerging evidence that it is by overcoming contradictions that development occurs[45-47].

In comparison to SNA, CHAT allows for a deeper understanding of how and why collaboration and learning develops. On the other hand, in comparison to CHAT, SNA allows for a deeper understanding of how and why individuals are connected and how knowledge flows between them. Throughout this thesis, a network perspective (SNA) will be used to study how CanTest gives substance to the Science in Transition movement by connecting researchers, while a group perspective (CHAT) is used to explore how ZOUT embraces a patient centred approach in connecting healthcare professionals and patients.

Outline of this thesis

The aim of this thesis was to contribute to the development of Learning Healthcare Systems by studying collaboration and boundary crossing between stakeholders. We used different analytical perspectives to provide insight and tools to help LHS move forward.

The learning healthcare system part I: Collaboration in research

To better understand research collaboration, our first interest is to explore how researchers create connections and expand their connections in networks. Who do they connect with, how, and why? In **Chapter 2** we describe the evolution and co-evolution of the CanTest network from academic social connections to research collaborations. The value and impact of creating these connections and initiating collaborations is discussed in **Chapter 3**. How does network development adds to the development of individual researchers?

The learning healthcare system part II: Collaboration in clinical practice

In part two we assess how the process of interprofessional and patient collaboration unfolds in clinical practice. This ranges from collecting and linking routine care data to reveal how the system works, to questioning the people behind the data, and bringing them together. A roadmap to collect and link routine care data from general practitioners and medical specialists is presented in **Chapter 4**. From this transmural care database capturing the collaborative behaviour of healthcare professionals, we move to capturing the collaborative behaviour of patients. **Chapter 5** explores the role of patients in establishing care continuity. Finally, we introduce an integrated approach towards collaboration across contexts in **Chapter 6**, where healthcare professionals and patients discuss clinical practice together.

Understanding how people collaborate within LHS is a first step towards realizing change. Although change efforts are often difficult in established systems, we have witnessed the disruptive force of change of our healthcare systems during the Covid-19 pandemic. What can we learn from this period, and how can we leverage the new and improved collaborative practice? In **Chapter 7** we explore how our healthcare system was able to so radically and rapidly change.

In **Chapter 8**, considerations on improving collaboration within LHS are explored, illustrated by the work presented in this thesis on understanding collaboration from both a network and group perspective, and supplemented by the work on realizing change.

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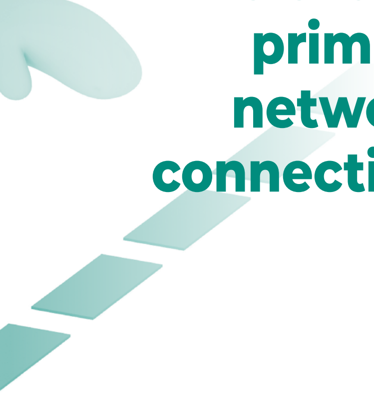

The evolution and co-evolution of a primary care cancer research network: from academic social connection to research collaboration

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Abstract

Academic networks are expected to enhance scientific collaboration and thereby increase research outputs. However, little is known about whether and how the initial steps of getting to know other researchers translates into effective collaborations. In this paper, we investigate the evolution and co-evolution of an academic social network and a collaborative research network (using co-authorship as a proxy measure of the latter), and simultaneously examine the effect of individual researcher characteristics (e.g. gender, seniority or workplace) on their evolving relationships. We used longitudinal data from an international network in primary care cancer research: the CanTest Collaborative (CanTest). Surveys were distributed amongst CanTest researchers to map who knows who (the 'academic social network'). Co-authorship relations were derived from Scopus (the 'collaborative network'). Stochastic actor-oriented models were employed to investigate the evolution and co-evolution of both networks. Visualizing the development of the CanTest network revealed that researchers within CanTest get to know each other quickly and also start collaborating over time (evolution of the academic social network and collaborative network respectively). Results point to a stable and solid academic social network that is particularly encouraging towards more junior researchers; yet differing for male and female researchers (the effect of individual researcher characteristics). Moreover, although the academic social network and the research collaborations do not grow at the same pace, the benefit of creating academic social relationships to stimulate effective research collaboration is clearly demonstrated (co-evolution of both networks).

Introduction

Until recently, efforts to improve diagnostic accuracy for cancer were based on enlarging capacity in secondary care. This can lead to longer access times, higher costs and greater risks of error and delay[1]. Increasingly, primary care is regarded as the optimal setting to initiate health care improvements[2]. Timely and adequate diagnosis in primary care is vital for improving diagnostic accuracy in cancer, and therefore more research capacity focused on diagnostic testing in the primary care setting is required[3]. Scientific progress may particularly benefit from multi-disciplinary collaborations between researchers, across different research institutes and countries, as well as across the entire continuum from test development to clinical implementation. Indeed, collaboration between researchers is known to increase scientific productivity and the quality of research compared to individual research efforts[4-7].

Across academic disciplines, networks are developing to connect researchers worldwide and underpin scientific progress[8-10]. In these networks, researchers establish relationships through a variety of social-academic activities and platforms. The CanTest Collaborative (CanTest) is a clear example of such a network and serves as case study for this manuscript (https://cantest.org). CanTest was formally constituted in 2017 with funding from Cancer Research UK , building upon several individual collaborations between senior primary care cancer researchers in its participating centres. It comprises nice academic centres in five different countries and across three continents; individual researchers from 10 other academic centres are also involved by invitation[11]. Its main objectives are to increase capacity and sustainability of research into early detection and diagnosis of cancer – recruiting and supporting the development of a new generation of researchers to establish themselves – and to assess and evaluate approaches to improving early detection and diagnosis of cancer in primary care (the work carried out in this study will shed insight in how CanTest has addressed the first objective). By spanning disciplinary, organisational and national boundaries, academic social networks (networks of researchers connected by informal interactions and social relationships) such as CanTest can capture the social substrate of scientific productivity and promote interactions among researchers that facilitate the sharing of meaning and completion of their tasks[12]. Ultimately, through increased social support and better access to critical resources, membership and active participation in such networks is considered to enhance collaboration and scientific outputs (such as joint projects and co-authorship), as well as the individual development of more junior researchers[7,13,14].

However, academic social networks do not necessarily translate into effective collaborative research networks (networks of researchers connected by collaboration); individual characteristics of researchers in networks are considered to play a significant role in their development[15-17]. Two characteristics of researchers that have been thoroughly studied are gender and seniority[18,19]. Females are more often reported to appreciate relationships and the process of collaboration, whereas actual collaborative activity is reported to be higher for males[20-22]. Comparably, where junior researchers are more likely to increase their number of academic social relationships to gain access to new resources for collaboration, senior researchers may be more reserved in creating new relationships because they have many collaborative relationships already[23-25]. Yet, studies that link academic social relationships and collaboration – to explore the effect of gender and seniority in academic social relationships and collaboration in more detail – are lacking.

Another factor that may play a prominent role in explaining the development of networks is individual network positions[26,27]. Along with the individual characteristics of researchers, their positions in relation to each other may steer their relationships. In research on academic collaboration, the logic of network embeddedness (friends of friends tending to become friends) and preferential attachment (individuals seeking out relationships preferentially with others who are popular already) has demonstrated that researchers tend to connect with the connections-of-their-connections and with well-connected researchers[28-31]. Yet, again, while existing studies looking at the impact of network positions on collaboration have provided a variety of important insights, we still have limited understanding of how individual positions and individual characteristics relate to each other while conditioning academic relationships and collaboration.

Although there is increased financial support for academic networking, there is little published evidence that this type of research collaboration actually accelerates research output[32,33]. Previous research studies have explored separately the development of academic relationships and collaboration (the separate 'evolution' of two networks). Yet, although academic interaction is considered an important factor in collaboration, we still have limited understanding of how the expansion of academic social networks translates into effective research collaboration, i.e. to what extent one leads to the other (the 'co-evolution' of two networks)[34,35]. **Figure 1** visualizes both processes, with the evolution aspect depicted on the vertical axis (solid box) and co-evolution on the horizontal axis (outline box). Evolution is about how a network changes over time, whereas co-evolution describes how changes in one network impact the other network (i.e. how academic social relationships influences collaboration). The objectives of this study are to increase knowledge on (1) the evolution of academic social networks and collaborative networks, (2) the co-evolution of academic social networks and collaborative networks, and (3) the influence of individual researcher characteristics and their network positions on evolution and co-evolution.

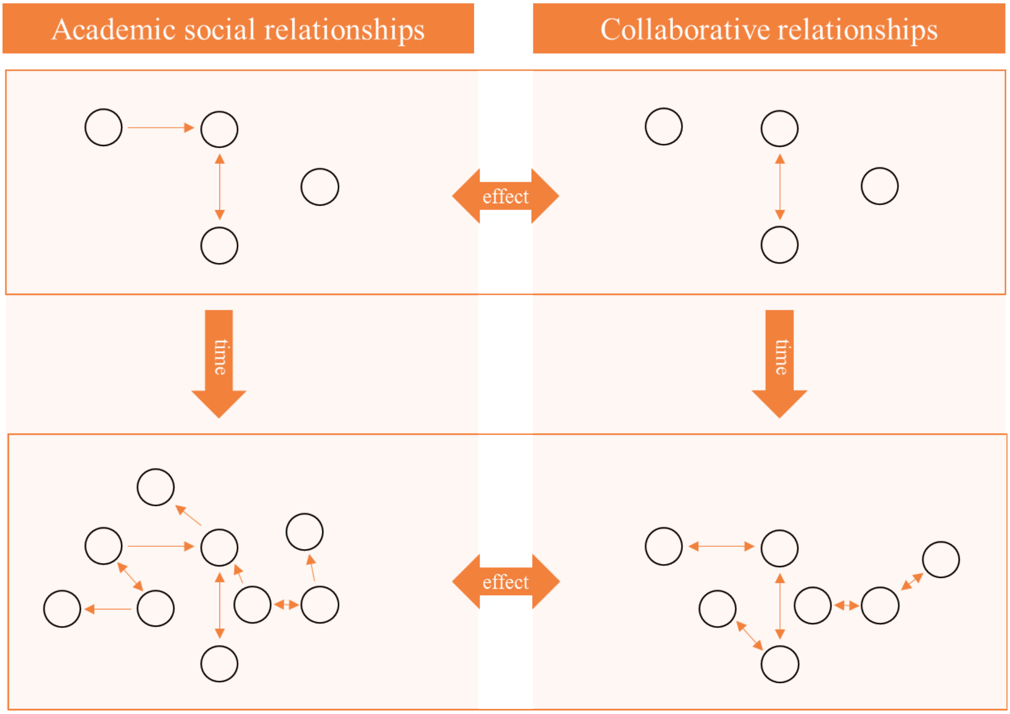

Figure 1 Evolution and co-evolution of the academic social network and collaborative network. The vertical axis shows the evolution of the academic social network and the collaborative network, with two different snapshots in time (top and bottom) for the purpose of illustration. The horizontal axis shows the co-evolution of both networks.

Methods

Context

To assess the transition of academic social networks into effective research collaborations, we collected longitudinal network data from an ongoing, international network in primary care cancer research - CanTest. This international research collaborative facilitates international collaboration in primary care cancer research through (1) promoting joint research, (2) providing various training opportunities and (3) boosting academic exchange. CanTest organizes numerous networking events, the most notable of which is the annual CanTest International School. During this week-long residential activity, researchers in the network are brought together to exchange knowledge and experiences. Two of these International Schools were held in 2018 and 2019. Due to the impact of the coronavirus epidemic, virtual networking events took the place of the 2020 School, and a virtual School was held in 2021. While some network interactions are formally organized, other more spontaneous forms of interaction are also encouraged[36].

Data

Data on the academic social relationships between all 60 researchers in the CanTest network at the time of this study were collected through online surveys at three points in time:

- T0 - Point of entry to CanTest (April 2017/2018) – before the first International School
- T1 - April 2019 – just before the second International School
- T2 - June 2019 – just after the second International School.

Informed consent was obtained at the start of each survey (**Appendix 1**). As is customary in network research, one matrix question, or roster, explored the relationships between researchers in the CanTest network ('academic family') at these three points in time: "*Which other members of the CanTest family do you know professionally, and how did/do you connect and interact with them?*"[37]. From this roster of all researchers in the network, researchers were asked to identify other researchers with whom they were connected. For each of the 60 researchers in the network, they selected either 'yes' or 'no' for any of four possible ways of being connected: (1) exchanged emails or WhatsApp messages, (2) met at a conference, workshop, meeting or training event, (3) involved in the same individual project, and (4) working at the same institution or department (**Appendix 1**). For the analysis, it was necessary to aggregate the results; we did so by recoding any number of ways of being connected (either by 1, 2, 3 or 4 items) as 1 = "yes" and recoding the absence of any connection as 0 = "no". The network was directed so a distinction was made between outgoing relationships (i knows j) and incoming relationships (j knows i). Moreover, since "knowing someone" is assumed to be irreversible, existing relationships could not be terminated but were necessarily maintained. Prior to sending the network survey to the CanTest researchers, the face validity of the survey was assessed by a group of native speakers. They reviewed the survey for ease of use and understanding. All of them deemed the network survey to be acceptable.

We used co-authorship as a proxy measure for research collaboration. Data on co-authorship relations between researchers in the network were derived from Scopus. The time windows searched for the three points in time were 'up to entry to CanTest' (T0), 2018 (T1) and 2019 (T2). Scopus was searched by Author Identifiers and relevant key words (TITLE-ABS-KEY(cancer* OR tumour* OR tumor* OR neoplasm* OR malignan* OR carcinoma* OR sarcoma* OR melanoma* OR lesion* OR leukaemia OR leukemia OR lymphoma* OR myeloma*)) to collect data on the co-authorship relationships between the researchers in the network. Using the Author Identifiers, we corrected for different spelling of researcher names, and merged them when one researcher turned out to have different Author Identifiers. Thereafter, data were entered in a matrix of size 60x60, each row and column representing a researcher. A co-authorship relation between two researchers was coded as 1 = "yes", and absence of a co-authorship relation was coded as 0 = "no". The co-authorship network was non-directed (connections between co-authoring researchers are by definition reciprocal) so there is no distinction between incoming and outgoing relationships. **Box 1** summarizes how the definitions of the academic social network and the collaborative network were operationalised.

The CanTest member register was consulted to collect individual researcher characteristics. Gender was treated as a constant, categorical actor covariate and was coded as either 0 = "female" or 1 = "male". Data on researcher seniority was treated as a changing, categorical actor covariate and was coded as 0 = "junior researcher" (early stages of PhD or pre-PhD), 1 = "early-career researcher" (later stages of PhD or early post-doc; also pre-PhD with multiple first author publications in the cancer domain), 2 = "mid-career researcher" (more experienced post-doc; three or more first/last author publications in the cancer domain, supervising more junior researchers/been awarded personal grant(s)), or 3 = "senior researcher" (senior lecturer and above; e.g. been awarded an institutional grant, managing a research group, senior lecturer status). In addition, data on physical workplace (i.e. country and institute) and professional background (i.e. researcher or clinical researcher were extracted and added to the model to control for sources of scientific embeddedness[6,33,38-42]. Data on the physical workplace covered 18 research institutes across five countries (UK, Denmark, USA, Australia and the Netherlands). The professional background of each researcher was coded as either 0 = "researcher" or 1 = "clinical researcher". All data were kept in a locked file cabinet and were anonymized prior to analysis to maximize confidentiality.

Box 1 Definitions

Academic social network	Network of researchers connected by informal interactions and social relationships *Who do you know?* – self-reported
Collaborative network	Network of researchers connected by co-authorship as a proxy for collaboration *Who do you collaborate with?* – database-derived

Model for analysis

We investigated the process of network evolution and co-evolution using stochastic actor-oriented models[43-45]. Statistical analysis of longitudinal network data is not possible with conventional statistical methods assuming independence of observations because, in networks, changing connections are typically interrelated with other simultaneous processes (i.e. changes in other connections in the same network or characteristics of the individual researchers involved). Stochastic actor-based models use a combination of simulation methods with statistical model fitting. For this study, models were estimated with the data-analysis package SIENA in R (Simulation Investigation for Empirical Network Analysis), which is suitable for binary social network data in which a pair of researchers is represented in either state 1 (relationship) or 0 (no relationship)[46]. For all models, t-ratios (indicators of convergence) were obtained of less than 0.1, and overall convergence of less than 0.25, which signals good model convergence[46]. Goodness of fit was assessed with auxiliary statistics (outdegree distribution, indegree distribution and triad census) and was deemed acceptable[47].

To explore the evolution and co-evolution of both networks, we created three models. Model 1 and 2 capture the separate evolution of the academic social network and the collaborative network respectively. Model 3 captures the co-evolution of both networks, exploring the influence of the academic social network on the collaborative network (to measure how both networks are inter-related, considering that (1) some initiatives, although intended to become publications, do not progress, and (2) there are lag phases between informal interaction and publication). All three models contain a combination of effects to control for both individual researchers' positions and an individual researcher's characteristics. Effects express, for example, whether researchers are likely to get to know the connections of their connections (*network embeddedness*; *transitivity*), or whether researchers with many relationships are more likely to have additional relationships over time (*preferential attachment*; *indegree popularity*). **Figure 2** visualizes the effects included in the three models. Detailed explanations of these effects and whether these effects are present in each of the three models are provided in **Appendix 2**.

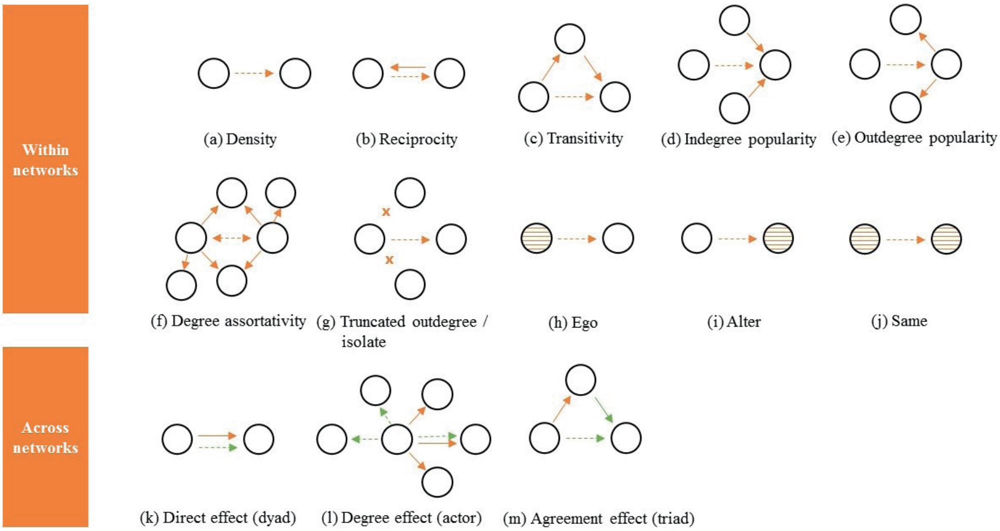

Figure 2 Effects used in the three models. Adapted from Stadtfeld et al[48]. The continuous arrows represent existing relationships at the start of this study; the dashed arrows represent new relationships created over the course of this study. For the cross-network effects, the difference between relationships in the two networks is represented by different coloured arrows.

Results

Network development

The development of the academic social network and the collaborative network is depicted in **Figure 3**, showing a rapidly growing and very dense academic social network, and a collaborative network that is less dense and grows more slowly. Additionally, **Figure 4** shows a more detailed view of development of the academic social network, showing the seniority and country of each researcher. A description of the development for both networks is provided in **Table 1**. The average number of (outgoing) relationships for both networks increased over time, revealing researchers got to know each other as well as starting to collaborate. Furthermore, the academic social network showed a strong tendency toward reciprocity (the co-authorship network is reciprocal by definition). Clusters of researchers were present in both networks.

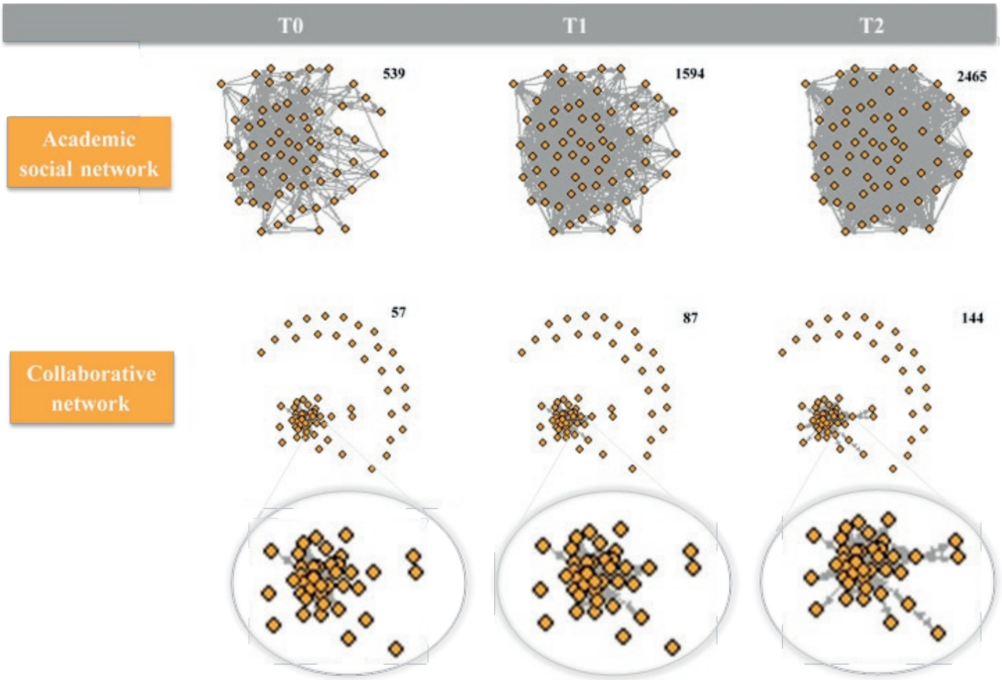

Figure 3 Development of the academic social network and the collaborative network. The top three figures, from left to right, visualize the development of the academic social network over time (i.e. from April 2017/2018 up to June 2019). The middle three figures, from left to right, visualize the development of the collaborative network – zooming in on the core of the network in the bottom three figures. The numbers in the top right corner of each figure represent the number of connections (total outdegree) in each figure.

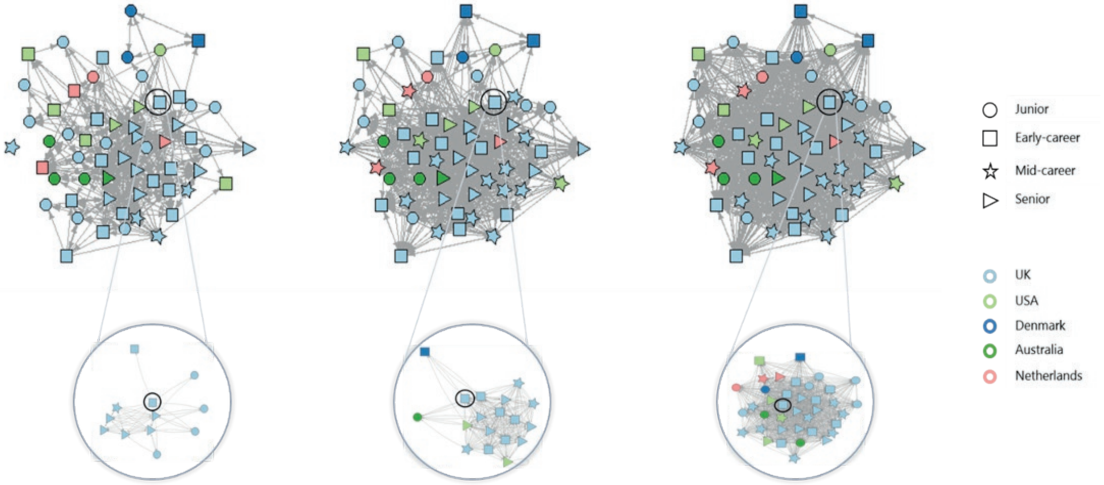

Figure 4 Development of the academic social network showing the seniority and country of each researcher. Again, the top three figures, from left to right, visualize the development of the academic social network over time (i.e. from April 2017/2018 up to June 2019). The relationships of one anonymized, early-career researcher from the UK have been highlighted in the bottom three figures to better illustrate how researchers of different seniority and country get to know each other over time.

Table 1 Descriptives for the evolution of both networks

	Definitions	Academic social network			Collaborative network		
		T_0	T_1	T_2	T_0	T_1	T_2
Average (out)degree[1]	Average number of (outgoing) relationships amongst researchers	9.0	20.2	39.5	1.9	2.0	3.4
s.d. (out)degree[2]	Standard deviation of (out)degrees	6.8	11.4	13.1	3.5	3.8	5.1
Reciprocity[3]	If i is connected to j, what is the probability that j is also connected to i?	0.65	0.73	0.79	-	-	-
Transitivity[4] (clustering)	If i is connected to j, and j to k, what is the probability that i is also connected to k?	0.51	0.66	0.84	0.53	0.44	0.65

[1] An average outdegree of 9 means that researchers know on average 9 other researchers; [2] An s.d. outdegree of 6.8 means that on average the difference between the average outdegree and individual measurements is 6.8; [3] A reciprocity of 0.65 means that 65% of the connections between researchers are mutual; [4] A transitivity of 0.51 indicates that 51% of the connections were transitive (referring to network embeddedness/transitivity).

Next, the association between the networks is given in **Table 2**. It shows the correlation between the number of (outgoing) relationships for both networks, for each observation moment. These numbers can be regarded as indications of the association between the development of the two networks. The correlations were positive, but decreasing over time, again reflecting a difference in the pace at which both networks developed. In addition, the association at the relationship-level (how many relations between researchers in the academic social network are also present in the collaborative network and vice versa) can be expressed by the Jaccard similarity index. This is a measure of similarity between two sets of data, formally defined as the number of connections in both networks divided by the number in either network, with higher values being indicative for higher similarity. The Jaccard similar index for each of the three observations was 0.19, 0.13, and 0.11 [45,49]. If independence between the networks was assumed, the expected Jaccard coefficients would be 0.03, 0.04, and 0.08. The observed values, while not very high, were higher.

Table 2 Correlations between the (out)degrees of the networks, for the three time points separately

	T_0 Collaborative network	T_1 Collaborative network	T_2 Collaborative network
Academic social network	0.71	0.39	0.14

Network evolution

The two central columns of **Table 3** report the parameter estimates for the separate evolution of both networks with their associated standard errors. Irrelevant effects for the different models are left empty. The academic social network (Model 1) exhibited positive *reciprocity* and *transitivity* parameters, indicating that researchers over time tended to get to know (1) those researchers who they were known by, and (2) the ‘friends of their friends’ (i.e. they are likely to cluster in groups). Yet, the negative interaction between reciprocity and transitivity indicates that, compared to one-to-one relationships, in clusters scientists are less likely to reciprocate relationships. The positive *indegree popularity* signifies that well-known researchers are inclined to become even more well-known over time. Conversely, the negative *outdegree popularity* parameter indicates that researchers who know many others are not necessarily well-known to others as well.

Table 3 Evolution and co-evolution of the academic social network and the collaborative network: parameter estimates and standard errors of SIENA models

	Evolution				Co-evolution	
	Model 1		Model 2		Model 3	
	Academic social network		Collaborative network[1]		Academic social network → Collaborative network	
	par.	(s.e.)	par.	(s.e.)	par.	(s.e.)
Within network						
Degree (density)			-3.134***	(0.375)	-5.133***	(1.080)
Reciprocity	5.324***	(1.538)				
Transitivity[2]	3.200**	(1.201)	2.232***	(0.362)	2.575***	(0.669)
Indegree popularity[3]	0.464*	(0.195)				
Outdegree popularity[3]	-0.201**	(0.065)				
In=outdeg. popularity/activity			0.112***	(0.025)	0.152**	(0.055)
Degree assortativity			-0.311***	(0.089)	-0.432**	(0.157)
Outdegree <10	-12.063***	(1.197)				
Network isolate			-0.749	(0.867)	-1.688	(1.533)
Gender (male) ego	-3.787***	(0.967)				
Gender (male) alter	0.041	(0.079)				
Gender (male) ego+alter			0.254*	(0.119)	0.247	(0.167)
Same gender	0.259***	(0.081)	-0.095	(0.139)	-0.242	(0.192)
Seniority (senior) ego	-1.708***	(0.505)				
Seniority (senior) alter	0.001	(0.031)				
Seniority (senior) alter[3]	-0.005	(0.036)				
Seniority (senior) ego+alter			-0.031	(0.044)	-0.016	(0.055)
Seniority (senior) ego+alter[3]			0.077	(0.057)	0.086	(0.066)
Seniority similarity[3]	-0.008	(0.016)	-0.043	(0.032)	-0.056†	(0.034)
Same professional background	0.106†	(0.062)	0.158	(0.131)	-0.037	(0.154)
Same country	-0.044	(0.110)	0.112	(0.129)	0.026	(0.163)
Same institution	2.395***	(0.347)	0.847***	(0.205)	0.529	(0.236)
Between-network: direct effect						
Academic social network					2.554**	(0.896)
Between-network: degree effects						
Outdegree activity					-0.373	(0.278)
Indegree popularity					0.296	(0.265)
Between-network: agreement						
Academic social network					-0.010	(0.077)
Interactions						
Gender (male) x seniority (senior)	-3.962***	(1.007)	0.151	(0.182)	0.028	(0.266)
Transitivity x reciprocity	-2.149***	(0.782)				

par. = parameter for the effect (estimate); (s.e.) = standard error; † p <0.1; * p <0.05; ** p <0.01; *** p <0.001;

[1] _For the independency assumption of the stochastic actor-oriented model, only papers with a maximum of five co-authors from within CanTest were included._

[2] _gwespFF for Model 1 and gwesp for Model 2/3_

[3] _Square-root transformed_

With increasing seniority, researchers are less likely to get to know additional researchers within the network (negative *seniority ego*). Similarly, males are less likely to get to know others (negative *gender (male) ego*). The interaction between gender and seniority (*gender (male) x seniority (senior)*) further signifies that males of higher seniority are less likely to get to know additional others. Finally, significant positive effects for *same gender* and *same professional background* assume that researchers are more likely to get to know others of the same gender and of the same professional background.

The negative *degree (density)* parameter for the collaborative network (Model 2) indicates that researchers were selective in their collaborative relationships. Yet, having collaborative relationships increases the initiation of new collaborations (positive *in=outdeg. popularity/activity*) – especially with low-collaborators (negative *degree assortativity*). Although male researchers were less likely to get to know others compared to females, they are more likely to collaborate (positive *gender (male) ego+alter*). Finally, collaboration is encouraged by working in the same institution (positive *same institution*).

Network co-evolution

The results for the co-evolution of the academic social network and collaborative network are reported in the right hand column of **Table 3**. The direct effect of a relationship in the academic social network on the likelihood of a relationship in the collaborative network was positive and significant (between network: direct effect – academic social network). When researcher i knew researcher j, they were likely to start collaboration (i.e. co-authorship) over time. Other cross-network effects were not significant.

Discussion

The CanTest network is clearly successful in connecting researchers with each other. Researchers within the network establish connections promptly and effectively (objective 1: evolution of the academic social network), allowing for considerable exchange of information and ideas to increase capacity and support sustainability of early detection and diagnosis of cancer research. Seniority and gender seem to play a major role in the development of relationships within the network (objective 3: individual researcher characteristics), not affecting who is known or not, but who gets to know others (objective 3: individual network positions). We found that more junior researchers built and expanded their academic network, but that with increasing seniority researchers were less likely to get to know others. This closely aligns with one of the key objectives of CanTest to recruit and support a new generation of researchers to establish themselves and reach early independence[11]. Moreover, compared to male researchers, female researchers seem to expand their academic social networks faster. The interaction between gender and seniority stresses even more how males of increasing seniority are less likely to expand their academic social networks over time.

Yet, in contrast with how more junior researchers expand their academic social networks, they seem to expand their collaborative research networks more slowly (objective 1 and 3: evolution of the collaborative network and the influence of individual researcher characteristics). The positive but decreasing association between the CanTest academic social network and the collaborative network over time further confirms this (objective 2: co-evolution of the academic social network and the collaborative network). The concurrent development of effective research collaboration is indeed a time consuming process – being connected informally, e.g. by being involved in the same project, may lead to collaboration on ideas and study design, application for funding, exchange visits, conduct of research, and only finally co-authorship. Despite this lengthy sequence, our results demonstrate that the transition from social connections into research collaboration does take place: creating an academic social relationship between two researchers significantly increases their chances to collaborate. The existence of the CanTest Collaborative and the structure, events and coordinated communications that go with it, has most likely contributed to the observed results. However, it is not possible to know how the networks studied here would have evolved without the existence of CanTest. The timing of the significant increase in academic social connections since the start of CanTest in April 2017 makes it likely, though, that CanTest has been instrumental in the process of creating and accelerating informal interactions and social relationships and hence collaboration.

Findings from previous studies suggesting higher co-authorship activity for males compared to females are confirmed in the current study[21]. However, we also found evidence to support findings from other studies that females are more appreciative of collaboration and so they expand their academic social networks faster[20]. Frequently assumed tendencies for same-gender relationships are confirmed as well; however, no evidence was found for same-gender collaborations[50]. Our finding that more senior researchers tend to collaborate more often may have played a role in this. Indeed, based on a large academic bibliographic database research, Combes and Givord (2018) argued that same-gender collaborations occur more commonly at the beginning of a researcher's career and fade with seniority[51]. Furthermore, national background didn't seem to play a role in the development of individual relationships amongst researchers, although the international collaboration does strengthen the network as such. A perhaps surprising finding was that, among participants from the same institution, CanTest seems to have boosted within-own-institution collaborations, beyond boosting between-institution ones.

Therefore catalysing new ‘internal’ network formations seems one of the means by which the network intervention has been effective. This may reflect the fact that most modern universities often encompass multiple campus sites/buildings (the boundaries between them acting as practical barriers) and different departments (the boundaries between them acting as organisational or disciplinary barriers), which mean that the potential for within-institutional collaborations cannot be taken as a given. Therefore, the CanTest network may also have boosted collaborations that – although relating to participants working at the same institution – would not have otherwise happened.

The main strength of the current study is that longitudinal rather than cross-sectional network data of a whole research network was used for understanding network evolution and co-evolution. Specifically, we were able to control for effects from researcher’s positions in the network as well as their seniority and gender across three points in time. A limitation of the study was that the study period was relatively short, and co-authorship relationships may take longer to flourish. As a result, the dynamics of collaboration in CanTest may not have been fully captured. Future research will be needed to show whether ‘knowing each other” translates into “collaborating with each other” even more when considered over a longer period of time. Moreover, it should be acknowledged that collaborative research activity is not limited to co-author behaviour. Other metrics for collaborative research activity could have been used, e.g. co-funding, but co-authoring activity was preferred as it is the most common metric for collaborative research activity in the literature and its data was readily accessible.

Future research should further address the evolution and co-evolution of relationships and collaboration within (cancer) research networks; in particular between less and more senior researchers as it remains unclear whether it is the bridge function that senior researchers may have towards junior researchers, the density of the CanTest network itself (densely linked networks are more efficient at diffusing information to all their members when compared to sparsely linked groups), or a combination of both that encourages researchers to move forward[23,52]. A combination of a densely linked network and the availability of one or several ‘bridging researchers’ – often referred to as brokers – might be ideal, pursuing a network that is maximally effective in facilitating collaboration between its members[53]. In addition, more research into the extent to which males and females of different seniority seem to expand their networks is warranted. There is evidence for a ‘saturation point’ for social connections, arguing that researchers are likely to refrain from initiating new connections if they already have many connections, or for females being more likely to create more diverse social capital[51,54]. Yet, there may be countless other mechanisms that address the interplay between seniority and gender in (academic) social network formation.

Simply establishing the infrastructure for a network of researchers to get to know each other will not necessarily make them collaborate. It may be just a matter of time, but the current study – unique in using longitudinal data to study the co-evolution of social connections and collaboration considering both researcher's characteristics and positions in networks – shows how the seniority and gender of researchers are particularly worth paying attention to when establishing effective research networks. Increased understanding of how to address and balance researcher's characteristics might help other research initiatives or funding agencies in developing effective research networks to promote research output. This study shows how facilitating and supporting a dense research network, through formal and informal network interactions, positively affects the translation from "getting to know each other" into collaboration – time will tell whether the established social connections will lead to further collaborations in the future.

Acknowledgements

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Appendix 1: Survey: matrix question and informed consent procedure

1. Matrix question

Which other members of the CanTest family do you know professionally, and how did/do you connect and interact with them? Select ‘yes’ for all the columns that apply by clicking the drop-down arrow; leave the box blank for ‘no’ or ‘not applicable’

	Exchanged emails or WhatsApp messages		Met at a conference, workshop, meeting or training event NOT organised by CanTest, e.g. Ca-PRI		Involved in the same individual project (may be multi-institutional)		At same Institution / Department	
Name1	Yes	-	Yes	-	Yes	-	Yes	-
Name2	Yes	-	Yes	-	Yes	-	Yes	-
Name3	Yes	-	Yes	-	Yes	-	Yes	-
…	Yes	-	Yes	-	Yes	-	Yes	-

2. Informed consent procedure

2.1 Introductory e-mail text

Dear member of the CanTest family,

We are starting an exciting new project within the CanTest Collaborative and would like to ask for your help. CanTest is funded by Cancer Research UK’s first ever Catalyst award and aims to support capacity building and collaboration in cancer detection research in primary care.

Our new project aims to understand and demonstrate how well CanTest is achieving its goal of strengthening and developing the Primary care cancer research community and network. The project is being run jointly by two of the nine CanTest institutions (Utrecht and Cambridge) and has a steering group consisting of …, …. and …. from the CanTest Senior Faculty.

CanTest started on 1st April 2017 and, since that time, you have become a member of the CanTest family. We would like you to answer some questions in a brief online survey so that we can retrospectively determine the baseline for the CanTest Network and also the current status of the Network.

This survey asks questions about which other members of the CanTest family you were/are connected with and how you interact with them.

In the short term, we would like to follow up on this survey with questions about how you collaborate with those members of the CanTest family for which you have indicated a connection and also to ask about further connections you may make. In addition, at several points in the future, we will contact you to ask further questions so that we can see how the network changes and grows in time.

The success of this project relies on as many of you as possible taking part, so we would very much appreciate it if you would take the time to participate in this project both now and in the future.

So, please reflect on your connections to CanTest and click the link below to complete the survey.

[link]

The survey can be a little slow to load on some pages, due to the fact that we ask network questions, so please be patient.

Please don’t hesitate to contact the core project team if you have any questions or concerns.

2.2 Introduction page of the survey

Introduction

CanTest is funded by Cancer Research UK and aims to support capacity building and collaboration in the international cancer detection research in primary care community. This project aims to understand and demonstrate how well CanTest is achieving its goal of strengthening and developing the primary care cancer research community and network.

The results of this survey will be used to map the relationships between the researchers directly associated with CanTest. Analysis will be carried out to determine how these relationships contribute to the goal of building a network of researchers in primary care cancer research**.** Social Network Analysis methodology will be applied for this analysis of the CanTest network.

Completion of the survey should take less than 15 minutes of your valuable time. Participation does not contain any risks.

Use and storage of data

All information gathered in this study is strictly confidential. All data will be kept in a locked file cabinet and password protected computer. At any point during the research, you are free to opt-out and your data will not be used after that time.

If you require further information

If you have any questions – before, during or after the study – you can contact the survey researcher through the contact information provided below.

2.3 Informed consent question

I have been sufficiently informed about this study, and accordingly I agree to participate in this survey.

Yes	No

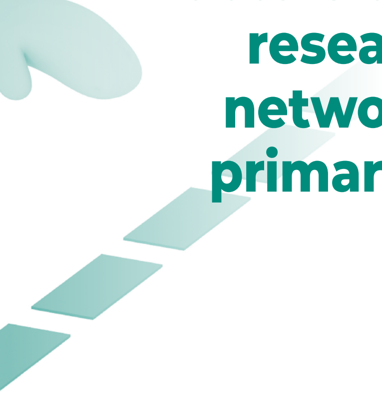
Appendix 2: Effects used in the three models

		Evolution		Coevolution
		Model 1	Model 2	Model 3
		Academic social network	Collaborative network	Academic social network → Collaborative network
Within networks				
Individual researcher's positions				
Outdegree/ density	Figure 2a: tendency of researchers to create or terminate relationships with others independent of other processes1		X	X
Reciprocity	Figure 2b: tendency of researchers to reciprocate relationships2	X		
Transitivity	Figure 2c: tendency of researchers to have relationships in small dense clusters in the network (network embeddedness)	X	X	X
Indegree-popularity	Figure 2d: tendency of researchers who have many incoming relationships to receive more incoming relationships over time (preferential attachment)	X		
Outdegree-popularity	Figure 2e: tendency of researchers who have many outgoing relationships to receive more incoming relationships over time	X		
In=outdegree popularity/ activity	Figure 2d,e: combination of the above-explained degree popularity and the degree activity3		X	X
Out/in degree assortativity	Figure 2f: tendency of researchers with many relationships to be related		X	X
Truncated outdegree	Figure 2g: tendency of researchers with less than x outgoing relationships to create new relationships	X		
Network isolate	Figure 2g: tendency of researchers with zero relationships to create relationships		X	X
Individual researcher's characteristics				
Ego	Figure 2h: tendency of researchers with higher values for a related characteristic (e.g. higher seniority) to create more outgoing relationships	X		
Alter	Figure 2i: tendency of researchers with higher values for a related characteristic (e.g. higher seniority) to receive more incoming relationships	X		

Ego+alter	Figure 2h,i: combination of the above-explained ego and alter effect3		X	X
Same/similarity	Figure 2j: tendency of researchers to have relationships with other researchers that are similar to themselves (e.g. researchers of similar gender)	X	X	X
Between networks				
Direct effect ('dyad-level')	Figure 2k: tendency of researchers to have a relationship in one network if they also have that relationship in the other network (entrainment effect)			X
Degree effects ('actor-level')	Figure 2l: tendency of researchers to have many (incoming/outgoing) relationships in one network if they also have many relationships in the other network			X
Agreement effect ('triad-level')	Figure 2m: tendency of researchers to have the same relationships in one network as those of the researchers they are related to in the other network			X
Interactions				
Ego x ego	Tendency of researchers with higher attribute values (e.g. gender and seniority) to have more relationships	X	X	X
Transitivity x reciprocity	Tendency of researchers to reciprocate relationships in clusters	X		

3

Factors determining development of researchers within a research network on cancer diagnosis in primary care: an interview study



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BMJ Open, 2022;12(e046321)

Abstract

Objectives

Developing connections with other researchers in a network, learning informally through these connections, and utilizing them to reach goals, is expected to increase research capacity and strengthen performance. So far, this has not been empirically demonstrated. We assessed what and how network collaboration adds to development of researchers.

Design

Exploratory qualitative study using semi-structured online interviews, analysed by inductive and deductive methods. For the deductive analysis, an existing value creation framework to study informal learning in networks was used and adjusted to our context.

Setting

The CanTest Collaborative - an international team of primary care cancer researchers working on early detection and diagnosis of cancer.

Participants

Sixteen primary care cancer researchers.

Results

Connections with other researchers in an international network created diverse value cycles, where most outcomes were in the potential value cycle, acquiring knowledge, skills, social capital, resources and ideas. Not all potential value will be applied but many interviewees described realized- as well as transformational value. In our context, the transformational value from the framework appeared to be related to other perspectives on the research process. Advancement of the network depends on opportunities, timing, role models, and connections between different perspectives.

Conclusions

Focus on the factors that are relevant for network advancement will support researchers in early detection and diagnosis of cancer research who participate in an international network, and bring sustainable change in this domain. When, subsequently, researchers in the CanTest network bring about more realized and transformational learning outcomes, this will contribute to capacity development.

Strengths and limitations of this study

- The deductive part of our analysis applied and adjusted an existing framework developed specifically to study informal learning processes in networks. This leads to robust results.
- The inductive part of our analysis brings to the fore why researchers advance into subsequent cycles of value creation as shown in the deductive part.
- A qualitative analysis based on value creation stories contributes understanding of researcher's development to more quantitative studies that look at the growth in connections.
- Distinguishing regular supervisory connections from network connections was complicated.

Key-words: capacity development; research personnel; qualitative research; international collaboration; cancer diagnostics

Introduction

Capacity development is essential to stimulate high quality research in healthcare that contributes to solutions for important health problems. While capacity development is a concept that has different meanings, here, it is about development of individuals via enabling new attitudes, knowledge, skills, and relationships and not about the need to increase the number of researchers in a specific research domain. Individual development of researchers leads to sustainable change in a research domain[1]. Traditionally, capacity development is often realized through the management of research groups[2], or interventions such as formal education and training, also in the context of research skills development in networks[3]. At the same time, collaborative networks are recognized as a means of advancement in a research domain for individual researchers[4,5]. Most learning in organizations occurs in an informal way, and a greater focus on informal learning could enhance the opportunities for capacity development in collaborative networks. Thus far, the role of more informal learning within collaborative networks has received less attention in studies on networks of researchers. The literature on networked learning advocated opportunities for development of individuals who "can enhance and critique each other's work" and "convey tacit knowledge or knowledge of technique"[6]. Developing connections within networks provides opportunities for sharing ideas, co-constructing knowledge, and exchanging experiences[6]. Also in the domain of cancer research, collaborative networks of researchers may provide a platform for collaborative learning. Cancer research networks have been studied previously, but with a focus on research output and translation to practice rather than concentrating on the development of the researchers[7,8].

To study the process of capacity development, we used a framework of value creation cycles within networks, which prioritizes value as learning, in its widest sense, over impact or monetary value. This framework, developed by Wenger, Trayner and De Laat[6], captures self-defined outcomes of network participation and conceptualizes value creation as "(…) the value of learning enabled by community involvement and networking" (p. 7). According to the framework (**Figure 1**), learning occurs in interconnected cycles according to perceived value, ranging from immediate to potential to realized value[6]. However, one cycle does not necessarily lead to the next, for example potential value may never be realized if the individual never has the opportunity to apply a newly developed skill.

Previously this value creation framework has been applied in studies on networks of educators, students and museum volunteers[9,10]. In this study, we apply it to explore value creation in an international research network. The CanTest Collaborative (CanTest) funded by Cancer Research UK (CRUK), is composed of primary care cancer researchers from the UK, Europe, USA and Australia with clinical and/or other methodological training,

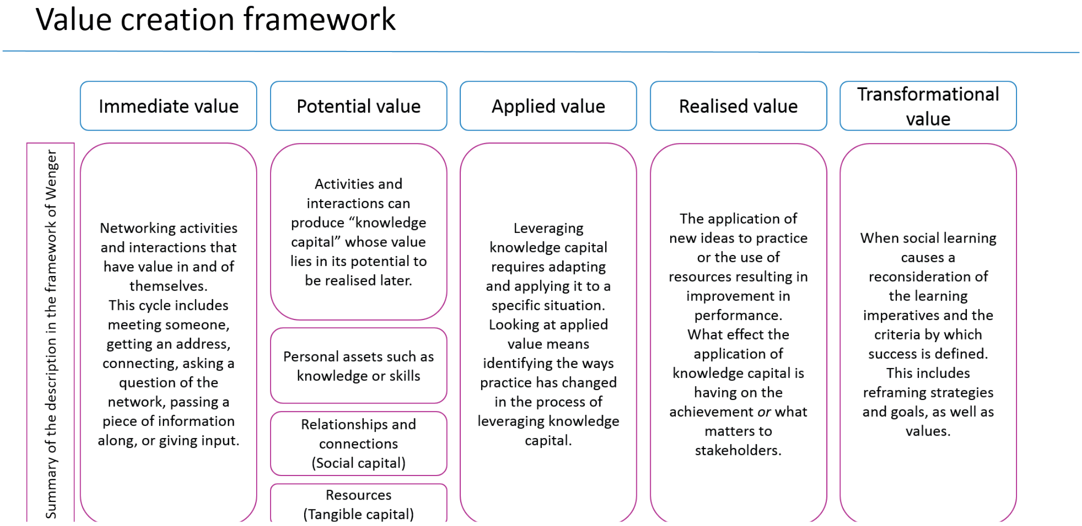

Figure 1 A visualization of – a summary of – the value creation framework as described by Wenger et al.[6]

working on the early detection and diagnosis of cancer[11]. The CanTest research focus is on identifying and evaluating novel, and refining existing, approaches to cancer detection in primary care. A second key objective of CanTest is to increase both the capacity and sustainability of cancer detection research in primary care in the UK and internationally. It seeks to do this by (1) promoting joint research, (2) providing various training opportunities, and (3) boosting academic exchange. Some activities are organized such as residential schools for researchers, but self-driven researcher-to-researcher interactions clustered around research activities are also encouraged. At the time of this study, CanTest was in Year 3 of a 5-year programme[12].

The aim of this study is to describe and evaluate how primary care cancer researchers themselves consider their development within a research network, and to determine which factors facilitate or constrain researcher's development.

Methods

We used semi-structured, in-depth interviews to understand the perspectives and experiences of junior and mid-career primary care cancer researchers. The interview schedule was based on the value creation framework (see **Figure 1**), and follow-up questions

(**Appendix 1**), asking interviewees to reflect on reasons for network relationships, were formulated during the conversation. Researchers were selected for interview using principles of maximum variation sampling[13]. Selection was based on the following criteria ensuring a balance representative of that seen in the wider network: stage in career (early, early-mid or mid-career); contractual relationship to CanTest (directly funded, funded by other sources but affiliated); gender, and country where currently working.

Interviewees were informed in writing about ethical aspects and the background of the project in advance and also verbally consented to participate in this research study at the start of their interview (**Appendix 1 and 2**). The usually one hour long interviews were performed online by an interviewer with a clinical background who works as a teacher in medical education (SM) and recorded. The interview questions were piloted in an interview with someone who no longer took part in the CanTest network. The transcripts of the recordings were cleaned and anonymized, and the names of all researchers, locations, and research institutes removed. We adhere to a constructivist qualitative research approach where the researcher's theoretical and methodological expertise is different from the perspective of an individual participant. As a result, member checking is considered not very informative, and therefore we did not send the transcripts back to participants or ask for their feedback on the analysis[14].

At the end of the data collection phase, data from the anonymized interviews were analysed using NVivo 12, using the value creation framework in a deductive manner. In addition, we analysed in an inductive manner (i.e. without a predefined theoretical framework) how these researchers connect with each other in the network. During the analysis, the existing value creation framework was adjusted to support data analysis in our context of researcher networks.

Adjustments to the Wenger, Trayner, and De Laat's framework are visualized in **Figure 2**. We separated the immediate value cycle and the potential value cycle more explicitly. We placed 'getting ideas and input from others' under potential value as this is something that might be used in a later stage, but kept immediate value for feelings only. Another adjustment was in transformational value. The initial framework looks at how students acquire different conceptualizations of learning, as a result of taking part in the network[7]. In our study, participants, even though they were learning at and from the workplace, they reflected less on how their perception about learning changed. However, acquiring transformational value in a network was about developing new perspectives on the research process. Nevertheless, the rationale of the transformation cycle in the adapted framework is still about innovation and a broadening of ideas, which is crucial for taking up leadership roles and thus for capacity development.

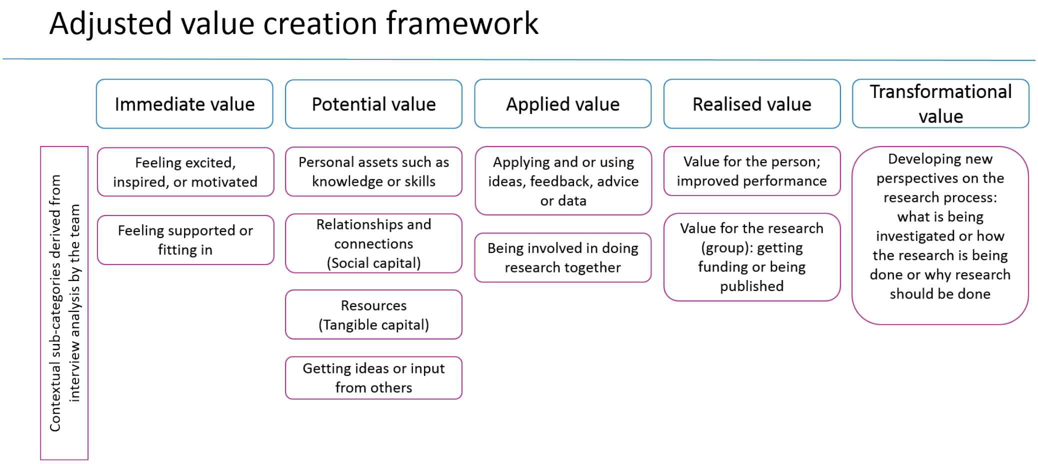

Figure 2 The adjusted value creation framework developed with and applied to data from the CanTest researcher network during the analysis.

A set of three interviews was initially analysed with thematic analysis by three researchers (VS, DV, EG) independently. After formulating and discussing the first version of a coding tree, another set of three interviews was analysed by the same three researchers. After further discussion, the coding tree was adapted (described above). DV and EG then coded two sets of five interviews individually. The coding tree and descriptions for each code were discussed with the whole research team afterwards. After coding, constant comparative methodology was applied by EG to further explore the data with cross case comparisons and obtain an overview of the development of value. The researchers compared and contrasted the final categorization to ensure reliability. Based on the fact that the research team observed that during the interviews remarks were becoming recurrent and the data was rich enough, we concluded that we reached saturation[14]. The standards for reporting qualitative research (COREQ) were applied[15].

Patient and Public Involvement

No patient(s) were involved in this study because we did not consider this suitable for answering the research question.

Results

Study population

Participating researchers were predominantly female (70%), came from the UK (70%) and 50% were funded directly by CanTest. The career stage split was 40% early, 40% early-mid and 20% mid-career (see **Table 1**).

Table 1 Characteristics of interviewees

CTM-number	Type of involvement	Country	Gender	Career stage*
63	Funded by CanTest	UK	F	Early
64	Funded by CanTest	UK	M	Early
67	Funded by CanTest	UK	M	Early-mid
42	Funded by CanTest	UK	F	Early-mid
45	Funded by CanTest	UK	F	Early-mid
46	Funded by CanTest	UK	M	Early
58	Not funded by CanTest	UK	F	Early-mid
26	Not funded by CanTest	NL	M	Mid
36	Not funded by CanTest	NL	F	Early-mid
79	Not funded by CanTest	USA	F	Early
92	Not funded by CanTest	UK	F	Early-mid
88	Not funded by CanTest	UK	F	Early
48	Not funded by CanTest	UK	F	Mid
77	Funded by CanTest	AUS	F	Early
84	Funded by CanTest	UK	M	Early-mid
25	Not funded by CanTest	USA	F	Mid

** Early (initial stages of PhD or pre-PhD), early-mid (later stages of PhD or early post-doc), and mid (more experienced postdoc, may be starting to supervise more junior researchers).*

The results from the study are presented below starting with a summary of how researchers learn and interact within the CanTest network, moving on to report on researchers' development via value creation and concluding with information about factors facilitating or constraining researcher development.

How researchers develop within the network

Researchers learned in an informal manner as a result of their participation in the international network. Social learning occurred individually, for example, when a researcher hears a lecture and reflects on what they have heard by comparing and contrasting differences between research systems in various countries. Moreover, researchers learned during their social interactions: while talking with other researchers (live or using online tools) or during actual collaboration with others, for example, through giving a workshop together or co-writing a paper.

Naturally, CanTest researchers developed as a result of the activities that were formally organized, such as the residential CanTest School. The School entails an intensive few days of formal education and interaction during which knowledge and skills can be acquired in the formal sessions and during social events. Besides, relationships were built that made connecting afterwards easier. In addition, CanTest travelling fellowships enable visits to other institutions, a learning opportunity mentioned by 9 of the 16 interviewees.

> *I did email [researcher 16] about some questions about some of his work. And I think if I hadn't spoken to him at the CanTest school, I probably wouldn't have felt so comfortable doing that. (CTM-64)*

Researchers' development within CanTest via value creation

Most value creation narratives were about immediate, potential or applied value. Realized and transformational value were less prominent. The diverse cycles are presented below.

Immediate value

Immediate value was mostly reported as spontaneous, emotionally loaded expressions indicating excitement, inspiration, and the feeling of belonging to others. Participants enjoy taking part in the network.

> *It inspires you, gives you more positive energy. And I think that is really useful because it's from that kind of energy and enthusiasm the ideas are generated. (CTM-88)*

> *Well, they do, they do really impressive stuff with large datasets and sort of epidemiological work. And as that just appeals to me, I just think that that's something that I would like to orientate myself to in the future. (CTM-67)*

Potential value

Potential value refers to the value produced by a community or a network that is not immediately applied but available to draw on later ('this might be useful one day'). Such potential value is a kind of social capital which comes in a variety of forms, including personal assets or access to relationships (**Figure 2**). Our interviewees acquired knowledge about early detection and diagnosis of cancer and networking or presentation skills.

Some referred specifically to skills required to become the next generation of senior and supervising researchers.

> *And having the opportunity to get involved in supervision and to kind of contribute to people's projects really solidifies that I think that you feel valued as a researcher and your skills and knowledge are valued and that you can contribute to something that's not necessarily doing primary research yourself. (CTM-48)*

Apart from knowledge and resources, the social capital acquired in the network helps members to gain ideas for their career, for example, on life post-PhD or on what kind of researcher one wants to become. Social capital is embedded in connections with more senior researchers in the network or with researchers at the same level of seniority. Thanks to social capital, researchers have the ability or the opportunity to ask questions or start collaborations because they know which researchers to ask and who to trust.

> *So instead of just seeing names and papers or having these kind of distant email conversations [...] Ehm, it actually made me feel that I could, that I was kind of part of it, or I potentially could be part of it and that these people were right more than just names or emails. They were people that you could interact with and bounce ideas off (CTM-88)*

By taking part in a network, people may also acquire or gain access to resources (also called tangible capital) such as specific pieces of information, documents, and tools. In our research setting, tangible capital turned out to take the form of references to papers that escaped your attention, access to a special database or also 'a pair of hands' to get the work done.

> *They had come up with some papers we hadn't identified in our searches. That was useful. (CTM-92)*

> *So just yeah it's interesting to see what databases are available in different countries for my health records and discussing that actually. So she was sort of showing what her data looked like compared to ours. (CTM-58)*

Applied value

Sometimes, especially with (early) mid-career researchers, new knowledge or access to resources at other institutions was applied by developing collaborations with other researchers. This step in the cycle of value creation is situated between potential value and realized value; outcomes such as publication in a peer-reviewed journal may have not yet become concrete but are no longer described as: ‘this might be useful one day’. Applying what you have learned, using materials you have gained access to, or getting in touch with new contacts may occur at an individual’s local level. For example, knowledge obtained at the CanTest residential school can be applied back at a researcher’s own institution, without actual involvement of those researchers from the network that provided the new perspective. On the other hand, applying potential value also occurs within the network, when researchers start a project or plan to apply for a grant together.

> *We’re getting data from [institute] to look at diagnostic pathways of people who have […] cancer. [...] It’s available for us to use. (CTM-79)*

> *She has contacted me recently, she said she and [researcher 6] are thinking of writing a small grant, and she asked me if I wanted to contribute and to spend a small percentage of my time, because of my lab expertise. That is something we will hopefully develop in the next months together. (CTM-42)*

Realized value

Realized value is about the application of new ideas or the use of resources resulting in improvement in individual or group performance. In the network of researchers in the early detection of cancer, the achievement that is sought in the end is improved patient outcomes. However, in value creation stories of researchers, realized value is on the individual level and the group level of performance. First, the category of personal development where, as a result of their interactions with others in the network, several researchers performed more confidently and competently. These changes are broader, more fundamental and sustainable than acquiring a specific skill or gaining access to certain researchers (classified under potential value). The second category of realized value is about outcomes that are not only of value for the researcher but also for the research group, for example, relationships that increase chances to have papers published or grants awarded.

> *I’ve kind of progressed so much, I feel as if I’ve developed quite a lot this year. [..] And that is much wider, it is much wider. And I think we need to be a bit braver in thinking about, just actually changing things. (CTM-88)*

> *As a result of that together with this group we wrote an editorial for BJGP, which was accepted last week. It is my first publication as part of CanTest. And we’re open to collaborate more in the future, if there’s the possibility, we have this common interest. (CTM-42)*

In a network of researchers, the connections between different cycles in the framework appeared to be different from what Wenger *et al* describe[6]. Especially realized value was distinctive. In the literature from the learning sciences, network members acquire skills during earlier cycles in the same network. In our work, some respondents spoke about individual or group performance improvement through applying new ideas or using resources. However, these were not acquired in the present CanTest network but from earlier collaborations and interactions outside and preceding CanTest.

Transformational value

In the value creation stories, it became apparent that some researchers, thanks to their connections with other members of the network, not only become inspired (classified under immediate value) but also develop fundamentally different ideas about the content of research and research collaboration. This network changed their beliefs about international collaboration and about the importance of a diversity of perspectives for good research: ‘a better appreciation for the wider view’ as one of the participants (CTM-84) put it.

> *Yeah and I think CanTest in particular, because it’s such a multi-institutional, multi-national kind of collaboration that you, kind of I guess that’s opened my eyes to how you can collaborate and on a large scale a kind of around the world really rather than just being, kind of, based in the one place where you are. (CTM-64)*

Factors that facilitate or constrain researchers’ development

In their stories about value creation, we identified three themes that might explain why researchers connect with other researchers in the network and hence advance into subsequent cycles of value creation:

1 Opportunities and timing
2 Role models
3 Differences versus similarities

Opportunities and timing

Interviewees spoke about the difficulty of combining the development of connections and the start of collaborations with their own research process. Seven interviewees spoke about not feeling experienced enough or sufficiently advanced in their studies to (re)connect with other researchers in the network (CTM-46) and feeling unsure what connections would be most valuable for them later on. Others said that it was not the right moment because their studies were already too far advanced, which made learning new methods less useful (CTM-88). More practical reasons were related to the fact that researchers were not able to combine networking and (international) collaboration with their own research project because of time available - having other obligations in life (four interviewees) or when focusing on finishing their own research, mostly notably their PhD, was the key priority (CTM-88).

> *And, by that time … all my focus was just purely on my PhD, and actually do my PhD,[…] . This is why you've got your fellowship and it's the only thing that you're able to do. (CTM-88)*

> *Not yet because I've only started to develop my PhD concept and started doing studies so collaboration comes later. I've still got two and a half years left. There's still opportunity to do it. I think perhaps for me it's still a bit early. (CTM-46)*

Role models

Within the network, role models were influential in stimulating researchers to become involved. Existing members not only give support to newcomers, set an example on how good research collaboration flourishes, but also help with building relationships with other researchers or connecting lines of thinking in research without actually linking people.

> *Some of the senior faculty did a little bit on it, their most disappointing rejection of publication that kind of thing, just to show everyone has to start somewhere and work their way up. I think having a mentor and some development of your trajectory is important […]. (CTM-92)*

Differences versus similarities

Connecting (more) with other researchers in the network is also influenced by differences and similarities between individuals as well as the content of their research. With respect to the latter, the value of diverse perspectives was viewed in two ways. On the one hand, a few respondents (three) mentioned that participating in this network is valuable for them because of the differences in perspectives, for example, between countries. On the other hand, nine researchers emphasized that, for combining different perspectives, it is important to have common interests or a shared knowledge area.

> *it's just knowing that there's other people who are interested in the same stuff. (CTM-88)*

> *People who do research totally unrelated to mine came and talked to me about my study and how important the patient perspective is, just it wasn't the work they do. I think a lot of people saw the value in it even if it's not specifically what they're doing. (CTM-25)*

> *I didn't have continuing conversation with him, because there wasn't, our work doesn't overlap enough and there wasn't any real need at the time. (CTM-77)*

> *because we've got this sort of strange 'meeting in the middle' situation where we're coming from such different perspectives and well, "meeting in the middle" is harder than, well, harder than I thought. I don't know about everyone else but for me I found that. A bit challenging I guess. (CTM-45)*

Discussion

Principal findings

Participating in a network is expected to contribute to capacity development of individual researchers: how they develop as researchers in their chosen discipline, in this case early detection and diagnosis of cancer. Our results show that, at the initial phase of the network, CanTest researchers primarily acquire knowledge, skills, and social capital. To gain advantage from social capital, connections with people and resources are essential[16]. The CanTest network provides researchers with these connections. The fact that not all immediate or potential value is translated into realized value and publications is not problematic, as this may be a first step to more advanced and sustainable levels of learning. Themes that might explain why researchers connect with other researchers in the network and hence advance into subsequent cycles of value creation are opportunities and timing, role models, and differences versus similarities.

Strengths and weaknesses of the study

The main strengths of this interdisciplinary study are: (1) to apply and use an existing framework to underpin the analysis and explore competency development through informal learning in networks. (2) The inductive part of our analysis brings to the fore why researchers advance into subsequent cycles of value creation as shown in the deductive part. (3) A qualitative analysis based on value creation stories contributes understanding of researcher's development to more quantitative studies that look at the growth in connections. A limitation of this study was that, for some interviewees, other more senior researchers in the network were their institutional supervisors. As a result, it was difficult to differentiate what they obtained additionally from the network of researchers and which opportunities they already possessed in the regular researcher-supervisor dyad within their research institute. In addition, during the interviews, we found that asking for value creation stories led to an emphasis on the positive. However, we did seek to mitigate this by adding a question to the interview schedule on whether they were dissatisfied in any way about their participation in the network. This question helped us understand, for example, how dissimilarity with others in the network may influence value creation (see differences versus similarities).

Relation of our findings to other studies

Participation in the network in the form of actual research collaboration with others depended on the amount of time available and on competing demands from progressing or finishing researcher's own work. In earlier studies, not only has it been described that competing priorities for network members hinder collaboration[17] and that work/personal life is challenging for PhD completion[18] but also that having good international connections is an essential step in developing toward a research leader[2]. In our work, research collaborations were primarily taken up by (early) mid-career researchers, which accords with the purpose of the CanTest project.

From our results, as well as other studies about research networks, a few strategies come to the fore with respect to what junior researchers themselves could do to reach out more to other members of the network and what senior researchers could do to help them. In our study, mentors were valued and their openness about their own career paths particularly prized. So, senior researchers should continue to focus on mentorship while remaining sensitive to the delicate balance between guidance and fostering independence[19]. The design of CanTest's capacity building, combining formal and informal learning, enables early-career researchers to approach more senior researchers who they otherwise would not interact with. Interviewees also referred to inspiring interactions and collaborations with like-minded researchers at the same level of seniority. A recent review has shown that mentoring by senior researchers and facilitation by researchers at a slightly higher level are both essential within networks that aim to support capacity development[20,21].

Some interviewees reported on the value of a diversity of perspectives, lauding opportunities for worthwhile research through contrasting and comparing. In contrast, others emphasized alignment in perspectives as essential for research collaboration. Bridging different perspectives and establishing research collaboration is known to be difficult when there is heterogeneity in research approaches, as can be the case with international or interdisciplinary collaborations[22,23]. Junior researchers could be more aware of diverse gains from the effort to connect with dissimilar others in a network and thus develop what been called semantic capacity which makes identifying differences valuable[24]. Senior researchers need to provide room for exploratory interdisciplinary interactions between junior and mid-career researchers. Also, our study has shown that learning in networks is affected by the delicate balance between ensuring sufficient overlap in research approaches while also introducing the different approaches necessary to allow innovation. Senior researchers may demonstrate example behaviour by showing how discussions with people who, at first sight have nothing in common with your own interests, can be conducted and how this can bring innovative research approaches[8].

Implications for policymakers

We showed that value creation in a research network is a complex process, where the hard outcomes measure that most interest policymakers only materialize later in the process. Funders should therefore recognize that investment in building research networks can substantially help to reach their mission but they are in it for the long haul.

Future research

Our study indicates that, in this early stage of the network, the focus is primarily, but not exclusively, on the development of individual members within the network (through potential value). It is important to carry out further studies to better understand how well the other value creation cycles are achieved because the final two cycles, realized and transformational value, are anticipated to be key for capacity development into research leaders. In addition, the value creation literature emphasizes that, when studying networks, there should be a focus on whether the network brings value for individual member(s) or for the network as a whole[9]. Likewise, the literature about capacity development[1,17] recommends that the macro level, meso level and micro level of the research system should also be considered. As such, future research should also look into capacity development from a system's perspective. For the design of formal activities and studies thereof in the future, the literature on interdisciplinary collaboration deserves attention, where strategies for handling differences between disciplines were described[22,23].The interviews were completed shortly before the COVID-19 lockdown and the impact of the pandemic on the network will be explored in future work.

Conclusion

Researchers within an international network focused on early detection and diagnosis of cancer, learn and develop by making connections and interacting with others in the network. In our study, we have adjusted a framework used to study learning in networks to the context of a network of international researchers. In time, the researchers in the CanTest network will acquire more realized and transformational value, both of which are essential for capacity development. Advancement of the network depends on opportunities, timing, role models, and connections between different perspectives. Focus on those factors supports researchers to establish themselves and go on to reach independence in early detection and diagnosis of cancer research, which brings sustainable change in this domain.

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Appendix 1: Interview guide CanTest

The interview is conducted to explore value creation stories. As such, not each and every sub-question was relevant during each interview. During the deductive part of the analysis, answers on questions were coded with the framework.

Read aloud at the beginning of the interview: We have sent you an information letter, with an informed consent form attached. Have you read this information and do you give consent for taking part in this sub-study?

Immediate value. What happened? Things that can be valuable in and of themselves.
Could you give me some examples of meaningful and/or significant interactions with CanTest members in the past year? This could be small, such as receiving a relevant paper from someone, or larger, such as preparing a workshop together or even larger and more long-term such as doing joint research, etc. Could you give me a brief idea on what the interaction consisted of?

Potential value - What did being part of the CanTest network help you get access to?
In what manner did being part of the CanTest network give you access to new skills or knowledge or change your feelings about yourself as a researcher? Has this interaction changed your understanding of the domain of early diagnosis? Or maybe skills in a specific research method? If yes, how? In what manner has this interaction affected the inspiration for the work you do? In which way has the interaction changed your confidence in your ability to engage in research practice?

How has your participation in the CanTest network transformed your view of how you could develop yourself as a researcher? For example, do you see opportunities for learning and development that you did not see before?

How has being part of the CanTest network changed your social relationships within the research world? (inside and outside CanTest) Have you gained access to new people through the interaction/contact? And do you know them well enough to know what they can contribute to your development as a researcher? Do these changed social relationships help you feel less isolated? If yes, could you tell more?

Do you now have access to new tools, methods, or processes, which you would not have otherwise?

Have you noticed that you or your work has been taken more seriously since you participate in the CanTest network? Did being part of the CanTest network add credibility?

Applied value - How did you use these new resources, ideas, documents, connections in your research practice?
What difference have these new connections, skills, ideas, documents, status* made to your work as a researcher? What behaviours of yourself or others in your research group did it enable? What actions would not have happened otherwise? Where have you used the products/outputs of the CanTest network? Where have you applied the skills you have acquired in the CanTest network? [can be outside the network] Did it assist with accomplishing a task? In what manner? Were you able to engage others who could help you reach your goals? How did you implement an idea or suggestion that you got?

Realized value - What were the outcomes? These questions will only be posed when they have done something with the skill / document / connection
What difference has applying these new *skills/ ideas/ documents/ status/ connections** made to your ability to achieve results in your research? Or the ability of others? What aspects of your performance have changed as a result? Could you explain? Have you saved time or achieved something new? Did any of this affect metrics that are used to evaluate your performance in research? For example the number of papers you publish? What has your organization or research group been able to achieve something new / different because of your participation in CanTest network?

Reframing value
Has your participation in the CanTest network changed the way you think about what is important in research about early diagnosis of cancer in primary care?

Has the CanTest network changed your understanding and definition of what matters in doing research in general?

Appendix 2: Information letter and informed consent

Information letter

CanTest Network Analysis Study
Qualitative sub-study - The value created by participation
within CanTest - a primary care cancer diagnostics network

Introduction

You have been asked to participate in the above named scientific research study. In this mixed methods study, we aim to understand more fully the impact of the CRUK-funded CanTest program on the primary care cancer diagnostics network. In order to do so, you as a member of the CanTest family, have been asked to participate in a semi-structured interview. Please read this information letter thoroughly and if you agree, we will ask you whether you give informed consent at the start of the interview. The interview will be conducted with a video communication tool similar to Skype (Zoom) .

2. How will the research be conducted?

In this study, semi-structured interviews will be carried out by (in the document for the participants, name of the researcher was provided here) of UMC Utrecht. These interviews will last approximately 45 minutes and be audio-taped and transcribed. Each interview will be conducted using the ZOOM teleconferencing service.

3. What do we expect from you?

We expect you to respond to the questions during the interview in an open and personal manner. We want to know your own personal opinions and therefore all answers are correct answers.

4. What are the potential risks?

In this study personal data will be collected (including your name and email address (affiliated institution and your function). Collecting personal data always comes with privacy risks. The collected data will only be used for this study. Your name and the name of your institution will not be published. Descriptive information in the final publication about your background will be formulated in such a manner that it cannot be traced easily back to you or your institution.

5. What are potential advantages or disadvantages in participating in this study?

The only disadvantage of participating in this study is the investment of time. Approximately 45 minutes for the interview. There are no direct advantages for you as a person or your institute. However, this study might provide useful insights regarding the CanTest collaborative program and networks of researchers more broadly.

6. What happens if I don't want to participate in this study?
Participation is voluntary. You decide whether or not you want to participate. If you decide not to participate you don't have to take further actions or provide us with a justification. If you do decide to participate you can withdraw from the study within 2 (two) weeks after data collection has taken place, after this period it is not possible to withdraw from the study. Withdrawal can only take place by sending an email to one of the three main researchers (see below). If you decide to withdraw from the study you don't need to provide a justification for your choice and any previously collected data involving your participation will be destroyed.

7. Will I be informed if in the course of the study relevant information becomes apparent?
If information becomes apparent during the study that could possibly influence your consent we will inform you about this in a timely fashion.

8. What happens with my data?
Your raw research data will be stored for 10 (ten) years after the end of this study (date of publication of the results), this is in accordance with the Netherlands Code of Conduct for Research Integrity. You give permission for this if you participate in this study. If you do not agree to this then you cannot participate. After 10 (ten) years, the raw research data will be destroyed. If there is a reason to use the data for another research aim, you will be asked for permission again. Due to practical reasons ZOOM will be used. ZOOM is a subscription based tool where recordings are stored in a safe server. You will receive further instructions on the requirements of this application.

Your data will be stored on a protected server of Utrecht University; the Netherlands. Your data will be handled according to the European General Data Protection Regulation (GDPR). Principal investigator (in the document for the participants, name of researcher was provided here) is responsible for processing your personal data. Your data will be coded by (in the document for the participants, name of researcher was provided here). Coded data means that it cannot be directly traced to a person. The file containing the keys of the codes will be saved in another location. Only (in the document for the participants, name of the researcher was provided here) (or her successor) will have access to this file and thus to the directly traceable data. The other members of the research team (in the document for the participants, names were provided here) will have access to the coded data only. Members of the steering committee for this study (in the document for the participants, names were provided here) have access to the interim results of the analysis only which will not include fragments of your interview recording. When specific quotations from your interview are considered for the final research paper and are considered potentially sensitive we will ask for your permission before submission. The audio tapes of the interview will be transcribed by an external bureau. They are obligated by law to handle your data according to the GDPR legislation.

9. What are my rights in the processing of data?

As a participant in this study you have several rights, e.g. the right to see how your data are stored. For general information see the website of the Dutch Data Protection Authority (https://autoriteitpersoonsgegevens.nl/en). If you have questions or complaints about the processing of your personal data we advise you to contact the principal investigator (in the document for the participants, name of the researcher was provided here) first. You can also contact the Data Protection Officer of the (in the document for the participants, name of the organization was provided here) whose contact details will be provided by the principal investigator upon request.

10. Are there any costs involved or is there a (financial) compensation if I decide to participate in this study?

No

11. Did an ethical review board for medical education approved this study?

In the Netherlands, it is not mandatory to get formal approval for this type of study. For the information letter, we complied with the forms (and the actions implied in those forms) that are provided by the ethical review board of The Netherlands Association for Medical Education (NVMO-ERB). The principal investigator in this study is a member of this ethical review board. Our study does not belong to the domain of what this ethical review board gives feedback on.

12. Do you have further questions?

If you have any further questions or require more information before, during or after the study or have complaints about the study, please contact the principal investigator (in the document for the participants, name and e-mail address was provided here).

13. Giving the informed consent

If you have sufficient information and time to consider participation and do decide to participate in this study please say so at the beginning of the interview when asked by the interviewer. This will be recorded and transcribed.

Thank you, the research team (in the document for the participants, names and e-mail addresses were provided underneath this document).

Informed consent

Title study: “the value created by participation within a primary care cancer diagnostics network”

I have read the information letter for participants. I was able to ask additional questions. My questions have been answered sufficiently. I had enough time to decide whether I would like to participate.

I know that participating in this study is completely voluntary. I am aware that I can withdraw from the study within 2 (two) weeks after data collection has taken place, after this period it is not possible to withdraw from the study. In doing so I do not need to provide justification.

I know that some people will have access to my data. Those people are mentioned in the information letter. I have the rights to see how my data are stored.

I give permission to use my data in concordance with the aims as described in the information letter.

If there is reason to use the data for another research aim, I will be asked for my permission again.

I give permission to store my raw research data for 10 (ten) years after the end of this study (date publication of the results) for further analysis concerning this study (if applicable).

At the start of the interview, the interviewer will ask you about this. If you want to participate in this study, please say your name and that you agree with participating.

4

Developing a regional transmural care database: a roadmap

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Abstract

Introduction

In primary care health care systems, primary care physicians (PCPs) provide most basic care services, and if necessary, refer to secondary care for specialized work-up and treatment. If hospital care is required, agreement between PCPs and secondary care physicians (SCPs) on the conditions for patient referral and back-referral are considered crucial to providing high quality patient care. The regional healthcare network of Utrecht, a region in the Netherlands, developed a set of collaborative patient care agreements (CPCAs) for specific chronic conditions. Even though these CPCAs are endorsed by all relevant regional health care organizations, the adoption of these agreements in practice remains substandard. In this project, through linkage of routine care data, as registered in daily practice by PCPs and SCPs, a regional transmural care database (RTD) was developed for monitoring the use of the CPCAs. Its data was transformed into 'mirror data' used to support PCPs and SCPs in discussing and improving current practice and to support a learning healthcare system within the region.

Methods

The development of the RTD is part of a larger action research project on joint care, called ZOUT (an acronym which is translated as "The right care at the right place in the Utrecht region"). The RTD includes data from three regional hospitals, and about 70 affiliated primary care practices which are united in the Julius General Practitioners Network (JGPN). These data were extracted, linked and presented in the form of mirror data, following simple methods to allow replication of our approach. CPCAs addressing transmural care for three chronic conditions were selected. Data from the primary care practices and the hospitals were linked by an independent trusted third party. This enabled relevant hospital data to be added to the primary care dataset, thereby providing transmural routine care data for individual patients.

Results

During the development of the RTD, a roadmap was created including a detailed step-by-step checklist of the organizational, administrative, technical and legal arrangements which needed to be made. Legal and administrative challenges proved most challenging. Also, incompleteness of data and the impossibility to translate several agreements into extractable data limited the potential for providing a comprehensive overview of the extent to which agreements in the CPCA were adhered to in daily care.

Discussion

We present a systematic, comprehensive (technical as well as practical) and reproducible roadmap to developing a regional transmural care database suitable for generating mirror data on joint transmural care between PCPs and SCPs. This approach includes all technical steps in data selection and linkage, as well as the substantive steps that need to be taken in the analysis and application of the results. The mirror data, which reflects the follow-up of agreements formulated in the CPCAs, enabled shared reflection and discussion between PCPs and SCPs. This supports the search for bottlenecks and potentialities for improving daily collaborative care, thereby showing great potential to serve a learning regional healthcare system.

Key words: Transmural care, data linkage, mirror data

Summary table

What was already known on the topic

- Care provided jointly by primary care physicians and secondary care physicians is associated with better patient outcomes in comparison with acting alone, but cooperation and coordination between them can be problematic.
- Feedback processes (or 'mirroring') are often used in healthcare organizations to improve health professional's performance.
- Transmural record linkage might support these processes, and the technical prerequisites for record linkage has been described before.

What this study added to our knowledge

- A regional transmural care database provides insight in the transmural patient trajectories throughout the regional healthcare system, and thus also in the collaboration between primary and secondary care.
- A comprehensive roadmap towards developing a regional transmural care database, including the technical prerequisites but also the substantive choices that come with interpretation of the results, is presented.
- Mirror data from the regional transmural care database can be coupled directly to the agreements that are used by different physicians (f.i. primary and secondary care physicians) in the selected region, to improve its relevance and applicability to their daily practice.

Introduction

In primary care health care systems, primary care physicians (PCPs) provide most basic care services, and if necessary, refer to secondary care for specialized work-up and treatment. If hospital care is required, agreement between PCPs and secondary care physicians (SCPs) on the conditions for patient referral and back-referral are considered crucial to providing high quality patient care[1]. Indeed, care provided jointly by PCPs and SCPs is associated with better patient outcomes in comparison with acting alone[2,3]. Joint care requires appropriate patient referral. A referral constitutes the handing over of patient care from one caregiver to another. This could be either the handing over of care from the PCP to the SCP (referral) or the handing over of care from the SCP to the PCP (back-referral). Agreement between PCPs and SCPs on the conditions for patient referral and back-referral are considered crucial to providing patients the right care, at the right place and time.

In Europe, there are roughly three types of referral systems: i) where patients have direct access to most types of SCPs (e.g. Austria, Belgium, Switzerland), ii) where patients have direct access to most type of SCPs as long as costs of the visit are paid privately (e.g. Czech Republic, France, Ireland), and iii) where patients need a referral for visiting most of the SCP services (e.g. Hungary, Scandinavian countries, Spain, the Netherlands). In each of those referral systems, cooperation and coordination between PCPs and SCPs can be problematic, even in the third, where a more direct link between PCPs and SCPs exists[4].

The referral system in the Netherlands is of the third type: in the Netherlands patients need a referral from their PCP to consult any SCP. From the ambition to improve cooperation and coordination between PCPs and SCPs in the Netherlands, national policy on this topic was introduced, and subsequently translated to the regional level (collaborative patient care agreements). These collaborative patient care agreements (CPCAs) consist of agreements between PCPs and SCPs on how to cooperate and coordinate (see **Box 1** for an example). The CPCAs allow for a more customized and focused approach towards collaborative transmural patient care and referral for different regional healthcare networks. The CPCAs concern chronic disease management topics, for conditions such as type 2 diabetes (DMII), chronic obstructive pulmonary disease (COPD), and cardiovascular risk management (CVRM) as these especially require joint care.

Box 1 Example from the CPCA CVRM

PCP	Consider a referral to an internist vascular medicine if triglyceride levels are > 5 mmol/L despite lifestyle adjustments and potential medication
SCP	The internist vascular medicine refers back to the PCP if the target value (or a stable situation) is reached

Nonetheless, adoption of CPCAs in daily practice does not occur spontaneously. Since their introduction, the adoption of the CPCAs remains poor[5,6]. As in current practice, improvement is increasingly driven by data[7,8], increasing CPCA adoption warrants monitoring, e.g. by checking routine patient data for a (back) referral if the condition for that (back-)referral is present. For this, a database would be required that includes patient data from both primary and secondary care in a region. To date, such a database, or a roadmap to develop one, does not exist within the Netherlands or elsewhere. This project is the first to create a (roadmap to) a transmural database; named the "regional transmural care database" (RTD). Through linkage of routine primary care data and routine secondary care data, this RTD will: 1) provide insight in the transmural patient trajectories throughout the regional healthcare system, 2) compare these observed trajectories with the agreements captured in the CPCAs, and 3) support PCPs and SCPs in discussing and improving their (back-)referral behaviour[9].

This paper describes the steps required to develop and employ an RTD to support transmural joint care, along with the lessons learnt. We will address the process and challenges of translating transmural agreements to extractable data-units from routine care data, the technical prerequisites for this data extraction and subsequent record linkage, the substantive choices that come with interpreting an RTD, and finally, the translation to 'mirror data'[10].

Methods

This study is part of a larger action research project on joint care, called ZOUT (an acronym which is translated as "The right care at the right place in the Utrecht region"). For this study we created an RTD in which we linked patients' routine primary and secondary care electronic health records (EHRs). The availability and reliability of routine care data in a region's health system primarily depends on the extent to which patient contacts with healthcare providers are registered systematically. Both primary and secondary care in the Netherlands have a long-standing history of electronically registering routine healthcare data. We developed the RTD using secondary care data from three hospitals; the University Medical Center Utrecht, a 1000-bed academic hospital, the Diakonessenhuis, a 500-bed general hospital, and the St. Antonius, a 750-bed general hospital, each situated in Utrecht, a city in the Netherlands. These data were linked to the routine primary care data of 70 referring primary care practices affiliated with the Julius General Practitioners Network (JGPN), who primarily refer to one of the three selected hospitals[11]. The impact of this process – in hours or euros – depends strongly on what's already available in the region's health care system. In-kind contributions and the existing JGPN infrastructure reduced costs considerably.

The pathway to an RTD, and the subsequent translation to mirror data, consists of several steps, summarized in **Figure 1**:

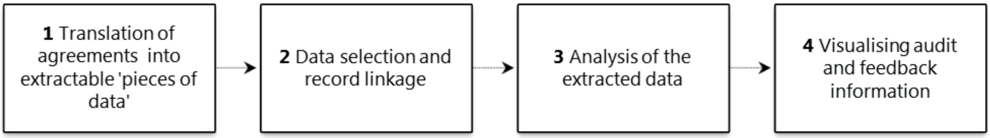

Figure 1 Steps required to develop mirror data from a regional transmural care database (RTD), based on the occurrence of collaborative patient care agreements in daily practice.

Translation of agreements into extractable "pieces of data"

A roadmap to develop an RTD should be practical and applicable across settings, since it should not only be useful for specific healthcare ICT systems where specific technical expertise is available. Accordingly, in the development of the RTD we abandoned the use of complex methodology (such as word recognition in free text) in the data extraction phase, and when designing a strategy for presenting the data in the form of mirror data, we chose simple methods, to allow for replicating our approach.

To build the RTD, we selected CPCAs addressing transmural care for three chronic conditions: DMII, COPD and CVRM. These CPCAs were the only CPCAs implemented over two years ago, thereby offering sufficient follow-up time for evaluation of their integration in daily practice. In these CPCAs, we first determined relevant and extractable indications for recommended (back-) referral. Based on the assumption that an agreement consists of two components – 1) a situation or condition that requires action, and 2) the corresponding, agreed upon, action –, we translated agreements in the CPCA to "IF"-"THEN" statements. Conditions that were described in the CPCAs as being indicative for (back-) referral were classified as "IF". The corresponding agreements on referral actions were classified as "THEN" (see **Box 2**). Since we aimed to monitor transmural collaboration, the situations or conditions ('IF") should be in primary care and the corresponding actions ("THEN") in secondary care or vice versa. These "IF" and "THEN" definitions were translated to data-units which were extractable from routine care data. The feasibility of extraction of these statements from the RTD, and their translation into extractable data-units, was determined and tested with the support of the local data-management teams.

Box 2 Example translation from the CPCA CVRM

CPCA agreement	Consider a referral to an internist vascular medicine if HDL-cholesterol levels are very low (< 0.6 mmol/L)
Translated to	IF – HDL-cholesterol levels are below 0.6 mmol/L THEN – there is a registered visit at the internist vascular medicine

For the final selection of “IF”-“THEN“ statements, to ensure that the chosen statements were not only extractable but also the most relevant and representative for the CPCA recommendations, the statements were presented to PCPs and SCPs who developed the CPCAs (see **Figure 2**).

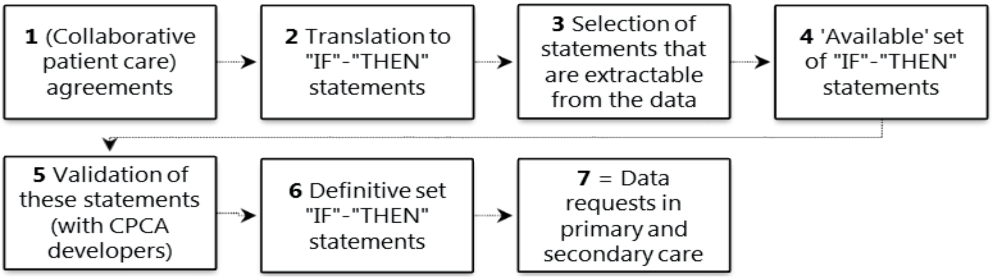

Figure 2 Translation of collaborative patient care agreements (CPCAs) to relevant “IF”-“THEN” statements that can be extracted from daily care registrations.

Data selection and record linkage

Primary care data selection

Routine primary care data were extracted from the JGPN[11]. The JGPN database contains coded, numerical and free-text information from electronic health records (EHRs) of over 360,000 patients. Coded and numerical information includes ICPC diagnostic codes (codes used in primary care indicating the presence of DMII, COPD or CVRM), Anatomical Therapeutic Chemical Classification (ATC) codes for medication use, and laboratory findings. Free texts consists of clinical notes of all patient consultations, i.e. presented complaints, results of physical examination, clinical reasoning of the general practitioner (GP) and the management plan. These data are registered as part of routine daily clinical practice. Records of all patients aged ≥18 years were selected for linkage.

Secondary care data selection

Routine secondary care data were extracted from databases from the three hospitals where PCPs in the region generally refer to. Selection of relevant patients in secondary care was based on age (≥18 years), 4 digit postal code (patients with postal codes matching those of the involved PCP practices) and the registration of a relevant diagnosis treatment combination (DTC) code (DMII, COPD, CVRM) within the study period. Records of these patients were selected for linkage by the local data-management team of each participating hospital.

Record linkage

The linkage process included two steps. First, a “pre-match“ was performed, to determine which patients were registered in both the hospital datasets and the JGPN. This pre-match was based on the hospital data to make sure that all patients who were seen in any of the three hospitals had a PCP who was affiliated with the JGPN.

To perform the pre-match, full postal codes, date of birth and sex were retrieved for each selected patient in both JGPN and hospital data. These “patient identifiers” were sent to a trusted third party using a secured pathway, built specifically for such data-transfer. Based on these patient identifiers, the trusted third party created pseudonyms for each patient using the same algorithm. Therefore, these pseudonyms were identical for patients with the same postal code, date of birth, and sex. The use of pseudonyms enabled linkage on an individual level, but prevented the possibility of tracing back the linked data to individual patients.

In the second step, all relevant patients were selected for data extraction. For inclusion of the relevant secondary care patients, all matching patients were included. For inclusion of the relevant primary care patients, all (matching and non-matching) patients with a relevant ICPC code for DMII, COPD or CVRM were included, to ensure inclusion of all patients who were seen in primary care with a referral condition (whether or not they were actually referred).

Analysis of the extracted data

After data selection and linkage, the “IF” and “THEN” parts were analysed in relation to each other. In case an “IF” condition was present, the prevalence of the corresponding “THEN” action was determined. Using the example presented in **Box 1**, this meant that in case primary care data revealed triglyceride levels above 5 mmol/L (“IF” condition in CPCA CVRM), the secondary care data was searched for a registered visit of pseudonymized patient X at the internist vascular medicine (corresponding “THEN” action). In addition, the secondary care data was searched for registrations of pseudonymized patient X at other SCPs, who could be relevant but were not recommended in the CPCA.

Visualization and discussion of mirror data

Finally, the “IF”-“THEN” statements were presented in table format. **Figure 3** shows a simplified example of such a table. Formative intervention was proposed to support PCPs and SCPs in discussing the data openly (rather than judging their performance), and was conducted according to Change Laboratory methodology[12,13].

IF	**THEN**	**THEN**
Condition for referral according to CPCA	Referral to relevant specialism, according to CPCA	Referral to relevant specialism, but not according to CPCA
“The situation below is present at PCP visit”	*“There has been a visit to the recommended SCP in …% of the situations”*	*“There has been a visit to another SCP in …% of the situations”*
Situation 1	% of IF	% of IF
Situation 2	% of IF	% of IF
Situation 3	% of IF	% of IF
Situation 4	% of IF	% of IF

Figure 3 Mirror data example: in case of an observed condition for referral according to the CPCA (left), observed prevalence of the corresponding action is provided (middle and right).

Ethics

Research using only patient files is not subject to the Dutch Medical Research Involving Human Subjects Act (WMO). Hence the Medical Ethics Review Committee (METC) waived from the necessity for formal approval. Dutch Civil Law allows the use of electronic health records for research purposes under certain conditions. Moreover, under certain conditions – e.g. when very large numbers of patients make it a lot of effort to obtain informed consent, or the possibility of selection bias when obtaining informed consent, Dutch General Data Protection Regulation (GDPR) implementation allows to collect data without informed consent.

Results

Roadmap to the RTD

Figure 4 shows the domains in which conditions had to be met, challenges occurred, and choices had to be made. It also shows the corresponding steps towards developing the RTD.

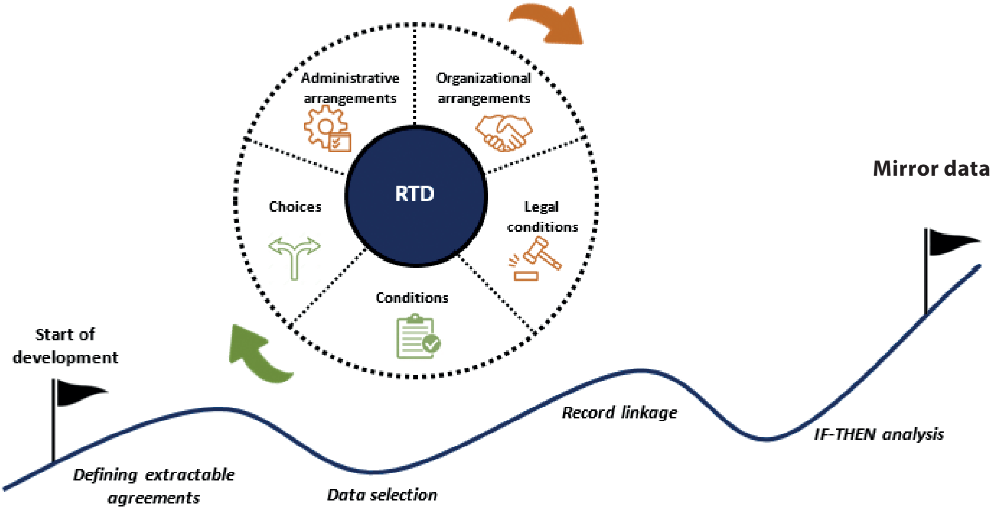

Figure 4 A roadmap towards a regional transmural care database suitable for generating routine mirror data.

Challenges

Administrative and organizational arrangements

Building an RTD requires collaboration with many different parties who work together within the region. The hardest part of establishing such a collaboration was not to generate the enthusiasm for starting collaboration, but rather to officially arrange and maintain momentum needed for progress. Especially the collaboration with large organizations, each with their own dynamics in administrative procedures and many simultaneous projects, prioritizing the signing of agreements, such as data collaboration agreements and data processing agreements, was a considerable hurdle. Although measures were taken to meet the sensitivity of health care data in the design of the process (e.g. generating pseudonyms, using a trusted third party for linkage and extracting coded or numerical information only), this has been difficult to communicate with all those different professionals involved. As a result, record linkage and data selection procedures, which in itself were not very time-consuming, experienced major delay. Promoting administrative/managerial ‘buy-in’ and repeatedly engaging in face-to-face activities stakeholders from the different organizations, with different levels of hierarchy and dissimilar positions, eventually promoted a sense of trust, shared responsibility and ownership, and enabled the required steps to progress[14,15].

Legal requirements

In addition, before starting any data processing procedure, a data protection impact assessment (DPIA) was required to identify and minimize the data protection risks. Other legal steps to consider included the development of a data management plan, the establishment of collaboration agreements, and the requirement of data transfer and processing agreements for the legality of the data transfer itself and the processing of these data against privacy requirements. A detailed step-by-step checklist of these and other potential legal requirements for record linkage in international context was developed, and is provided in **Box 3**.

Data availability

Once record linkage, data selection and transfer of secondary care data for enrichment of the primary care dataset was established, the interpretation and analysis of data faced challenges. Data were not fully complete – e.g. if a patient was referred to another hospital outside the study region, we did not have access to this patients’ secondary care data – or entirely homogeneous in composition – e.g. when different hospitals had different organizational arrangements for data registration. The incomparability of data can be illustrated with the example provided in Box 1: the CPCA addressing CVRM included agreements advocating referral to the internist vascular medicine (THEN). However, not all hospital registrations had such specific information availed, e.g. some hospitals limited registrations to the aggregate level (‘internal medicine’) instead of subspecialties.

Another challenge that touched on the availability of data followed from the choice to extract only coded and numerical data. Again using the example of **Box 1**, **Box 4** provides an illustration of how we dealt with that issue. “Lifestyle adjustments” required access to open text fields so they were left out in the IF-THEN statement. Likewise, “potential medication” could not be captured in coded and numerical data, but with support of the CPCA working group (**Figure 1**, step 5) could be interpreted as “lipid modifying agents”, and could as such be included in the “IF”-“THEN” statement. The ambiguous (non-extractable) recommendation to “consider a referral” was interpreted as ”refer”.

Box 3 Checklist for legal data processing steps; collection, linkage and storage.
Note that procedural steps may vary by setting

1. Check General Data Protection Regulation (GDPR) compliance
- This check is performed by all local data processing parties to assure that procedures are in compliance with the revised EU privacy regulations (http://gdpr-legislation.co.uk/) and all country and regional specific regulations of participating sites.

2. Consent for project including data collection, linkage, storage, access and analyses, such as University ethics / institutional review board (IRB) and, if needed, the respective National health organisation.

3. Consent for <u>routine care data;</u> collection, linkage, storage and access (generally as 'package') following local regulations of network contracts. This may include:
- Patient consent; following national requirements for data handling
- Data holder consent; PCPs provide consent in person, by representing committee or as part of data use agreement.
- Dataset controller/management consent; generally through data-management of EMR / advisory board / board of representatives, usually after;
  - ☐ Agreeing on local conditions for data collection, linkage and storage (safe haven)
  - ☐ Privacy procedures*
  - ☐ If necessary; development of anonymization tool
  - ☐ Local contract

4. Consent for other <u>(registry) data;</u> collection, linkage, storage and access (generally as 'package'), and if applicable, for additional datasets
- Patient consent; following national requirements for data handling
- Dataset controller consent; generally through advisory board, usually after;
  - ☐ Agreeing on local conditions for data collection, linkage process and storage (safe haven)
  - ☐ Privacy procedures*
  - ☐ Local contract

5. Consent for data storage and access (parallel to 6)
- Consent on requirements for analyses
- Consent on possible and feasible access
- Local contract

6. Data collection – routine care data / additional datasets (parallel to 5)
- Local collection and storage contract
- Local data application
- Local coordinator and data-management of registries guide data redaction / collection process
- Use of anonymization tool if required

7. Linkage (parallel to 4)
- Local contract with safe haven, including
  - ☐ Consent on linkage process and use of safe haven
  - ☐ Conditions for storage and requirements for analyses
  - ☐ If necessary; Additional privacy procedures*
  - ☐ Local contract with all parties
- Local contract with Trusted Third Party (TTP)
- Check consent of data controllers, safe haven, TTP
- TTP performs linkage as agreed upon guided by local coordinator and local data controllers

8. Collection, storage, harmonisation and access of linked data
- Safe haven approves Linked dataset
- Linked data stored in Safe haven
- Data harmonisation performed by data scientist and data manager, guided by local coordinator.
- Data access is continuously monitored

* Including Data protection Impact Assessment (DPIA)

Box 4 Example of adapted translation from the CPCA CVRM

CPCA agreement	Consider a referral or consultation to [a cardiologist or other relevant specialist in] secondary care if triglyceride levels remain > 5 mmol/L despite lifestyle adjustments and potential medication.
Translated to	IF – triglyceride levels are above 5 mmol/L despite potential medication (e.g. ATC code for lipid modifying agents) THEN – there is a registered visit at the cardiologist or other relevant specialist (e.g. internist)

Discussion

In this paper, we present a systematic approach (”roadmap”) towards developing a regional transmural care database suitable for generating routine care mirror data on joint transmural care between PCPs and SCPs. We formulate an approach that incorporates all technical steps in data selection and linkage, as well as the substantive steps that need to be taken. Informed by our own experience, we elaborate on the challenges that need to be addressed in developing an RTD from routine care data registries. Moreover, we illustrate how transmural agreements can be translated to data-units that are extractable from these routine care data, and how these data units in turn can be translated into understandable mirror data to support negotiations on interprofessional learning.

Given the limitations of the RTD (e.g. that routine healthcare data are in essence not gathered for feedback purposes[16]) and the nature of the CPCAs (not a protocol, but a guideline), the RTD should not be used as a comprehensive and objective assessment of quality of care, but as a way to guide discussions and serve a regional learning healthcare system.

This study is the first to provide a comprehensive (technical as well as practical) and reproducible approach to developing an RTD. Transmural record linkage has been described before. In the UK, for example, the Clinical Practice Research Datalink (CPRD) research service links primary care data to other patient level datasets[17]. Similarly to the role of the trusted third party in the current project, CPRD receives patient identifiers from general practice and other relevant datasets (e.g. hospital episode statistics). However, this study adds a description of the conditions, assumptions and considerations during this process of record linkage, and during the interpretation and translation of these linkages. Particularly given our experience that the main challenges are not technical in nature, comprehensive understanding of these steps is crucial. Our roadmap makes these challenges easier to overcome, hereby enabling transmural record linkage, which is vital to truly understand what is going on in the healthcare system.

Developing an RTD opened up plenty of opportunities. To start with, the RTD provided an indication of the use and adoption of transmural agreements within the region. This insight increased the visibility of actual transmural collaboration in daily practice, which in turn supported the discussions between different healthcare professionals aiming to improve their collaboration. These discussions are not considered to improve implementation of the CPCAs in a direct and measurable manner, but rather indirectly through promoting awareness of the own and others' behaviour, and by getting to know each other. This approach may form an equally valuable contribution to a learning health care system as it drives the collaborative health care system out of a place of judgement and control to a place for reflection and inquiry[18].

In addition, observations in the RTD can contribute to the development of future CPCAs, or guidelines in general, by exposing gaps and challenges in collaborative transmural care and in the implementation of (regional) guidelines. Finally, the indication of the adoption of CPCAs provides insight in the efficiency as well as the feasibility of implementing guidelines. Repeating RTD observations over time allows iterative improvement of guidelines, care and implementations strategies. In the current project discussions were conducted within the own improvement cycle of each participating organization. The next step would be to realize a regional improvement cycle that is systematically embedded.

Discussions on the RTD – rather than the RTD itself – opens up possibilities to reflect on daily practice, to explore the different wishes and goals regarding that practice, and to search for the bottlenecks and potentialities. This way, the RTD can be interpreted as a tool to bridge across professional boundaries rather than as an assessment tool. It promotes the ability to explore, clarify and challenge multiple professional views about the workflow and the roles that each professional plays in healthcare delivery[19]. Such an evaluation of daily practice can support PCPs and SCPs in (1) improving consensus on the incentives for patient referral, and (2) discussing and improving their referral behaviour. This way, the RTD supported a learning healthcare system, aimed at joint care for patients with chronic conditions, more specifically sharpening the actual practice of referral and back referral – ultimately to realize that patients receive the right care.

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5

Dealing with discontinuity in cancer care trajectories: patient's solutions

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Abstract

Introduction

Patients with cancer require specialized care from different care providers, challenging continuity of care in terms of information, relation and/or management. The recognition of discontinuity of care has led to different initiatives by the healthcare system over the years. Yet, making use of the theory on boundary objects and brokers, this research explores the active role of patients themselves in resolving discontinuity along their care trajectories.

Methods

Semi-structured interviews were conducted with 33 patients to unravel the discontinuities that they experience and their attempts to resolve these. Interview data were analysed using directed-content analysis informed by concepts from boundary crossing literature (i.e. data were searched for potential boundary objects and brokers).

Results

To re-establish continuity of care patients actively use the objects and people provided by the healthcare system when these meet their needs. Patients also introduce own objects and people into the care trajectory. As such, information and management discontinuity can typically be resolved. Relational continuity appears to be more difficult to resolve, in some cases leaving patients to take drastic measures, such as changing care providers.

Discussion

The use of boundary crossing theory in improving care from a patient perspective is relatively novel. When patients and providers together address the objects and people that support in establishing continuity of care, a continuous care process may be encouraged. We advocate an integrated approach, rather than provider's or healthcare system's initiatives exclusively, to patient care and continuity.

Key points for Decision Makers

- Patients are very active in (re-)establishing continuity of care across their own care trajectories, but relational continuity in particular requires special attention and efforts from both patients and providers.
- The boundary crossing theory, addressing how people bridge and connect different settings, may support patients and providers to establish continuity of care in the current context of increasingly fragmented healthcare systems where patients are seen by multiple doctors in different settings.
- An integrated approach towards continuity of care that takes full advantage of both provider's and patient's roles may provide new opportunities for healthcare to enhance the patient experience.

Introduction

"*When you start talking about a radiologist and an internist, an oncologist and an assistant here, and an intern, resident – well, how should I know?*" (patient being treated for cervical cancer). Patients requiring substantive specialized care are often treated by different care providers. Because of complex needs, they receive consultation and treatment from multiple healthcare specialties. Yet, as a result of specialization patients experience a lack of coordination that integrates the care provided by different care providers[1,2]. Continuity of care is threatened as a consequence[3-5]. Patients are required to navigate between different care providers, but experience boundaries between them. These boundaries are typically considered as relatively impermeable barriers to communication and coordination, and undeniably lead to discontinuity of care with occasionally severe consequences (e.g. psychological distress or medical errors with higher rates of hospitalization)[6-12]. Meanwhile, research has convincingly shown that boundaries are not insurmountable and offer opportunities for change[13-18]. Accordingly, by understanding the discontinuities that patients experience, and considering these as opportunities to re-establish continuity, healthcare systems may optimize their approaches towards the increasingly specialized patient care[19].

Patients experiences of continuity and discontinuity can be understood along three dimensions: informational, relational and management[7]. Discontinuity along the informational dimension refers to a lack of relevant patient information amongst different care providers (e.g. on prior events), but also includes deficits in the care provider's knowledge about the patient's preferences, value and context. The importance of (ongoing) relationships between patients and providers is captured in the relational dimension: relational discontinuity refers to the absence of such relationships. Furthermore, discontinuity along the management dimension refers to circumstances in which patients receive care from different providers that is not connected in a coherent way[5,10]. Continuity and discontinuity of care should not be viewed as rigid opposites, but as two ends of a spectrum: care experiences may tend, to a greater or lesser extent, towards one end[20]. The recognition of discontinuity of care had led to different initiatives by the healthcare system over the years (e.g. facilitating communication via the electronic medical record, improving patient education and/or introducing discharge planning), but the active role that patients themselves play is typically overlooked.

Accordingly, in contrast to much research on continuity and discontinuity of care, which has largely focused on how discontinuity is resolved (and continuity established) from a provider or organizational perspective, this research invites patients to consider what discontinuities they experience, and how they (attempt to) resolve them. The theory on boundary crossing is particularly helpful to improve understanding of the relatively unknown role of the patient in resolving discontinuity at boundaries[17,21,22]. Within the field of integrated care, as in other fields concerned with collaboration across boundaries, this theory has received growing interest[23,24]. It offers potential approaches to cross boundaries, the most notable approaches are boundary objects and brokers. Boundary objects and brokers are objects and people, respectively, that bring different social worlds or working practices together, or bridge the gap between them[25-28]. Boundary objects are typically portrayed as "both inhabiting several intersecting worlds and satisfying the informational requirements of each of them" – hence they are a "means of translation"[22,29]. According to Star (2010), boundary objects can be interpreted flexibly, are tailored to local information and work needs, and are dynamic in use within and across practices[17,29]. Brokers – sometimes referred to as boundary subjects – have been depicted as "interlocutors": translating, coordinating and aligning different perspectives or meanings across practices[30-33]. As boundary objects and brokers arise from both information and work needs, we posit that they may resolve discontinuity in care trajectories along all three dimensions depicted above[29].

Examples of objects and people introduced by the healthcare system to bridge boundaries (i.e. *intended* boundary objects and brokers) are numerous (e.g. the electronic medical record or a care coordinator), but the necessity and productivity of these objects and people – as experienced by patients – remains a largely unexplored area. As the bridging capacity of boundary objects and brokers is not an inherent property of the object or the person, but rather comes to life in active work and sense-making, we aim to explore whether the objects and people that are introduced by the healthcare system (i.e. intended boundary objects and brokers) are productive to patients[22,25,34]. Secondly, we aim to explore whether patients introduce objects and people themselves to (re)establish continuity of care. In doing so, the active contribution of patients, as potential levers for effective change, might be more successfully utilized[19].

Methods

Study design and sample

This study is part of a larger action research project on collaborative care, called ZOUT (a Dutch acronym for "The right care at the right place in Utrecht"). The aim of that project is to explore the current interprofessional collaboration within a regional healthcare system (Utrecht, the Netherlands) but especially to delve into possibilities for improvement.

In this exploratory study, interviews with patients diagnosed with cancer were conducted to unravel the discontinuities that patients experience and their attempts to resolve these. Patients diagnosed with cancer were selected because of the inherent complexity and fragmentation of cancer care, for which achieving continuity of care across the cancer care pathway is particularly complex. Patients were invited to participate by email based on their indication in another, related study that they could be approached for comparable research into cancer care. Of the 127 invited patients, 88 patients did not respond and 6 did not want to participate. The remaining 33 patients received an information sheet about the study, including study procedures, and were then approached to schedule an appointment for the interview.

Data collection and analysis

Using video or audio calls, two researchers with backgrounds in biomedical and educational science (DV and SeH) conducted semi-structured interviews with 33 patients diagnosed with cancer. The interview questions were pilot tested in an interview with both researchers present. At the start of the interviews, consent was obtained (in addition to the written consent in the other, related study that they participated in) to record the interview. Patients could ask questions about the information they had received in advance. On average, an interview lasted 55 minutes (range 23-95 minutes) and followed the interview guide that focused on mapping the patient trajectory and the collaboration between different healthcare providers in particular (electronic supplementary material). In light of the theoretical nature of the boundary crossing concepts, patients were not asked to identify (dis)continuity, (intended) boundary objects or brokers themselves, rather these were identified in the patient's stories by the researchers.

The interviews were transcribed ad verbatim and anonymized, and uploaded to the qualitative data analysis software NVivo 12 for analysis. We used the directed-content analysis method informed by conceptually theoretical concepts stemming from the literature on boundary crossing[35]. These concepts guided the initial development of the codebook, and were complemented by inductive coding. Each transcript was coded independently by two researchers (DV, SeH), with discrepancies reconciled through negotiated consensus. A third and fourth researcher (EdG, LB) were consulted when consensus could not be reached.

Coding matrices and crosstabs were used to explore the experience of (dis)continuity across patients, and to find out if and how patients responded to that. For each patient, several expressions of the same (dis)continuity experience were counted as one. Data saturation was considered to have been reached, although saturation is a contested concept in the qualitative research domain[36]. Given the fact that the interpretation of data was primarily guided by the researcher's theoretical and methodological expertise on (dis)continuity and boundary crossing, participants were not asked to provide feedback on the data[36]. The standards for reporting qualitative research (COREQ) were applied[37].

Results

At one or several points across their care trajectories, all 33 patients experienced continuity of care, and 30/33 patients also experienced discontinuity of care (**Table 1**). Of the three dimensions of discontinuity, discontinuity along the relational dimension was experienced most often, across all age categories and types of cancer and independently of gender. Relational discontinuity referred to either a lack of trust or a sense of being known or seen as well as the lack of sustainable, ongoing relationships:

> *Well, I'd have liked to wait a day longer to discuss the results rather than talk to another doctor about it, and to have a choice about that. So I'd have liked them to say 'You can come on Monday and talk to another doctor than the one who operated on you or you can come on Tuesday and talk to your own surgeon.' (patient 20)*

This excerpt signals how discontinuity in one domain can be associated with pursuing continuity in another. Providing test results quickly (important for information continuity) in this case resulted in discontinuity in the relational domain (receiving these results from another care provider). Experiences of information discontinuity were mostly the result of conflicting information: *"It's the surgeon telling me 'I'd have your lymph nodes removed' even though the dermatologist had said 'Are you sure you really want to have that done?'"* (patient 5).

The majority of the patients, except for those who suffered from skin cancer, also experienced a form of discontinuity in the management of their care. Particularly often, patients missed a coherent referral management strategy addressing their psychosocial problems associated with patients' illness experiences: "*Well, in the hospital you're in the hospital and you have an operation and what I really miss is the psychological part [...] Because in my experience, you have to check out everything for yourself, you have to ask everywhere. Just give us some guidance.*" (patient 33).

Table 1 shows that, regardless of the extent to which patients experience discontinuity, the vast majority of them uses (initiated by the system) or introduces (initiated by themselves) objects and people to (re)establish continuity of care.

Table 1 Number of discontinuities and use of objects and people for each patient

	Age	Gender	Type of cancer	Discontinuities[1]				Objects	Objects	People	People
				T	I	M	R	Initiated[2]	Introduced[2]	Initiated[2]	Introduced[2]
1	50-70	Female	Intestinal	0	0	0	0	✔	✔	✔	✔
2	70-80	Male	Prostate	0	0	0	0	-	-	✔	✔
3	50-70	Male	Skin	0	0	0	0	✔	✔	✔	✔
4	50-70	Male	Multiple	1	0	1	0	✔	-	✔	-
5	70-80	Male	Skin	1	1	0	0	✔	-	✔	✔
6	50-70	Male	Skin	1	0	0	1	✔	✔	-	✔
7	70-80	Female	Skin	1	0	0	1	-	-	-	-
8	50-70	Female	Breast	2	0	0	2	✔	-	✔	✔
9	50-70	Male	Intestinal	2	0	1	1	✔	-	✔	✔
10	80+	Male	Skin	2	1	0	1	✔	-	✔	✔
11	50-70	Female	Breast	3	3	0	0	✔	✔	✔	✔
12	<50	Female	Breast	3	0	2	1	✔	✔	✔	-
13	<50	Female	Skin	3	2	0	1	-	✔	✔	✔
14	50-70	Female	Breast	4	2	0	2	✔	✔	✔	✔
15	70-80	Female	Breast	4	0	2	3	-	-	-	✔
16	70-80	Female	Intestinal	4	0	1	3	✔	-	✔	✔
17	50-70	Female	Lung	5	0	0	5	✔	-	✔	✔
18	50-70	Male	Multiple	5	3	3	2	-	-	✔	✔
19	50-70	Female	Breast	6	4	5	0	✔	✔	✔	✔
20	50-70	Female	Breast	7	5	1	4	✔	-	✔	✔
21	50-70	Female	Breast	7	2	2	4	✔	-	✔	-
22	80+	Female	Multiple	7	1	5	2	✔	✔	✔	✔
23	50-70	Female	Multiple	7	1	6	1	✔	-	✔	✔
24	50-70	Female	Multiple	7	3	3	3	✔	✔	✔	✔
25	<50	Female	Breast	8	1	3	5	✔	✔	✔	✔
26	50-70	Female	Breast	9	4	5	5	-	✔	✔	-
27	70-80	Male	Intestinal	9	6	6	5	✔	-	-	✔
28	80+	Female	Breast	10	6	5	2	✔	✔	✔	✔
29	50-70	Male	Intestinal	10	8	6	3	✔	✔	✔	✔
30	70-80	Male	Multiple	11	2	7	5	✔	-	✔	✔
31	70-80	Female	Breast	12	3	6	4	✔	✔	✔	✔
32	<50	Female	Cervical	12	4	3	6	✔	✔	✔	✔
33	50-70	Female	Multiple	24	14	10	6	✔	✔	✔	✔

[1] *T = total; I = informational; M = management; R= relational*

[2] *Initiated = initiated by the system; Introduced = introduced by patients themselves*

** Separate numbers may exceed the total number of (dis)continuities due to overlap along the distinct dimensions of (dis) continuity.*

Examples of objects and people that patients used or introduced across their care trajectories are listed in **Table 2** and discussed below.

Table 2 Examples of objects and people patients used to re-establish continuity of care

Object	Object	People	People
Initiated[1]	Introduced[1]	Initiated[1]	Introduced[1]
Electronic medical record	Notebook/diary	General practitioner	Self
Information leaflet	Recorder	Case manager	Partner
Appointment card	Internet forum	Nurse	Friend

[1] *Initiated = initiated by the system; Introduced = introduced by patients themselves*

Objects initiated by the system to establish continuity

Numerous objects are initiated by the system and identified by patients: 27/33 patients (82%) recognized that the system initiated an object to establish continuity of care (i.e. *intended* boundary objects). These objects ranged from the electronic medical record to patient information leaflets. The use of objects occurs across all ages, sexes, and among all types of cancer.

However, not all of these objects were deemed necessary by patients, or perceived as enhancing the patient experience: *"No, I didn't feel the need for them [information leaflets]."* (patient 1). Also, the effectivity of the objects was questioned. A patient explained that she wanted to consult her medical record to establish (information) continuity, but that accessing her medical record in fact only had the opposite effect and caused confusion: *"Well that really, uhm, uhm, freaked me out. And I read it on Friday afternoon, just before the weekend. So there's no one available then."* (patient 20).

In line, other patients recognized the difficulty to comprehend medical information themselves: *"Well, then you just think: what is this actually saying? Because I don't know what it means."* (patient 33). They avoid using the object for that reason and advise care providers accordingly for using the medical record: *"If I could offer one piece of advice to uhm… uhm… doctors, it would definitely be to remember that people read their own medical records too."* (patient 20).

Objects introduced by patients to establish continuity

Patients also actively introduce objects themselves to establish continuity of care. It became clear from about half of the patient stories (17/33) that they introduced one or several objects throughout their trajectories. The objects that patients introduced range from the use of notebooks to prepare and answer questions to organizing all information in one folder:

> *So I had a notepad at home and I'd think, oh yeah, I have to ask about this and that. Because when you're sitting there, you can't think of any questions. So I actually write things down, when I have an important appointment I always write everything down. (patient 14)*

> *Yes. I made a file for the breast operation... because it's all pretty confusing and you can look up a lot of things on the internet... so I thought, well I'll just make a separate folder [...] I even have the operative report in there. I asked for it afterwards [...]. And that's, that's, that's extra information you don't get when you come in for a check-up. (patient 28)*

Relying on objects for information, management and relational continuity

Although the number of experiences of discontinuity along the informational dimension across all patients was the lowest, it most often elicited the use of objects. For example, the use of the internet: *"No, no, not really. Because I remember I googled it and then I was like uh oh, it's this, shit, this is it."* (patient 13). Object use for establishing continuity along the management dimension was often related to bring clarity in turbulent times ("*it is a rollercoaster*"), for example using an agenda within the electronic medical record.

Relational continuity was the only dimension of continuity for which objects appeared of little help. In exceptional cases, patients resolved discontinuity along the relational domain using objects, avoiding face-to-face interactions in doing so:

> *No, that's uhm... we had to fill in a questionnaire [at the hospital] about our dealings with our general practitioner, I think. And my husband wrote that down [poor communication with general practitioner]... And I think she read it and then she started showing more of an interest. (patient 16)*

Yet, patients occasionally chose to leave the relational discontinuity unresolved and sought healthcare somewhere else instead:

> *So, uhm, well, then you just wait a few weeks for her and you think: okay, nothing's going to come of this. Hahaha. And then I lost all motivation to have another check-up in July. I got a call to go for a check-up [from hospital A] and I said: 'I'm out of the country and uhm I'll make an appointment another time.' Anyway, I did do that later at hospital B. (patient 26)*

People initiated by the system to establish continuity

In addition to the use of objects by the majority of patients, most patients (29/33) also referred to at least one person introduced by the healthcare system to help them throughout their care trajectory (i.e. *intended* brokers). These people included the nurse practitioner (especially in the case of breast cancer) and the general practitioner.

However, comparable to what patients experienced regarding objects provided by the system, not all people that the system offers to help enhanced the patient experience. Disagreement on the necessity and effectivity of the general practitioner to translate and coordinate care was the highest. Some patients expected the general practitioner to have this translating and coordinating role and were disappointed if he or she did not fulfil this role. Others recognized this role of the general practitioner but had no need for that or considered it ineffective:

> *Patients have a lot of questions a lot of the time and they ask them at the most impossible moments and they need somewhere to go to get answers. And their general practitioner doesn't know enough of the whole picture to be able to make a decision. It has to be someone who has a close relationship with the specialist. (patient 27)*

Similarly, the role of the nurse practitioner was appreciated differently by different patients. However, most of the patients considered the nurse practitioner important for continuity of care within the hospital:

> *No, no. No, I just think that they really shouldn't underestimate the role of the nurse practitioner... And there should also really uhm....uhm.... be time for that, say... because you see an oncologist, a surgeon, a, a, a, uhm.... plastic surgeon, a radiologist. You see them all and you build up relationships with them, but they aren't constant factors and she's the only constant factor. (patient 24)*

People introduced by patients to establish continuity

Throughout their care trajectories, 28/33 patients also actively introduced people to establish continuity themselves: family and friends were often taken to consultations or asked for help otherwise. In other situations, patients translated between different perspectives themselves.

Patients translated and coordinated between different healthcare providers or organizations, either because they seized that role or because they had the feeling that the design of the healthcare system requires them to do so: *"Of course I made sure by asking the surgeon and the dermatologist whether their findings would be passed on to my general* *practitioner too."* (patient 10). To some extent, either or not using objects, patients may also act as an interlocutor between their own experiences. A notebook, for example, may act as a means to manage knowledge from diverse practices *within* a person over time. In addition, they bridged between the healthcare system and their family and friends:

> *So my sisters saw it, my husband, my mother. I said, if you want, you can come with me to where the screens are and you can see where I am now and what they're doing to me. That way you'll see that it's not scary. It's intense, but it's not scary [...] So, well, they said that it did help them understand what I'm going through. (patient 32)*

Moreover, occasionally people and objects were employed simultaneously: *"I printed out two questionnaires, one for myself… And the other one for my friend, or whoever was going with me, so that we could copy down the answers on it."* (patient 14).

Relying on people for information, management and relational continuity

Patient experiences with regard to employing people to (re)establish continuity of care were mostly related to experiences of discontinuity along the informational and management dimension. Again, discontinuity along the relational dimension remained mostly unresolved. Following management discontinuity (e.g. long waiting times) support was often found amongst family members or friends. When patients faced information discontinuity, they often felt the need to align perspectives themselves:

> *And, if I remember correctly - it was almost five years ago now - I noticed a subtle difference between the dermatologist and the surgeon [...] No, that just makes it easier. It did make me feel like: This is real life. This is a real choice, it's really up to me. (patient 5)*

When patients experienced relational discontinuity, intended brokers by the system were of less help. In line with the earlier excerpt on how the efforts from care providers to minimize (information) discontinuity only increased (relational) discontinuity, people introduced by the system may also have the opposite effect of what was intended. In fact, when the introduction of an intended broker raises expectations of relational continuity in patients, and these expectations are not met, things only got worse:

> *And when I send an e-mail uhm to the attending nurse in hospital B and I get a reply four days later saying 'Go see your general practitioner,' then I'm like: thanks, but no thanks. So I broke off all contact with her. I was like, I really don't want to have anything to do with her anymore. I also told my specialist, don't ever mention her name to me again. It made absolutely no sense, I said. It would defeat the purpose. (patient 27)*

Discussion

In considering new interprofessional approaches towards increasingly specialized patient care, the healthcare system might benefit from understanding the discontinuities that patients experience, and if and how they re-establish continuity. This study explored patient's experiences with regard to discontinuity along the informational, relational and management dimension, as well as their actions to deal with it. Based on our analysis from a boundary crossing perspective, this study demonstrates that patients are very active in resolving discontinuity (or establishing continuity) across their own care trajectories. They often employ the objects and people that are provided to them by the health care system (i.e. *intended* boundary objects and brokers), especially in the case of information and management discontinuity, but also introduce objects and people to establish continuity in their care trajectory themselves.

Yet, the productivity of objects and people in establishing continuity of care, and accordingly their classification as boundary objects and brokers, should not be taken for granted. The current study showed how, information leaflets, for example, introduced by the healthcare system as an (intended) boundary object, do not always have a bridging function. Similarly, a general practitioner may be a broker, but may also be experienced as 'just one of the care providers involved'. Moreover, theoretically the objects introduced by patients in this study (e.g. the notebook or the self-created folder with collected information) to establish continuity may not (yet) be considered boundary objects in the traditional sense of the concept. Currently, these objects appear to be used only by the patients themselves, and can thus not be said to 'inhabit intersecting worlds', even though patients did report how these objects satisfied their own informational requirements in trajectories of care across different practices[22]. Accordingly, we argue that, rather than debating the definitions of boundary objects and brokers, it is particularly the underlying rationale of boundary objects and brokers – bridging different worlds – that may help in understanding and advancing continuity of care. As such, the added value of using concepts as boundary objects and brokers to advance continuity of care does not lie in prescribing the use of certain objects and people, but in understanding why and how objects and people support and sustain continuity of care differently for different patients.

The extent to which objects and people bridged different worlds in the current study varied for the three dimensions of discontinuity. Patients often relied on objects and people to resolve discontinuity along the informational dimension, and to a lesser extent in response to discontinuity along the management dimension. Although discontinuity along the relational dimension was experienced most often, it remained largely unresolved – patients rather changed care providers to avoid it. In the light of previous research pointing to relational continuity as the dimension of continuity that patients value the most, this is particularly relevant[7,38,39]. The core of the difference may be in the nature of the discontinuity: the nature of the patient-provider relationship prevents the use of a 'cookbook' approach and requires a more contextual, individualized understanding of individual needs and preferences[40,41]. Relational continuity is a 'two-way street' where the face-to-face interaction between patient and provider is key. In contrast, information and management continuity benefit from general initiatives at the system level, e.g. by initiating *intended* boundary objects (e.g. automated exchange via the electronic medical record) or *intended* brokers (e.g. the general practitioner) to establish continuity across a patient's trajectory.

Relational continuity may rather benefit from initiatives on a more personal level, specifically bridging differences between care providers and patients, i.e. 'humanization of care'. Humanization of care adopts a more holistic perspective to the process of care and their interactions compared to other, well known concepts such as patient-centred or person-centred care[42]. It explicitly focuses on all the stakeholders involved in the care process (i.e. patient as well as provider) and accordingly may best address the relational aspect of care. Patient-provider relationships mostly benefit from a basis of trust and a sense of being known or seen[43-45]. Especially when patients expect such properties in relationships with their providers (in their relationships with *intended* brokers in particular), relational discontinuity is a hidden risk. Yet, our findings indicate that patients may face difficulties to raise relational discontinuity towards their providers. Accordingly, the role of providers may be to actively seek patient feedback, put the subject of relational continuity explicitly on the agenda with patients and develop more positive and sustainable relationships with their patients[46,47].

While the theory on boundary crossing is more often used in considerations to improve interprofessional care, its use in understanding care from a patient perspective is relatively novel[48,49]. The importance of involving the patient perspective has been widely recognized over the last decade, but research is often limited to rather 'passive' patient participation[50-52]. Again, the question is often about how patients can be empowered to play an active role in their care process, as if patients are not yet seen as active players[38,53,54]. By approaching the care process the other way around, starting from the role of the patient, this study responds to previous calls to shift from the traditional view of the patient as a "passive recipient of care" to the new view of patients as "integral to the improvement of the innovation process"[55-58].

This study revealed that patients already make a substantial contribution to establishing continuity of care. In contrast to previous studies, we found that patients are, to different degrees, active in managing their care[7]. Their active role has turned out to be most evident in situations of discontinuity along the informational and management dimension. Our results suggest that patients employ (boundary) objects especially to resolve information and management discontinuity, and that they take on a coordinating role, or even broker, mostly when they experience discontinuity along the informational dimension. Accordingly, instead of continuing to explore what patients might be able to add, we advocate (1) gaining more insight into what patients already contribute, and (2) providers to start routinely asking their patients about, and acting upon, the objects and people they rely on to do that while explicitly addressing expectations on relational continuity. It is time to put a hitherto mainly theoretical concept in practice: addressing (intended) boundary objects and brokers in daily care may provide opportunities to respond to those and to take healthcare to a next level.

The main strength of this study is the examination of patient experiences from a boundary crossing perspective, highlighting patient's active roles in establishing continuity of care by using and introducing objects and people (intended boundary objects and brokers). A limitation may be that these objects and people were identified in the patient's stories by the researchers rather than by the patients themselves, and may thus be underestimated. Furthermore, the majority of the patients included in this study had practically completed their care trajectories. Emotions and feelings regarding their experiences of discontinuity may thus have been weakened or forgotten. However, since we primarily focused on their actions upon experiences of discontinuity – and not on the experiences themselves – we do not expect this to have had a significant impact on our results. Rather it may have helped because patients could now view their care process from a distance.

Advocates for patient involvement argue that seeking the active contribution of patients and families in the coordination of care can help mitigate the complexity of the specialized healthcare system, and lead to improvements in care continuity. This study extends and develops the line of argument for patient participation by exploring the role that patients already have in crossing the boundaries between multiple care providers. We do not argue for initiatives from the healthcare system exclusively to resolve this in the future, but for an integrated approach in which the contributions of all are acknowledged to collectively improve care. Improved understanding of how patients employ objects and people to address discontinuity, and where they need help, may support the healthcare system to negotiate its way through the multitude of dependencies and influences that complicate the increasingly specialized, collaborative patient care.

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6

Healthcare professionals learning together from (and with) patients: bridging boundaries

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Submitted

Abstract

Introduction

The increasing prevalence of chronic disease calls for more collaboration across the sociocultural boundaries of healthcare professions to reduce complexity in disease management. Patients, who continuously cross these boundaries, may well contribute to the learning of healthcare professionals aimed at improving that collaboration. Using the expansive learning cycle of activity theory, this study explores how patients and visualizations of their care trajectories as a material object both promote the learning process within groups of healthcare professionals towards improved collaborative practice.

Methods

As part of a regional conference on improving collaboration between primary and secondary care, healthcare professionals exchanged and discussed their perspectives on their collaborative practice in four distinct learning sessions. Transcripts of these sessions were analysed for contradictions that initiate steps in the expansive learning cycle where learning and developing new ways of working co-occur.

Results

Patients and their material care trajectories play a significant role in the expansive learning process within groups of healthcare professionals. Care trajectories predominantly initiate steps in the expansive learning by grasping the temporal and spatial dimension of care. Patients initiate as well as advance steps in the expansive learning of the group by sharing their experiences, raising contradictions, and expressing their doubts about the outcomes of the discussion.

Discussion

This study adds a new perspective to the literature on patient participation in (expansive) learning processes on behalf of a learning healthcare system. We demonstrated that patient participation, combined with material patient trajectories, may support a group of healthcare professionals to create new professional knowledge and practice. Patients and their material care trajectories help forward the expansive learning process of healthcare professionals, and should more often participate in such processes.

Introduction

The organization of healthcare delivery across disciplinary boundaries is a major challenge within increasingly fragmented healthcare systems. Meanwhile, the urgency of integration and boundary crossing is larger than ever before, as the increasing prevalence of chronic disease induces a trend of patients moving back and forth between different healthcare professionals. At different points along a patient's care trajectory, different healthcare professionals may play a more central or distant role. As a consequence, challenges arise in care coordination and collaboration, and patients are at risk of discontinuous care[1]. Re-establishing continuity across patient's care trajectories requires a learning healthcare system, in which research evidence underlying continuous care is built into routine practice and outcome evaluation is fed back into the system[2]. Learning healthcare systems that engage healthcare professionals as well as patients are increasingly considered to best meet all different interests along a patient's trajectory and may – if addressing the relevant (ethical) challenges – transform collaborative patient care accordingly[3,4]. The contribution of patients to learning for the benefit of the learning healthcare system as a whole is, however, problematic. Their contributions are often labelled as episodic and thus patient participation is often considered inconvenient.

Visualizations of patient's care trajectories as material objects may well support groups of healthcare professionals in their learning process. Whole care trajectories, rather than descriptions of single care episodes, can well underline the spatial and temporal dimension of care and facilitate health care professional's situational awareness across the boundaries of their own practice[5-9]. A care trajectory ideally depicts the journey of an individual patient from symptoms to treatment outcomes in the context of the patient's own activities and experiences[10]. As such, it may reveal 'contradictions' (defined in the literature as historically accumulating structural tensions) between healthcare professionals and patients to generate new collaborative practice[9,11,12]. Learning that is triggered by contradictions is generally referred to as expansive learning – a concept that embraces contradictions as leverage to expand future practice across boundaries[13-15].

Adding the patient's voice to learning activities around material care trajectories may further stimulate the learning process of groups of healthcare professionals and the development of collaborative practice[16-18]. Where the material care trajectory as an instrument to discuss collaborative care may help healthcare professionals to 'zoom out', the patient him or herself may help to 'zoom in'. Interview and focus group reflections suggest that patients facilitate a more holistic perspective of care through telling their stories, stimulating reflection, sharing perspectives and initiating problem-solving[16,19,20]. Yet, little knowledge exists on the potential of learning from patients and their material care trajectories. Discussions between groups of healthcare professionals and patients are often considered as opportunities to discuss single medical patient problems, rather than as expansive learning activities that promote collaboration across boundaries[10,21].

Theoretical framework for studying expansive learning

A particularly helpful conceptualization to understand how patients and their material care trajectories may (actively) support the expansive learning process of healthcare professionals can be found in the idea of boundary crossing and its notion of boundary objects and brokers[22]. Boundary crossing refers to the movement of crossing boundaries, including both the physical and sociocultural transitions and interactions that come with it. Brokers (persons) and boundary objects (things or ideas) provide the means of crossing these boundaries[22-25]. Portraying patients and their trajectories as brokers and boundary objects, respectively, they promote the ability to explore, clarify and challenge contradicting professional views on patient care[6,26-28]. Revealing contradictions between healthcare professionals or practices – if they are addressed and untangled – is increasingly reported in the literature as promoting a process of learning and consolidating new practice development[9,15,29-34].

Cultural Historical Activity Theory (CHAT) is one of the cornerstones for depicting and better understanding contradictions. Its conceptualization and analysis of how contradictions manifest itself in language play a key role in depicting and better understanding the process of learning[35]. The expansive learning cycle of CHAT is central in this study because it supports understanding of how this learning from contradictions is a non-linear but orderly process of expected and unexpected outcomes[36,37]. Expansive learning is understood as a collective process in which participants learn something 'that is not yet there'; it is a process of creating new practices beyond the already known or existing[38]. The learning that occurs during this process can be best described as the collective learning of a group within a greater learning healthcare system[38]. In an expansive learning cycle, throughout different steps, an initial question or idea is transformed into a new form of practice (called a 'model'). Recent studies already provided the evidence and resources for using the expansive learning cycle as an analytical lens to get insight in learning and collaboration for patient care[6,15]. We add to this knowledge base by examining its potential for patient participation – involving patients and their material care trajectories – in learning healthcare systems.

Study aim

This study aims to analyse whether and how the patients' perspective and their material care trajectories benefit the expansive learning process of healthcare professionals during a group discussion. Through examining (discursive manifestations of) contradictions and analysing the subsequent (linguistic cues for) different steps in the expansive learning cycle, we progress understanding of the patient’s role in learning healthcare systems. We posit that the learning of professionals improves health care, but that the presence of patients is equally important – if not crucial – for that process.

Methods

Study design and setting

This study is part of a large collaborative care project called ZOUT (an acronym which is translated as “The right care at the right place in the Utrecht region”). The study entails a qualitative analysis of how patients and their material care trajectories support the interprofessional learning process. In the project four disease oriented meetings (two about diabetes type 2 (DMII), one about chronic obstructive pulmonary disease (COPD), and one about cardiovascular disease (CVD) were organized in which patients and health care professionals (general practitioners and medical specialists) discussed their collaborative care during the disease course to transform their practices (creating new ‘models’). Focusing on single meetings runs the risk that no meaningful cycles or incomplete cycles of expansive learning are accomplished[37,39]. Yet, we examine the possible evidence for (the first steps of) a cycle of expansive learning within such meetings.

The four meetings were simultaneously held at the same day and were part of a larger, regional event for healthcare professionals from primary and secondary care to discuss their collaboration. All four meetings were led by a facilitator, with a background as either medical coordinator or GP, to guide and stimulate the expansive learning process of the professionals. An instruction manual was at hand for the facilitators to support the exchange of perspectives where contradictions may be revealed.

Data collection

Prior to the sessions, interviews with four patients, one for each session, resulted in their care trajectories visualized on paper: a sequence of care episodes at different times and in different places connected by arrows. In each session, discussions between the participating health care professionals were based on the trajectory from one patient (with either DMII, COPD or CVD). Two of the sessions (COPD and CVD) also included the patient from whom the trajectory was discussed. The patients in the other two sessions were represented by a representative familiar with the patient and his or her story. All sessions were audio-recorded and transcribed verbatim. The sessions lasted between 60 and 90 minutes, and were attended by 33 healthcare professionals (13 general practitioners and 20 secondary healthcare professionals) equally divided among the four groups. The participants were informed about ethical aspects and the background of the research project beforehand and all gave their consent. The Medical Ethics Review Committee (METC) of the University Medical Center Utrecht confirmed that this research was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO), and hence waived from the necessity for formal approval.

Data analysis

A codebook for coding contradictions and expansive learning activities was created both deductively and inductively with a group of five researchers (DV, EdG, LM, VV, OL). Initially, a large set of linguistic cues (can, should, want, will be, find, what, think, knows, not, no, never, but) was used to search for fragments where anything contradictory happened. These fragments were analysed deductively to specify the different types of contradictions according to the typology of Engeström and Sannino (double binds, critical conflicts, conflicts and dilemmas)[14,40,41]. Because of the complexity and abstract nature of the different contradictions, after coding two transcripts, the codebook was adjusted to create a common understanding of what entails a contradiction. The final codebook only included three types of contradictions (double binds, conflicts and dilemmas). Engeström and Sannino's description of critical conflicts appeared too emotional in nature (including participant's inner doubts and feelings of being violated) that we could not uncover by analysing discourse only (**Appendix 1**).

The way in which groups of healthcare professionals followed up on these contradictions was analysed using Engeström's cycles of expansive learning[41]. Interactions that were not about current practice but exclusively about the patient's medical condition were not coded as part of the expansive learning process[10]. The seven steps of the expansive learning cycle (questioning, analysing, modelling, examining the model, implementing the model, reflecting on and evaluating, and consolidating and generalizing) and its subtypes were analysed deductively, but again defined in detail by the group of five researchers. It was of particular importance to be aware of linguistic cues for significant epistemic differences within and between the seven steps of the expansive learning cycle – e.g. it is not the same thing to question existing practice (action 1; sub-type 2) and to question a new development (action 1; sub-type 3), or to sketch the initial idea of a model (action 3; sub-type 1) and to enrich that model for implementation (action 4; sub-type 2)[37]. Moreover, since the four sessions were single meetings instead of a series as is customary in a change lab setting, the last three steps of the expansive learning cycle (implementing the model, reflecting on and evaluating, consolidating and generalizing) were deemed irrelevant for this study and excluded from the final codebook (**Figure 1**; **Appendix 2**)[37]. Upon consensus on the final codebook, one researcher continued coding the full set of transcripts.

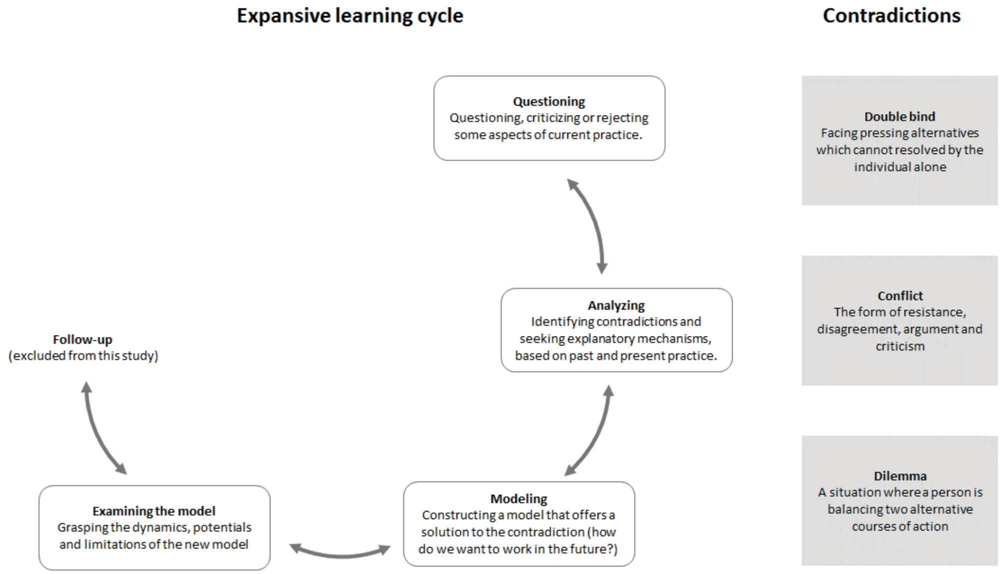

Figure 1 The expansive learning cycle, adapted from Engeström et al[39]. Contradictions may occur at any step of the expansive learning cycle, triggering shifts between the steps.

Results

Following presentation of the material patient trajectory, in iterative loops participants questioned each other, analysed the situation, modelled their newly found solution in a first explicit model, and examined that model to discuss its dynamics, potentials and limitations for their collaboration (**Box 1**):

Box 1 Expansive learning cycle (HCP = healthcare professional; P = patient)

Questioning Challenging participants into questioning	***HCP1:*** *At some point you think to yourself: Okay, there's a system of protocol-based care. We have that as well. We also just have three boxes to check telling us what we need to do. But where does the person-centred part come in?*
Analysing Identifying contradictions	***HCP2:*** *Different perspective. If you look at a straightforward problem like a broken toe, well we all know what has to be done. But real life isn't that simple. So if the problem involves several different things, you have to look at it from several different angles. But you need to have the time for that, and the ability.*
(dilemma)	***HCP3:*** *That's exactly what those patient care agreements prescribe...: 'Do your thing, send it back, do your thing, send it back'. In fact, we actually only look at one aspect. We do the plumbing work and send it back.*
	HCP2: *If that's what's being asked of you, if the request is: Look at this problem and you provide an answer, then you're allowed to look at just one aspect.*
Modelling Sketching the initial idea of a model	***HCP4:*** *Then maybe that needs to be communicated clearly to the patient: Go to the cardiologist with this problem, and if you have time: See your general practitioner.*
Examining the model Enriching the model	***HCP2:*** *Exactly, but then we should also be telling the patient: I'll refer you to the cardiologist, the cardiologist will examine this chamber or will test this and that and then you'll make another appointment with me and we'll discuss the outcome.*
	P: *Yes, that would be a lot better.*

Patients and their material trajectories (printed visualizations that were available to the participants), each separately, initiated a process of expansive learning. The role of the material patient trajectory was predominantly to facilitate a discussion on the bigger picture of patient care while also allowing to zoom in on specific care episodes. **Figure 2** shows the material patient trajectory (of the patient that was present), with arrows between specific care episodes to visualize his or her care in time and place. This object, a printed visualization, was on the table. In **Figure 2**, we show not only this object as it was made before the meetings (depicted in grey) but also example sentences of the way that healthcare professionals questioned each other based on that (depicted in blue). In their questioning, they used the arrows for analysing the (relationships between) specific care episodes.

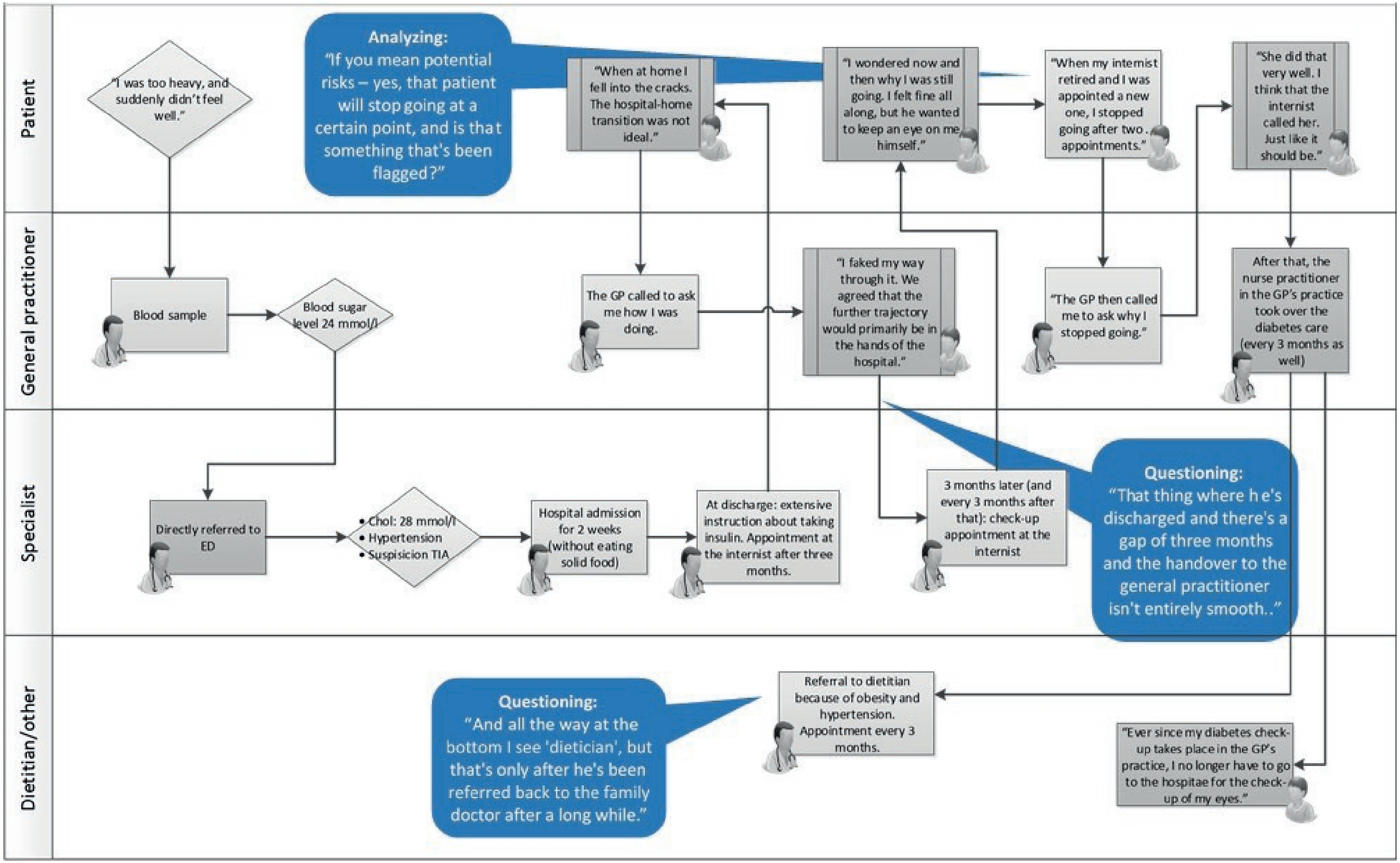

Figure 2 Fragments of an excerpt of the group discussion (in blue) about the patient trajectory. In the meetings, only the grayscale trajectory was on the table, i.e. without the blue speech bubbles. The blue speech bubbles in this figure represent their first reactions on specific parts of the trajectory.

Patients, in turn, provided depth to the discussion through facilitating a change from talking in the third person to discussing in the first person. Through articulating their problems and challenges (for example being uncertain about the communication between healthcare professionals), they created an environment that encouraged the group of healthcare professionals to share their own perspectives and analyse the situation as well (for example being annoyed by the lack of insight into each other's files). The shared analysis in turn created new models to improve future practice, for example in **Box 2**: introducing duty shifts. A meaningful cycle of expansive learning was accomplished.

Box 2 Expansive learning cycle (F= facilitator; HCP = healthcare professional; P = patient)

	F: *So your general practitioner or the walk-in clinic – they're no longer the go-betweens. You can call the hospital directly.*
Analysing Articulating problems and challenges	***P:*** *Of course, I don't know whether the outpatient clinic will call or inform my general practitioner…*
Analysing Identifying contradictions (double bind)	***HCP1:*** *Hospital A lets patients view their own records. So why can't general practitioners just do that too? Any patient can view their whole record. So general practitioners should be able to do that too, shouldn't they? […]*
Modelling Sketching the initial idea of a model	***HCP2:*** *The solution is to have a shared record. If we had all the general practitioners' records communicating with all the hospital records...*
	F: *Would it help if general practitioners could view patients' hospital records?*
Questioning Questioning the proposed development (dilemma)	***HCP3:*** *As one of my colleagues always says: if you can, then you must. It immediately puts us under an obligation, to be honest. Because a patient will think: You can view my hospital record, so why don't you look it up? Then before you know it, we're spending a lot of time on that too, and of course there's not just the lung specialist but all kinds of other things in there, and we come across stuff that contradicts what's in our own records.*
Modelling Sketching the initial idea of a model	***HCP1:*** *But why not just start with the duty shifts? Then you can say that when general practitioners are on duty, they simply have access.*

Similarly, patients initiated the expansive learning process by bringing up new contradictions (in contrast to the previous example, where the patient articulated a problem but the contradiction in turn was brought up by one of the healthcare professionals). **Box 3** shows how a patient introduced a double bind (*"It seems it wasn't an option at all [to go back to the general practitioner]"*), after which one of the healthcare professionals challenged the others into questioning using explicit expressions as *"What do we think about this?"*. Different perspectives were analysed and integrated into a potential new model for future practice (yearly evaluation regarding preferences for place of care):

Box 3 Expansive learning cycle (HCP = healthcare professional; P = patient)

(double bind)	***P:*** *[…]That's why I wasn't allowed to go back to my family doctor. Anyway, the general practitioner called me right after I'd been released from the hospital and he also told me: You have to remain under the internist's care for this. Apparently there wasn't any other option.*
Questioning Challenging participants into questioning	***HCP1:*** *So let's talk about this now. What do we think about someone in that situation remaining in the care of the internist and about the internist deciding what happens?*
Analysing Historical analysis	***HCP2:*** *Well, I sometimes see patients with type 1 diabetes again, but only in very close consultation, because, for example, people don't stick to their treatment plan and the specialist can't do much about it, so in those situations it might be better to keep things closer to home and low-threshold, so we can talk about it.*
Analysing Articulating needs and ideas	***HCP1:*** *It naturally also depends on the extent to which the hypercholesterolemia and probably hypertriglyceridemia are under control. Because it's very difficult when patients have long-term problems that way. But I think we're able to get those under control for almost everyone these days, so then the question is, what most people want, and what patient X also wants – is for care to be organized closer to home. […]*
Modelling Sketching the initial idea of a model	***HCP3:*** *Yes, or I would say when discharging a patient from the hospital: I think it's very important that I continue to see you for an indefinite period of time. So I'll see you for at least a year and let's agree that we'll then evaluate whether you should remain under my care or go back to your general practitioner.*
	HCP4*: So you'd want to have something like an assessment session after a year?*
Questioning Questioning the proposed development	***HCP5:*** *But that assessment session can also be done in the primary care setting. So it would take place with the patient if we think that the general practitioner can do it and if it turns out after a year that the general practitioner can't.... general practitioners are very good at assessing that.*

The material patient trajectory did not only play a role in making the group of healthcare professionals question each other, but also came back in the view after each time an expansive learning cycle was accomplished. It provided an anchor for the discussion: after discussing specific care episodes, participants could fall back on the trajectory to explore remaining issues for discussion. **Box 4** shows an example of this (how health care professionals benefit from how the material patient trajectory provides the temporal and spatial dimension of care). In this fragment, the questioning of two healthcare professionals (about long-term specialist treatment) prompted a third healthcare professional to analyse the situation and articulate his or her ideas on how things could or should have been done differently (sooner returning the authority and control over patients to the GP).

Box 4 Expansive learning cycle (F= facilitator; HCP = healthcare professional; P = patient)

	F: *So now everyone's gone through it [the care trajectory]. What do you think of it now that you see it visualized in this way?*
Questioning Criticizing existing practice	***HCP1:*** *What I noticed is that he was under the specialist's care for a very long time. [...]*
	HCP2: *I really like the fact that the general practitioner actively calls the patient to ask how things are going after he's been discharged from the hospital.*
Analysing Articulating needs and ideas	***HCP3:*** *I think that the coordination should be put back in the hands of the general practitioner.*

Apart from initiating expansive learning, patients also had an important role in advancing the further steps in the expansive learning cycle. This could be either on their own initiative or because healthcare professionals stimulated patients to share their perspectives on the discussion. Healthcare professionals often asked patients to reflect on current practice or an idea, suggestion or model developed during the session. Almost as often, the patient's response activated subsequent steps of the expansive learning cycle to developing the model further or aborting the model to reanalyse the situation.

For example, the group of healthcare professionals modelled a new solution – to reduce patient re-consultation of the pulmonologist from once every 6 months to once every 12 months. **Box 5** illustrates how they discussed this new solution with the patient, who in return brought up that he would rather just come back every 6 months and actively participates in the brainstorming process afterwards. Based on this direct patient feedback, the negotiations could immediately take a different turn without endlessly moving back and forth the expansive learning cycle towards undesirable models. A second example of how the patient's voice provides the group of healthcare professionals the opportunity to verify, clarify and critically evaluate their created models is provided in **Box 6**.

Box 5 Expansive learning cycle (F= facilitator; HCP = healthcare professional; P = patient)

Questioning Challenging participants into questioning	***HCP1:*** *How would you feel if the pulmonologist said: Come back in twelve months instead of six, since you're doing so well.?'*
Modelling Sketching the initial idea of a model	***P:*** *Then I'd say: I'd rather come back every six months if I can.*
Modelling Sketching the initial idea of a model	***HCP3:*** *Would you want to see the pulmonologist or do you see a role for your general practitioner?*
Modelling Sketching the initial idea of a model	***P:*** *My general practitioner could – my own general practitioner knows me. My own doctor knows exactly what's going on with me. He gets all the information… […]*
Modelling Sketching the initial idea of a model	***HCP3:*** *I can also imagine you saying: the lung check-up should be carried out by the pulmonologist and the other test by ...*
Questioning Questioning the proposed development	***HCP4:*** *I think that would be tricky in terms of policy, because you have to communicate a lot and think things through. […]*
	F: *Why do you think it would be difficult to alternate? What makes it difficult?*
Analysing Articulating problems or challenges (double bind)	***HCP4:*** *The records are separate. So if you write 'We're going to stop taking that medicine' in one record, you have to make very sure that that information also reaches the pulmonologist if the general practitioner has already discussed it… It's really very hard to get it all sorted out in the different places.*

Box 6 Expansive learning cycle (HCP = healthcare professional)

Questioning Challenging participants into questioning (dilemma)	***HCP1:*** *Is the patient's preference taken into account? I find that interesting, because there are actually two dimensions to this. In one dimension, you look strictly at the medical content and say 'Well, this can also be handled by the family doctor' or 'This should be done by the specialist for all kinds of medical reasons'. The other dimension is that I hear you [the patient] say, Gee, I think it'd really be nice – and I'm sure you're not alone in this – to see the specialist once every six months or once a year, because I'd feel safer and more at ease. So the question then is, what do you take into account?*

Finally, patients also expressed their doubts on some of the new models for collaborative care. Shortly after the conversation in **Box 5**, another healthcare professional points out that the role of the pulmonologist is not that important for treating 'typical' COPD patients. **Box 7** provides an example of how the patient questions this statement. When patients had their doubts about a new model, the expansive learning cycle was reset and participants moved back in their iterative process from the action of modelling to questioning. From revealing problems in the first place up to the final call, patients proved themselves indispensable.

Box 7 Expansive learning cycle (F= facilitator; HCP = healthcare professional; P = patient)

	HCP1: *The majority are under the care of their general practitioner and they may need secondary care now and again, but usually not.*
Questioning Questioning the proposed development	***P:*** *But my thinking is – and it may sound a little strange – but won't a pulmonologist know a little more than a general practitioner when I go for a consultation?*
	F: *That's a good question.*
Questioning Challenging participants into questioning **Analysing** Articulating problems or challenges	***P:*** *And wouldn't it be a lot easier for me to see the pulmonologist right away?… Because from what I'm hearing, I find it bizarre that this is happening to patient X, that he's been waiting there for hours.*
(dilemma)	***HCP2:*** *That is, of course – on the one hand, I'm sure everyone is doing their very best, but you're always dealing, inevitably, with a system, and that's an interesting aspect to consider. Care is organized on the basis of a system and that's organized in a certain way. On the one hand, things often work out well that way. On the other hand, there are always disadvantages to systems, so that things go less well. […]*
Modelling Sketching the initial idea of a model	***HCP1:*** *I think there's a really easy solution. A pulmonologist who has a patient like the gentleman who was just here should be able to say: You know what, we're going to make an exception for this patient and we'll add a note to his record and then he can just call the emergency room right away. That's a really easy solution. You can't turn an exception into a general rule, of course, but in extraordinary cases you just have to consider what is humane and convenient.*

Discussion

The results of this study demonstrate the contribution of patients and their material care trajectories to the collaborative learning of a group of healthcare professionals. Across all steps of the expansive learning cycle, patients were able to explore, clarify and challenge contradicting professional views on patient care. They made healthcare professionals challenge each other by articulating patient's needs and ideas, and contributed to the modelling of new collaborative practice. Besides responding to the contradictions and issues raised by the group healthcare professionals, patients also raised contradictions themselves and critically questioned healthcare professionals' ideas directly. As such, their presence helped to generate ideas relevant for patients.

The material patient's trajectories illustrated potential problems or contradictions at boundaries; discussing these may help professionals to cross these boundaries. This effect of the patient trajectory as a boundary object fits seamlessly with the literature that illustrates how providing an overview of a patient's care initiates processes of critical reflection and joint analysis[6]. Patient's experiences during their trajectory act as 'mirrors from work practice' to emphasize how healthcare professionals from different disciplines fulfil different roles over a longer time and to negotiate and critically evaluate past, present and future practice accordingly[11,15].

The complementary power of involving material patients' trajectories (zooming out) as well as patients themselves (zooming in) in the development of collaborative care has been shown. Before the meeting, the material patient trajectory was constructed together with the patient, without interference of the healthcare professional's perspective. During the discussion, patients made their trajectory come to life: specific episodes could be discussed in more detail to take the steps in the expansive learning cycle beyond questioning and analysing. Finally, the combination of both, material trajectory as well as the presence of the patient, helped to initiate and advance the expansive learning process. Confirming the survey results of Dammers *et al.* (2001), we showed how patients support learning healthcare systems by providing improved contextualization and increasing the ability to verify, clarify and critically evaluate patient care[16]. Participation of patients in the expansive learning process – rather than pre- or post-consultation of patients – effectively moves the expansive learning process back and forth from the step of questioning to that of modelling.

Common critiques on adding the patient voice to learning activities for groups of healthcare professionals include patients' unfamiliarity with the use of medical terminology and the perception of getting only the view of one single patient[42-44]. However, patients and professionals were given similar latitude and both engaged to a greater or lesser extent across all steps of expansive learning. Further analysis of these steps showed that almost complete expansive learning cycles could be accomplished in all four groups of healthcare professionals and patients. Four out of the seven steps of the expansive learning cycle – from questioning to examining the model – appeared in all meetings. The last three expansive learning actions (implementing the model, reflecting on and evaluating, and consolidating and generalizing) were excluded from the analysis beforehand (**Figure 1**).

This study has strengths and limitations. A limitation is that not all secondary healthcare professionals in the four meetings worked with the specific disease of the participating patient in their daily practice. Yet, as the aim of the meetings was to negotiate collaborative care in general, and not to model a final solution for treating all specific disease, we assume that this has not significantly impacted our findings on expansive learning accordingly. A strength of this study is that it adds a new perspective to the literature on patient participation in (expansive) learning processes by concentrating on the active role of patients and their material care trajectories. Moreover, using the theory on expansive learning as a theoretical framework, this study not only explored whát patients add, but also hów they do so. We revealed how raising contradictions expanded the conversation, and how dividing the discussion into smaller pieces according to the different steps of the expansive learning cycle provided insight into how, where and when patients and their trajectories contribute. For future research, it could be of interest to study how different types of contradictions initiate or advance expansive learning differently.

In conclusion, we consider patient participation in activities on behalf of learning healthcare systems to provide a rich learning experience, encouraging healthcare professionals to reflect on different perspectives on what entails good care and to access a wide and diverse range of learning resources[45]. We demonstrated that patient participation in learning of a group of healthcare professionals, combined with material patient trajectories, may support a process in which learning inherently translates to the creation of new professional knowledge and practice. As brokers and boundary objects, patients and their trajectories facilitated cross-boundary insights and helped to clarify the dynamics of collaborative care. Patients and their trajectories provide the context of the care experience across patient's trajectories that healthcare professionals aim to improve, and should, as a rule rather than the exception, participate in the discussion.

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Appendix 1: Contradictions

Table 1 Types of discursive manifestations of contradictions

Manifestation	Features
Double bind	Facing pressing or suboptimal alternatives in an activity system which cannot be resolved by the individual alone but requires collective action – involving an attempt at a transition from the individual "I" to the collective "we". Statements that reflect a mismatch between the current and ideal situation are also classified as double binds. Double binds are often accompanied with expressions such as "let us do that" and "we will make it", or with rhetorical questions of the type "what can we do?"
Dilemma	A dilemma implies a situation when a person is balancing two alternative courses of action (to get to the same result). It can be an argument presenting equally conclusive alternatives ("on the one hand […] on the other hand").
Conflict	Conflicts take the form of resistance, disagreement, argument and criticism, i.e. expressions of denial and all other linguistic forms that relate to a perceived divergence of interests or difference of opinion ("I disagree", "this is not true").

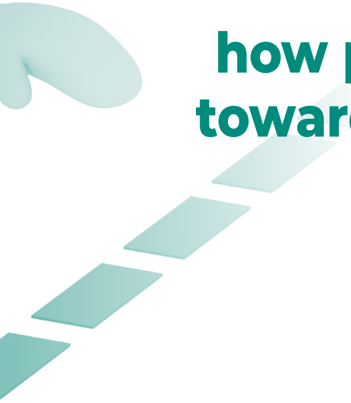
Appendix 2: Expansive learning

Table 2 Expansive learning – actions and sub-types

1	**Questioning**	Questioning, criticizing or rejecting some aspects of the accepted practice and existing wisdom. When an idea or issue is introduced and nominated for further communicative actions.
1.1	Challenging participants into questioning	Challenging other participants into questioning current practice as well as 'simply' asking participants about current practice
1.2	Criticizing existing practice	Criticizing current practice (without any notion of analysis or further consideration - otherwise coded as 2.3 'Articulating problems or challenges'); not necessarily related to the own practice (for example criticizing the situation in the trajectory of care under discussion).
1.3	Questioning the proposed development	Questioning after a proposal of another participant (not including questioning a proposed model to continue building on it – coded under 4.1 Discussing the model critically – but rather aborting the proposed model and starting over again.
2	**Analysing**	Focused on finding out causes or explanatory mechanisms, through mental, discursive or practical transformation of the situation. Analysis evokes "why?" questions and explanatory principles. This action seeks to explain the situation by constructing a picture of its inner systemic relations.
2.1	Articulating needs and ideas	Acknowledging and qualifying what is seen as important, from the participant's own (or the group they 'belong to') perspective
2.2	Historical analysis	Seeking to explain the situation by tracings its origins and evolution or showing the daily practice and the regular care (historical-genetic). For example, storytelling of specific patient cases by care providers, or explicating on current practice by patients.
2.3	Articulating problems or challenges	Revealing problems or challenges in exciting practice and explaining them from the participant's own perspective, drawing on local context. It relates to a personal unilateral experience, often clear and easily solvable and is close to existing practice.
2.4	Identifying contradictions	Identifying, naming and analysing a friction. It includes the perspective of the other(s) in the analysis given, stepping out of their own frame of reference. Within this action, the situation is meta-analytically exploited by explicitly identifying what the bottleneck is, and clarifying clearly in which direction the problem possibly can be solved. It expands the conversation; it is a 'step ahead' compared to when a problem or challenge is articulated.
2.5	Weighing alternative solutions	Considering different options, suggesting alternative solutions – between persons rather than within a person.

3	**Modelling**	Constructing an explicit, simplified model of the new idea that explains and offers a solution to the problematic situation.
3.1	Sketching the initial idea of a model	Shift towards creation of a model, suggesting the first principles of a new way of working. Includes discourse markers as “We could…”, “Why don’t we..”
3.2	Exploiting existing models	Referring to other guidelines and documents in order to use these as a base for the new model in construction.
3.3	Naming and defining the model	Based on consensus: summarizing what is the result of the discussion so far. Concrete suggestions for the new model are done, explicit formulations – suggesting an explicit move away from the problem – are proposed to the participants and agreed upon.
3.4	Fixing the model in material or graphical form	Specifying what will be written down and summarizing the decisions made, including discussions on design and form
4	Examining the model	Examining the model, running, operating and experimenting on it in order to fully grasp its dynamics, potentials, and limitations.
4.1	Discussing the model critically	A critical review on the created model (either agreed-upon or the initial idea of a model), discussing potentials and limitations.
4.2	Enriching the model	Adding new perspectives, ideas or suggestions to the created model to enrich it.

7



A delicate balance: how physicians manage change towards collaborative care within their institutions

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Abstract

Purpose

In response to the COVID-19 pandemic, in 2020-2022, the immutable and fragmented character of our healthcare system changed. Healthcare professionals and their institutional leads proved remarkably agile and managed to change toward collaborative care. The purpose of this paper is to examine experiences with collaborative practice in healthcare during the COVID-19 pandemic in two regions in the Netherlands, to explore and understand the relationship between policy and practice and the potential development of new collaborative care routines.

Design/methodology/approach

Using a methodology informed by theories that have a focus on professional working practice (so called 'activity theory') or the institutional decision makers (discursive institutionalism) respectively, the perspective of physicians on the relationship between policy and practice was explored. Transcripts of meetings with physicians from different institutions and medical specialties about their collaborative COVID-19 care were qualitatively analysed.

Findings

The findings show how change during COVID-19 was primarily initiated from the bottom-up. Cultural-cognitive and normative forces in professional, collaborative working practice triggered the creation of new relationships and sharing of resources and capacity. The importance of top-down regulatory forces from institutional leads was less evident. Yet, both (bottom-up) professional legitimacy and (top-down) institutional support are mentioned as necessary by healthcare professionals to develop and sustain new collaborative routines.

Practical implications

The COVID-19 crisis provided opportunity to build better healthcare infrastructure by learning from the responses to this pandemic. Now is the time to find ways to integrate new ways of working initiated from the bottom-up with those longstanding ones initiated from top-down.

Originality

This paper presents a combination of theories for understanding collaboration in healthcare, which can inform future research into collaborative care initiatives.

Introduction

However devastating the COVID-19 pandemic was, it may also have been a unique learning opportunity for changes in the healthcare system. Over the years, healthcare professionals and their institutions have developed distinctive roles in healthcare; with professionals taking the lead in changing clinical practice, and healthcare institutions directing changes from a governance or financial perspective. These dual roles occur in a complex, immutable and fragmented healthcare system, with different levels and sites of care, and with paralyzed collaboration between the key players[1]. In response to the COVID-19 pandemic, in 2020-2022, a change appeared. Healthcare professionals and their institutional leads proved remarkably agile and collaborated across the boundaries of medical specialties and institutions to meet the healthcare needs of service users that emerged from the pandemic[2,3]. Yet, despite this demonstration of new collaborative practice, the risk of professionals and institutions taking back their traditional positions once the pandemic is under control is imminent[4]. As a consequence, lessons learnt remain disregarded and renewed forms of collaborative care remain poorly adopted.

Considering the immutable character of the healthcare system in non-crisis times, and the societal needs that urge for its transformation, it is important to understand the change that happened during the pandemic. New collaborative patterns and routines were created within traditional structures and relationships[1,5]. Of particular interest is how the pandemic impacted the driving forces (i.e. ways of doing things that influence, pressure or force people to behave, interact with others and think in specified ways)[6] and triggered a rebalance of relationships between front line healthcare professionals and their institutions. In non-crisis times, top-down policy construction often fails because of lacking ownership amongst healthcare professionals on the front line[7]. Even if top-down imposed change has been successful, this can be short lived without underlying change in behaviour amongst healthcare professionals and the results achieved will probably be not sustainable[8]. On the other side, bottom-up policy legitimation – i.e. professional working practice giving policy its practical meaning – is a slow and inefficient process, and formal adoption of professional initiated change can vary substantially across different practices[9,10].

There is increasing recognition that the benefits of bottom-up and top-down approaches must be combined[11]. Yet, we lack understanding of how to change the driving forces of both professional collaborative practice and their larger institutions. The ease with which the COVID-19 pandemic stimulated integration and collaboration offers opportunities to enlarge this understanding. In this paper, we report experiences with collaborative practice in healthcare during the COVID-19 pandemic in three regions in the Netherlands. Using a methodology informed by theories that have a focus on professional working practice (activity theory) or the larger institution (discursive institutionalism) respectively, we aim to understand how the driving forces in both worlds changed simultaneously. Finally, we propose a model with recommendations for sustainable collaboration in the future.

Theoretical framework for studying collaborative change

Activity theory (AT) helps conceptualize and explain the driving forces in professional working practice by viewing activity and knowledge as situated in so-called 'activity systems'[12,13]. An activity system can be described as the context in which any activity, in this case collaboration, occurs. Considering different professional working practices as different activity systems may help to analyse how collaboration within and amongst practices unfolds. Activity systems consist of various components that help to understand this process. These components are the subjects (i.e. the people engaged in the collaborative activity), the objects (i.e. the specific motivations or purposes of collaboration), the tools (e.g. the technological trends), the rules (e.g. the guidelines), the community (e.g. colleagues) and the division of labour (e.g. the routine of who does what)[14].

Although the third generation AT provides direction for exploring how professional working practice may change institutions, it does not provide specific enough guidance to allow explorations of how institutions change working practice[15-18]. While it is acknowledged that AT needs to create and implement a unit of analysis that matches the complexity and coalescence of healthcare systems (including a focus on both professional working practice and the larger institution), the development of a fourth generation AT is still fragile[19]. Therefore, in this paper, we set aside that specific discussion, and compiled a conceptual analytical lens that integrates AT with a theory from the domain of political science: discursive institutionalism (**Figure 1**).

Discursive institutionalism (DI) provides a broadened unit of analysis which allows AT's focus on professional working practice to be extended and enhanced to the level of the institution[20-23]. Where AT focuses on the components that healthcare professionals consider relevant in their own practice, DI involves the broader forces (often called 'ideas') that live in their institutions.

DI, moreover, draws attention to the difficult balance between top-down policy construction and bottom-up policy legitimation[24]. It distinguishes three broad levels of driving forces that live within healthcare institutions: regulative, normative, and cultural-cognitive (**Box 1**)[25-29]. Cultural-cognitive and normative forces mainly originate in professional working practice and can constrain the regulative forces from institutional management (and vice versa). Implementing and sustaining change in healthcare systems benefits from selecting and combining elements at all three levels[30].

Box 1 DI's different levels of driving forces (ideas) within institutions

Regulative: *policy level ideas*	Laws and contracts which stipulate what <u>must</u> happen: *basic prescriptions for action to solve a given problem*
Normative: *programmatic ideas*	Assumptions and expectations about what <u>should</u> happen: *defining problems, consider the issues at stake, set goals, and select the methods or instruments to be applied to the problem*
Cultural-cognitive: *philosophies*	Taken-for-granted scripts and mental models about what generally <u>does</u> happen: *deeper sets of values, knowledge systems, beliefs, or worldviews*

Although typically being used to theorize macro-level changes in institutional structures, DI will be applied in this study on a more meso-level to support AT in analysing how healthcare professionals achieve institutional change and what institutional forces in turn help or hinder efforts to sustain those changes.

Figure 1 illustrates this process. It depicts the balance between AT's professional working practice and DI's larger institutional environment. The inner part of the rectangle illustrates professional working practices with their components of collaboration. This helps to understand how healthcare professionals achieve certain objects and outcomes through using different tools and rules, or by employing certain routines of who does what. Yet, we anticipate that if we aim to understand the complexity and coalescence of healthcare systems, an expansion of AT's unit of analysis is required. Accordingly, the driving forces of the larger institutional environment that may help or hinder collaboration in professional working practice are illustrated outside the rectangle of **Figure 1**. In this study, we focus primarily on these driving forces and analyse changes in professional working practice from an institutional perspective, even though we took concepts from activity theory (e.g. division of labour) as sensitizing concepts in our analysis.

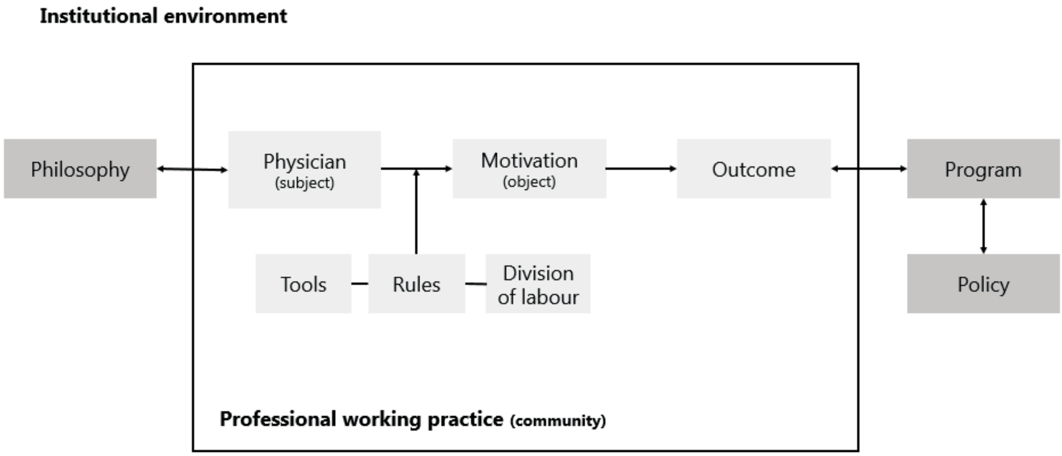

Figure 1 Integration of Activity Theory (AT) and Discursive Institutionalism (DI). Elements of AT are pictured in light grey: AT helps explaining the activity of how individuals (subjects) achieve certain outcomes through pursuing their motivations (objects) with the tools, rules and division of labour provided in their activity systems. Elements of DI are pictured in dark grey: DI separates different levels of ideas or driving forces that live within institutions (philosophies, programs and policies) to explain why and how things change. As a whole, the figure sketches the two-way influence between professional working practice and institutions.

Methods

Study design and setting

This study is part of a larger action research project on collaborative care, called ZOUT (a Dutch acronym for "The right care at the right place in Utrecht"). The study entails a qualitative exploratory analysis of how physicians from different medical specialties experienced the relationship between policy and practice in providing healthcare during the COVID-19 pandemic. Halfway the pandemic (end 2020/beginning 2021) online meetings with physicians from different medical specialties and institutions were organized to discuss ongoing and past collaboration in COVID-19 care, and to formulate recommendations for sustainable collaborative care. Policy makers were not involved in the meetings. In total 24 meetings took place, spread over six evenings and three regions in the Netherlands (Utrecht, Haarlem and Amsterdam). The meetings were designed according to the philosophy of AT in order to reveal how physicians achieved collaborative change during COVID-19. Particularly, the meetings aimed at understanding the factors that may help or hinder to sustain that change. During the analysis, the importance of the larger institute, as counterpart of professional practice, became clear and we chose to involve a second theory: DI. Accordingly, our research aim – to analyse professional working practice from an institutional perspective and explore how DI can support in expanding AT's unit of analysis – emerged as part of the research process, evolving from the data as they were collected[31,32].

Set up of the professional discussions

The meetings were all led by a facilitator to guide and stimulate the discussion. Their guideline includes questions such as "What additional agreements are required between the various stakeholders involved to enable change?", "What does help you?", and "Where are the difficulties?". The meetings lasted between 50 and 70 minutes, and were attended by about 200 physicians (a mix of public health physicians, general practitioners and secondary care hospital specialists in the region). The structure of the meetings was as follows: each meeting started with a short round of introduction, after which the facilitator introduced three possible discussion topics: professional involvement (about the way and quality of working and physical proximity to patients), organization of daily practice during COVID-19 (about the changes in daily practice and promises for the future), and collaboration and coordination of COVID-19 care in the region (about connecting, trusting each other, and promoting continuity of care). One or more topics were discussed, depending on the context that participants preferred to talk about. The discussion about each topic ended up formulating a positive recommendation to share with participants in the other meetings.

In two of the three regions (Utrecht and Haarlem), the meetings (n=18) were audio-recorded. In Amsterdam, we had no consent to record the meetings. Purposeful sampling was used to select 6 of the 18 meetings that particularly focused on the discussion topic 'collaboration and coordination in the region'[33]. The audio fragments of these meetings were transcribed verbatim. In total, 56 participants participated in the six meetings that were selected for analysis. The meetings were mixed in composition of physicians, but included general practitioners, internists, surgeons, paediatricians, geriatricians, rheumatologists and public health physicians. The participants were informed about the research project beforehand and all gave their consent for recording and analysis of the results. They were not involved in interpretation of the results. The Medical Ethics Review Committee (METC) of the University Medical Center Utrecht confirmed that this research was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO), and hence waived from the necessity for formal approval.

Data analysis

Anonymized transcripts of the six meetings were uploaded to the qualitative data analysis software NViVo and analysed using an integrated qualitative approach. We used the directed-content analysis method, iteratively informed by conceptually theoretical concepts stemming from the literature on AT and DI to develop a coding scheme[34]. These concepts guided the initial development of the codebook, and were complemented by inductive coding.

The deductive coding scheme included organizational characteristics, people characteristics, relational aspects, available instruments, and the external environment. Subsequently, codes were considered in the perspective of AT to explore underlying routines and forces. For example: using AT's notion of 'division of labour' helped to reveal the driving forces behind the code 'relational aspects'. The literature on collaboration in times of crisis further completed the coding scheme (adding, for example, resilience of the system). Finally, deductive coding was complemented by inductive coding, with changing forces and routines in professional working practice as sensitizing concepts.

Subsequently, we analysed the larger institutional environment in which collaboration took place. The coded fragments were searched for clues on what *does* happen (cultural-cognitive forces), what *should* happen (normative forces), and what *must* happen (regulative forces) in institutions to change collaborative patterns. We explored how the cultural-cognitive, normative and regulative forces changed within institutions and how that influenced professional working practice (and vice versa). Data saturation was considered to have been reached, although saturation is a contested concept in the qualitative research domain[35].

Results

Discussions about the three discussion topics (professional involvement, organization of daily practice during COVID-19, and collaboration and coordination of COVID-19 care in the region) raised several issues and provided insight in the driving forces behind care organization among physicians and within institutions. Accordingly, the first part of the result section is divided according to the three levels of driving forces that live within healthcare institutions according to DI. Mainly the cultural-cognitive forces and normative forces seemed to play a role in changing collaborative practice.

The driving forces for change

Cultural-cognitive forces: what does change

Perceptions of the contribution of different medical specialties to the care and cure provision ('division of labour') changed significantly during the pandemic. As a result, physicians started to see the added value of collaboration outside their own specialty:

> *But what I also find important myself is that the cooperation with the other disciplines is, uh, much clearer now.*
>
> *Yes, and – and I'd also like to involve the, um... involve the nursing home doctors, the nursing homes in that, or at least see if we can do something with them, um ... Because we're lacking some of that information too, as we saw just a moment ago.*
>
> *And what about psychiatry? That too?*
>
> *Psychiatry. Absolutely, the mental health services. Yes.*

This in turn initiated a feeling of 'doing it together'. The divide between 'us' and 'them' was downplayed to achieve a 'we'*, and the willingness to help out others increased**:

> ** I think there's a bit of idealism that I would like to hang on to from the present COVID period. We care for our patients together, as one medical team, one profession with the same goal: to provide the best possible care for patients and for the population in general. And in pursuing that goal, not compartmentalizing, not thinking 'Hey, you belong to this or that practice'.*
>
> *** I think that, um ... well, you do feel a lot of – a lot of job satisfaction that way. Because if you think, OK, this isn't such a nice chore but we've agreed that it's my chore, then you'll do it with more love than if you think hey, this is someone else's job.*

At the same time, prior scepticism among physicians about new instruments of care delivery such as joint video-consultations changed. More than before, during the pandemic participants felt the need to try the unanticipated or unknown under the pressure of the extreme situation. A renewed appreciation of instruments and tools followed. Where physicians previously tended to use new tools because their institutional leads believed that they were necessary or supportive, physicians now felt it was needed in their professional work. This intrinsic belief is very important for being able to change existing routines:

> *We suddenly learned how much more is possible ... for example, when I have a patient on the examination table and the specialist says, just a second, let me see that – that right there – just take another look at those, uh, MCP joints, just take that knee and press down. That way she does a physical examination too. And that's just fantastic.*

Normative forces: what should change

First of all, physicians agreed that they should make more time for each other structurally*. Also, they concluded that an important condition for managing change was, to break down professional walls and build bridges between different working practices. Knowing each other, being accessible and having short lines of communication – hence paying attention to what AT describes as the 'subjects' in your 'community' – were mentioned frequently as promises for change**.

> ** Of course. And... Yes, I think it would be very advisable, um... if we consulted more beforehand about referrals of any kind, quite apart from COVID … So I still think, um... that time should be set aside during the specialist's surgery hours for possible consultation with the GP.*

> *** Well, the lines of communication have become really short. I know the people who are involved by their first and last names and I can literally call them anytime I need them to ask a question or discuss a problem and they jump straight in to help me find a solution, because they know that if they have a question or a problem they can call me and we'll help them in return. So that sense of, um, equality and that interaction was very spontaneous and I think it's created a lot of opportunities going forward.*

During the pandemic top-down coordination of resources and professional capacity sharing was often replaced by coordination from the bottom-up. Professional working practice adapted towards what was needed for continuity in patient care, and discussions about financial management and reimbursement (that previously dominated collaboration) were not dominating but rather took place afterwards:

> *In Nieuwegein we had a severe shortage of flu shots, so we shared them out among ourselves. Tom had ten left over and Dick had ten, so we passed them around and that was that. And the financing will sort itself out afterwards, it's not a big deal.*

The excerpt above clearly shows how it was primarily the physician's creative workaround and mutual willingness – and not the formal institutional rules and instructions – that made the system more flexible during this crisis and initiated collaborative change. Yet, despite the absence of clear institutional policy, physicians agreed that institutional support should be present to facilitate clinical capacity and flexibility:

> *Another positive development in my view was that, even in an unwieldy building like hospital X, the administrators or management, or some of them, made themselves completely available to the healthcare professionals on the front line. And that was*

> *an incredibly pleasant way to work. So, yes, many of their decisions simply revolved around us. I mean, the nursing staff, the cleaning staff, just all the service providers, the physicians. And that was very gratifying … Practices that suddenly left you much freer in your work.*

> *And all the things that you used to do a certain way don't have to be done that way anymore. Because suddenly it's possible to do it all differently. And it's all happening so fast. And especially having meetings online, I love it.*

Regulative forces: what must change

Physicians did not have any formal policy or guideline that dictated what or how they 'must' have been doing during the pandemic. They rather exchanged ideas about how they changed their collaborative routines from the bottom-up. Yet, physicians provided some examples of policy changes that are emerging because professional working practice had already shown their beneficial effect, e.g. financing the 'listen-in consultation':

> *Zilveren Kruis health insurer now has a payment entitlement for this very type of question. What, um … what we normally do by phone, any medical queries about a patient, you don't get paid anything for those. Which is weird, because you do invest in your expertise and you share it. And, um … by promoting this kind of low-threshold consultation a bit more, since it ultimately also helps reduce costs of course, there's now a – a rate available for this as of 2021 and it's called the 'listen-in consultation'.*

Tensions between pursuing change and tendency to return to traditional practice

Working in times of a pandemic did integrate different perspectives and significantly drove collaboration. Yet, a lack of national (political) or institutional support often hindered physicians to maintain these new collaborative patterns:

> *I think that as a professional group, as doctors, our ability to practice our profession in fact depends on a party [health insurer] that won't even involve itself in the discussion.*

> *Look, this is a very tricky problem, nationwide. It's cultural problem and an organizational problem at the health insurance companies. Because at the overarching level they make all sorts of promises and say all sorts of things, but you've probably noticed in GP practices that if you talk to the salespeople, the purchasers, there's a huge gulf and they do their own thing.*

Moreover, the lack of a clear vision or management plan within leading institutions in healthcare is considered a serious barrier for sustaining new routines*. Physicians expressed their worries for not being able 'to see the wood for the trees' in the absence of a clear plan from top-down**:

> ** And what I feel is lacking is that, um … I feel that the government is capable of making quick decisions about health care now, but that their thinking is very short term and I'm missing the long-term view.*
>
> *** What was achieved during the initial crisis, we really ought to perpetuate that. And that immediately raises practical questions, like how on earth can I perform on five different platforms simultaneously? … And then, at a certain point, it reaches information overload. So not to be obnoxious or, uh, against cooperation, but at some point it's a question of how, how are we supposed to do that?*

A model for sustainable collaboration

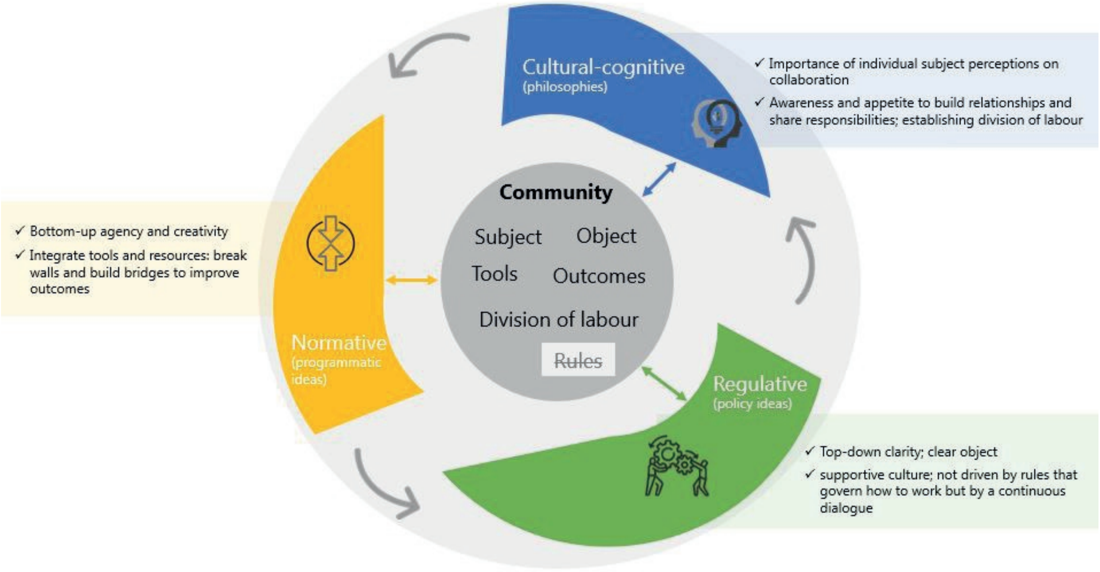

Figure 2 Model for sustainable collaborative change

The improvement in collaborative healthcare in times of COVID-19 was driven primarily bottom-up rather than top-down. The model in **Figure 2** helps to understand the driving forces and routines in professional, collaborative working practice (the community) and the larger institution, and provides recommendations for change and sustainable collaboration in the future. The figure illustrates how professional working practice and the larger institutional environment are related when it comes to establishing collaborative change. Our focus on the larger institutional environment helped to understand how and why collaborative change in professional practice unfolds. The previous sections showed how DI's driving forces changed and/or stimulated the subjects in professional working practice to achieve certain objects and outcomes through using different tools, or by employing certain routines of who does what. However, it is especially AT's rules that benefit from a wider, institutional unit of analysis. The previous section showed how AT's rules are less prominent in establishing collaborative change – it is not the institutional rules that should govern how physicians work, but the institutional support.

At the top right of **Figure 2** are the cultural-cognitive forces, illustrating how change often starts with changing perceptions, beliefs or deeper sets of values in subjects from the bottom-up. The results presented in the previous sections show the importance of physicians' intrinsic commitment to build relationships and share responsibilities (dividing labour) within their communities. Commitment in professional working practice helps the larger institution to initiate movement in the organization of care (and not vice versa).

The left side of the model depicts the normative forces. Ideas about what should happen include the integration of tools and resources across practices, including alignment of agendas to find each other (e.g. making reservations through timeslots)*. Yet, normative forces include bottom-up as well as top-down change management. Physicians discussed how top-down clarity should be provided while facilitating bottom-up agency**.

> ** So personally, I think, um, if you want something to be efficient and fast and, um, effective, then you should perhaps equip the existing platforms to do that even better, don't you think?*

> *** We need firmer national frameworks that get people to the discussion table regionally and also open the door to agreements. And as doctors, we should have a seat at that table.*

Finally, at the bottom right of the model are the top-down regulative forces. The key to changing routines in collaborative care resides primarily with physicians themselves – and not with their institutional rules. However, the physicians did discuss how it would help to be in conversation with their institutional leads to be provided top-down support for their daily work and decisions:

> *But that means that, at the national level, we aren't troubled by partitions between organizations, or by different sources of funding. Just give us that space. Facilitate that. And we do work in partnership, we agree on who is going to do what for which patient. In my view, that's not just a question of idealism. I think it's the future.*

Discussion

In this study, we explored the driving forces that enabled the development of new collaborative care routines when a pandemic faded the traditional ones. Through a combined lens of AT and DI, we aimed to understand the two-way influence between policy (the institution) and practice (professional working practice). Changes in the cultural-cognitive and normative forces opened the doors for new relationships and sharing of resources and capacity in professional working practice. In times of the pandemic, regulatory forces were less strong. Yet, both (bottom-up) professional legitimacy and (top-down) institutional support are deemed necessary to develop and sustain new collaborative routines.

The urgency of change during the pandemic tipped the balance in favour of professional legitimacy. This is in sharp contrast to many initiatives for healthcare changes in times before the pandemic. During COVID-19, physicians acted independent from the policy direction provided by institutional management[36]. Yet, we consider our results not to be unique to times of pandemics. One of the fragments cited that physicians felt as if their institutions finally had let go of the established, physical structures for collaboration during the pandemic. However, their institutions had not forbidden online meetings previously, and collaboration has also been their objective. In fact, institutional policy and practice got nearer to one another, and probably even reinforced each other, because legitimacy was now in the eye of the beholder[37].

Resonance of professional working practice and the institution benefited greatly from the sense that they no longer had 'just' a common objective, but also a common fate. The literature on collective behaviour in times of crises indeed explains how a sense of a common enemy (as COVID-19 was often called) can be the source of an emergent shared identity, which in turn provides the motivation to collaborate[38]. Our results, summarized in **Figure 2**, shed a light on how our healthcare system changed in response to 'sharing a common fate'. These results may support in sustaining new collaborative routines when the time arrives that 'sharing a common fate' changes back in simply 'having a common objective'. If we would pay more attention to the cultural cognitive forces that were triggered by 'sharing a common fate' (e.g. the force of individual perceptions) while finding a delicate balance between the normative and regulative forces (facilitating both top-down clarity and bottom-up agency), new collaborative routines may be sustained or even enhanced.

Figure 2 may also promote understanding of how changing routines occurs at different levels, how these levels are particularly intertwined (though the balance may tip one way or another), and how they are equally important to initiate change. Whereas the normative and regulative forces are generally considered as equally important, the cultural-cognitive forces are more often considered to reside in the background as underlying perceptions that are rarely contested except in times of crisis[39]. Indeed, our results show how the pandemic challenged the existing cultural-cognitive forces and how that changed professional practice. If the cultural-cognitive forces are of such great importance for changing professional practice in times of a pandemic, it is highly unlikely that they play no role in regular times. Indeed, one of the basic beliefs of AT for progressing professional working practice is to make the implicit explicit ("to take the invisible assumptions in your head and articulate them"). Focusing on the continuous interplay between professional working practice and the cultural-cognitive, normative and regulative forces in institutions may help to further restore the balance between 'bottom-up' and 'top-down' in future, post-pandemic times.

This study has several strengths and limitations. The main strength of this study is the methodology where AT and DI were combined to analyse changes in collaborative routines. We need to be mindful to undertake research that builds on existing knowledge, addresses known gaps, and makes the field advance. Collaborative care has been studied extensively and improved our knowledge on the many factors that facilitate or constrain collaboration. Yet, there is still a gap in understanding the underlying forces that drive these factors[40]. The combination of two theories, AT and DI, allowed us to reveal those forces. A limitation of the analysed meetings may be that policy-makers or healthcare professionals other than physicians were not involved, because the pandemic was not over yet and extra tasks therefore not expedient. Future research initiatives may bring together healthcare professionals who aim to influence the policy and actual policy-makers. A second limitation concerns the absence of patients and follow-up meetings to check upon the results. Yet, meetings were organized in different national health care regions in the Netherlands to increase the reliability of our findings.

The current study aimed to understand how the driving forces in professional working practice and the larger institution changed simultaneously during the COVID-19 pandemic, and how our healthcare system can sustain the resulting, positive collaborative changes. We provided insight into the dynamics of two-way change, referring to the bottom-up/top-down balance. The flexibility and input from professional working practice clearly stimulates innovation and brings power of change. Physicians played a dominant role in crisis management. Institutions were a bit more in the background when it came to direct action, but their support and facilitation is just as much needed to provide clarity and uniformity over professional responsibility. Now is the time to consolidate these experiences and integrate new professional-driven ways of working with longstanding policy-driven ones. The COVID-19 experiences are a special opportunity to build better healthcare infrastructure by learning from the responses to this pandemic. Future phases of this pandemic, other pandemics, and our learning healthcare system in general, all could benefit from a close partnership between clinical practice and (organizational) learning theories.

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8

General discussion

In this thesis, we studied the collaboration and boundary crossing between researchers, healthcare professionals and patients as part of the development of learning healthcare systems (LHS). We analysed two distinct processes in the learning healthcare system, each with another focus and analytical lens. In this final chapter, the key findings will be summarized and reflections provided. The chapter will end with recommendations for future research and clinical practice in developing LHS.

Key findings

- **Chapter 2** demonstrates the benefits of establishing a research network. A stochastic actor oriented model was developed to explore how connections and collaborations between researchers evolved over time. Using CanTest as a case study, we showed how particularly the more junior researchers are successfully encouraged to build connections and expand their networks. These connections in turn also stimulate research collaboration and publication of results. Knowledge about researcher positions and/or characteristics within networks will help to develop effective research collaboration and help LHS forward.
- **Chapter 3** demonstrates the value of these connections within research networks in more detail. Semi-structured interviews revealed how most of the value for individual researchers was in the ‘potential value cycle’: they acquired knowledge, skills, social capital, resources and ideas. Part of this value translated to the cycle of realized value (e.g. publishing results). Progress throughout these cycles (e.g. whether potential value will or will not lead to realized value) depends on – amongst others – the availability of role models in the researcher’s network and the extent to which research interests in the network overlap. Focus on these factors will help to facilitate sustainable progress and efficiency gain of the research done within LHS.
- **Chapter 4** addresses the development of a regional transmural care database to enable monitoring of collaboration on the clinical practice side of LHS. The roadmap we developed describes the main administrative and organizational arrangements (e.g. to officially arrange and maintain momentum needed for the progress of collaboration) and legal requirements. Promoting administrative/managerial ‘buy-in’ and repeatedly engaging in face-to-face activities with stakeholders from different organizations, with different levels of hierarchy and dissimilar positions, promote a sense of trust, shared responsibility and ownership, and may facilitate the required steps to progress the organization of data and collaboration in LHS.
- **Chapter 5** demonstrates the added value of active participation of patients in LHS. Semi-structured interviews with patients revealed how patients actively use and introduce objects (e.g. content from their electronic medical record or a notebook) and

people (e.g. their case manager or their GP) to facilitate better continuity in their care processes. This chapter in particular supports the integrated approach towards LHS that we plea for in this thesis. In attempts to improve LHS, both healthcare professionals and patients should be provided a key role, as two self-contained representations of clinical practice.

- **Chapter 6** demonstrates the benefits of integrating different perspectives of the LHS. Bringing together healthcare professionals and patients revealed how patients (and their visualized care trajectories) promote the learning process of healthcare professionals. In four distinct learning sessions, patients initiated as well as engaged in the (expansive) learning process of healthcare professionals by sharing their experiences, raising contradictions and expressing their doubts. This chapter further supports the idea that patients should be considered representations of clinical practice as much as healthcare professionals when trying to improve LHS.
- **Chapter 7** demonstrates the dynamics of a LHS under the pressure of the COVID-19 pandemic: resulting in an expanding role of healthcare professionals and patients (professional working practice) at the cost of the traditional administrative governance. A combined lens of activity theory and discursive institutionalism revealed how bottom-up forces gave a boost to collaborative care and how top-down administrative forces are less suitable for implementing change quickly. Yet, for long-term development of LHS, both bottom-up legitimacy and top-down guidance are deemed necessary.

What do these results mean for the development of LHS?

Through combining all relevant perspectives within the health care system, LHS aim to generate the best collaborative healthcare choices for patients. Using input from both research and clinical practice, in a LHS a cyclic process is promoted of continuous learning by collaboration.

This cyclic process requires (1) data from the entire healthcare trajectory to monitor developments, (2) structural collaboration between healthcare professionals across disciplinary and socio-cultural boundaries (boundary crossing), (3) up-to-date and efficient input from practice to feed research, (4) up-to date and efficient research output to innovate clinical practice , (5) deliberate patient orientation and active patient participation, and (6) continuous evaluation of collaboration within the system (**Figure 1**):

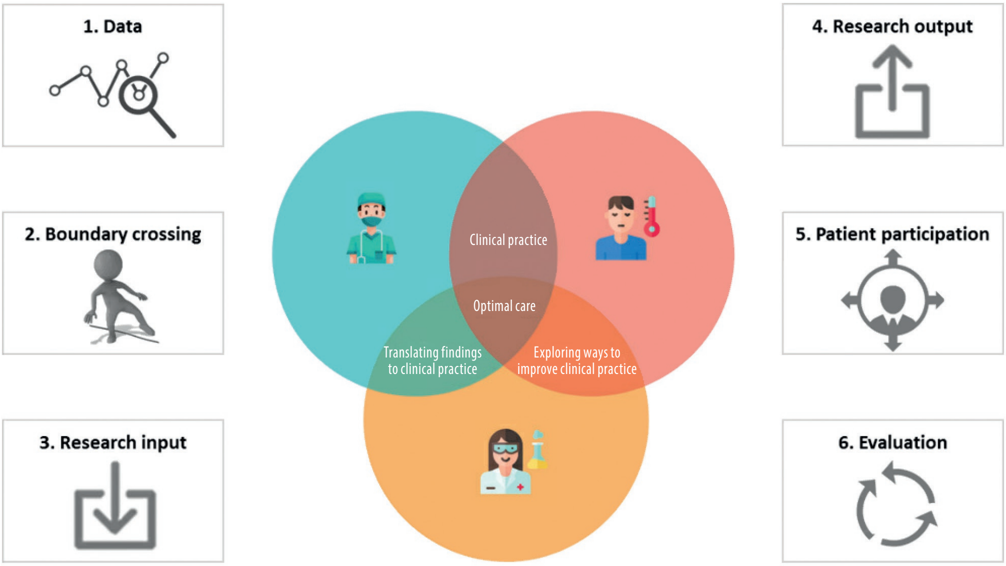


Figure 1 A learning healthcare system with its six pillars.

1 **Data from the entire healthcare trajectory to monitor developments:** An up-to-date transmural care database, using routine care data to provide an update of clinical practice performance every quarter or half year, helps to keep the improvement discussion going. A regular update on professional performance, preferably combined with relevant patient experiences, ensures that the learning process continues. Regional training organizations involved or responsible for the refresher course agenda (e.g. academic hospitals together with the umbrella organizations of various GP practices) may have an important role in facilitating this process. The roadmap created in **Chapter 4** can be built upon.

2 **Structural collaboration between healthcare professionals across disciplinary and socio-cultural boundaries (boundary crossing):** As opposed to current opportunistic and incidental collaboration a LHS requires structural collaboration between both individual professionals as well as their institutions. Collaboration agreements for healthcare professionals are ideally based on discussions amongst these healthcare professionals. The role and expertise of healthcare professionals is undermined when their superiors (hospital boards or national policy makers) construct the policies without them. As illustrated in **Chapter 7**, a combination of top-down and bottom-up decision-making probably works best. Again, there is probably a role for regional training organizations occupied with the agenda for continuing medical education to

bring together collaborating healthcare professionals. We also foresee a role for (post) graduate education programs, where future healthcare professionals are to be prepared for lifelong learning in pursuit of personal ánd collective development.

3 **Up-to-date and efficient input from practice to feed research:** The output of both the transmural care database and discussions amongst healthcare professionals are, in turn, the basis of new research questions. The term "science as a service" denotes how researchers serve practice and address the problems from practice by studying them in more depth. The example of CanTest as an international research network, addressing issues straight from the daily practice of primary care, may perhaps be challenging to realize. However, in the Netherlands we already have a Dutch national research agenda. This agenda is meant to point the way for Dutch research over a period of ten years – its purpose is to better equip Dutch researchers to find solutions to the challenges of our time[1]. An idea may be to delegate the implementation of this agenda to several research networks covering different research topics – as a challenge that these networks have for the coming years.

4 **Up-to-date and efficient research output to innovate clinical practice:** Healthcare systems work in two directions, so subsequently, outcomes from research should be the input for healthcare professionals and patients. **Chapter 2** clearly illustrated how research leads to publications and hence recommendations for clinical practice. Yet, in the present ocean of research results, it may be hard to decide which results will or will not be worth implementing. For this we need a continuous meta-analysis and dynamic guidelines development system that efficiently translates real time research results into recommendations for clinical practice. The Cochrane organization has developed a global system for meta-analysis of research evidence around key clinical questions. In addition, NICE in UK, and FMS and NHG in the Netherlands developed dynamic, practice oriented guideline programs that integrate the results of meta-analysis into professional guidelines for clinical practice. A wider application of such systems and programs will definitely help to innovate clinical practice. From evaluation of these guideline development programs, in turn, an agenda of 'missing evidence' can be composed, describing the missing jigsaw pieces and feeding them in the research agenda.

5 **Deliberate patient orientation and active patient participation:** Collaboration *for* patients should make place for collaboration *with* patients. How health care professionals orient their perspective toward patients is likely to affect the quality of patients' involvement. From passive patient consultation we should move to a form of active patient participation. **Chapter 5 and 6** illustrate that patients are more than

ready to take up this role. In discussions based on routine care data, in discussions to make or improve collaboration agreements between healthcare professionals, but also in deciding what topics have most priority or relevance to study or implement: patients have a say. Patient orientation and participation provide important pulses for efficient decision-making in all steps of the LHS. Not only in the consultation room, but also in the more general discussions to improve the system. This is a call to all researchers, healthcare professionals, educators and policy makers to involve patients in their plans as soon as they involve others (and not only when the plans have already been made).

6 **Continuous evaluation of collaboration within the system:** All steps preceding this last step are needed for a continuous loop with monitoring of process outcomes in the healthcare system. Semi-annual discussions of transmural routine care data amongst healthcare professionals in the regional health care network, supported by patient's stories, while considering the latest research: the ultimate LHS.

In project ZOUT, we already explored how such discussions may take shape. Following the meetings presented in **Chapter 6**, healthcare professionals and patients continued their discussion. However, the patient trajectory was replaced by data from the transmural care database. These conversations were not analysed in detail, but the following fragment gives some idea about what these discussions, or continuous evaluations, may look like in practice:

Healthcare professional 1:
"With a BMI<21, very little patients are referred to the pulmonologist by their GP, although the collaboration agreements apparently writes that this is good practice."

Healthcare professional 2:
"In my experience, then those agreements don't really help much. Otherwise we'll find our way to them. Apparently, no one in daily practice feels the need to have a look at them."

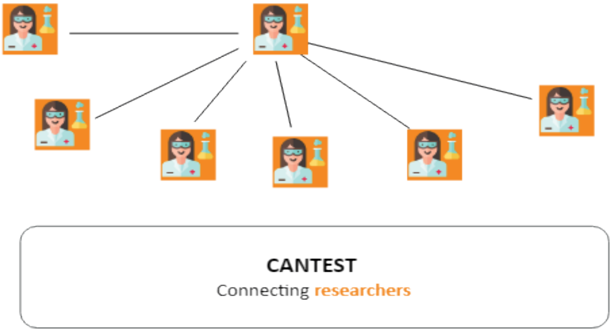
Healthcare professional 3:
"But of course that may also be missed opportunities. For example with the BMI<21 it may well be these patients are undertreated in terms of their COPD and therefore do not gain weight. So you may not need the agreements, but they may help patients."

The importance of research collaboration within LHS

LHS have a feedback loop from clinical practice to research, and from research back to clinical practice. For the importance of research collaboration in LHS (the first part of this thesis), the introduction raised two questions:

But how do researchers connect and develop?

And how may we facilitate that in the future?



The first question was dealt with in **Chapter 2 and 3**. The second question is dealt with here. For an optimal and efficient role of research in LHS, research should me more clearly linked to professional impact: where does it improve collaboration (and collaboration agreements as a first step within improved collaboration) and contribute to LHS. That is the fundamental reform of science that we need right now – ‘science in transition’, or otherwise explained: ‘science as a service’[2]. We should find the right balance between the value of research collaboration for individual researchers, and the value of research for clinical practice.

The network diagrams in **Chapter 2** clearly showed how the social network of all CanTest researchers increased enormously over the three time points. Yet, the collaborative network – based on joint publications – lagged behind. Although a relation between the two networks was found (i.e. being connected in the social network increases the chance to publish together), there were lots of social connections that did not (yet) result in scientific output. Those connections may equally benefit clinical practice compared to those that directly resulted in a publication[3,4]. Indeed, **Chapter 3** showed how research connections not only bring publications but also social capital, knowledge, skills, resources and new ideas.

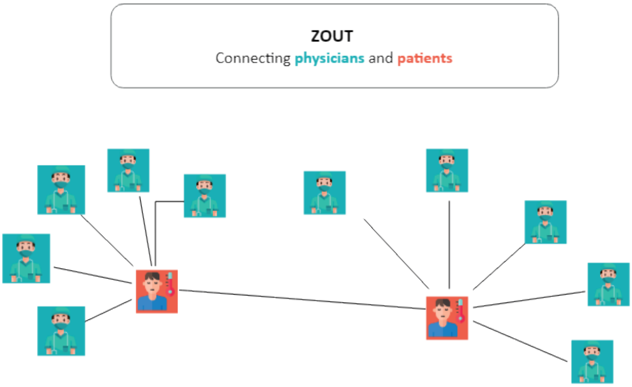
Imagine, for example, that researchers connect and share their knowledge and resources to find out if and how there is a relationship between local soil pollution and high gastric cancer prevalence in a small town in the Netherlands. The results of this research may be life-changing to the people living in the small town, yet it does not qualify for the big, high-impact journals. For an optimal functioning LHS, we believe the first is more important than the second: researchers in the LHS do not primarily research only to publish; they research to improve the societal health problem that is presented in the LHS, and share this through publication if it is relevant for the international scientific community.

The importance of interprofessional and patient-centred collaboration in LHS

To value the importance of patient-centred, interprofessional collaboration in LHS (the second part of this thesis), we raised the following questions in the introduction:

But how do healthcare professionals and patients connect and develop?

And how may we facilitate that in the future?



The first question was dealt with in **Chapter 4-7**. Again, the second question is dealt with here. **Chapter 4-7** provided the ingredients for negotiation and learning in clinical practice. Two things are crucial for the future of LHS: institutionalizing the interprofessional discussion, and giving the patient a structural role.

Institutionalizing the interprofessional discussion

Regarding the first, a continuous dialogue between healthcare professionals and monitoring of performance within institutions is needed. This has been discussed in more detail earlier in this chapter. However, important to emphasize is that ‘monitoring of performance’ in LHS does not refer in any sense to being subject to financial or legal evaluation by a health inspectorate or healthcare insurer. We rather see a role for monitoring in the LHS in the sense of discussing quality and efficiency outcome parameters of care together, without any pre-imposed formal administrative or regulatory framework. We recognize the potential counter arguments though:

“A dialogue without value judgement or decision-making doesn’t help us forward”

An argument that any healthcare professional could just make, as it is their job to judge and make decisions when treating their patients. However, in this thesis we plea for more interprofessional dialogues, focused on getting to know each other, sharing perspectives, and understanding frictions – in essence not to judge or make decisions right away[5,6]. **Chapter 7** illustrated how the psychological motives of healthcare professionals as well as the dynamics of power, money and culture in their (institutional) environment occasionally outweigh the agreed-upon guidelines[7]. Accordingly, an early focus on making decisions (to inform or adjust the guidelines) may ignore the many aspects (e.g. the ideas that live among healthcare professionals) that really help us forward.

“A discussion that does not include the regulatory and financial bodies does not have any formal legitimacy “

An argument in line with the previous one about how care innovation is only useful if it provides national guidance – for example by the National Health Care Institute, the Health and Youth Care Inspectorate or healthcare insurers. However, we argue that it is precisely this top-down quality discussion that does not work, because it does not match daily clinical practice. Accordingly, again, we plea to have a discussion amongst healthcare professionals on the front line first, and then translate it from the bottom-up such that it can be embedded in the existing quality or financing systems.

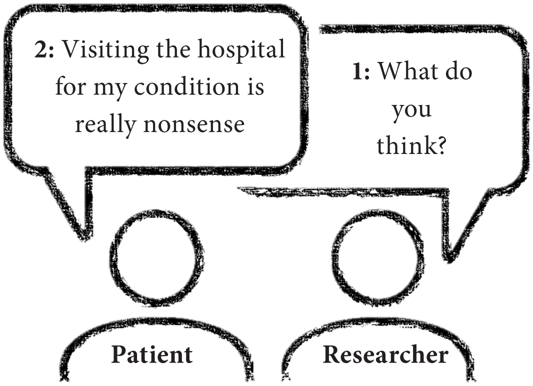
Giving the patient a structural role

The second aspect that we highlight for building a LHS is the role of the patient. The call for patient participation in LHS is a loud one[8,9]. There is an increasing need for the patient’s voice to be heard, for it to be invited, listened to, and taken seriously[10]. Patient participation is promoted as a ‘pivotal component’ of ethically sound research, of clinical translation, and of ensuring social acceptance of research findings[11]. Still it remains difficult to really give shape to patient participation in LHS[12]. The experiences, opinions and perceptions of patients are valued, but they also cause uncomfortable discussions amongst professionals[13]. Routine care data about large groups of patients, as well as passive illustrations of individual patients, are increasingly being used in the cycle of LHS (**Figure 1**), but the voice of the individual patient is still rarely taken into account[14,15]. As soon as individual patients get involved the problem of N=1 rubs off: “After all, the opinion of one patient is only the opinion of that one patient”. In this final chapter, we seize the opportunity to respond:

“Talking to individual patients doesn’t help us forward”

A common comment that argues against a structural role for patients in improving LHS. Yet, the previous chapters of this thesis proved the contrary. We showed that individual patients contribute to LHS, and how they are more than ready to have a structural role.

Opportunities are lost when we do not hear the stories of patients because the N=1 card is played. In one of my conversations with a patient with diabetes, he told me:



By inviting this patient as a discussion partner in our meetings with medical specialists and general practitioners (**Chapter 6**), this perspective came up and differences between the perspectives of healthcare professionals and patients became visible and were discussed. After this patient's argument followed a critical examination of referrals and back-referrals. Preferences were exchanged, and possible solutions identified.

The input and experiences of (individual) patients can be seen as a crowbar for initiating learning and collaboration in LHS. The direction and urgency of improvement are quite uncertain if we base it on the story of one patient, but at the same time this one story can be the start of a, in the end, dialogue with more enduring and sustainable results. And, not the least, if this dialogue produces concrete solutions, they can be tested against the experiences and preferences of patients right away.

In short, patient participation has increasingly become an 'option' in research, education and healthcare over the previous years. Yet, now is the time to continue. An 'option' is no longer enough: we need the participation of patients to become a 'mind-set' on which developments and changes are based. Healthcare is about patients, so they múst be central, and múst be involved: "not about us without us". In LHS we search together, on the basis of researcher, healthcare professional ánd patient (as the most important stakeholder of LHS) perspectives, for the triggers of collective improvement.

Methodological reflections for learning healthcare systems

Last but not least, in this final chapter we evaluate the methodology. Although being distinct in content, the different pillars of LHS (**Figure 1**) require comparable, even complementary, research approaches: having an eye for all who may be involved, and choosing the right pair of glasses to look at their distinct roles and actions. In this thesis, researchers, healthcare professionals and patients were studied individually, in groups and in networks (which are different units of analysis). In addition, we used different frameworks (an SNA approach as well as one based on CHAT) to facilitate a wide view on LHS.

Either unit of analysis or framework has its advantages and disadvantages. Therefore, we argue that a combination of multiple units of analysis and/or frameworks is necessary to contribute to a better understanding of a complex system as the LHS. With discussing methodology, we do not step away from practical implementation. On the contrary: we make this final move to methodology to show how abstract theories or methods can have a practical effect.

Studying different units of analysis

For our argument to look at different units of analysis within one thesis, we introduce the logic of complexity science and its relevance to LHS. Complexity science seeks to describe and understand the nature of different, interacting elements of a system[16]. That is, in fact, to describe and understand different units of analysis:

> *"When one approaches the problem of thinking and speech by decomposing it into its elements, one adopts the strategy of the man [person] who resorts to the decomposition of water into hydrogen and oxygen in his search for a scientific explanation of the characteristics of water, its capacity to extinguish fire or its conformity to Archimedes law for example. This man will discover, to his chagrin, that hydrogen burns and oxygen sustains combustion. He will never succeed in explaining the characteristics of the whole by analyzing the characteristics of its elements." [Gestalt psychologists]*[17]

Indeed, the physical and chemical features of water as its transparency, lack of smell, capability to extinguish fire, and so on, cannot be understood by studying the atoms or even a separate molecule of water. Ice, liquid water and steam have the same atoms and molecules but have many different physical features that can be only understood by studying the *interactions and relationships among* many molecules of water[18]. Similarly, anyone who studies the separate elements of LHS will search in vain for the unity that is characteristic of the whole. To understand LHS, we must search for the *interactions and relationships among* its elements. That is, large networks and smaller groups of individual researchers, healthcare professionals and patients[19].

Figure 2 illustrates how the different chapters of this thesis had different units of analysis.

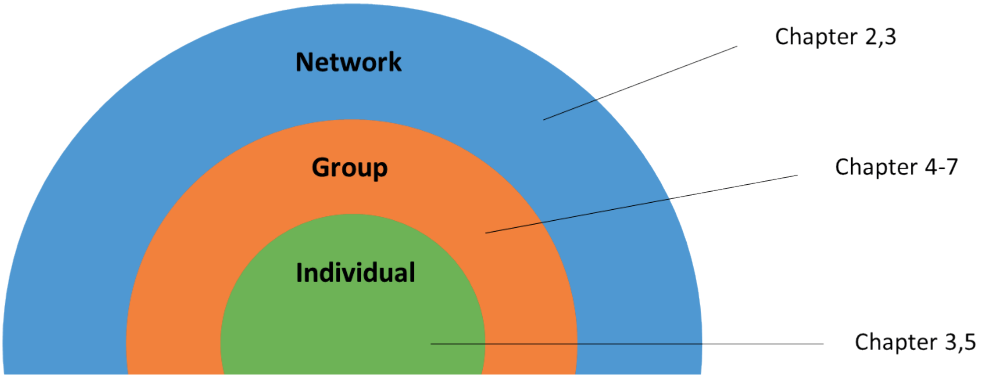


Figure 2 Zooming in on different levels of the LHS, or units of analysis. Chapter 2 and 3 focused on networks; while chapter 4-7 focused on groups. Chapter 3 and 5 additionally focused on the individuals within networks and groups respectively.

Studying different units of analysis helps to solve some common methodological problems – particularly the problem of reductionism (when claims about a particular unit of analysis are made based on data about another unit of analysis). First of all, it reduces the number of claims about a lower-level unit of analysis (e.g. individuals) using data from a higher-level unit of analysis (e.g. networks)[20,21]. For example, if the purpose of this thesis was to explore the motivations of individual researchers to create connections across the LHS, **Chapter 2** (network analysis) would not suffice. The data gathered in **Chapter 3** (individual interviews) would, however, be appropriate.

The other way around also holds, i.e. when claims about a higher-level unit of analysis (e.g. networks) are made based on data from some lower-level unit of analysis (e.g. individuals)[18,20,22]. Without the data gathered in **Chapter 6** (group negotiations between healthcare professionals and patients), the data from **Chapter 5** (individual patient interviews) would not be self-containing if the aim was to explore how patients behave in groups. Accordingly, choosing the right (combination of) units of analysis, but also being clear on that choice when reporting research results, is of great importance.

Our argument is not to say that using different units of analysis is the absolute perfect way forward. Studying different units of analysis also make things more complex (e.g. how do the results based on different units of analysis relate to each other, or what combination of methods suits what combination of units). Yet, in our search to understand a complex system as the LHS, we argue that a one-sided perspective is not enough, and hope to have started a discussion about how the combination of different units of analysis may help.

Using different frameworks

The combination of different theoretical and methodological framework similarly boosts our understanding of LHS. Social network approaches and those based on activity theory were used side by side in this thesis, illustrating how walking both paths may create different perspectives on one and the same system. As a next step for understanding and improving LHS, we argue for combining SNA approaches with those based on CHAT. The two frameworks take different perspectives on LHS, but are both concerned with understanding the interactions that take place between individuals, groups or networks in order to achieve a goal[23]. In SNA the relationships between individuals and networks form the central focus[24], while CHAT explores how a group of individuals work together to achieve their objectives[25]. Combining both will help to address the limitations, assumptions and underpinning standpoints of either of them[26].

In this thesis, SNA was used to study a network of researchers, and CHAT to study groups of healthcare professionals and patients. We argue that SNA will also be very effective for studying and improving healthcare networks – healthcare professionals working together in networks to improve the health outcomes of patients. Mapping the networks of healthcare professionals before and after interventions to improve their collaboration may be one example. The other way around, CHAT may provide insight into the wider context that helps researchers to collaborate. Understanding the rules and tools that facilitate or constrain research collaboration may very well support the development of research networks.

Using different frameworks only helps to give insight into the great dynamics of LHS. In the mixed-methods literature, discussions are well-evolved to support this mixing[27,28]. A variety of thorough, flexible and thoughtful guidelines have been created that may help forward future studies into LHS, such as the Mixed Methods Appraisal Tool[29]. The only thing is that these guidelines do not sufficiently address the mixing of different theoretical considerations (e.g. mixing the considerations from activity theory and discursive institutionalism as we did in **Chapter 7**). Detailed reflections on that fall outside the scope of this thesis but are presented elsewhere[30].

Our conclusion is that it is not the network approach versus the group or individual approach, but that all three approaches are useful in understanding and developing LHS. They are rather complementary than conflicting, as such they are friends rather than enemies.

Final recommendations – how to organize future LHS?

Going forward with the development of learning healthcare systems

It's time to… think in, design and invest in healthcare networks and research communities.

It's time to… let go of the focus on exclusively quantitative performance measures in research

It's time to… integrate the data we collect in routine practice, make them accessible and use them for innovation

It's time to… give patients a central role in improving their care process

It's time to… tweak (postgraduate) learning opportunities together with patients

It's time to… zoom in and out analytically to allow for integration of different components of the LHS

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A

Appendices

Summary

The complex balance between scientific evidence, clinical expertise and the patient's experience makes healthcare systems prone to inefficiency and fragmentation. As a consequence, continuity and quality of care is threatened. This sparks the interest into a care system that aligns the input from researchers providing scientific evidence, healthcare professionals building their clinical expertise on that, and patients experiencing the outcomes: a Learning Healthcare System (LHS). In LHS, researchers, healthcare professionals and patients cross organizational and disciplinary boundaries. As such, LHS generate and apply the best evidence for collaborative healthcare: they capture knowledge as a natural outgrowth of patient care, and ensure innovation, quality and efficiency in health care. Yet, to build such a system requires insight into the role of, and interplay between, researchers, healthcare professionals and patients.

In this thesis we aim to contribute to the development of LHS by studying collaboration and boundary crossing between researchers, healthcare professionals and patients. We use different analytical perspectives to provide insight and tools to help a healthcare system become a learning healthcare system. In the first part of this thesis we explore how researchers create connections and expand their connections in *networks*. Who do they connect with, how, and why? We use the CanTest network, an international network of primary care cancer researchers, as an example network to study this.

Chapter 2 shows how connections in the CanTest network evolve over time. Working in networks is expected to enhance collaboration and thereby increase research output. Yet, little is actually known about whether and how knowing each other translates into effective collaboration. Accordingly, we distributed surveys amongst all researchers in the CanTest network to explore who knows who ('the academic social network'. In addition, co-authorship relationships between all researchers in the CanTest network were derived from Scopus to explore who collaborates with who (the 'collaborative network'). Stochastic actor-oriented models were employed to investigate the evolution and co-evolution of both networks. We show that researchers within CanTest get to know each other quickly and also start collaborating over time (evolution of the academic social network and collaborative network respectively). Although the academic social network and the collaborative network do not grow at the same pace, the benefit of getting to know each other to stimulate effective research collaboration is clearly demonstrated (co-evolution of both networks).

The method used in **Chapter 2** provides increased understanding of how research networks develop. Such understanding may help LHS to build effective networks and generate the best evidence for making healthcare choices in clinical practice. A qualitative analysis contributes understanding of individual researcher's development to the quantitative analysis in **Chapter 2** that looks at the growth in connections. Accordingly, in **Chapter 3** we qualitatively analyse the value and impact of creating connections within networks. How does network development adds to the development of individual researchers?

Developing connections with other researchers in a network, learning informally through these connections, and utilising them to reach goals, is expected to increase research capacity and strengthen performance. Yet, again, this has not been empirically demonstrated. Using semi-structured interviews with 16 researchers within the CanTest network, we assessed what and how collaboration within a network adds to development of researchers. The analysis was guided by an existing value creation framework to study informal learning in networks, adjusted to our context. According to this framework, learning occurs in interconnected cycles according to perceived value, ranging from immediate to potential to realised value.

Connections with other researchers in the CanTest network created diverse value cycles, where most outcomes were in the potential value cycle, acquiring knowledge, skills, social capital, resources and ideas. Not all potential value was applied but many interviewees also described how they accomplished realised value (e.g. having papers published or grants awarded). Advancement throughout these cycles, and hence advancement of the network, depends on the available opportunities, the timing of these opportunities, the presence of role models, and the possibility to connect each other's perspectives. Focus on these factors will support individual researchers to increase their research capacity and strengthen performance, but also may bring sustainable change in the greater LHS.

The second part of this thesis focuses on collaboration in clinical practice. We assess how the process of collaboration between healthcare professionals and patients unfolds, and how this may help LHS to move forward. Our analysis of collaboration in clinical practice ranges from collecting and linking routine care data to reveal how healthcare professionals work together across boundaries, to questioning the people behind the data, and bringing them together. First, **Chapter 4** provides a roadmap to collect and link routine care data from general practitioners and medical specialists. Through linkage of routine care data, as registered in daily practice by general practitioners and medical specialists, a regional transmural care database (RTD) was developed for monitoring their collaboration.

The RTD includes data from three regional hospitals, and about 70 affiliated primary care practices which are united in the Julius General Practitioners Network (JGPN). These data were extracted, linked and presented in the form of mirror data, following simple methods to allow replication of our approach. During the development of the RTD, a roadmap was created including a detailed step-by-step checklist of the organizational, administrative, technical and legal arrangements which needed to be made. The 'mirror data' generated from the RTD enabled shared reflection and discussion between general practitioners and medical specialists in the region. This, in turn, may help current and future improvement initiatives to search for the bottlenecks and potentialities for improving clinical practice. As such, an RTD may have great potential to serve a LHS within the region.

Yet, collaboration between healthcare professionals is only one part of clinical practice. The (active) role of patients within care improvement initiatives remains relatively unexplored. Therefore, in **Chapter 5**, we move to the role of patients. We explore the role of patients in establishing continuity of care (or: resolving discontinuity of care) across the boundaries of their care trajectories. Using semi-structured interviews with 33 cancer patients, we unravel the discontinuities that they experience and their attempts to resolve these. The analysis was informed by concepts from the boundary crossing literature: boundary objects and brokers. Boundary objects and brokers are objects and people, respectively, that bring different social worlds or working practices together, or bridge the gap between them.

We show how patients actively use the objects (e.g. information leaflets) and people (e.g. a case manager) provided by the healthcare system to re-establish continuity of care. Moreover, patients introduce own objects (e.g. a voice recorder) and people (e.g. a friend) along their care trajectory. Using these objects and people, patients generally establish information and management continuity. Relational continuity appears to be more difficult to establish by patients, in some cases leaving patients to take drastic measures, such as changing care providers. The results in this chapter show us how patients have a very active role in establishing continuity of care across the boundaries of their own care trajectories. Taking full advantage of both healthcare professionals' and patients' roles may provide new opportunities for LHS to enhance the patient experience. Accordingly, we advocate an integrated approach towards building the 'clinical side' of our LHS.

After highlighting the separate roles of healthcare professionals and patients in **Chapter 4** and **Chapter 5**, an integrated approach towards collaboration in clinical practice is introduced in **Chapter 6**. Patients, who were shown to actively cross the boundaries between different healthcare professionals in **Chapter 5**, may well contribute to the learning of these healthcare professionals and improve their collaboration. Using the expansive learning cycle of activity theory, in **Chapter 6** we explore how patients and visualizations of their care trajectories as material objects promote the learning process of healthcare professionals. In four distinct learning sessions, healthcare professionals (general practitioners and medical specialists) exchanged and discussed their perspectives on their shared care models. Transcripts of these sessions were analysed for contradictions between healthcare professionals or practices (which are increasingly deemed useful to consolidate new practice development) and subsequent steps in the cycle of expansive learning. This confirmed the idea that patients may contribute to the learning of healthcare professionals. Patients (and their material care trajectories) initiate as well as advance the expansive learning process of healthcare professionals, and improve their collaboration accordingly. For the healthcare system to become a learning healthcare system, the active role of patients should be seriously considered.

Yet, realizing change is often difficult in established systems. The most recent developments in healthcare were triggered by the COVID-19 pandemic. We have witnessed the disruptive force of change of our healthcare systems during this pandemic. Accordingly, in **Chapter 7** we zoom in on this period and explore how our healthcare system was able to so radically and rapidly change. Was the change initiated by institutional leaders from top-down, or was it driven by healthcare professionals from the bottom-up? Using a methodology informed by theories that have a focus on healthcare professionals (activity theory) or their larger institutions (discursive institutionalism) respectively, transcripts of multidisciplinary meetings with healthcare professionals about their collaborative COVID-19 care were qualitatively analysed.

We show how both (bottom-up) professional legitimacy and (top-down) institutional support are necessary by healthcare professionals to develop and sustain new collaborative routines. Yet, in contrast to times before the pandemic, change during the COVID-19 pandemic was primarily initiated from the bottom-up. There is a special opportunity to build our LHS by learning from the responses to this pandemic. Now is the time to find ways to integrate new ways of working initiated from the bottom-up with those longstanding ones initiated from top-down.

In **Chapter 8** and general discussion of this thesis, we integrate and discuss our main findings in a broader context and provide suggestions for improving collaboration within LHS. We argue how considering different perspectives, in research and clinical practice, promotes a cyclic process of continuous learning by collaboration. For an optimal and efficient role of research in LHS, research should me more clearly linked to professional impact: where does it improve collaboration and contribute to LHS. We should find the right balance between the value of research for individual researchers, and the value of research for clinical practice.

For an optimal and efficient role of clinical practice in LHS, we plea for institutionalizing the interprofessional discussion to facilitate a continuous dialogue between healthcare professionals and monitoring of performance within institutions. Furthermore, the patient should be given a structural role in improvement initiatives ("not about us without us"). In LHS we search together, on the basis of researcher, healthcare professional and patient (as the most important stakeholder of LHS) perspectives, for the triggers of collective improvement.

Within this thesis, different units of analysis and theoretical frameworks were used to study the LHS. Within the last part of **Chapter 8**, we concluded that a combination of multiple units of analysis and theoretical frameworks is necessary to understand a complex system as the LHS. Furthermore, the recommendation is made to think in, design and invest in healthcare networks and research communities – and, essentially, include herein the patient perspective as one on which developments and changes are based.

Nederlandse samenvatting

De complexe balans tussen wetenschappelijke kennis van onderzoekers, klinische expertise van dokters, en de ervaring van patiënten, maakt zorgsystemen vatbaar voor inefficiëntie en fragmentatie. Hierdoor komen de continuïteit en kwaliteit van zorg in gevaar. We moeten daarom op zoek naar een systeem dat de inbreng van onderzoekers, zorgprofessionals en patiënten op één lijn brengt: een lerend zorgsysteem (*Learning Healthcare System, LHS*). In een lerend zorgsysteem overbruggen onderzoekers, zorgprofessionals en patiënten organisatorische en disciplinaire grenzen. Op die manier werkt een lerend zorgsysteem mogelijk het best om wetenschappelijk onderzoek te vertalen naar de dagelijkse klinische praktijk, en zo te zorgen voor innovatie, kwaliteit en efficiëntie in de zorg voor patiënt. Om zo een systeem te bouwen is echter inzicht nodig in de rol van, en het samenspel tussen, onderzoekers, dokters en patiënten.

In dit proefschrift willen we bijdragen aan de ontwikkeling van zo een lerend zorgsysteem door de samenwerking tussen, en het overbruggen van grenzen door, onderzoekers, zorgprofessionals en patiënten te bestuderen. We gebruiken verschillende analytische perspectieven om inzicht en tools te bieden om een zorgsysteem te helpen een lerend zorgsysteem te worden. In het eerste deel van dit proefschrift onderzoeken we hoe onderzoekers connecties met andere creëren en hun connecties in netwerken uitbreiden. Met wie komen ze in contact, hoe en waarom? We gebruiken het CanTest-netwerk, een internationaal netwerk van eerstelijns kankeronderzoekers, als voorbeeldnetwerk om dit te onderzoeken.

Hoofdstuk 2 laat zien hoe connecties in het CanTest-netwerk zich in de loop van de tijd ontwikkelen. Het idee heerst dat het werken in netwerken de samenwerking tussen onderzoekers zal versterken en daarmee de onderzoek output vergroten. Toch is er maar weinig bekend over of en hoe ‘elkaar kennen’ zich vervolgens vertaalt naar een effectieve samenwerking met elkaar. Om dit verband te onderzoeken hebben we vragenlijsten verspreid onder alle onderzoekers in het CanTest-netwerk. In die vragenlijsten werd het ‘academische sociale netwerk’ uitgevraagd: wie kent wie? Vervolgens is hun ‘samenwerkingsnetwerk’ in kaart gebracht: wie werkt met wie samen? Co-auteurschapsrelaties werden daarvoor geëxtraheerd uit Scopus. Om de evolutie en co-evolutie van beide netwerken te onderzoeken werden stochastische actor-georiënteerde modellen gebruikt. We laten hiermee zien dat onderzoekers binnen CanTest elkaar snel leren kennen en ook na verloop van tijd gaan samenwerken (evolutie van het academische sociale netwerk respectievelijk het samenwerkingsnetwerk) Hoewel het academische sociale netwerk en het samenwerkingsnetwerk niet in hetzelfde tempo groeien, wordt het voordeel van elkaar leren kennen om effectieve onderzoekssamenwerking te stimuleren duidelijk aangetoond (co-evolutie van beide netwerken).

De methode die in **Hoofdstuk 2** wordt gebruikt geeft meer inzicht in hoe onderzoeksnetwerken zich ontwikkelen. Een dergelijk begrip kan lerende zorgsystemen helpen om effectieve netwerken op te bouwen en de beste kennis te genereren voor het maken van keuzes in de klinische praktijk. In aanvulling op deze kwantitatieve analyse kan een kwalitatieve analyse bijdragen aan het begrip van de ontwikkeling van connecties tussen onderzoekers. Daarom analyseren we in **Hoofdstuk 3** op kwalitatieve wijze de waarde en impact van het creëren van connecties binnen netwerken. Hoe draagt netwerkontwikkeling bij aan de ontwikkeling van individuele onderzoekers?

De verwachting was dat het ontwikkelen van connecties met andere onderzoekers in een netwerk, het informeel leren via deze connecties, en het gebruik van deze connecties om doelen te bereiken, de onderzoekscapaciteit vergroot en prestaties verbetert. Maar nogmaals, dit was niet eerder empirisch aangetoond. Aan de hand van semigestructureerde interviews met 16 onderzoekers binnen het CanTest-netwerk hebben we daarom onderzocht wat en hoe samenwerking binnen een netwerk bijdraagt aan de ontwikkeling van onderzoekers. De analyse werd gestuurd door een bestaand theoretisch kader voor waardecreatie (*value creation*) om informeel leren in netwerken te bestuderen, aangepast aan onze context. Volgens dit kader vindt leren plaats in onderling verbonden cycli op basis van gepercipieerde waarde, variërend van onmiddellijke tot potentiële tot gerealiseerde waarde.

Het onderzoek laat zien dat connecties met andere onderzoekers in het CanTest-netwerk diverse waarde-cycli creëren, waarbij de meeste resultaten in de potentiële waarde-cyclus lagen: het verwerven van kennis, vaardigheden, sociaal kapitaal, middelen en ideeën. Niet alle potentiële waarde werd benut, maar veel geïnterviewden beschreven ook hoe ze deze potentiële waarde vervolgens realiseerden (bijvoorbeeld het publiceren van papers of het toekennen van subsidies). De overgang van potentiële naar gerealiseerde waarde, en daarmee de voortgang van het netwerk, hangt af van de beschikbare kansen, de timing van deze kansen, de aanwezigheid van rolmodellen en de mogelijkheid om verschillende perspectieven aan elkaar te verbinden. Meer focus op deze factoren binnen het onderzoeksdomein zal individuele onderzoekers ondersteunen om hun onderzoekscapaciteit te vergroten en prestaties te verbeteren, maar kan ook leiden tot duurzame verandering in het grotere, lerende zorgsysteem.

Het tweede deel van dit proefschrift richt zich op de samenwerking in de klinische praktijk. We beoordelen hoe het proces van samenwerking tussen zorgprofessionals en patiënten verloopt en hoe dit een lerend zorgsysteem vooruit kan helpen. Onze analyse van samenwerking in de klinische praktijk varieert van het verzamelen en koppelen van routinematige zorggegevens om te laten zien hoe zorgprofessionals over de grenzen heen samenwerken, tot het bevragen van de mensen achter de gegevens en het samenbrengen daarvan. Allereerst wordt in **Hoofdstuk 4** een stappenplan uitgezet om gegevens uit de routinezorg van huisartsen en medisch specialisten te verzamelen en te koppelen. Op basis van deze koppeling kon een regionale transmurale zorgdatabase (RTD) ontwikkeld worden om de samenwerking over de grenzen van de huisartspraktijk en het ziekenhuis te monitoren.

De RTD bevat gegevens van drie regionale ziekenhuizen en ongeveer 70 aangesloten huisartspraktijken die zijn verenigd in het Julius Huisartsen Netwerk (JGPN). Deze gegevens werden geëxtraheerd, gekoppeld en gepresenteerd in de vorm van 'spiegelinformatie'. De methode die we hiervoor gebruikte was eenvoudige om replicatie van onze aanpak mogelijk te maken. Tijdens de ontwikkeling van de RTD is een stappenplan opgesteld met daarin een gedetailleerde stapsgewijze checklist van de organisatorische, administratieve, technische en juridische regelingen die moeten worden getroffen. Vervolgens faciliteerde de uit het RTD gegenereerde spiegelinformatie een gezamenlijke discussie tussen huisartsen en medisch specialisten in de regio. Op soortgelijke wijze kan spiegelinformatie uit een RTD huidige en toekomstige verbeterinitiatieven binnen het lerend zorgsysteem helpen bij het zoeken naar knelpunten en mogelijkheden voor verbetering van de klinische praktijk.

Samenwerking tussen zorgprofessionals is echter slechts één onderdeel van de klinische praktijk. Zorgverbeteringsinitiatieven waarin een rol is weggelegd voor zorgprofessionals zijn de afgelopen jaren flink toegenomen, maar de (actieve) rol van patiënten zelf is nog relatief onbekend terrein. In **Hoofdstuk 5** schakelen we daarom over naar de rol van patiënten. We onderzoeken in dit hoofdstuk de rol van patiënten bij het tot stand brengen van continuïteit van zorg. Aan de hand van semigestructureerde interviews met 33 kankerpatiënten onderzoeken we de (dis)continuïteit die zij ervaren tijdens hun zorgtraject en hun pogingen om deze op te lossen. De analyse is gebaseerd op twee bekende concepten uit de literatuur over grensoverbrugging (*boundary crossing*): grensobjecten (*boundary objects*) en bruggenbouwers (*brokers*). Grensobjecten en bruggenbouwers zijn respectievelijk objecten en personen die verschillende sociale werelden of werkpraktijken bij elkaar brengen, of de kloof daartussen overbruggen.

We laten zien hoe patiënten actief gebruik maken van objecten (bijvoorbeeld bijsluiters) en personen (bijvoorbeeld een casemanager) die door het zorgsysteem reeds worden verstrekt om continuïteit van zorg te waarborgen. Bovendien introduceren patiënten eigen objecten (bijvoorbeeld een voice-recorder) en personen (bijvoorbeeld een vriend) gedurende hun zorgtraject. Met behulp van deze objecten en personen lukt het patiënten over het algemeen om informatie- en managementcontinuïteit te creëren. Relationele continuïteit blijkt voor patiënten zelf moeilijker te creëren, waardoor patiënten in sommige gevallen gedwongen worden drastische maatregelen te nemen, zoals het veranderen van zorgverlener. De resultaten in dit hoofdstuk laten zien hoe patiënten een zeer actieve rol spelen bij het realiseren van continuïteit van zorg over de grenzen van hun eigen zorgtraject heen. Door optimaal gebruik te maken van de rol van zowel zorgverlener als patiënt, kan een lerend zorgsysteem nieuwe kansen bieden om de ervaring van de patiënt te verbeteren.

Nadat in **Hoofdstuk 4** en **Hoofdstuk 5** de afzonderlijke rollen van zorgverleners en patiënten zijn onderzocht, wordt in **Hoofdstuk 6** een geïntegreerde benadering voor samenwerking in de klinische praktijk geïntroduceerd. In **Hoofdstuk 5** werd aangetoond dat patiënten actief de grenzen tussen verschillende zorgprofessionals overschrijden. Patiënten zouden derhalve een stevige bijdrage kunnen leveren aan het leren van deze zorgprofessionals om zo hun samenwerking te verbeteren. In **Hoofdstuk 6** maken we gebruik van de expansieve leercyclus (*expansive learning cycle*) uit de activiteitentheorie (*activity theory*) om te onderzoeken hoe patiënten en visualisaties van hun zorgtrajecten het leerproces van zorgprofessionals kunnen bevorderen. In vier verschillende leersessies wisselden zorgprofessionals (huisartsen en medisch specialisten) perspectieven op hun gezamenlijke zorg uit. Transcripties van deze sessies werden geanalyseerd op contradicties tussen zorgprofessionals of hun praktijken en daaropvolgende stappen in de cyclus van expansief leren. Het bespreekbaar maken van contradicties – in plaats van continu te zoeken naar consensus – wordt namelijk in toenemende mate nuttig geacht om ontwikkeling te bewerkstelligen. De resultaten laten zien dat patiënten (en hun visuele zorgtrajecten) inderdaad het leerproces van zorgprofessionals initiëren en bevorderen, en zo potentieel hun samenwerking verbeteren. We pleiten dat om het zorgsysteem een lerend zorgsysteem te laten worden, de actieve rol van patiënten serieus moet worden overwogen.

Toch is het realiseren van verandering in gevestigde systemen vaak moeilijk. De meest recente ontwikkelingen in de gezondheidszorg werden veroorzaakt door de COVID-19-pandemie. Met zijn allen zijn we getuige geweest van de ontwrichtende veranderkracht die de pandemie met zich mee bracht. Daarom zoomen we in **Hoofdstuk 7** in op deze periode en onderzoeken we hoe ons zorgsysteem nu opeens zo radicaal en snel kon veranderen. Werd de verandering geïnitieerd door institutionele leiders van bovenaf, of werd deze door zorgprofessionals van onderaf aangestuurd? Met behulp van een methodologie op basis van theorieën die zich richten op respectievelijk zorgprofessionals (activiteitentheorie; *activity theory*) of de grotere instituten waar zij onderdeel van zijn (discursief institutionalisme; *discursive institutionalism*), werden transcripties van bijeenkomsten met zorgprofessionals over hun gezamenlijke COVID-19-zorg kwalitatief geanalyseerd.

In de resultaten hiervan laten we zien hoe zorgprofessionals zowel (bottom-up) professionele legitimiteit als (top-down) institutionele ondersteuning nodig hebben om nieuwe samenwerkingsroutines te ontwikkelen en in stand te houden. Maar, in tegenstelling tot tijden vóór de pandemie, werd verandering tijdens de COVID-19-pandemie vooral van onderaf in gang gezet. Er ligt een speciale kans om ons lerend zorgsysteem op te bouwen dan wel te verstevigen door te leren van de reacties op deze pandemie. Vandaag de dag, net na de pandemie, is het moment om nieuwe – van onderaf geïnitieerde – manieren van werken te integreren in de al langer bestaande – van bovenaf geïnitieerde – werkwijzen.

In **Hoofdstuk 8** en algemene discussie van dit proefschrift integreren en bespreken we onze belangrijkste bevindingen in een bredere context en doen we suggesties voor het verbeteren van de samenwerking binnen een lerend zorgsysteem. We beargumenteren hoe het overwegen van verschillende perspectieven, in onderzoek en klinische praktijk, een cyclisch proces van continu leren door samenwerking bevordert. Voor een optimale en efficiënte rol van onderzoek in een lerend zorgsysteem moet onderzoek duidelijker worden gekoppeld aan professionele impact: waar verbetert het de samenwerking en draagt het bij aan een lerend zorgsysteem. We moeten de juiste balans vinden tussen de waarde van onderzoek voor individuele onderzoekers en de waarde van onderzoek voor de klinische praktijk.

Voor een optimale en efficiënte rol van de klinische praktijk in een lerend zorgsysteem pleiten we voor het institutionaliseren van de interprofessionele discussie om een continue dialoog tussen zorgprofessionals en monitoring van de prestaties binnen instellingen mogelijk te maken. Verder dient de patiënt een structurele rol te krijgen bij verbeterinitiatieven ("niet over ons zonder ons"). In een lerend zorgsysteem zoeken we samen, vanuit het perspectief van onderzoeker, zorgprofessional en patiënt (als belangrijkste stakeholder van het lerend zorgsysteem) naar de triggers voor collectieve verbetering.

Binnen dit proefschrift werden verschillende analyse-eenheden (*units of analysis*) en theoretische kaders gebruikt om het lerend zorgsysteem te bestuderen. In het laatste deel van **Hoofdstuk 8** hebben we geconcludeerd dat een combinatie van meerdere analyse-eenheden en theoretische kaders nodig is om een complex systeem als een lerend zorgsysteem te begrijpen. Verder wordt aanbevolen om te denken in, te ontwerpen, en te investeren in zorg- en onderzoeksnetwerken – en daarin het patiëntperspectief op te nemen als hét perspectief waarop ontwikkelingen en veranderingen in essentie zijn gebaseerd.

List of publications

Scientific publications based on studies presented in this thesis

Vermond, D., de Groot, E., de Wit, N. and Zwart, D. (2022). A delicate balance: how physicians manage change towards collaborative care within their institutions. Journal of Integrated Care, 30(5), 125-137. https://doi.org/10.1108/JICA-04-2022-0027

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Vermond, D., Helsper, C. W., Kortekaas, M. F., Boekema, N., de Groot, E., de Wit, N. J., & Zwart, D. (2021). Developing a regional transmural care database: A roadmap. International journal of medical informatics, 148, 104386. https://doi.org/10.1016/j.ijmedinf.2021.104386

Other publications

Debbie Vermond, Esther de Groot, Charles Helsper, Marlous Kortekaas, Nicole Boekema, Denise Seelen, Niek de Wit, Dorien Zwart. 'ZOrg op de juiste plek UTrecht' verbindt de regio. https://www.zorgvisie.nl/zout-zorg-op-de-juiste-plek-utrecht/

Conference presentations and posters

CanTest Network Analysis Project, *European Conference on Social Networks (EUSN)*, 9-12 September 2019, Zurich, Switzerland

Rediscovering the value of the single patient trajectory, *SIG17 – Methods in Learning Research*, 7-10 September 2020, online

De rol van (huis)arts-onderzoekers in kliniek en wetenschap: een netwerk perspectief, *NHG Wetenschapsdag*, 5/11 februari 2021, online

ZOrg op de juiste plek in UTrecht (ZOUT): Interprofessioneel leren en verbeteren door patiëntparticipatie en transmurale spiegelinformatie, *NHG Wetenschapsdag*, 5/11 februari 2021, online

Stochastic Actor Oriented Models in the CanTest Network Analysis Project, *AdSUM-2021 Advanced Siena Users' meeting*, 11-12 February 2021, Groningen, the Netherlands

The development of CanTest: from social connection to collaboration, *CanTest International School*, 12-14 April 2021, online

Healthcare providers learning together with patients: re-negotiating health care across boundaries, *Onderwijs Research Dagen (ORD)*, 7-9 July 2021, online

Een netwerkperspectief op samen werken en leren: bundeling van inzichten uit gezondheidszorg en onderwijs, *Nederlandse Vereniging voor Medisch Onderwijs (NVMO) congres*, 18 February/29 March/17 May/10 June 2022, online

Healthcare professionals learning together with patients: bridging boundaries, *WONCA congress,* 28 June – 1 July 2022, London, United Kingdom

The evolution and co-evolution of a primary care cancer research network: from academic social connection to research collaboration, *WONCA congress,* 28 June – 1 July 2022, London, United Kingdom

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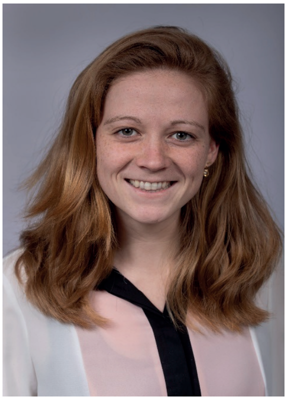
About the author



Debbie Vermond was born on March 25th, 1994, in Leiden, the Netherlands. In 2012, she started her study in Biomedical Sciences at Leiden University. During her bachelor research internship on older hospitalized internal medicine patients at the Department of Gerontology and Geriatrics of the Leiden University Medical Center, her interest in geriatric medicine and chronic diseases grew. Accordingly, she followed a master's program on Vitality and Ageing at the Leyden Academy on Vitality and Ageing in the year after. This study sparked her interest for the combination of science and clinical practice. Accordingly, she obtained a second master's degree in Biomedical sciences, combined with a track in science communication, in 2018.

In 2019, Debbie started working as a junior researcher and project manager in the field of transmural collaboration and care at the Department of General Practice of the Julius Center. Subsequently, in 2020, she started working as a PhD candidate. Under supervision of Prof. dr. Niek de Wit, dr. Dorien Zwart and dr. Esther de Groot, she worked on the two projects that resulted in this thesis: ZOUT and CanTest. She has been provided the opportunity to present her work at several (inter)national conferences, including the Dutch College of General Practitioners Scientific Congress (*NHG-wetenschapsdag*), and the European Conference on Social Networks.

The unique experience of a PhD trajectory helped Debbie to grow both in her scientific career and as a person. In the future she aims to combine research and project management related to improving transmural collaboration and care for patients.