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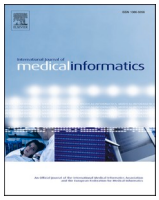

Developing a regional transmural care database: A roadmap

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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 CPCA are endorsed by all relevant regional health care organisations, 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.

1. Introduction

In primary care health care systems, primary care physicians (PCPs) provide most basic care services, and if necessary, refer to secondary care for specialised 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.

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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

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.

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].

2. 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 Fig. 1:

2.1. 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.

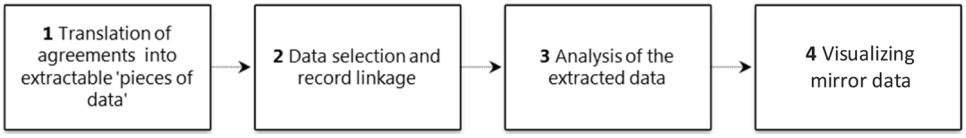

Fig. 1. Steps required to develop mirror data from a regional transmural care database (RTD), based on the occurrence of collaborative patient care agreements in daily practice.

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

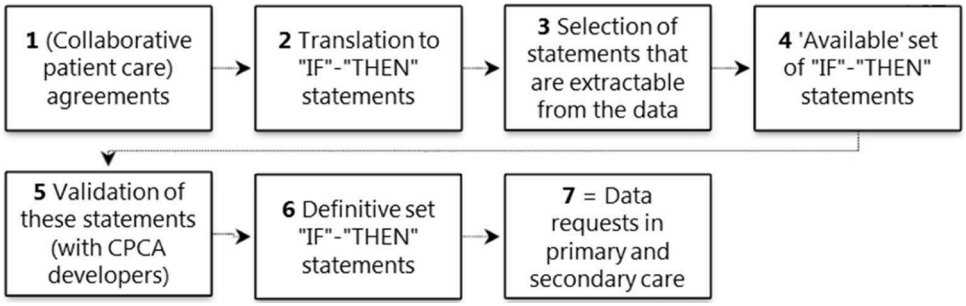

Fig. 2. Translation of collaborative patient care agreements (CPCAs) to relevant "IF"-"THEN" statements that can be extracted from daily care registrations.

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.

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 Fig. 2).

2.2. Data selection and record linkage

2.2.1. 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.

2.2.2. 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.

2.2.3. 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).

2.3. 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

IF Condition for referral according to CPCA *"The situation below is present at PCP visit"*	THEN Referral to relevant specialism, according to CPCA *"There has been a visit to the recommended SCP in ...% of the situations"*	THEN Referral to relevant specialism, but not according to CPCA *"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

Fig. 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).

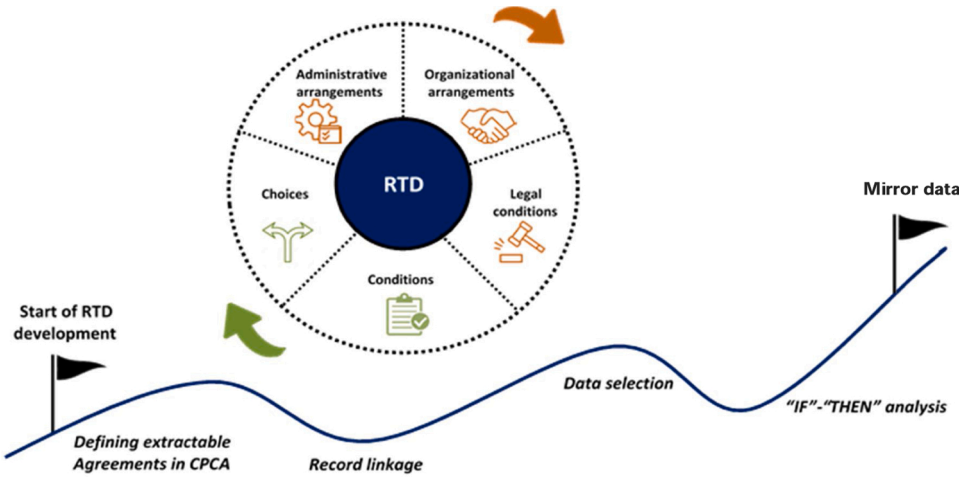

Fig. 4. A roadmap towards a regional transmural care database suitable for generating routine mirror data.

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.

2.4. Visualization and discussion of mirror data

Finally, the "IF"-"THEN" statements were presented in table format. Fig. 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].

2.5. 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.

3. Results

3.1. Roadmap to the RTD

Fig. 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.

3.2. Challenges

3.2.1. 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

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 routine care data; 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 (registry) data; 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)*

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].

3.2.2. Legal requirements

In addition, before starting any data processing procedure, a data protection impact assessment (DPIA) was required to identify and minimise 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

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)

record linkage in international context was developed, and is provided in Box 3.

3.2.3. 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 (Fig. 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".

4. 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

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 organisations 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.

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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Authors' contributions

All authors have made a substantial, direct contribution to this study. DZ, NdW and EdG designed the study and developed the study protocol. CH, MK and NB organized the data collection. CH conducted the data analyses. All authors were involved in discussing and interpreting the results of the analyses, and in translating the different steps of developing a regional transmural care database to a comprehensible roadmap. DV wrote the manuscript. All others critically revised the manuscript for valuable intellectual content. All authors approved the final version.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.ijmedinf.2021.104386.

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